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This book explores the diversity of methodological approaches to researching ageing, considering which methodological paradigm best captures the phenomenon. Interdisciplinary in scope, it brings together research from scholars from Austria, Canada, France, Hong Kong, Israel, Poland, UK and USA to uncover the conditions under which qualitative and quantitative approaches to research on ageing can best be reconciled and rendered complementary. Presenting international reflection on methods for studying old age from a variety of research backgrounds, *Researching Ageing* showcases the latest research in the field and will appeal to scholars across the social sciences, including sociology, demography, psychology, economics and geography, with interests in gerontology, ageing and later life.

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Researching Ageing

Methodological Challenges and their Empirical Background

Edited by
Maria Łuszczyńska

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Introduction

Maria Łuszczyńska

In recent decades, the process of extending life and improving its quality has become a reference point for a growing group of researchers who define themselves as gerontologists, as well as for an emerging field of gerontology that draws on perspectives from medical science, the humanities and the social, technical and natural sciences.

The ageing of the global population is a fact confirmed by quantitative and qualitative data from the many spheres that are affected by the extension of human life. Here I have in mind such diverse fields of human engagement as (for example) healthcare, new media, the labor market, education, legal systems, social participation, marketing, tourism, the production of goods and social assistance, not to mention pharmacy, automobile travel, air travel, spirituality and culture. Representatives of these and many other spheres in which the presence of older people has a considerable influence are vitally interested in studying the role, impact, purchasing power, tastes, opinions, preferences, needs, expectations and significance of older people as it relates to their presence and engagement. It can thus be generally asserted that all those areas of activity and knowledge in which older people play a meaningful role have a gerontological character, despite the fact that gerontology has so far reserved for itself a narrower field of research that is connected to the ageing processes of living beings – and in particular, of the human being (Zych, 2010).

For the purposes of this publication, such a narrow understanding of gerontology is reversed, and (in accordance with N.R. Hooyman's view), "gerontologists" are taken to include researchers and practitioners in the fields of biology, nursing, medicine, criminology, dentistry, social work, physical and occupational therapy, psychology, psychiatry, sociology, economics, political science, architecture, geography, pharmacy, public health, housing and anthropology (Hooyman and Kiyak, 2011). This list could also be extended to include pedagogues and educators, caregivers and assistants, social animators, social policymakers, specialists in marketing, media and fashion and other persons whose professional and social activities are centered around older people. This means that gerontology may be the most multidisciplinary (as well as one of the youngest) fields of scientific knowledge.[1] This publication is addressed to all such people who are engaged with this field.

The dynamic process of global ageing brings many new questions, problems and challenges whose answers are sought in the course of research. Such issues absorb those who (more or less) consciously participate in research activities on a large or small scale. The question of what is really being studied when research deals with ageing, old age and the elderly – as well as the question of why and how such studies are conducted – are fundamental questions related to the methodology of gerontological research, regardless of the specific field involved. Meta-reflection on gerontological research must engage in the same discussion that continues to reverberate through mainstream philosophy of science. As in that case, the starting point may be a desire and search for objectivity in scientific research. However, it readily becomes apparent that the postulate of objective knowledge was already being overturned by Kant and his epistemological Copernican revolution. Since his time, philosophers and scientists have continually discussed the subject of science. The result of these debates is a general compromise known as the "scientific method" (Popper, 1959: 28), which involves the development of methods for collecting relevant data, creating logical generalizations that would explain such data and, finally, formulating ways to test those generalizations. The scientific method makes it possible to obtain knowledge that is "scientific" – i.e., proper, true and consistent with reality. In the opinion of twentieth-century philosophers of science (like, for example, T. Kuhn and I. Lakatos), it is only by observing the rules of this method that one can gain real knowledge about the world. The scientific method is considered to be a highly specialized tool for describing, explaining and understanding the world, which scientists employ in seeking answers to the questions posed and building a non-arbitrary, reliable and coherent image of the world. Traditionally, it has been said that it is a way of seeking the truth (Bronk, 2006); social, subjective, psychological and cultural elements obscure such truth and lead to a decrease in the quality of scientific knowledge. It might be said that the scientific method was the final weapon developed as a means of trying to answer the question of whether there is a specifically "scientific" approach to understanding the world. Here I do not want to delve into the history of the development of the scientific method or discuss the detailed debates about it conducted by philosophers of science (see Grant, 2005; Russo, 2005). However, it can be noted that when we presume the scientific method – with its strictly formalized procedures, advanced formal tools and cult of quantitative methods – to be the only means for learning the truth that might be acceptable to all scientists, this leads to a depreciation of qualitative methods, the humanities and the social sciences. It was thus only a matter of time before those fields would attempt to introduce other scientific paradigms. The trends of analytical philosophy (T. Kuhn, P. Feyerabend) and phenomenological philosophy (E. Husserl, M. Heidegger, H.-G. Gadamer) contributed to the recognition that the rejection of existing theories and adoption of new theories is determined largely by social factors and various research paradigms. Philosophers emphasize the social nature of scientific communities (T. Kuhn) and the "myth of method" (P. Feyerabend), which recognizes that the development of science thus far has only been possible because of approaches that contravened the sanctioned views of the scientific method. In the latter philosopher's view, the only rule that should be defended in science is the "anything goes" thesis which postulates that all ways of researching – even those that are "crazy" – are equally justified (Feyerabend, 1975). Similarly, Gadamer draws attention to the fact that the methodical way of knowing (as it is understood in science, and particularly in the natural sciences) cannot be applied in every field: "valuable" ways of knowing cannot simply be identified with "methodical ways". The scientific method only is not the only way to the truth (as various "scientisms" have claimed); rather, it sometimes even inhibits the development of knowledge (Gadamer, 1993).

And so, spurred by the recognition that other *perspectives* – whether cultural, social, individual, intersubjective, temporal, spatial or otherwise – possess the same level of importance (despite the lesser verifiability of their results), there have emerged over time other research approaches like the cognitive, existentialist, feminist, constructivist, phenomenological, postmodernist and deconstructivist perspectives. Researchers are willing to adopt a wider range of perspectives and to accept the *practices*, systems of practical activity and systems of attitudes, behaviors and beliefs that emerge within these perspectives. Along with them, *material and cultural products* – methodological, political and normative perspectives – enter the boundaries of research. The studied reality is not seen to be a finished thing given to human knowledge once and for all time, but as something created and constructed – which means that it also can be (and often is) imagined as something better; it is something that can be improved. Through such rebellion against the scientific method, it is possible to first recognize some separate reality that had been overlooked, and then somehow elaborate methods for studying it, after defining perspectives, practices and products. In this way, methods are shaped not only by that which is social and collective but also by that which is individual; they are formulated by (but also formulate and format) that which is social. The expectation that method will be something finished, structured and proven is – while dear to the creators of the scientific method – far from the minds of such researchers who are penetrating the human world and, within it, phenomena like ageing in a multidimensional perspective. They recognize that the human world is a realm that is boundless, open, multi-threaded and, to some extent, concealed. They agree to discover it piece by piece, in a fragmentary, non-total manner, but also (importantly) with a recognition of what is practical. In this fashion, a great transformation of science – and of that which is recognized as scientific – is underway. The horizons of researchers' interests are no longer defined by total systems of premises, axioms, laws, scientific theories, various conflicting "-isms" and a hope of absolutely determining the correctness of a given theory; such horizons are now being expanded by networks of practice, relationships, multiplicity, diversity, transgressiveness, praxeology, agility, technology, globality, selectivity and depth of study.

Such are the horizons that define our area of inquiry. It is a moment in the development of research and its methodology in which we move beyond extremes like nature/culture, human/inhuman, micro/macro and physical/mental and examine things like relations, dependencies, processes, actors, objects, institutions and strategies, with regard to their universalistic, holistic and transrelational nature.

Our location is another issue. Each of us is located somewhere, in some space, as well as in time and in a systemic, cultural and social context. This does not mean that research from such a perspective will be subjective; however, in the search for objectivity, one needs to be aware of one's "social location", which is precisely an embedding in a certain reality of time, space and culture. The awareness that full objectivity is not achievable – that objectivity is always, in some sense, partial – underlines the need not only to recognize one's social location but also to subject social knowledge bases to research. Knowledge creators, researchers and theorists are always part of what they study, and the methods they use should take this element into account, rather than pretending that it doesn't matter (Harding, 1993).

This book has been co-created by almost 50 authors from 11 countries around the world. Their social locations constitute a map with a fairly large geographical area. Among these "locations" – understood as both the terrain where studies have been performed as well as the terrain for scholarly, cultural and social reflection – we should mention Norway, the United States, Turkey, Portugal, Brazil, New Zealand, Canada, Ireland, South Africa, India, Chile, Australia, France, Germany, Sweden, Greece, the United Kingdom, Poland, Italy, the Netherlands, Taiwan, France, Japan, Israel, Austria, the Hong Kong Special Administrative Region of the People's Republic of China, rural China and Belarus. Thanks to such a diverse collection of research areas (and the international diversity of the researchers and methodologists who are the volume's authors), a reader will be able to encounter social locations on a global scale, while also having the opportunity to carry out his or her own meta-reflection on the parallel methodologies employed in various places around the world.

This can serve as the beginning of a discussion about reconciling various research patterns – but it also demonstrates the extraordinary richness of the fundamental field of human activity that is the conducting of research.

The intention of this publication's authors was not so much to create a textbook from which students in various countries of the world who are studying gerontological questions could draw instructions, definitions, tips and guidelines for conducting their research; rather, the objective has been more about capturing the wealth of methodological thought and encouraging the reader to undertake his or her own theoretical search. Above all, the book aims to share its authors' own experiences and research reflections in order to inspire ever better research-based representations – whether they be objective, intersubjective, subjective, known, constructed or transformed – of the reality of the ageing world. It is hoped that the publication can contribute to discussions on the methods and subjects of studies, applications, collaboration and ways of drawing on the achievements of other research disciplines and fields.

One main purpose of the publication is to explore the diversity of methodological aspects of research around ageing and to contextualize it within a discussion about which of the main methodological paradigms more effectively and reliably illustrate the phenomenon of ageing. This goal fits within the ongoing conversation between researchers employing qualitative and quantitative paradigms. The objective of the publication is not so much an exchange of arguments involving these two approaches, but rather the reconciliation of the conditions of their coherence and complementarity. Interdisciplinary and social perspectives, as well as the qualitative dimension of research on old age, are emphasized.

The editorial decision was made to highlight this wealth of reflection on gerontological research through arrangement of the book's content into particular parts. The first part includes chapters that consider gerontological research in relation to (and using) the methodological output of other fields that study and describe the world, such as philosophy, sociology, legal science, economics, and management and marketing.

The book opens with a chapter from Zbigniew Woźniak that highlights a multidisciplinary perspective in the search for context for research into old age. It shows the correlation between the approaches of gerontology and other scientific disciplines and their tangent points. The author formulates a useful tabular summary about research priorities in gerontology, the functions and aims of gerontological diagnosis, and categorial profiles of older adults.

In the chapter by Angus McMurtry and Jenny Sasser, the authors illustrate the difference between multidisciplinary and interdisciplinary/transdisciplinary approaches to ageing and gerontology. It is a rare phenomenon in gerontological research and reflection to investigate deeper interdisciplinary interdependencies and to attempt to formulate a perspective that considers in depth the interdisciplinary relationships existing in research on old age. However, it seems that gerontological studies constitute a fruitful material for such reflections, due to their "genetic" involvement with many disciplines.

In their chapter, Martine Lagacé, Najat Firzly and Alura Zhang rely on a qualitative methodology for a scoping review. Such scoping reviews allow for the identification of broad and common themes related to a topic. In this particular case – in which self-reported scales of ageism in the workplace were studied – the scoping review has made it possible to assess the psychometric properties of the scales as well as the dimensions of ageism that they address.

Marcel Mérette and Julien Navaux investigate ageing in the population using National Transfer Accounts (NTA), showing how the NTA is an extension of the System of National Accounts (SNA). Such systems make it possible to implement complete and consistent techniques for measuring the economic activity of a nation or a region. SNA accounts quantify in a rigorous way fundamental economic variables such as production, consumption, savings and investment. NTA extends SNA at the individual level for each age. Such extension is necessary for a deep investigation of the economic implications of population ageing. About 90 countries have developed NTA at the national level, and the data provided by these countries allows interesting international comparisons. A reference manual published by the United Nations in 2013 describes the technical details of NTA.

Anna Szafranek shows that a methodology for research into the protection of older adults' fundamental rights should include: (1) the legal perspective (research into the implementation and effectiveness of particular legal acts), (2) the administrative perspective (research related to the effectiveness of institutions that reinforce the law) and (3) the perspective of the relationship between institutional and socio-economic factors. All the aforementioned perspectives ought to intertwine, in order to present the phenomenon in the broadest possible way. Research into the protection of the fundamental rights of older adults was carried out using a qualitative, narrative, gerontological approach, and the chapter presents this context.

In her chapter about ethical perspectives in gerontological research, Maria Łuszczyńska argues that every well-constructed methodological framework must also take into account ethical assumptions. The chapter illustrates the way in which these assumption permeate every stage of the research process; it also proposes audit questions for each stage that verify a given research procedure's orientation toward the ethical dimension.

The second part of the book presents various research perspectives. Here the intention was to move beyond the age-old methodological dichotomy of quantitative and qualitative approaches and to show mixed models, along with other perspectives such as the cultural model, life course perspective, longitudinal statistical models and approaches to studying sensitive issues. Among other topics, this part investigates previous considerations on the inclusion of a researcher in methodological reflection, especially when the researcher intends for his or her research activity to encompass a larger segment of reality.

Combining design research and social innovation methodologies, Yanki Lee focuses on the observations of T. Blair and M. Minkler (2009) on why researchers do not conduct Participatory Action Research (PAR) but continue to employ the more traditional investigator-driven gerontological methodology.

Barbara Szatur-Jaworska shows that the life course perspective can be adopted in research belonging to either the normative or interpretative paradigm (according to the division proposed by Thomas P. Wilson). The chapter describes two life course conceptualizations: (1) as a normative social construct and (2) as an empirically experienced process of biological, psychological and social changes in an individual's life.

Annie Robitaille and Graciela Muniz Terrera consider methodology, with a focus on the different statistical models used to study the ageing process when longitudinal data is available. More specifically, the latent growth curve model, multivariate latent growth curve model, latent growth curve model with a time-varying covariate, latent class analysis, growth mixture model, multi-state model and change point model are discussed in the context of ageing.

Piotr Czekanowski deals with concepts generally employed in the methodology of social research, such as quantitative, qualitative and mixed approaches, research methods, techniques and tools. The considerations presented in his chapter touch on the differing treatment of quantitative and qualitative methods, which has been consciously reduced primarily to a technical (i.e., neutral) distinction between these methods. In the background of the issues presented in this chapter, the author also references the theoretical positivist approach, usually associated with quantitative methods and focused on the standardization of research, and the humanistic approach associated with various interpretative trends.

Using qualitative methods (in-depth interviews and narrative interviews), Małgorzata Halicka and Jerzy Halicki reflect on research into sensitive topics within the area of violence. They show how to prepare, conduct and summarize such research, whose narrators find themselves in a very specific situation. They also analyze the importance of the research attitude and action when issues of harm are on table. Their study involved research conducted in Poland as well as one project in Belarus.

In her chapter, Carolin Kollewe discusses how research on old age can be innovated through perspectives that have become paramount in the social and cultural sciences in recent years, in particular those used in material culture studies and science and technology studies. In concrete terms, this calls for a qualitative, in-depth, reconstructive investigation. Regarding methodology, such an approach starts from the various material objects that are employed in people's everyday social practices and looks at related representations. On the one hand, such an approach analyzes the diverse social meanings that are both attached to objects by the individuals using them and materialized in these objects. On the other hand, by investigating social practices in which these objects take part, it is possible to unravel how people and things co-construct old age and ageing practically. To analyze how age and ageing are constituted, the study that Kollewe presents as an example employs the methods of object description, participant observation and interviews. Concomitantly, her analysis is based on an inductive and hermeneutical approach, partly influenced by the methodology of grounded theory (Glaser and Strauss, 1967) and its latter elaboration as situational analysis (Clarke, 2005).

Henglien Lisa Chen has prepared a chapter that fills a significant gap in the discussion of qualitative research methods and methodologies in cross-national comparisons by a solo researcher. It details the challenges and opportunities inherent in conducting cross-national research in long-term care of older people by a solo researcher using qualitative methods, which has been rarely been carried out or discussed. The chapter identifies and addresses the central challenges of time and space, comparability and the culture and language encountered in the research process, as a means of illustrating this distinctive methodological approach. The chapter draws on a cross-national study from a PhD project.

The third part of the book deals with issues connected with the use of research results. The authors consider the role of studies aimed at improving not only living conditions, health, physical activity and fitness but also mental condition and social relations. These chapters contribute to a discussion of the role that a study's utility should play in research, while also illustrating various tools like the SoBeezy program gerontopoles and social marketing, which can constitute a meta-reflection of the scope, meaning, purpose and consequences of the treatment of ageing research as application research.

The team of French colleagues comprising Linda Cambon, François Alla and Karine Pérès considers ageing interventions as complex interventions. Hence, they refer to the paradigm for the evaluation of complex interventions developed in the guidelines of the Medical Research Council (MRC). In particular, this highlights the process of evaluation that is necessary for understanding how complex interventions work. This evaluation helps define the conditions of transferability of interventions by understanding their mechanisms of effect. More precisely, the authors argue that one of the various existing evaluation paradigms – that of theory-driven evaluation – makes it possible to understand these mechanisms and should be thus integrated in all evaluation designs. Moreover, they recognize the social utility of intervention research and advocate for the consideration of real-world conditions in intervention design and evaluation through viability studies.

Elise Verot and Alexandra Lelia Dima demonstrate how mixed-methods designs are increasingly being applied in order to combine different types of complementary evidence for developing new care protocols and tools. Implementation science is emerging as a rich set of practical tools for generating evidence that can guide organizational change processes at different levels of the healthcare system, and the authors discuss the research procedures that support it.

Though there is now agreement that physical activity (PA) is effective in practice, there are many barriers to participation. Indeed, several such barriers exist among the elderly, such as a belief that one is no longer able to participate because of a loss of physical capacity, an image of sport as being for young, healthy people, and poor awareness of the tailored activities on offer. Luc Goethals, Nathalie Barth, David Hupin, Frederic Roche, Karine Gallopel-Morvan and Bienvenu Bongue argue that campaigns promoting physical activity generally have the ultimate goal of changing the behavior of individuals. However, between campaign exposure and behavioral change, several steps are needed – i.e., changing beliefs, attitudes and intentions. Very often, evaluation of the effectiveness of preventive campaigns is limited to measures of recall of the message and of appreciation of advertising. But is knowing the key recommendations that promote physical activity among seniors enough to change behaviors? Social marketing research emphasizes the need to focus on behavioral change to identify effective levers for preventive action.

The next chapter presents the gerontopoles as a unifying structure of all the actors of a region. In this context, collaboration is essential for carrying out projects. Theoretical approaches related to such collaboration have made it possible to define different concepts such as transactive memory, coordination, collaboration and cooperation. The research by Nathalie Barth, Clara Pizzolo, Solène Dorier, Régis Gonthier and Thomas Célarier demonstrates the effectiveness of collaborative work within teams and the partnership work that appears essential to the success of gerontopoles. Finally, the methodology of the Living Lab seems to be central in the actions of gerontopoles that wish to place the user at the heart of projects. Specific research on the different Living Labs of gerontopoles could advance the work of this first chapter to investigate the importance of this innovative methodology.

Daniela Wetzelhütter, Katrin Hasengruber, Renate Kränzl-Nagl and Tina Ortner develop a model based on the modified stress–strain concept (Metz and Rothe, 2017) to measure the influences upon and consequences of subjectively perceived work-based stressors among people working in nursing and care. Their aim was to compare different nursing and care concepts to identify differences in people's subjective perception of work-related stressors. A summative evaluation design was therefore applied: more precisely, a semi-experimental design with a control group and an experimental group, collecting data in two waves ("before and after" measurements). This permits the simultaneous evaluation of the experimental group (in which a new concept is introduced) in one or more care homes and the control group (in which the specific concept is not implemented) in comparable care homes. Changes over time can thus be studied under controlled conditions.

Einav Segev and Yael Hochman, who are qualitative researchers, have grounded their research methodology in postmodernist and constructivist theories of reality and of how it should be explored. The model they use in the chapter has thus enabled them to observe participants' subjective perception of their loss and of family relationships. This was accomplished within the phenomenological tradition that seeks to explore phenomena from the perspective of those who experience them. The model is based also on the ecosystems theory (Bronfenbrenner, 1979) that enables exploration of relationships in various environments – here, the subjective perception of participants in the research, dyadic relationships and integrative observation of all the families that participated in the study.

The fourth and final part of the book focuses on our primary sources of knowledge about ageing – i.e., on the persons directly affected by this process. This part begins with a chapter about involving older people themselves in research into old age, with the authors pointing out the strengths and weaknesses of this research technique. In this part of the book, one can also learn how to conduct research with residents of nursing homes who have impaired communication or are less educated and learn about the Photovoice technique as used in participatory research.

The chapter prepared by the Hong Kong research team comprising Ke Chen, Justin Chun Ting Cheung, Joy Juan Wang and Vivian Wei Qun Lou is a part of a growing body of studies that involve older adults as co-researchers in the study of ageing – a participatory peer research method. As described by Glanz and Neikrug (1997), "Those who are intended to benefit from the research should be involved from its inception in the formulation of the research agenda and conceptualization of the research questions and design, as well as its implementation." Critical questions are immediately raised: in what kind of research activities and to what extent should older people be involved? Who should shape the research agenda and carry out the research? What are the roles of older people and academic researchers? What is the impact on the research process and validity of involving lay older people as research partners? How should the ethical and practical issues and risks of using this method be managed? There are various strands to the discussion, and many gerontologists are hesitant to embrace this method, because a coherent and systematic framework has not yet been developed, and there are very few models of good practice on which to draw.

In their chapter, Linda J. Garcia and Louise Bélanger-Hardy focus on participant selection in research, and more specifically on the involvement of older adults with difficulties in communication. Until recently, actors within the research community have been hesitant to include participants whom they perceive as lacking the capacity for providing informed consent because of age or functional limitations or to adapt their protocols to those who may struggle to offer information during language-dependent tasks. According to the authors, this trend is changing, and researchers, institutional review boards and granting agencies are increasingly encouraged to be more inclusive in their practices. Relying on an ethico-legal framework, Garcia and Belanger-Hardy consider some of the perceived limits on participation, including capacity, informed consent, substitute decision-making and, finally, the notion of vulnerability. After noting that international human rights instruments provide a strong basis for the inclusion of older adults in research protocols, they argue that researchers must provide a "safe space" for participants to fully take part in research projects. Drawing on the developing literature on the inclusion of dementia patients in research and the extensive literature on aphasia, the authors highlight a number of suggested strategies to increase participation in research of older adults with communication challenges while ensuring their safety and well-being.

In exploring the life experience of rural older adults, Shirly HZ Chen and Vivian Wei Qun Lou use a life-story interview strategy that was facilitated by the life story method and oral history method, with technical matters having been adjusted. Unlike a traditional life-story approach or oral history method that emphasizes the "natural emergence" of participants' life experience, this strategy suggests a starting point, a triggering "linguistic frame" and an "acceptable interview field" to promote interview involvement.

Although a growing number of studies deal with quality of life among nursing home residents, only a small number examine the practical aspects of such research in any detail. Against this background, Renate Kränzl-Nagl and Daniela Wetzelhütter focus in their chapter on the preparation and implementation of research activities in nursing homes for the elderly, based on experiences of research carried out in Austrian nursing homes. Special attention is given to methodological challenges with regard to the individual steps in the process of investigation. This chapter's contribution is also characterized by a multi-perspective approach that considers numerous actors in the context of research in nursing homes for the elderly. The model of factors influencing empirical research with nursing home residents developed by Ackermann (2005) provides the theoretical approach for the analysis undertaken in this chapter.

Photovoice, a participatory research methodology, facilitates the elucidation of the experience of certain populations and groups through the use of photography. Building on general principles for how to use this methodology, this study conducted by Frances Lu Yang, Vivian Wei Qun Lou and Carman Ka-Man To has flexibly adapted it for investigating the specific population group of male caregivers in Hong Kong. This adaptation affects how Photovoice is defined in the context of this study, in that the collaboration between researchers and participants and the empowerment of participants should be emphasized. Rooted in the theoretical assumptions of critical consciousness, feminist theory and phenomenology, Photovoice is redefined in this study.

The division into parts adopted for the book – along with the content of the individual chapters – tries to capture those diverse aspects of gerontological research that may develop over time as subdisciplines of gerontology. It is also worth noting what has been left out of the book: nowhere will the reader encounter a tabular summary of old age research methods. Such a comparison could be made with regard to the thought of the authors of this book, but we recognize that it would be only a fragment of the possible research reality. Moreover, our aim was to prepare a publication that is primarily inspirational rather than educational in nature; we have therefore consciously avoided a framework that primarily organizes reflections from gerontological research on the basis of their use of, for example, feminist, historical, existential, naturalistic and other perspectives – although elements of these perspectives appear in individual chapters.

How, then, should "methods" and "methodologies" be understood when introducing a book whose title speaks of methodological challenges? Most generally, method can be understood in accordance with its etymology as following someone, as moving along a path (from the Greek *methodos*, or *meta* and *hodos*). Understood broadly, it means a way or path of conduct, which is divided into steps or stages that must be performed in a certain order so as to achieve a certain goal, to accomplish a given task. Scientifically understood, method indicates a way of solving theoretical or practical problems (Kotarbiński, 1961: 516). Functionally, a method is a system of more or less ordered activities (i.e., occurring in a specific sequence) that serves to increase the efficiency and economy of a certain action. When it comes to a directive or regulatory understanding, method is a set of more or less uniform provisions (i.e., rules, directives, guidelines or maxims) that determine the course of a certain action, facilitating the more effective and economical implementation of a specific goal or solution for a specific task. The term "method" (*methodus*) appeared in Latin culture in the twelfth century as a translation or calque of the Greek *methodos*, gradually displacing (in knowledge-related contexts) earlier translations that employed terms like *via*, *ars*, *ratio*, *disciplina*, *doctrina*, *regula*, *compendium*, *habitus*, *scientia* and *techne*. In the concept of method there is something of a norm, but also of art and invention (Bronk, 2006). Nowadays, method is associated with a mode of action, the achievement of goals, a technique of operation, a technology of operation or instructions for operation. What is important is that method is related to action; it has a practical dimension and therefore can be modeled, modified and transformed. It is therefore creative; that is its general context.

What sort of understanding of methodology do the authors of this publication present? We define methodology as a framework and justification for pursuing research. Methodology must suit the phenomenon that one is studying and the research context, including one's own position as a researcher. We would also argue that interdisciplinary integration and transdisciplinary collaborative action constitute valuable methodological frameworks. Methodology places value on conducting research in a particular way and determines how studies are conducted. Moreover, the authors emphasize the practical dimension of research. It should serve some goal by contributing to positive change for a specific population along a particular social, cultural, political, economic, health or other dimension. This reality brings with it an emphasis on reliability in preparing the whole process, as well as an awareness of fact that choosing the purpose for which the research effort will be undertaken and (later) choosing the research methods and sources of knowledge constitute the most "authorial" moments of the research process for one studying old age, in which researchers can explore the limits of their imagination.

It is undeniable that the researcher permeates the entire research process. Such a researcher moves in a world with a great diversity and abundance of research fields, topics, methods, tools and innovative approaches, as well as of cultural circles and social locations. The quality of the entire research process depends on the researcher's inventiveness, insightfulness, dependability and courage, as well as on the ability to cooperate in an investigating team. The art of research (including gerontological research) is dependent on the manner in which a researcher deals with diversity and differences – between the researcher and the source of knowledge, between his or her attitude and reality, between the researcher and other people's ideas – and on the way in which such diversity and differences are found. A researcher is supposed to transform the world, expanding borders (if only to a small degree) and creating alternative and better solutions. This does not mean that one must accept that everything is possible and that the world consists of infinite possibilities – and that one just needs to find a method that is innovative enough in order to turn it upside down. And yet, a wide range of research methods is at the disposal of the researcher, and it is worth studying the experiences and reflections of other practitioners of research on old age in order to search for and find inspiration.

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It is my hope that all readers will find in this publication a source of inspiration and encouragement for working to change the situation of older persons, because the changes that we are able to make now will lay the groundwork for a better experience of ageing for future generations – and for ourselves.

Note

1 The term itself was created in 1903 by Élie Metchnikoff (1845–1916), a Russian microbiologist living and working in France, for whom "gerontology" was understood as the science of old age.

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Part I

Peculiarity of research on ageing in the context of other research areas

1 Older adults – terra incognita?*

Zbigniew Woźniak

This chapter makes an attempt to show the richness of gerontological areas of research. It shows the correlation between the gerontological and other scientific disciplines approaches and their tangent points. The author makes the useful tabular summary about the research priorities in gerontology, functions and aims of gerontological diagnosis and categorial profiles of older adults.

The chapter also reveals the gaps in knowledge about ageing and old age indicated by international experts, and signals the need to synthesize the national achievements of gerontology and to undertake in-depth research on the profiles of older people revealing the real diversity of older citizens. For this purpose, it is necessary to establish the National Gerontology Institute to coordinate research on the ageing and old age process in Poland and to collect and synthesize the achievements of Polish and world gerontology.

Introduction

Ageing is not one but several processes, characterized by an individual, ontogenic course, which don't manifest themselves during the same period of life or in the equal manner. Not all changes occur simultaneously and their individual and social consequences alter depending on the living conditions, place, time, sex or the social status of the ageing person. The majority of changes evidenced among ageing people are associated with the normal physiological process of ageing of cells, organs and systems; however, some of them stem from pathologies (chronic diseases), others are the effect of the excess use or disuse of life resources (lifestyle, organization of collective life).

Ageing as a state may generate so-called personal problems, which are related to and focused on one individual (e.g., poor health and mobility, poverty, lack of social contacts) and their immediate environment. Not every individual case becomes a public issue but, if it does, it can impact on personal problems in lives of particular people. In such an approach, old age is not a social problem per se[1] but the effects of population ageing may bring social problems that require a deliberate intervention of various collective and individual entities in order to resolve, eliminate or even alleviate them.

Population ageing also poses questions of an ethical and political nature with regard to older adults' equal access to resources and their distribution, full participation of the eldest generation in social life, improvement of the quality of life of ageing citizens, selecting the method of medical and social intervention which is adequate to their state of health, the proportion of public and private funding for care, delaying and accelerating death of an ageing person. Moral dilemmas are also posed by issues connected with public and private expenditure in long-term care, access to this sort of care and its duration, as well as the protection of civil rights of poor, disabled and older people.

Old age (the state) and ageing (the process) are sufficiently varied in their manifestations so that we may, depending on the problems we consider/describe/resolve (health and physical condition, psycho-emotional support, activity, conditions and quality of life, social status, estimation of needs senior citizens, development of the institutional infrastructure of care for the eldest etc.), build:

1 multidimensional, interdisciplinary and holistic concepts, models, patterns of ageing and differentiation of situation of the eldest generation in terms of their status (the theoretical and cognitive function: basic research of the universal, bio-psychosocial aspects of ageing and its consequences, conducted within particular branches of science – Figure 1.1);
2 empirically documented profiles of older adults that are varied depending on their health, socio-demographic, socio-economic and cultural features (the implementational function – utilitarian objectives: the development of the social policy strategy aimed at older adults and creating gerontological programs – see Table 1.2, later in the chapter).

Science must, therefore, make an effort to elucidate the multidisciplinary knowledge on the sources, diverse forms and manifestations of the process of ageing for the real world of

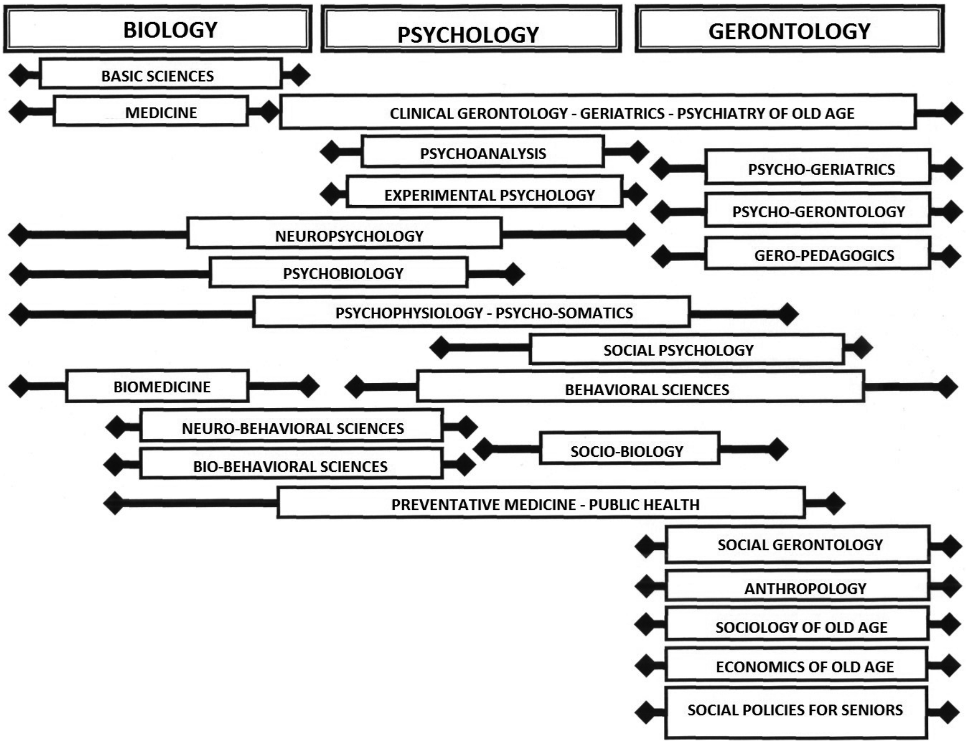

Figure 1.1 The interdisciplinary character of the knowledge of ageing and old age.

Source: updated and extended proposal of Eyde and Rich (1983: 39).

ageing people, as well as to rebuild and bring to public awareness the problems caused by ageing of populations and individuals. Thus, having a relatively accurate diagnosis of the situation is essential to describe and explain the phenomena related to ageing as well as to assign steps that are adequate to the situation and potential of older adults and allow them to age in a satisfying manner and provide health and social security which is worthy of a person and a citizen.

The majority of countries with an ageing demographic structure (particularly those at different stages of a political transformation) face the necessity of expanding the area of research on ageing and funding for it.

The most frequently researched areas include the following (Bengtson, Putney and Johnson, 2005: 3–20; Bartlett and Harper, 2006; Andrews et al., 2006: 7–14):

1. demographic trends;
2. issues related with the role of grandparents;
3. the informal input (contribution) of the eldest generation for the family and local community (e.g., child-minding, help in running the household of their offspring, intergenerational transfers, voluntary work of older adults, involvement in activities for local development);
4. matters pertaining to the productivity of older adults and their presence in the labor market;
5. analysis of the infrastructure necessary in the process of facilitating autonomy and independence of the eldest generation (e.g., housing, healthcare and welfare, pensions);
6. care for older adults (e.g., potential carers).

In view of inadequate gerontological knowledge, international expert groups, having reviewed the subject research to date, have been signaling, for several years, an urgent need for expanding the research area, taking into account a few significant methodological issues (see Table 1.1).

Over recent years, there has been a growing number of social policy strategies and/or solutions aimed at various social categories, adopted by public authorities on different levels. However, this is not accompanied by the development of universal diagnostic tools, employed in repeated research and comparative inter-regional studies on the regional/district level. Despite the modest number of geriatricians, particularly gerontologists (in Poland, gerontology is still “patchy” in nature), there is a relatively large body of research that is thematically repetitive, non-representative and restricted territorially, which offers descriptive material for select categories of older adults, the state of their health and constitution, material and social needs etc.

The process of population ageing is not only a cost/burden, but it is also a unique opportunity for making use of the potential of older people and, at the same time, a necessity to deal with the needs of a society characterized by a large share of the eldest generation in its structure (in the family, local community, greater social groups). Thus, there is a need for obtaining a multidisciplinary diagnosis (empirical knowledge) performing the cognitive, analytical, educational, managerial, motivational and lobbying function, which allows synchronizing various policies (population, economic, health, social) and proper allocation of assistance for the eldest generation (Table 1.2).

The objective and extended view of Polish old age is distorted by the one-dimensional, polarity-based perception both of the process of ageing as well as of older persons:

Table 1.1 Research priorities in gerontology indicated by international experts

Key methodological challenges
A necessity for developing, consolidating/unifying appropriate concepts, notions and standardization of research tools that would allow comparative analyses of the situation, needs and functioning of older adults on the international, national, regional and local level. Developing methods for integrating bio-psycho-social research with due diligence for securing high ethical standards (particularly in the new areas of bio- and psycho-medical research) coupled with accepting social responsibility for interpretation of findings and their dissemination as well as protection of human and citizen rights and privacy of test subjects. Priority for multifaceted longitudinal research (cohort and intergenerational studies) allowing tracking of the process of ageing and its consequences on the individual and social group level. Consolidating and archiving information originating from various sources, including data bases, as well as conducting primary and secondary analyses of existing data, followed by sharing the data with international and national researchers.

Problem	*Research priorities*	*Research indicated as urgent*
Macrosocial changes and development.	Mutual relations: ageing population and socio-economic development. Scenarios for the projected development of the ageing society. Older adults' contribution to the collective life – economic intergenerational transfers. Senior citizens in the labor market and the function of the "silver economy". Current and optional forms of maintaining/fostering economic security of ageing citizens.	Documenting, monitoring and analysis of the influence of demographic transformations on the functioning of older adults and society as a whole. Needs of the eldest generation caused by economic and technological changes. Ability to work and possibilities for employment for older people (man for work–work for man). Older adults as consumers. Redistribution and transfers of public funding and material and financial resources and services for older adults. Identification and categorization of risk factors for the loss of life independence of the eldest (old-old) people as well as those qualified as members of the "socially vulnerable groups". Level and correlates of poverty in various categories of older adults.

Health, fitness and well-being of older adults.	Interactions between the genetic and biological markers, environment and health behaviors of ageing people. Biomedical, social and economic implications of health and life span (including biotechnology and anti-ageing medicine programs). Mental health and old age. Epidemiology and determinants of major diseases and disabilities of older people. Geriatric care – infrastructure and human resources.	Individual and social correlates of healthy ageing of men and women. Effectiveness of programs for promoting health and preventive treatment. Availability of medical benefits and services to older adults. Intervention and rehabilitation strategies intended for persons at risk of disability. Long-term and palliative care – the demand and supply of institutional and informal caregivers.
Quality of life in old age.	Establishing working definitions and indicators for the quality of life on the national/international level. Meta-analysis of the quality of life of older adults, based on the available research results. Key parameters of the quality of life of ageing people in the physical, psychological, spiritual and social dimension (hierarchization of parameters). Environmental diversity of the quality of life among older adults.	Indicators for the quality of life of older adults (existential profile, relations with the environment as well as achievement of personal goals, fulfilment of needs and aspirations). Quality of life of older adults living with their families, in independent households as well as those living in care centers. Quality of life of the eldest (old-old) citizens. Adaptive strategies of older adults and coping with difficult situations.
Social integration and participation of older adults.	Intergenerational relations – the perception of old age by generations on the extreme ends. Determinants of the participation of older adults in the social mainstream. Manifestations and level of age discrimination (ageism). Older adults in the education system.	Strategies and programs for intergenerational integration in local communities and larger groups. Image of old age and social attitudes towards old age and older adults. Adaptive strategies and programs of the education system aimed at the needs and challenges posed by population ageing (adult education, lifelong learning, retraining, requalifying etc.). Psychosocial determinants of social integration and participation of older adults (*priority*: persons living alone and socially vulnerable groups). Manifestations and level of the integration of residents of care centers with the environment. Extent and correlates of negligence, abuse, exploitation and violence against older adults. Social marginalization and isolation of older adults in the countryside and city.

continued

Table 1.1 Continued

Problem	*Research priorities*	*Research indicated as urgent*
Family of an older person.	Older adult in the family and the senior's family. Family roles of older adults. Intergenerational transfers in the family.	Changes in the structure and functions of a family with an older adult. Benefits/drawbacks as well as barriers related to an older person's dwelling with their family. Functioning of older adults running an independent, single-person household (priority: *aged people*). Family caregivers – resources, competencies and needs.
Welfare systems aimed at citizens in later life.	The impact of changes in the structure and functions of the family on the shape of the care and welfare system for older adults. Older patients' access to medical services on each reference level of the welfare system.	Determinants of older adults' capacity for self-care. Documenting, monitoring and designing resources and forms of formal and informal care for persons in later life. Neighbors as a potential source of assistance for older adults. Situation and functioning of residents of care facilities.
Social policy against ageing and in aid of older adults.	Objectives and tasks of the gerontological social policy as well as directions of development of gerontological programs (needs of today – capabilities of tomorrow). Evaluation of the expenditures-effects relation in governmental, self-governmental and non-governmental policies for older adults as well as gerontological programs.	Place of gerontological policy in goals and tasks of the social policy. Strategies of gerontological policy and the periodical evaluation of effects. Collecting and disseminating "good practices" in social policy – foreign, national and local practices. Influence of migration on the employment policy of ageing people.

Sources: Powell and Biggs, 2003: 2; Bengtson, Putney and Johnson, 2005: 3–20; Bartlett and Harper, 2006; Andrews et al., 2006: 7–14; Blood and Bamford, 2010; Araujo de Carvalho et al., 2012; Czekanowski 2012).

1 Pole One presents old age as an individual's life drama, a time permeated by anguish and despair, a period perceived solely through the prism of deficits and pathologies, rising costs of living, medical treatment and care of the eldest generation. This over-medicalized image of old age and ageing does not foster the proper understanding of these phenomena by the other participants of the collective life, nor does it contribute to changing the negative image of old age in public awareness or devising programs intended for diverse categories of older persons. The reality refutes this over-medicalized vision of old age since gerontological research findings conclude that despite the increased frequency of chronic diseases among older adults, the majority function independently (even among representatives of the most aged groups). Indeed, we may observe long-term medical conditions among older adults, however, only 3–4 percent of them are bedridden or use wheelchairs, a further 6 percent experience problems with moving around their apartments and, lastly, another 6 percent are unable to leave their homes. It may thus be stated that depending on the country, approximately 70–80 percent of older adults function autonomously, in spite of their diseases and impairments, whereas only a small part of them require specialized forms of support and care from their environment (Woźniak, 2016).
2 Pole Two is dominated by the over-optimistic (heroic) models of old age, resembling manifestos, of sorts, characteristic for minority groups. Such perceptions are common among socially active older adults and/or organizations advocating for older adults, which is not really conducive to objectivizing the situation and potential of older adults. In this convention of idealizing old age we may also find endless and futile discussions on the appropriateness of using, in speech and writing, the terms that have been in use for decades, such as "old person", "old people", "the elderly", in turn, proposing the more favorable words such as "older persons", "ageing people", "members of the third age", "seniors" etc., which is dictated by political correctness and not completely justified moral argumentation (dignity, respect). Nevertheless, the "alchemy" of wording will not be able to "re-forge" attitudes and behaviors that discriminate against old age into positive counterparts. Therefore, all possible names defining persons belonging to the "third age" should be employed as synonyms, without any intentions of valuating the use of "harder" terms pertaining to old age or ageing. This does not undermine the image of the older generation, whereas using them interchangeably in texts undoubtedly allows authors to avoid frequent repetitions, which improves the clarity of the message. I am one of the few who opt for the use of these notions as synonymous. I have been "called to order" for refraining from the use of euphemisms more than once; nevertheless, whenever I address this issue, I recall a situation which took place many years ago when I was asked by one of the participants of classes of the University of the Third Age about the use of the term: "an older person? – older than whom?" (Czekanowski, 2012: 104–107).

The "polarity" of the overview of problems experienced by older adults in Poland is "sustained" by the following gaps and inadequacies of knowledge on ageing and old age:[2]

1 absence of syntheses – prevalence of frequently repeated studies of issues of the secondary nature and local scope, characterized by a low degree of generality;
2 lack of longitudinal studies that would allow examining processes and phenomena related to ageing of individuals and populations (it is a secondary effect of the way science is funded);

Table 1.2 Functions and aims of gerontological diagnosis

Cognitive function

Making use of the existing, and always limited, potential of institutions, organizations (including the non-governmental sector), social benefits and services as well as taking political decisions which are rational and adequate to needs, necessitates that the decision-makers are in possession of the information that is suitable, objective and available at the right time. In order to initiate a program of creating an effective strategy of social (senior) policy, it is essential to find answers to the following questions:

1 What is contained within the information resources at the disposal of public authorities that may be used for the benefit of the system of social support?
2 What sort of data from this source may be useful for diagnostic and professional purposes?
3 What information is still missing on the level of national/regional/local structures in order to achieve a complete picture of resources available for gerontological programs?
4 What data will have to be input to routine reports of all sectors so that programs intended to resolve problems of older adults are effective and pertinent to their needs?

Research and analytical function

Public authorities must/should have at their disposal an information-diagnostic system which expands the “signal network”, which fosters better understanding of needs, social expectations, opinions of decision-makers and executors (officials), who guarantee proper allocation of assistance, control over the use of resources and modifying (expanding) the array of benefits and services in the sector of social services and welfare. The goal of the diagnosis is to obtain information concerning the state and needs of citizens in later life as well as institutional resources in order to:

1 know, so that events can be predicted and pre-empted;
2 assess the potential, functioning and access to the infrastructure supporting gerontological programs;
3 categorize the areas of life of ageing citizens who are under the threat of dysfunctionality, requiring a reaction/support;
4 make realistic choices that are appropriate to older adults’ needs and projections of future policies.

Educational function

Work on the development of the program and monitoring of the social policy strategy intended for the eldest generation ought to be the basis for evaluation of the effectiveness of inputs and outputs (evaluation) for public authorities. The experiences of joint efforts, however, should serve the education of all participants of the process of planning, carrying out and assessing gerontological strategies and programs (assessment of substantive issues and civic opinions of older adults themselves)

Managerial function

Results of analyses, recommendations and projections based on diagnosis ought to provide public authorities with the following tools:

1 decision-making support at various stages of implementations of social programs and current tasks;
2 development of strategies and tasks of strategies aimed at different segments of the population of older adults (profiles of older adults and risk groups);
3 assessment of their own situation as compared with other self-government entities of the region/country;
4 synchronization of various policies (population, economic, health, social etc.).

Motivational function

1 Research reports, analyses and interpretations provide public authorities with evidence that the information and reports that are passed on:
  a don't disappear without a trace but return to authors and their partners in the form of synthetic publications, proposals for changes/amendments of the current and future actions;
  b become useful in the daily work of local governments and the public administration;
  c allow partners of local authorities to objectivize their own position toward public affairs;
2 diagnosis provides data enabling promoting and disseminating original and innovative solutions for the social policy and sectoral policies (including the senior policy) as well as the social support system.

Lobbying function

Analytical and program materials generated in the course of devising the strategy for the senior social policy and its programs should aim at:

1 playing the role of the advocate of interests of the eldest generation in relations with public authorities of all levels as well as institutions and organizations;
2 promoting innovative solutions in gerontological programs at various organizational levels of public authorities, the public and civic sector as well as the media;
3 promoting organizational and institutional solutions for expanding the range of services and benefits as well as assuring their quality.

Source: author's own elaboration.

3 scarcity of research projects that would allow creating generic categories from databases of particulars:
    a corresponding to the health and psychosocial diversity,
    b constituting a premise and foundation for developing well-aimed gerontological programs,
    c useful to a wide array of intended recipients of this kind of information (science, public authorities, non-governmental sector, media, etc.) as well as its dissemination;
4 shortage of comparative studies of the social situation and functioning of older adults in the family, local community, region, country and within the European Union;
5 too great arbitrariness of the use of terms and notions in empirical research.

Thus, there is a need for a more comprehensive and extensive array of research programs characterized by a diversity of issues and in-depth analyses since, generally, studies are conducted and repeated in different parts of the country and consist in sociographic research of selected problems related to the ageing and situation of the elderly by means of the so-called boundary values (variables are described separately: age, sex, health condition etc.).

In this situation, a pressing issue would also be establishing the National Institute of Gerontology (NIG),[3] which would:

1 coordinate research on the process of ageing and old age in Poland;
2 gather and synthesize the scientific output of Polish and world gerontology;
3 perform diagnostic and prognostic functions;
4 constitute a platform for the exchange of experiences of national and international researchers and practitioners;
5 educate gerontological staff (postgraduate education);
6 combine objectivized knowledge with concepts and proposals of public authorities in the process of developing strategies for resolving issues and satisfying needs of older adults;
7 be a center for formulating premises justifying the decisions of public authorities concerning the vital interests of the eldest generation;
8 constitute an institution collaborating with similar organizations abroad, in particular, countries that are members of the European Union and United Nations.

Another step toward expanding the scope of gerontological research ought to be allocating budget funds to nation-wide/regional programs (*priority*: *commissioned research*), whose outcomes are intended to aid in monitoring the social situation, health and functioning of diverse categories of older adults (research of categorical profiles of older adults – Table 1.3).

I have been trying, for many years and with mediocre results, to divert the prevalent vector of description and analysis of old and ageing adults to one that would allow generating categorical profiles of older adults (CPOA), based on data from empirical research:

1 covering similar subsets of older adults, categorized in terms of thematic groups as well as independent variables and characteristics, which would reveal the realistic diversity of older adults;
2 allowing for isolating groups of older adults on the basis of a particular aspect of their life (e.g., health, functional efficiency, psychological potential, family and financial situation) as well as their socio-demographic and territorial modes and correlates;

Table 1.3 Categorical profiles of older adults

I. Health profile	*II. Psychological profile*	*III. Social profile*
Sub-profiles		
Self-assessment of the state of health	Sense of control over one's own life	Relations with the family and remaining primary groups
Level of functional efficiency (*mobility, functional autonomy, orientation in the environment*)	Aptitude for and skill of problem-solving	Styles of communicating
Type and severity of functional limitations	Special assets, skills and physical and intellectual capabilities	Forms of social activity
self-care ability	Capacity for adapting to changes	Income and savings
Psychophysical health – somatic and Psychiatric symptoms	Self-criticism	Material resources
Subjective prognosis of one's health condition and functionality level	Ability to plan and carry out tasks	Budgeting
Availability of medical benefits and services	Self-assessment of one's capabilities	Level of dependence on others
	Ability to control emotions	Availability of social infrastructure and system of support (*healthcare, welfare, services, counselling, voluntary work, non-governmental organizations etc.)*
IV. Functional profile		
The synthetic indicator is based on the value of the profiles: health, psychological and social		
The functional profile defines the variants of the socio-health and psychological potential of the older adult as: optimal (high), moderate or low		
The potentials of the particular categorical profiles reveal bio-psycho-social resources of older adults and increase the quality of life of the ageing person; deficits, however, characterize groups of attributes of older adults that limit their autonomy and lower their life independence.		
Each of the sub-profiles and the functional profile modes are selected for analysis with the set of socio-demographic variables (age, sex, education, type of town, marital status, family status, size and composition of the household, financial standing, senior's activity).		

Source: author's proposal.

3 facilitating identification of older persons who belong to the so-called vulnerable social groups[4] (older adults isolated socially (Rathbone-McCuan and Hashimi, 1982: 1–3, 15),[5] victims of violence, homeless members of ethnic groups, older persons of a different sexual orientation);
4 cataloguing similarities and differences of older adults living with their families, those living in households that are run independently as well as those staying at round-the-clock care nursing institutions;
5 enabling the assessment of individual and group resources and reserves thanks to which older persons, in particular those with disabilities and chronic medical conditions, can function on a par with their potential, as well as at the maximum level of autonomy for their age and capacity;
6 objectivizing and elucidating the criteria and selection of directions and goals in the social policy dedicated to older persons;
7 constituting the basis for comparative analyses so that public authorities of various levels could be granted access to universal diagnostic tools used for establishing hierarchy of older adults' needs in accordance with the adopted system of values as well as the role and scope of commitment of particular entities of the public system, which take part in the process of shaping and implementing the senior policy (*also outside the public sector*);
8 making it easier for holders of public funds as well as the public administration to indicate the areas in the policies that are to be promoted and protected;
9 allowing for bringing closer the activities of the authorities to the real world of older adults' needs as well as rational use of resources and addressing gerontological programs at appropriate target groups (ongoing corrections to the programs).

The proposed research of categorical profiles of older adults constitute a cognitive and organizational, as well as implementable, answer to transformations in the demographic structure of the country/region/community, as well as changes occurring in social and institutional systems, which derive from them.

The categorical profile of the senior is a tool intended for the in-depth analysis of the status and demands of the eldest generation: it will also be a global independent variable which will allow for more adequate – in terms of the potential of particular categories of older adults – allocation of activities aimed at facilitating ageing that is satisfying as well as guaranteeing decent living conditions for a human being and a citizen to people belonging to the group at a high risk of deprivation of social health security.

It has not been possible, as yet, to find a sponsor in the public sector that would finance such a national or even regional study of profiles of older adults. As a result of this endeavor, new research tools and analytical matrices would be created to be used in particular regions of the country.[6]

Notes

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1 A social problem is a series of phenomena, conditions and situations which hinder or preclude the achievement of social goals, disturb the functioning of society as a whole or its segmen ts – the collective, society, social groups and/or upset the balance of social life. The existence of social problems is proof for the functioning of states of affairs necessitating changes or, at least, activity

in the light of the given system of values and ambitions. The principal source of social problems is the organization of society (collective life), i.e., the method of functioning of social systems and institutions.

2 Despite the fact that the Polish population has entered the path of accelerated ageing, the holders of public funds for research have not seen the need for financing gerontological projects for numerous years: the first such initiative, with a national scope, started in 1974 and was finally completed after 35 years; the following one – in 2008 (*PolSenior* under the commissioned research project number: PBZ-MEIN-9/2/2006).

3 At the European level, there is no similar institution of coordination and research character – the foundation for such an institution may be the existing entities such as: the European Network in Ageing Studies (ENAS), European Centre for Gerontology – University of Malta and International Institute on Ageing, United Nations – Malta.

4 The Latin word *vulnerare* denotes a risk of being/becoming hurt, harmed, harassed, worried. Thus, if we follow this line of reasoning, we may state the individuals/groups that are vulnerable are entities that are at a higher risk of being exposed to social, cultural, political and economic phenomena and processes that limit their ability to cope with the negative effects of such phenomena, which leads to their marginalization and exclusion from the mainstream of collective life. The terms "susceptibility" and "vulnerability" are often used interchangeably, however, in order for the situation to be fully transparent, we need to distinguish between them, i.e., susceptibility denotes a risk stemming from endogenic factors (e.g., the state of nutrition of an individual, the state of immunity system, psychological predispositions, genetic determinants), whereas vulnerability is connected with external socio-cultural and economic conditions, manifesting itself in a higher probability of being exposed to environmental threats, a lower ability of coping with difficulties and adapting to new conditions and challenges (a deficit of means and potential). Social vulnerability is, most frequently, related to poverty, but may also be associated with isolated persons, deviants, individuals under a lot of pressure, those who helplessly face risk or unexpected/extraordinary events – it is a function of exposure and resistance/sensitivity to risk factors.

5 As regards older adults, social isolation describes a process in which older persons lose the sense of personality integrity as well as ties with other social resources. These are situations or events which can be perceived as an impediment to maintaining personality integrity and social entanglement. We may identify the "rhythm of isolation" (personal patterns of variability in relations with other people may be established during earlier stages of development, and be sustained until late old age) and the "relativity of isolation" (individuals may evaluate their status on the basis of a comparison of their own situation with the one of their peers).

6 The consortium of three universities in Poznan and the Polish Gerontological Society, initiated by the author of the present chapter, in 2013, applied to the National Centre for Research and Development (*Polish* NCBiR) for funding of the project under the title "Health and psychosocial profiles of older persons as a foundation for building regional programs for positive ageing. A model approach" (Herudzińska and Przybył, 2018). The project proposal had been rejected at the first stage, i.e., the pre-selection, and was not sent to the merit-based assessment since, according to the Team of Experts at NCRD: "the project was not geared towards implementing a solution offering an increase in the quality of life of the society, … the proposed ideas were not an innovative solution but merely a standard and commonly used tool" (excerpt from the NCDR document No. DZP_SKB.7011.7.2013.JM:29). Among 16 projects qualified for implementation, only two were targeting older adults: "GRADYS", a project developing software for enhancing cognitive functions of older adults, and "E-religious tourism".

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2 Interdisciplinary and transdisciplinary approaches to ageing and gerontology

Angus McMurtry and Jenny Sasser

This chapter articulates and practically illustrates what it would mean to consider the complex multifaceted phenomena of ageing in an interdisciplinary and/or transdisciplinary manner – that is, by considering and integrating biomedical, experiential, sociological, economic, stakeholder engagement and many other factors. A rich literature on interdisciplinary and transdisciplinary research and education has emerged in recent decades. In the fields of ageing and gerontology, however, researchers and educators have mostly proceeded in merely disciplinary or multidisciplinary manners. In addition, the authors argue that interdisciplinary and transdisciplinary methodologies prompt novel epistemological frameworks that transcend traditional assumptions about objectivity, subjectivity and correspondence.

Introduction

It will likely come as a surprise to no one if we say that ageing is a complex and multifaceted phenomenon, arguably the central experience in our life journey. What is surprising is that most researchers investigate this topic through single disciplinary and epistemological lenses. For example, one researcher might adopt a quantitative positivist biomedical approach to research neurological changes, while another might use post-structural and sociologically informed qualitative interviews to make sense of intergenerational relationships. While valuable, these narrow perspectives are limited – not only conceptually, because they can provide only a partial view, but also practically, because taken in isolation they fail to consider whole persons and how they are situated in particular times, places and spaces.

In this chapter, we review disciplinary, multidisciplinary, interdisciplinary and transdisciplinary thinking in general and in relation to ageing research and gerontology specifically. To practically illustrate these differing approaches, we will apply them to a case we have created. As we shall see, ageing and gerontological research already takes multiple disciplinary forms. These diverse insights are, however, rarely integrated (or even held together) in an interdisciplinary or transdisciplinary manner.

The complexity of the ageing experience is rarely foregrounded and gerontological inquiry and practice often fails to be predicated upon and informed by the experiences and participation of stakeholders like ageing people themselves – key principles of transdisciplinary research and activities.

Finally, we will discuss how interdisciplinary and transdisciplinary research and action prompt us to transcend traditional dualisms of objectivity and subjectivity, as well as the assumption that knowledge must be framed in terms of correspondence between objective realities and subjective representations. This more progressive view of knowing in turn offers a strong recommendation for adopting more transdisciplinary approaches to ageing and gerontology.

Definitions

Before exploring the above issues, however, we should clarify several terms that will be used frequently in this chapter.

Multidisciplinary activities draw upon two or more disciplinary perspectives in order to better understand or address a certain issue or problem. *Interdisciplinary* is used to describe activities that also attempt to integrate such disciplinary perspectives in a way that may lead to the development of new, overarching knowledge that transcends these perspectives (Klein, 2017; Repko, 2012). Interdisciplinary approaches are often used to study "wicked" problems whose complexity resists uni-disciplinary or simple explanation.

Transdisciplinary appears at several points in this chapter. There are at least two ways in which this term is used in current discourse. One is employed by a team of science researchers based primarily in the United States. They define transdisciplinary research as the development of "shared conceptual and methodological frameworks that not only integrate but transcend their respective disciplinary perspectives" (Klein, 2017: 79). This definition is compatible with the definition of interdisciplinarity above.

Another definition of *transdisciplinary* – one that will strongly inform our discussion in this chapter – is problem-driven research that involves collaboration among not only diverse academic researchers (like interdisciplinarity) but also non-academic stakeholders (Klein, 2017). These stakeholders could be members of a local community pursuing sustainable development; or patients, family members or health lobby groups seeking input into the health research, policy or practice that affects them or those whom they represent.

However, disciplinary diversity and stakeholder engagement are not, alone, sufficient to make research transdisciplinary in this latter sense. Other authors have stressed the importance of collaborative and inclusive processes (Sasser, 2017); engagement in a particular kind of ongoing praxis (Augsburg, 2014); a focus on "wicked" problems needing creative solutions and engaged, socially responsible research (Bernstein, 2015); and a focus on context, reflexivity and outcomes that are "not easily measurable or subject to traditional, reductionist forms of quality control" (Byrne, Mullally and Sage, 2016).

Ageing and gerontology

Ageing is a universal feature of human life, although its expression is exceptionally heterogeneous because of the mediating forces of biology, economics, culture, social structures, environment and history. Put another way, all human beings experience ageing as they travel through the life-course, but ageing unfolds within individual lives; as such, there are as many ageing experiences as there are individuals who are ageing. Furthermore, ageing can be studied from a variety of disciplinary perspectives, including geriatric medicine and social work, social and health policy, the traditional human sciences, business, technology, ethics, legal theory, nutrition, public health, leisure studies … to name just a few!

Gerontology is commonly described as the academic area of research, theory and practice subsumed within the larger field of ageing. Gerontology is concerned with the multifaceted and complex aspects of adult ageing – biological, psychological, social, cultural, technological, political, economic – as well as the policies and programs associated with adult ageing. What differentiates gerontology from related fields of study as well as allied disciplines is that its "unit of analysis" is the universal phenomenon of human ageing.

Illustrative case

It was during a two-week trip together that Sylvia's mid-life daughter and young adult granddaughter became quite alarmed. Throughout the trip as well as in the weeks afterward, Sylvia, who was 73 years of age at the time of the trip, seemed quite confused and struggled with activities such as deciding what to eat, keeping track of her schedule and participating in conversations. She complained of back pain, slept a lot and was frequently impatient and disgruntled. Sylvia's daughter and granddaughter each alone and then together expressed their concerns to her; her response alternated between bouts of uncontrollable crying, and defensiveness, denial and anger.

Sylvia had experienced anxiety and depression for as long as they could remember and while she had been prescribed various combinations of prescription medications to try to manage her symptoms, she'd participated only briefly and intermittently in mental health counseling. A decade previously, Sylvia had survived a serious stroke which fortunately resulted in only residual mild cognitive impairment, though recent routine neuro imaging had revealed the possibility of vascular dementia. Another co-morbidity, hearing loss, had grown increasingly worse to the extent that hearing aids, which she wore in social situations, seemed mostly unhelpful.

Sylvia had been living independently in a congregate senior housing community for the past several years in the same neighborhood where her daughter and her family live. She moved to the community after her most recent relationship ended abruptly. Sylvia had been married previously twice and in several other serious co-habitation relationships; each relationship had involved some degree of domestic violence and economic insecurity. Her post-work years – she had worked full time until her stroke a decade earlier – have fortunately been more economically secure as she receives social security, a pension and a monthly stipend from an inheritance from her parents.

While Sylvia has a small group of close friends, they tend to turn-over regularly and be replaced by new friends. When she's experiencing a bout of anxiety and depression, she often self-isolates from both friends and family. As well, while she has some abiding interests – walking, reading, gardening and attending cultural events – her participation in them is inconsistent.

Of her family members, Sylvia is closest to her daughter, upon whom she relies for emotional and social support, as well as caregiving when needed. Her daughter and granddaughter wonder how best to address their concerns with Sylvia and encourage her to seek out the help they feel she needs.

Disciplinary perspectives

Ageing and gerontological researchers have pursued a wide variety of disciplinary angles, from medicine, psychology and sociology, to humanities, political science and humanities (Sugar et al., 2014). Although researchers in these fields may share an interest in the complex phenomena of adult ageing, they share no common or unified paradigm. Under the banner of gerontology, for instance, there are numerous disciplinary-based, specialized foci; and within each it is possible to find a plurality of theoretical, methodological and practice approaches operating simultaneously (Alwin and Hofer, 2008; Sasser, 2017).

The case you have just read can certainly be examined from such specific, individual disciplinary perspectives. For example, a medical doctor might analyze the presence of co-morbidities – the hearing loss, residual impairment from the stroke, a degenerative condition leading to back pain – and how each on their own and taken together impact Sylvia's functioning and quality of life. The doctor might pose questions about the medications Sylvia has been prescribed, whether she's receiving any therapeutic interventions to improve her functional abilities and perhaps suggest additional medical and life-style protocols from which Sylvia might benefit.

By contrast, a psychologist would be keenly interested in the implications of the previous stroke and the potential vascular dementia for Sylvia's cognitive and socio-emotional capacities in the present but also as she moves farther into later life. Sylvia's life-long experience of anxiety and depression would be seen as important factors affecting her quality of life. The psychologist would likely want to know about the quality of Sylvia's social support system and living situation in order to get a sense of her daily life context and the extent to which she has positive connections to others and a sense of purpose. She or he would be particularly sensitive to the presence of self-neglect or elder abuse. Perhaps the psychologist would construct a care plan for Sylvia and her family outlining psychotherapeutic activities that she could engage in to help her maintain and even improve her cognitive capacities.

From yet another perspective, a sociologist might wish to focus on how Sylvia's generational placement – she's a leading-edge baby boomer – may have shaped her life chances and expectations in relationship to social structures such as education, work, family life and even older adulthood. Sylvia's individual lived experiences would serve as a window into larger socio-historical patterns and perhaps offer insight into some of the challenges women who share her characteristics might face as they grow older. A sociologist would also be interested in a more local view of the social structures at play that shape Sylvia's ageing experience, such as the age-friendliness of and access to services in the community in which she lives.

While all these perspectives may be valuable, they can only tell part of the story. Taken in isolation, their utility for understanding and dealing effectively and ethically with the case above is quite limited. We will therefore turn next to a perspective that enables such perspectives to co-exist side-by-side: multidisciplinarity.

Multidisciplinary perspectives

Multidisciplinary perspectives draw upon two or more disciplines in order to better understand or address a certain issue or problem. Unlike interdisciplinary and transdisciplinary activities, there is no mutual influence between the perspectives, nor any effort to integrate them. Rather, the insights gained from a multidisciplinary approach exist alongside each other as different possibilities for addressing facets of a complex phenomenon.

As we saw above, researchers in the fields of ageing and gerontology have largely adopted (uni)disciplinary approaches. However, because insights from these approaches exist side-by-side, these fields – taken as a whole – can be seen as developing in a multidisciplinary manner. In other words, the fields as a whole have articulated – but not integrated – a wide variety of disciplinary angles, from medicine, psychology and sociology, political science and humanities (Sasser, 2017; Sugar et al., 2014). The deeper, integrative and empowering approaches of inter- and transdisciplinarity are, as yet, quite rare (Alwin and Hofer, 2008; Sasser, 2017).

While some researchers have made claims about unifying scientific paradigms (see, for example, Ferraro, 2007) that bring together varied approaches, a handful of provocative disciplinary mash-ups and counter-paradigms have emerged to problematize these claims. Notable examples of such alternative approaches include critical gerontology (Biggs, 2005; Wellen, 2018), cultural gerontology (Twigg and Martin, 2015), narrative gerontology (de Medeiros, 2013) and age studies, a hybrid field that emerged as a challenge to mainstream gerontology (Gullette, 2004).

To illustrate a multidisciplinary approach, let us continue with the case above and the three disciplinary perspectives described there: medicine, psychology and sociology. If the three disciplinarians each contributed her or his insights, without any attempt to integrate them, then a multidisciplinary perspective would emerge. Sylvia's situation as presented in the case would be viewed through each of the disciplinary lenses and each would address a different facet or level of the complex situation Sylvia is experiencing: the body, the mind or the social context.

As we have seen above, the medical doctor may view Sylvia's co-morbidities largely as the effect of her various acute and chronic health issues, intensified by normal ageing processes. Her or his primary concern would then be how best to intervene. The psychologist, on the other hand, might focus on Sylvia's functional capacity, emotional well-being and connections with others. She or he might feel strongly that individual and family counseling would be of great benefit to Sylvia, as would cognitive training to help her overcome some thinking habits that are getting in the way of her ability to maintain independence. Finally, the sociologist would likely be interested in the larger social, economic and gender-based norms and forces that have shaped Sylvia's ageing experience.

Multidisciplinary approaches might treat these different perspectives as if they are of equal explanatory power. Or they might seek to determine which has the greatest explanatory power and appears to "fit" the complex situation best.

A multidisciplinary approach would therefore involve moving from one disciplinary perspective to another, trying on each one to see what it might reveal. From a pragmatic standpoint, then, we might ask which level seems to present the most pressing need for intervention in support of Sylvia's well-being: Her complex co-morbidities? Her emotional and mental health? Her living situation, access to services and resources, and social support network? Let's say that we determine that each of these areas should be addressed; a multidisciplinary approach would involve developing different versions of Sylvia's story, each with its own foregrounded issue or problem and corresponding intervention or solution. But there wouldn't be any attempt to synthesize these different approaches into an integrated explanation of Sylvia's situation and possible beneficial, interconnected responses.

Interdisciplinary perspectives

Many of the most challenging issues society faces today are ones that cannot be fully understood or addressed through single disciplines – or even through multidisciplinary approaches that aggregate differing disciplinary perspectives but do not attempt to integrate them. Examples include poverty, diabetes and climate change. They are complex, messy, "wicked" problems that "cannot be solved by simply applying new information and tools or adding more variables to existing decision models and computer programs" (Klein, 2004).

As a result, many researchers have called for *interdisciplinary* approaches that not only draw upon, but also attempt to integrate, disciplinary perspectives in a way that may lead to the development of new, overarching knowledge that transcends these perspectives (Klein, 2017; Repko, 2012). To construct such perspectives, interdisciplinary thinkers have in recent decades developed step-by-step models for bringing together and integrating diverse disciplinary inputs (Repko 2012; Repko, Newell and Szostak, 2012). These models typically include steps such as defining a question, determining relevant disciplines, negotiating roles, identifying conflicts and, especially, creating common ground.

There is dispute about whether common ground can always be found and whether this should even be the driving goal on interdisciplinary work (McMurtry et al., 2012; Sasser and Dreyfuss, 2015). One thing that makes finding common ground challenging is that disciplines' theories and methods often conflict or are incommensurable. As Petrie writes in his classic and influential article on interdisciplinarity, "[q]uite literally, two opposing disciplinarians can look at the same thing and not see the same thing" (1976: 11). Further, one cannot – and should not – attempt to avoid or eliminate these conflicts: "difference, tension, and conflict are not barriers that must be eliminated. They are part of the character of interdisciplinary knowledge negotiation" (Klein, 2005: 45).

Regardless of the position one takes in relation to the above issues, the step models proposed by interdisciplinary thinkers are undeniably useful as a starting point or heuristic for researchers dealing with the challenge of integrating differing disciplinary perspectives.

In the fields of health science and care – related to ageing and gerontology but more general in scope – there has been a push in the past few decades to integrate both research and practice perspectives, as well as to pursue interdisciplinarity in collaborative teams – since one person rarely comprehends all the knowledge necessary to solve complex problems (McMurtry, Kilgour and Rohse, 2017; Stokols et al., 2008).

Ageing and gerontology are also considered by many to be fields where interdisciplinary approaches are urgently needed, including approaches that involve collaborating teams of specialists that gather from various fields and disciplines; indeed, some have claimed that the field of gerontology is *inherently* interdisciplinary (Sasser and Moody, 2018; Schultz, Keyser and Pincus, 2011; Sugar et al., 2014). As we saw above, however, this has not proven to be the case. Much ageing and gerontological research has proceeded in a narrow disciplinary or, at best, multidisciplinary manner.

We will now imagine the case above from the perspective of an interdisciplinary team – again, we will consider, for illustration, the medical doctor, the psychologist and the sociologist. Working in an interdisciplinary and collaborative manner, the three professionals would take steps to identify tensions and find commonalities or complementarities in their approaches. For example, the doctor and psychologist might consider the relationship between the chronicity of Sylvia's physical pain, on the one hand, and her functional capacity, emotional well-being and connections with others, on the other. They would hopefully take into account the complex interweavings of physical, mental and social factors and tailor their treatment plans accordingly. For example, they might insure that Sylvia's physical therapy and pharmacology were structured in a manner that would support her counselling and cognitive training – and vice versa. The sociologist might stress the need that such treatments also adopt a critical awareness of how Sylvia's life has been shaped by, for example, economic insecurity, domestic abuse and discrimination based on age or gender.

When interdisciplinary integration works well, therefore, it can produce knowledge or action that is "more-than-the-sum-of-its-parts". That is, people can elicit, build on and challenge one another's insights – in effect, synthesizing differing disciplinary ideas. They are empowered to produce new knowledge that exceeds their individual disciplinary understandings – knowledge that could not have been predicted in advance of interdisciplinary collaboration. In concrete terms, such integration may give rise to new research, concepts, terminology, methods, diagnoses, care plans or procedures (McMurtry, Rohse and Kilgour, 2016).

By contrast, without such integration of disciplinary and professional insights, interdisciplinarians would argue, one runs the risk of implementing treatments that interfere or even undermine one another. For example, pain medications that leave Sylvia drowsy might limit the effectiveness of counselling and cognitive training; counselling sessions distant from public transportation routes might risk her physical health and recovery; and treatment or counselling plans that ignore the subject of domestic abuse might be only address superficial issues.

Transdisciplinary perspectives

While interdisciplinary perspectives offer a broader and more integrated perspective on ageing and gerontology, something important is still missing: the perspectives and participation of people, families and communities who are actually affected by research and other interdisciplinary activities. As we wrote above, the term *transdisciplinary* has been used to describe research that involves collaboration among not only academic researchers but also non-academic stakeholders (Klein, 2017).

Stakeholder engagement in transdisciplinarity involves more than just consulting people, for example, through consumer-based research. It means actively engaging stakeholders as co-participants in research and change, and viewing them as experts in their own right (about their own experiences). Stakeholder engagement is not alone sufficient, however; Sasser (2017) has added the following additional criteria for genuinely transdisciplinary research:

- embraces and foregrounds complexity, resisting dualisms and other simplistic form of thinking;
- commits to addressing current “wicked problems” while envisioning (and creating) better possible futures;
- recognizes the multiple, interconnected levels and dimensions of life and reality;
- transgresses institutional, disciplinary and paradigmatic boundaries;
- takes on the challenge of communicating and collaborating across differences;
- commits to the difficult work of critical self-reflection on one’s own lived experiences and attempts to live transdisciplinarity life-wide; and
- makes room for play, creativity, spirituality, the unconscious and that which cannot be contained or explained.

Echoing this transdisciplinary ethos (though not explicitly naming his “participatory enactment” approach transdisciplinary) Biggs urges:

> [I]t follows that research would need to be undertaken in a spirit of partnership that both parties interrogate ageing from their particular perspective and the reciprocal skills and aptitudes of each party are made recognizable. Growing interest in the role of older people in social research requires a detailed analysis of the strengths and weaknesses of different age groups as researchers, with no party playing servant to the other.
>
> (2005: S126)

In recent years, there has been a call for transdisciplinary approaches to research from a wide variety of fields, from philosophy to healthcare and sustainability (td-net, 2019; McMurtry, Kilgour and Rohse, 2017). Within the areas of ageing and gerontology specifically, a small number of thinkers have begun to articulate the need for transdisciplinary and similar approaches (Biggs, 2005; Proctor, 2001; Sasser, 2017).

Drawing again upon the case above, a transdisciplinary approach would first and foremost foreground the complexity of the situation presented and background the various (multi- and inter-) disciplinary perspectives contributing to the development of a rich, synthetic understanding. We (since we consider ourselves transdisciplinarians) would begin our exploration thick in the complexity of the situation and bring in the various perspectives – uni-, multi- and interdisciplinary – we described above.

In addition, there would be an intentional commitment to discovering ways into the experiences of each family member as well as the family system as a complicated whole. In other words, the potential participants to include (in the process of inquiring more deeply into the various intertwined issues embedded in the case) would be Sylvia, her daughter, her granddaughter, as well as other close-in people who are an important part of Sylvia's milieu. This group might also encompass her care providers, neighbors, current close friends and other family members, perhaps as well as persons not yet identified, such as a member of the clergy, a new or previous partner, or a pet.

Identifying who these important persons are in Sylvia's current lifeworld would begin, of course, with asking her who she considers to be members of her "inner circle". It is quite possible that, given the current conflict with her daughter and granddaughter, they would not be identified; this would be important information in and of itself and could lead to a question regarding where Sylvia currently situates her daughter and granddaughter in her daily life. It is certainly not necessary to include every member of Sylvia's relationship network in the inquiry and subsequent planning process. But knowing who these members are from Sylvia's perspective (as well as from her daughter's and granddaughter's perspectives) provides significant context upon which to co-create a deeper understanding of her current situation.

Related to this, we would expect that the case as presented to us is only a partial representation of the complex situation in which Sylvia, her daughter and granddaughter are embedded. We would therefore ask probing questions to help us discover whether there are other life-long or current issues contributing to the complex situation. We would first ask questions grounded in *experience and meaning*, for example: What is most important to you in your life right now? When do you feel most contented and satisfied with how your life is going? What gives your life a sense of purpose and meaning? What are some of your biggest concerns or challenges? When you think about the next few months, do you have any ideas about things you'd like to do that would help you manage these concerns and challenges? Notice that these questions do not just identify problems and solutions; they honor Sylvia's agency as an individual and encourage appreciation and creativity. These and other questions like them signal that the ageing journey is the human journey, that ageing is a process of growth and not just loss, and that even in the context of great challenges there are opportunities for change.

While we as transdisciplinary researchers are committed to resisting dualistic and reductionistic thinking, we would also want to ask questions that touched on the various multifacets of Sylvia's experience: body, mind, spirit in context (or, to put it in more disciplinary terms, the biophysical, emotional, cognitive, social, environmental, economic, etc.). We would then harness (multi- and inter-) disciplinary perspectives and insights as appropriate.

Approaching this case as a transdisciplinary *gerontological* endeavor would mean that we would frame Sylvia's complex situation as, first and foremost, an adult ageing situation (as opposed to a medical or mental health or neurological or family systems issue; all of these areas and more are intertwined in the case). This means that we would bring to bear what gerontology as a field tells us about the "normal" adult ageing experience; how it is a process of gains, losses and stability in functioning across multiple domains; how it unfolds across the long life-course and is strongly shaped by the contexts in which it occurs; and how ageing is expressed at the individual level and with great variability. This means that we would strive to disentangle the developmental challenges – for Sylvia as well as her family members – of different life-course stages, from ageing-related (but not caused by ageing itself) mental and physical health challenges, to life-long patterns of functioning that are exerting an influence on current functioning.

Epistemological implications/complications

Multidisciplinary, interdisciplinary and transdisciplinary research prompt one toward more pluralistic epistemological perspectives. After all, if quantitative and qualitative, natural sciences and social sciences – not to mention the humanities – can all offer valuable insights into a particular topic or problem, then it is difficult to cling to the notion that any particular disciplinary approach "owns" the truth (Welch, 2012).

Most interdisciplinarians accommodate this plurality of epistemological perspectives. As in other fields, however, few explicitly challenge two deeply entrenched and conventional assumptions about knowledge: (1) that it must be framed in terms of correspondence between an external objective world and our subjective understandings or "representations" of it, and (2) that we are moving toward a complete or comprehensive understanding of the world (McMurtry and Dellner, 2014; McMurtry and McMurtry, 2016).

A frequently invoked parable in naive interdisciplinary writing is one about the blind men and the elephant. In it, each blind man feels a different part of the elephant. The one who feels the trunk, for example, concludes that an elephant is like a snake, while the one who touches the leg thinks it is like a tree. The king, or rajah, who watches this process, however, puts all the pieces together to acquire a supposedly complete or comprehensive understanding of the elephant.

This epistemological assumption underlies much interdisciplinary research: while disciplines accurately describe slices or facets of reality, interdisciplinary research can provide the "big picture". As Klein and Newell write in their oft-quoted definition of interdisciplinary studies:

> A process of answering a question, solving a problem, or addressing a topic that is too broad or complex to be dealt with adequately by a single discipline or profession.… [It] draws on disciplinary perspectives and integrates their insights through construction of a more comprehensive perspective.
>
> (1997: 393–415)

We, however, believe that inter- and transdisciplinarity present an even deeper challenge to conventional epistemologies: they prompt us to move beyond a notion of knowledge as correspondence between objective realities and subjective representations, as well as the conviction that we are moving toward more complete and comprehensive understandings of the world.

Let's start with subjectivity and objectivity, the two poles that delimit most commonsense discussions of knowledge. While we view all disciplinary knowledge as situated and partial, that does not mean that it is entirely subjective. After all, our physical and social worlds place hard limits on what knowledge can work. For instance, believing that we can fly will not help us if we jump off a building without a parachute, and treating our students like serfs will probably get us fired. Similarly, disciplinary, multi-, inter- and transdisciplinary knowledge must work effectively in the contexts in which it is employed.

This does not mean, however, that the world dictates one specific objective or complete truth. For example, many different sorts of knowledge have helped people in different cultures to grow agricultural crops, construct buildings, navigate using celestial bodies like stars or negotiate social structures like families, workplaces or governments. Furthermore, as Kuhn (1970) and others have shown, paradigms are revolutionized or reformulated on a fairly regular basis. What we used to think was an objective representation of the world has usually turned out to be an imperfect human construction – albeit, like Newtonian physics, a very useful one. As Einstein and Infeld put it, "[p]hysical concepts are free creations of the human mind, and are not, however it may seem, uniquely determined by the external world" (1967: 3).

Indeed, many researchers in the past two decades have argued that complex systems (like human beings, social collectives, cities, economies and ecologies) are never entirely reducible to any overarching rules or laws (Sasser and Dreyfuss, 2015; McMurtry, 2011). As Osberg, Biesta and Cilliers write:

> [M]odels and theories that reduce the world to a system of rules or laws cannot be understood as pure representations of a universe that exists independently, but should rather be understood as valuable but provisional and temporary tools by means of which we constantly re-negotiate our understanding of and being in the world.
>
> (2008: 218)

There is no final truth of the matter, only increasingly diverse ways of interacting in a world that is becoming increasingly complex (223).

What this means for research on ageing and gerontology, is that we should both (1) respect and value the disciplinary and multi-, inter- and transdisciplinary knowledge we construct and (2) acknowledge and embrace the fact that it is evolving as we as researchers and practitioners collectively expand, challenge and elaborate on it. There is no final, objective or complete truth; that is not the job of human knowledge. Its job is more pragmatic: to provide (hopefully) ever more effective, nuanced, ethical and empowering tools for interacting with our shared physical, social and ecological worlds.

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3 Self-report measures of ageism in the workplace

A scoping review

Martine Lagacé, Najat Firzly and Alura Zhang

The chapter relies on a scoping review which is an increasingly common approach used for mapping broad themes in relation to volume, nature and key findings on a specific topic. As such, the chapter aims to summarize and analyze existing validated self-reported scales on ageism in the workplace as well as uncover gaps in ageism research. More so, it enables a comprehensive identification of key trends related to how ageism in the workplace is measured, through identifying validated self-reported scales, assessing their scope and psychometric properties. The five-step scoping review framework outlined by Arksey and O'Malley (2005), that includes "study purpose, study identification, screening process, data extraction, collation and summarization of data", was enacted. The scoping review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009).

Introduction

Populations are rapidly ageing throughout the world (United Nations Department of Economic and Social Affairs, 2017). In Canada for example, individuals aged 65 years old or older, outnumber those aged 14 years old (Statistics Canada, 2017). These demographic trends have an impact on the Canadian workforce where labor shortages are affecting the manufacturing, retail, construction and healthcare sectors (Conference Board of Canada, 2018). Economists argue that the situation is here to stay and imposes on employers to rethink their hiring and retention strategies. Life-long learning and training of employees to build knowledge pipelines could partly address retention. Encouraging the better integration of groups often left outside job markets, such as Indigenous Canadians, new immigrants and older adults, is another way to address labor shortages. However, the latter requires a shift in the way ageing and older adults are perceived in the workplace. For example, although more older Canadians chose to keep working as shown in the latest 2016 census – over 53 percent of men and 38 percent of women aged 65 or older were working in some form in 2015 considerably more than were doing so in 1995 – they still face important barriers. Ageism is among those barriers (Berger and Hodgins, 2012; Malinen and Johnston, 2013; McQuigge, 2017; Posthuma and Campion, 2009).

Kite and Wagner (2002) conceptualize ageism as a combination of – mostly negative – age-based stereotypes, attitudes and behaviors. This tripartite model expresses the different channels through which ageism can be expressed, i.e., cognitive, affective and behavioral. For example, an individual may subscribe to negative age-based stereotypes in believing that ageing is mostly a process of decline and become anxious about his/her own ageing process;

in turn, this may translate into distancing oneself from older adults. In the workplace, employers who hold negative beliefs and attitudes toward older workers may discriminate against them through hiring and retention processes. Harris et al. (2018) have conducted a scoping review of 43 scientific publications describing the most common ageist stereotypes conveyed by employers toward older workers. Results show that while perceived as possessing soft skills and being loyal and reliable employees, older workers are negatively portrayed as being less capable of adapting to change – especially to new technologies – less capable of learning, less competent and less productive than younger workers. In a rapidly changing workplace, employers place a high value on fast learning and multitasking, and associate such skills mainly to younger workers. As such, being perceived as loyal and having soft skills may not suffice to outweigh the detrimental effect of negative stereotypes such as resistance to change, decreased capacity to learn and decreased productivity.

More important, ageist stereotypes often translate into discriminatory practices on the part of employers. Neumark, Burn and Button (2019) designed and implemented a large field experimental study to test how age-based discrimination permeates employment, namely through discrimination at *hiring*. Based on evidence from more than 40,000 job applications for administrative jobs, submitted by young applicants (aged 29 to 31), middle-aged applicants (aged 49 to 51) or older applicants (aged 64 to 66), results show that, after controlling for confounding variables, middle-aged and older applicants are significantly more discriminated against, with a callback rate 6.3 percent lower than for younger applicants. Findings from this study are particularly important since they reveal the importance of including older workers nearing the normal retirement age when addressing age-based discrimination.

Studies also show that ageism has a negative impact on older workers' well-being. Findings from an empirical study conducted by Peters et al. (2019) among Dutch workers involved the comparison of three groups of workers (those under than 30, those 30 to 49 and those 50 to 67 years old) as for their perceptions of being the target of ageist stereotypes in the workplace. Findings suggest that perceptions of negative age-based stereotyping have a significant and negative effect on older workers' (in this case, those aged 50 to 67) self-perceived employability, which may in turn have an impact on career decisions. Along the same lines, Lagacé et al. conducted studies among Canadian older workers from the healthcare sector show that ageism generates discontent, which in turn, leads to disengagement, lower self-esteem and professional exit (Lagacé et al., 2008, 2010).

In summary, labor shortages in many Organisation for Economic and Co-operation Development (OECD) countries constrain employers to address barriers related to recruitment and retention. Ageism is undoubtedly one of these barriers and, if not countered, may threaten the long-term sustainability of organizations. A first step in addressing ageism is to document and measure how it is expressed in the workplace (through stereotypes and/or discriminatory practices), and how it is experienced by older workers (i.e., how they recognize and react to ageism). The documentation and the measurement of ageism are particularly important, taking into account that this form of discrimination continues to be socially accepted and does not get the same level of public attention as racism and sexism (North and Fiske, 2012). Hence, the goal of this chapter is to identify and critically analyze existing measures of ageism in the workplace. To do so, a scoping review is undertaken.

Design and methodology

A scoping review is an increasingly common approach used for mapping broad topics in relation to volume, nature and key findings on a specific topic (Plam et al., 2014).

The current scoping review aims to summarize and analyze existing validated self-reported scales on ageism in the workplace as well as uncover gaps in ageism research. As such, it enables a comprehensive identification of key trends related to how ageism in the workplace is measured, through identifying validated self-reported scales, assessing their scope and psychometric properties. The five-step scoping review framework outlined by Arksey and O'Malley (2005), that includes "study purpose, study identification, screening process, data extraction, collation and summarization of data", was enacted. This scoping review is also in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009).

Study identification and screening

During the months of October and November 2019, team members undertook a major online search to identify academic publications that included the word "ageism" in combination with terms related to "scales" and "workplace" (using the operators *or* and *and*). A total of six databases (i.e., AARP Ageline, ABI Inform Global, Business Source Complete, Medline (Ovid), PsycInfo, Scopus) were searched with all possible combinations of the three broad terms (and related terms). Databases were selected after consulting with the university librarian as they were the most likely to comprise the majority of non-gray literature on the scoping review topic. A comprehensive search string on "ageism" was initially developed for AARP Ageline and subsequently transferred for searches in five additional databases (i.e., ABI Inform Global, Business Source Complete, Medline (Ovid), PsycInfo, Scopus). To insure rigor, coherence and optimize reproducibility of the process, a track record of all search terms was maintained for each database. The following key words were used: ageis* or (age* *n3* (discriminat* or bias* or stereotyp* or prejudic*)); scale* or test* or questionnaire* or assess* or measure* or inventor* or instrument* or evaluat*; work* (depending on the database, the *n3* – meaning that a certain word could be separated by at least another three words – changed). Accordingly, terms were truncated to search multiple prefixes and suffixes (i.e., searching on *ageis** would include results for both *ageism* and *ageist*). For instance, articles that included an *instrument* or *measure* of *attitudes* or *beliefs* toward *older workers* or *old* employees would have been included in the results. As indicated above, team members also consulted with a university-based librarian to address search methods and database selection.

Results of all searches were entered into the Covidence software program for systematic reviews (Covidence systematic review software, 2017). Results of subsequent steps are illustrated in Figure 3.1, below, based on the PRISMA's flow diagram (Moher et al., 2009). Following an initial phase of removing duplicates ($n=807$), titles/abstracts ($n=2030$) were screened to determine inclusion by two independent raters. No contact with authors to identify additional sources was undertaken. Records were divided randomly across raters, and disagreements were resolved through consensus with a third rater.

A total of 1746 titles/abstracts were rated as irrelevant records. Moreover, full-text review ($n=284$) was performed independently by two raters, who resolved disagreements through consensus with a third reviewer. A snowball search was conducted to identify additional records for full-text review by using Google Scholar's "related to" and "cited by" functions for each of the articles included in the original search.

Eligibility

Instruments identified throughout the searches were retained for analysis and review if they met the following inclusion criteria: (a) available in English or French; (b) published between 2000 and 2019; (c) aimed to develop/evaluate measurement properties of a quantitative self-reported scale on ageism targeting older adults in the workplace, either from the perspective of the perpetrator or the victim; (d) relied on original research; (e) available electronically in full-text, peer-reviewed; and (f) reported evidence of reliability or validity with different samples. The rationale for this last criterion is that a minimum number of independent studies is needed for the psychometric validation of a scale. In addition, studies that assessed a modified scale to measure ageism (e.g., Ospina, Cleverland and Gibbons, 2019) or included a subscale of ageism, rather than an entire scale, were excluded. Finally, instruments that assessed related but distinct constructs were also excluded.

Data extraction

Data was extracted from all selected peer-reviewed papers ($n=284$) and these papers were analyzed by two reviewers. A good number of scales contained in these papers were either modified, had not been validated or were not directly related to ageism in the workplace – hence, 117 papers were excluded. In addition, many of these papers relied on a methodology other than self-reported scales or assessed ageism as targeting younger workers and, consequently, were excluded ($n=162$). Once extraction was completed, researchers reviewed all extraction tables and any discrepancies in data included in various sections, were discussed and resolved. Following the full-text screening stage, five self-reported scales were found to be relevant for the scoping review, according to the six inclusion criteria (see Figure 3.1).

Collation, summarizing and synthesis

The final step involved a descriptive summary of the scales included in the synthesis through categories analysis. Three main categories of data were extracted: (a) scale characteristics (items and factors, dimensions assessed, language of scale); (b) methodological quality of measurement properties; and (c) number of citations per study in Google Scholar. Table 3.1 summarizes these three main categories. In continuity with Ayalon et al.'s work (2019), seven psychometric properties were assessed in regards to each scale (see Table 3.2): (a) content validity, (b) structural validity, (c) internal consistency, (d) cross-cultural validity, (e) criterion-related validity, (f) convergent validity and (g) discriminant validity.

In the following, a short description of the types of validation is provided. Content validity is determined by asking individuals about the relevance, comprehensiveness and comprehensibility of scale items, response options and instructions. Structural validity relates to the degree to which scores of a scale are an adequate reflection of the dimensionality of the construct measured (Mokkink et al., 2018). On the other hand, internal consistency refers to how well a scale actually measures what it is intending to measure. It also refers to whether the effects observed in a study are due to the manipulation of an independent variable and not to some other variable. Cross-cultural validity aims to determine whether items are similar in different populations (e.g., in different ethnic, gender or language groups). Criterion-related validity (sometimes known as concurrent or predictive validity) relates to the extent to which what is measured by the scale properly, relates to an

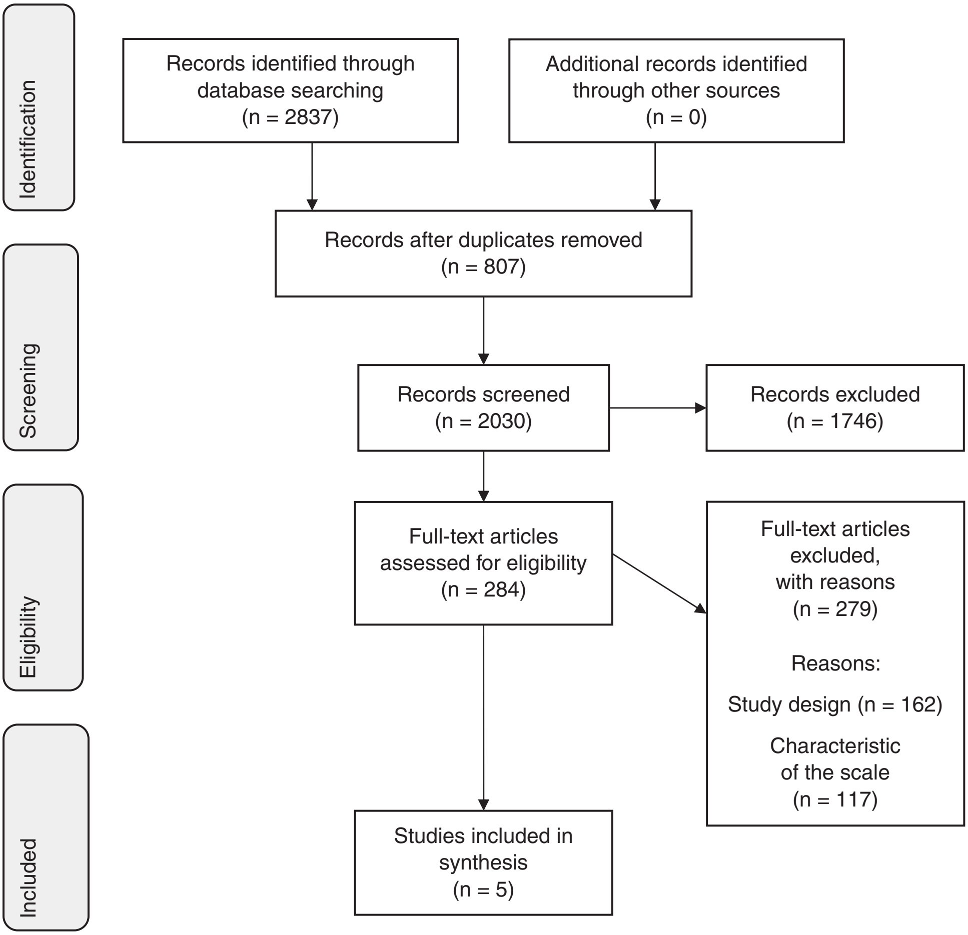

Figure 3.1 PRISMA 2009 flow diagram illustrating the selection of the ageism scales in the workplace.

outcome (McLeod, 2013). In the case of ageism, the outcome could be older workers' level of workplace satisfaction. Convergent validity refers to the degree to which two scales that measure constructs that should be related, are in fact related. Finally, discriminant validity (or divergent validity) allows determination of the extent to which constructs that are not supposed to be related are actually not related.

Results

Our search methods yielded 2837 abstracts, and a total of five self-reported scales on ageism in the workplace met the inclusion criteria for the current scoping review. The five scales selected for this scoping review are the following: the *Workplace Intergenerational Climate Scale* (WICS; King and Bryant, 2016); the *Nordic Age Discrimination Scale* (NADS; Furunes and Mykletun, 2010); the *Workplace Age Discrimination Scale* (WADS; Marchiondo, Gonzales and Shan, 2016), the *Work-related age-based stereotypes scale*

Table 3.1 Results according to three coding categories

Scale name (year)	*1.a) Items and factor*	*1. b) Dimensions covered*	*2. Psychometric properties*	*3. Citations in studies according to Google Scholar (since November 2019)*
The Workplace Intergenerational Climate Scale (WICS) 2016	18 items 5 factors Intergenerational contact, workplace intergenerational retention, positive intergenerational affect, workplace generational inclusiveness and lack of generational stereotypes	Self-report instrument Generational stereotypes; positive intergenerational affect; intergenerational contact; workplace intergenerational inclusiveness; workplace intergenerational retention Participants' age range 18–67 Available in another language: No	Content validity: Yes Structural validity: Yes Internal consistency: $\alpha=0.87$ Cross-cultural validity: No Criterion-related validity: No Convergent validity: Yes Discriminant validity: Yes	Cited by 24
Nordic Age Discrimination Scale (NADS) 2010	6 items 1 factor Monitoring age discrimination in promotion, training, development, development appraisals, wage increase, and change processes	Self-report instrument Behavioral component of ageism; discrimination (promotion, recruitment, training, professional development) Participants' age range: group of age not specified Available in another language: Yes (Spanish)	Content validity: Yes Structural validity: Yes Internal consistency: between 0.82 and 0.87 Cross-cultural validity: Yes The nature of the data opens for validation of the NADS in three different languages; Norwegian, Swedish and Finnish. Criterion-related validity: Criterion-related validity: Yes Convergent validity: No Discriminant validity: No Additional information: the criterion validity was acceptable when applying age inequalities and exposure to bullying and harassment as criteria.	Cited by 73

			In addition, the construct validity was supported through correlations for psychological state measures and job and life satisfaction.	
Workplace Age Discrimination Scale (WADS) 2016	9 items 1 factor Perceived workplace age discrimination that assesses overt and covert forms of discrimination	Self-report instrument Overt and covert discriminatory workplace practices; affective component of ageism Participants’ age range: older (50+), middle-aged (31–49) and younger (18–30) workers’ experiences Available in another language: No	Content validity: Yes Structural validity: Yes Internal consistency: $\alpha = 0.93$ Cross-cultural validity: No Criterion-related validity: Yes Convergent validity: Yes Discriminant validity: Yes Additional information: the WADS contains convergent and discriminant validity and a unidimensional structure across age groups. It demonstrates criterion-related validity among older and younger workers but not middle-aged workers, given their low experiences of age discrimination.	Cited 20
Work-related age-based stereotypes scale (WAS) 2016	20 items 3 factors Competence adaptability, warmth	Self-report instrument Ageist stereotypes based on tripartite model: incompetence, inadaptability and warmth Participants’ age range: younger and older participants Available in another language: No	Content validity: Yes Structural validity: Yes Internal consistency: α between 0.82 and 0.90 Cross-cultural validity: Yes Criterion-related validity: Yes Convergent validity: Yes Discriminant validity: Yes Additional information: for two samples, the scale demonstrates criterion-related validity evidence for the WAS scale.	Cited by 7

continued

Table 3.1 Continued

Scale name (year)	*1.a) Items and factor*	*1. b) Dimensions covered*	*2. Psychometric properties*	*3. Citations in studies according to Google Scholar (since November 2019)*
Instrument for measuring managers' attitudes toward older workers 2016	20 items 5 factors Adaptability, value of older workers to organizations, organizational conscientiousness, social capital and generosity, performance	Self-report instrument Five types of managers' attitudes toward older workers: adaptability, value of older workers' competencies, organizational conscientiousness, social capital/generosity and performance Participants' age range: managers 38–41 years old Available in another language: No	Content validity: Yes Structural validity: Yes Internal consistency: α between 0.60 and 0.78 Cross-cultural validity: Yes Criterion-related validity: No Convergent validity: No Discriminant validity: No Additional information: the convergent/discriminant validity and replication were not performed and are left to future studies.	Cited by 14

(WAS; Marcus et al., 2016) and the *Instrument for measuring managers' attitudes toward older workers* (IMAOW; Rego et al., 2016). These scales measure a variety of factors related to ageism, from intergenerational contacts, stereotypes (e.g., competence, warmth, adaptability) to discriminatory workplace practices. Only the NADS has been translated into another language than English (Carral and Alcover, 2019).

Table 3.2 summarizes the aggregated rating of the psychometric properties of each scale as well as overall quality of evidence. Following the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines (Mokkink et al., 2018; Terwee et al., 2018), two independent raters evaluated each scale. Information on discriminant validity was not provided in Table 3.2 since COSMIN does not include a category related to this type of validity. The overall rating of each psychometric property per scale was based on COSMIN, stemming from *very good* (VG), *adequate* (A), *doubtful* (D), *inadequate* (I) to *not applicable* (N/A). These criteria were used for all first published versions and first proposed structure of scale (factors and subscales). As COSMIN guidelines require reviewers to conduct their own assessment of the content validity, raters independently assessed the face validity of each scale. To insure reliable judgment, raters examined whether the items included in the scale were relevant to the concept of ageism, whether the items included under each subscale fell into a cohesive domain, as well as whether the phrasing of items and the instructions were easy to understand (Ayalon et al., 2019; Terwee et al., 2018). As shown in Table 3.2, content validity, structural validity, internal consistency, criterion-related validity and convergent validity of these five scales range from *acceptable* (A) to *very good* (VG).

Discussion

This scoping review aimed at understanding how ageism in the workplace is measured and identifying potential knowledge gaps. As stated previously, it is crucial to counteract ageism in the workplace taking into account the rapidly ageing workforce within many nations. Ageism is a barrier that works against recruitment, participation and retention of older workers although these are key factors in addressing labor shortages. The first step in addressing ageism in the workplace is to document its expression and manifestation, notably by measuring it.

This scoping review has allowed the identification of five self-report scales that focus on ageism in the workplace. Although there are a number of other scales targeting ageism in the workplace, these were not included in the review as their psychometric properties, validity and reliability amongst others, have not yet been assessed. Two of the five scales, i.e., the WICS and WADS, address ageism from the perspective of workers who perceive to be the target of age-based stigma, in other words, they measure self-ageism (e.g., "I have been treated with less respect due to my age"). However, both these scales also allow for the measurement of ageism from a multidirectional perspective, i.e., older, middle-aged and younger workers' experiences. Interestingly, the WICS measures employees' attitudes and perceptions about workers of different ages *and* generations, hence it implies that stereotypes and discrimination may result from prejudiced views in regards to age as well as generations,

On the other hand, the three other scales (NADS, WAS, IMAOW), do not address ageism from the respondents' self-perception and/or experience but more so from an out-group perspective. Precisely, all items in these scales begin with the statement "Elderly workers …" or "Older workers …". As such, when younger, middle-aged and older adults

Table 3.2 Overall rating of each measurement property per scale and grading of the quality of evidence per measurement property

Scale name (year)	*Content validity*	*Structural validity*	*Internal consistency*	*Cross-cultural validity*	*Criterion-related validity*	*Convergent validity*
The Workplace Intergenerational Climate Scale (WICS) 2016	VG • Experts from many disciplines contributed to the content validity. • Authors also used well justified method for qualitative research.	VG • Confirmatory factor analysis was performed. • Chosen model fits well to the research question.	VG • Cronbach's values are >0.80.	D • Good description of the participants is provided. • Clear information and further analysis on cultural aspects are not provided.	A • Adequate gold standard.	D Analysis showed that the WICS is correlated with scales: Stereotypes about Older Workers (St-Y) and Stereotypes about Younger Workers (St-O) – however, these two scales are not valid and developed by the research team.
Nordic Age Discrimination Scale (NADS) 2010	A • Only quantitative methods were used. • Assumable professionals are included in the process but the steps are not clearly described.	VG • Confirmatory factor analysis was performed. • Chosen model fits well to the research question.	VG • Cronbach's values are >0.80.	VG • Groups are well described and there are some relevant characteristics (multiple countries) but there is a lack of analysis to compare the cultural groups.	A • Adequate gold standard. • Correlations were calculated (results showed low correlation of harassment and bullying with age discrimination).	N/A

Workplace Age Discrimination Scale (WADS) 2016	VG • Assumable experts from the field contributed to the development of the scale. • The research team met to discuss and evaluate the items. • Authors included qualitative data from older employees.	A • Exploratory and confirmatory factor analysis were performed. • Chosen model fits adequately to the research question.	VG • Cronbach's values are >0.90.	D • Authors included diversity of age. • There is a lack of diversity in other demographics.	A • No evidence provided for gold standard. • Results showed significant correlations.	VG • WADS is correlated with Nordic Age Discrimination Scale (NADS), Workplace Incivility Scale (WIS) and Interpersonal Conflict at Work Scale (ICAWS). • Cronbach's values are between 0.31 and 0.58.
Work-related age-based stereotypes scale (WAS) 2016	D • Authors did not clarify if participants and professionals from all disciplines were asked whether items are relevant.	A • Exploratory factor analysis was performed. • The fit indices do not follow the criteria. • Authors used appropriate number of participants.	A • Cronbach's values are close to >0.80. • One sample (sample 3) has a population of <100.	D • Clear description of participants is provided. • Lack of different populations is noted. • Further analysis on cultural aspects are not provided.	A • Adequate gold standard. • Correlations were calculated.	A • Sufficient measurement properties of the comparator instrument (sample <100)
Instrument for measuring managers' attitudes toward older workers 2016	VG • Authors used well justified method for qualitative research.	A • Confirmatory factor analysis was performed. • Reasonably well-fitted model was found.	VG • Cronbach's values are >0.70.	A Group variables are clearly described.	N/A	N/A

Note
Based on COSMIN: very good (VG) adequate (A), doubtful (D), inadequate (I), not applicable (N/A).

answer these scales questions, they provide their views about elderly/older workers but for the latter group, they may not be thinking of their own experience depending on the extent to which they self-identify as an older adult. Interestingly, as previous studies suggest, some older adults may express negative attitudes toward their peers but view themselves under a more positive, and non-ageist light (Lagacé and Firzly, 2017). Hence, answering questions related to what one considers his or her own experience as an older adult vs that of "other" older adults may yield quite different results. Consequently, when assessing older workers' perception and experience of ageism both a measure related to the "self" and one related to "others" may be more accurate in capturing the complexity of ageism.

Three of the scales included in the scoping review focus on the behavioral component of ageism (WISC, WADS, NADS); in addition, the WADS includes an affective component of ageism (by asking respondents to what extent does each of the stated situations typically bother them). More precisely, the WICS assesses the frequency and quality of contact between workers of the same age and generation as well as of different age and generation. The WADS and the NADS both assess age-based exclusion work practices through recruitment, retention, training, support and promotion processes. In the case of the WADS, overt, in addition to covert, discrimination is measured (with items such as "My contributions are not valued as much due to my age"). On the other hand, the two others scales (WAS and IMAOW) mainly target the cognitive components of ageism, i.e., stereotypes about older workers. Precisely, the IMAOW measures stereotypes related to adaptability, value of older workers' competencies, organizational conscientiousness, social capital/generosity and performance, while the WAS is a three-dimensional stereotype content model including both negative (incompetence, inadaptability) and positive (warmth) stereotypes of older workers. It is interesting to note that the IMAOW assesses how managers perceive older workers and how such perceptions may influence their hiring decisions in terms of selection and training of older workers vs younger workers. The validation of the scale relied on a sample of 224 Portuguese managers and 249 Brazilian managers. Findings reveal that while managers generally attribute positive traits to older workers, they perceive them as having lower adaptability than younger workers (i.e., less able to adapt to new situations and more resistant to change). This finding is in continuity with Posthuma and Campion's (2009) study who have identified the "resistance to change" stereotype about older workers as one of the most prevalent one in the workplace. More so, this stereotype has been found to negatively influence managers' decisions related to hiring and training older workers (Rego et al., 2016).

The five self-reported instruments captured in this review, while revealing acceptable psychometric properties, speak to the need for more research aiming to develop tools to measure ageism in the workplace, especially in regards to managers' perception of older workers. Indeed, findings of studies suggest that manager's decision-making about older workers often relies on ageist stereotypes and attitudes (either conscious or unconscious). For example, as stated in the beginning of this chapter, Neumark, Burn and Button (2019) designed and implemented a large field experiment study to test how age-based discrimination permeates employment, namely through discrimination at *hiring*. Based on evidence from more than 40,000 job applications for administrative jobs, submitted by young applicants (aged 29 to 31), middle-aged applicants (aged 49 to 51) or older applicants (aged 64 to 66), they found strong evidence of discrimination (i.e., call back rate) against applicants near retirement ages (aged 64 to 66) in comparison to young applicants. Interestingly, workers nearing the normal retirement age (64 to 66 years old) were the ones mostly targeted by discriminatory practices.

Along the same lines, participation in training is another area where ageist practices on the part of employers have been documented. While life-long learning is one of the means to address an ageing workforce, i.e., by retaining older workers, there is still uncertainty and ambivalence among managers regarding the desirability and feasibility of training older workers. One of the outcomes is that employers generally provide less training to older employees, starting at age 50, than they do to younger employees. Findings from a 2015–2016 study (Lössbroek and Radl, 2019) involving nine European countries and 2517 employees and their managers spread over 228 organizations, confirms the age-based differential treatment. According to Lössbroek and Radl, the reasons for such practices relate to prejudice and stereotypes about ageing in the workplace, where older workers are considered less willing and less able to be trained. Consequently, managers consider the return on investment in training older workers too low. In summary, findings of studies, such as Lössbroek and Radl's, as well as Neumark et al.'s, point to the need for developing more tools to measure managers' views, feelings about ageing and older workers as well as behavioral intentions. In other words, further self-report ageism scales need to be developed that will allow measuring the *cognitive*, *affective* and *behavioral* components of ageism from the perspective of managers. Recruitment and retention of older workers can only happen if managers do not subscribe to ageist stereotypes, express a dislike toward older workers and discard them during recruitment processes and workplace retention initiatives.

Like any form of discrimination, ageism does not exist in a void. A growing number of studies show how ageism intersects with other discriminatory attitudes, including sexism. For example, reinforced by a popular culture that displays ageing women more negatively than ageing men, gendered ageism translates into women being more strongly judged on youth-based physical attractiveness.

In the case of employment, while negative ageist stereotypes may be partially counterbalanced by positive stereotypes that value experience, studies suggest that this appreciation is far stronger for older men than it is for older women. To this effect, Neumark et al.'s, findings not only suggest that the oldest applicants (64 to 66 years old) are targeted by age discrimination in hiring but among those, women are placed at greater risk (Jyrkinen, 2014). To our knowledge, there are no scales that address the differential experience of older female employees in the workplace, or how managers view and treat them.

More generally, there is a need to expand the study of ageism in the workplace using observational, experimental and longitudinal methodologies in addition to self-reported scales. This will allow a better understanding of perceptions related to ageism in the workplace but more importantly of its expressions. Self-reported measures are limited by the threat of social desirability bias and the measurement of behavioral intentions rather than behaviors per se.

Conclusion

Notwithstanding rapidly ageing populations, ageism remains a prevalent and insidious form of discrimination, one that is under-reported in comparison to racism and sexism. Although ageism can target younger and older adults, the latter are the ones that are primarily the object of age-based stereotypes and discrimination. This is especially the case as relates to older workers who face important barriers stemming from organizational ageist beliefs and practices. Although governments, including the Canadian government, have put in place a number of initiatives to increase the participation and retention of older workers, few of them directly address ageism. However, in the face of current and future labor shortages, examining attitudes, notably employers' attitudes toward older workers, is the first step to counteract ageism. Doing so implies that researchers and policymakers can rely on valid instruments that allow measuring implicit and explicit age-based stereotypes and discrimination. The current scoping review has identified five self-reported scales that measure ageism in the workplace, through stereotypes and discriminatory behavioral intentions. Although these scales prove to be reliable, their limited number points to the need for further tools to measure the complexity and multidimensional nature of ageism.

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4 Investigate population ageing using national transfer accounts

New economic age profiles for Canada and France

Marcel Mérette and Julien Navaux

In this chapter, authors provide national accounts by age for economic flows of consumption and labor income using the National Transfer Accounts (NTA) methodology. We analyze the new data set we developed for Canada for the year 2011 and we compare the age profiles with the ones reported in France the same year. NTA per capita age profiles suggest that per capita age profiles of labor income are remarkably similar in the two countries. Moreover, age profiles evidence that public expenditures are higher at old ages in Canada than in France, but that France's public expenditure exceeds Canada's public expenditure during working life. Moreover, NTA age profiles show that private consumption is much higher in Canada than in France with a remarkably constant ratio at each age. Consequently, current behavior with respect to private consumption may well be challenged in the following years in the context of population ageing.

Introduction

It is well known that with rising life expectancy and declining fertility rates for many years, inverted dependency ratios such as the number of people aged 20–64 over those aged 0–19 and 65+ are alarming from an economic point of view. Indeed, as the number of active middle-age individuals is declining compared to the dependent younger and older generations, one may be concerned about the capacity of the working age groups to support the increasing number of dependent individuals. In Canada, the inverted dependency ratio was 168 workers per 100 dependents in 2011. Canada's inverted dependency ratio is projected to decline to 115 workers for every 100 people of dependent age by 2063 (Statistics Canada, 2015). The concerns refer to issues such as healthcare costs, pension and, to a lesser degree, labor productivity. Healthcare costs are known to increase rapidly for individuals aged 60 and over. By definition, retired people get pension benefits, and labor productivity is believed to decline with age. Healthcare and public pensions may threaten the balance of government budgets, whereas declining labor productivity may slow down economic growth. To summarize, some scenarios suggest that an increase in the number of elderly adds fiscal pressure, while the economy is slowing down because of the lower productivity of older workers (see for instance Maestas, Mullen and Powell, 2016). Some research argues that the fiscal pressure will be such that systems of public transfers to the elderly, as currently structured, will not be fiscally sustainable as populations continue to age rapidly in the first half of the twenty-first century (see for instance Chojnicki, Navaux and Ragot, 2016). In accordance with the theory that suggests a clash between ages, some authors claim that maintaining public transfers to the elderly will lead to a decline in educational spending for the young (Poterba, 1997, 1998; Harris, Evans and Schwabb, 2001). To this gloomy scenario, others propose a much more optimistic one (Evans et al., 2001; Denton and Spencer, 1997, 2000; Fougère et al., 2009; d'Albis, Cusset and Navaux, 2016). The fact that there is no clear consensus on the economic impact of ageing in Canada suggests that further investigation is warranted, especially if a new data set is providing new insights.

Better understanding of the economic challenge of ageing undoubtedly requires access to resource allocation across ages. Recent developments in social sciences investigate new ways to improve measurements on economic flows, either on specific topics like long-term care (Grignon and Spencer, 2018) or on a global perspective like the National Transfer Account (NTA) methodology (Lee and Mason, 2011a, 2011b). The NTA provides national accounts by age for economic flows such as labor income, consumption, public transfers and private transfers. The profiles are useful to identify the role of per capita economic variables and that of demographic change. In this chapter, we introduce such a data set for Canada. We focus on per capita consumption and labor income age profiles to provide a different angle on the challenge ahead with respect to population ageing.

The NTA age profiles are clearly subject to economic conditions. Higher economic growth rates and lower unemployment will improve labor income and raise consumption; however, the per capita age profiles also reflect preferences, culture factors, incentives found in various public policies and institutional arrangements, especially between the private (individuals, corporations) and public sector. As part of this chapter, we intend to demonstrate that the NTA we developed for Canada gives a different perspective about the challenges of population ageing in Canada. In other words, we proceed by examining the NTA data to infer what kind of information can be extracted regarding the economic challenge of ageing in Canada. To facilitate the discussion and analysis, we compare the NTA data for Canada with a country with a similar standard of living, France, and for an identical year, 2011.[1]

This chapter is organized as follows. The next section briefly explains the NTA methodology and required data sources. The following section reports labor income and consumption profiles for Canada and France respectively, and then introduces a decomposition of total consumption between the private and public components. The last section is the conclusion.

NTA methodology

The NTA originates from the work of Lee (1980) and Mason (1988). NTAs are based on a unified international methodology that consists in the introduction of age in the national accounts. The methodology is described in a technical manual published by the United Nations in 2013. Some recent developments using NTAs are found in Mérette and Navaux (2019) and d'Albis et al. (2017a, 2017b, 2019). Today, the NTA is a well-established empirical tool used to understand cross-age economy, with harmonized data available for about 70 countries (see www.ntaccounts.org).

NTAs are based on an accounting identity, introduced in Equation 4.1, such that the difference between consumption (C_a) and labor income (Y_a^L) at each age a corresponds to the lifecycle deficit (Lee, 1994). The gap between consumption and labor income results in net public or private transfers, $T_a^N = T_a^I - T_a^O$, equal to the difference between transfer inflows T_a^I and transfer outflows T_a^O, and in asset-based reallocations, equal to the asset income net of savings $Y_a^K - S_a$.

$$C_a - Y^L_a = (T^I_a - T^O_a) + (Y^K_a = S_a) \qquad (4.1)$$

The methodology relies on three stages for each of its components:

- Per capita age profile f_a is extracted for each component from survey data or an administrative database.
- Each age profile is smoothed with a level 2 polynomial. This smoothed profile, denoted as $\tilde{f}_a$, is multiplied by the number of people at each age a, N_a to get an aggregate flow $F = \Sigma^n_{a=0} \tilde{f}_{aNa}$.
- The age profiles are adjusted to insure that the aggregate amount F fits perfectly with the corresponding aggregate AG from the national accounts.[2] The corrective term $c = F/AG$ is then calculated and applied to the aggregate smoothed series. The corrected profiles are $\tilde{F}^c = \tilde{F}/c$ at the aggregate level and $\tilde{f}^c = \tilde{F}^c/Nc$ at the individual level.

For the purpose of this chapter, we built Canadian age profiles of labor income and consumption for 2011 and for ages between 0 and 90. Aggregates are made consistent with the CANSIM tables of the System of Macroeconomic Accounts produced by Statistics Canada (see Table 4.1 for the aggregates in 2011) following the United Nations manual (2013).

NTA age profiles are computed from various databases at the individual level. The three components of labor income (labor earnings, employer contributions and self-employment labor income) are calculated from the Survey of Labour and Income Dynamics and from the Canadian Income Survey, which are available at the individual level. Employer contributions are calculated by applying the parameters of employer contributions to individual wages. Private consumption age profiles (education, health and other consumption comprising imputed rents)[3] are calculated using the Survey of Household Spending (SHS). The four variables are available at the household level. Private consumption profiles in education and health are obtained by regression methods, following the strategy suggested in the United Nations manual (2013). Household consumption in education is assumed to be a function of the number of household members aged five to 29. The regression coefficients obtained at each age are then used

Table 4.1 Control aggregates for consumption and income in 2011

Aggregates in millions ($CAD)	
Labor income	**1,078,017**
Gross wages	933,178
Labor earnings	810,086
Employer contributions	123,092
Self-employment labor income	144,839
Private consumption	**876,868**
Health	37,343
Education	12,832
Other	826,693
Public consumption	**375,141**
Health	140,847
Education	90,787
Other	143,507

to allocate private consumption in education within the household. Following the works of d'Albis et al. (2015, 2017b), household health expenditure is assumed to be a function of the number of household members in each five-year age group, except for the first year of life (age zero), which is treated separately. Other consumption, including imputed rents, are allocated across ages with the piecewise linear scale suggested by Lee and Mason (2011a). Private consumption other than health and education is assigned to each member by weight. The weight is 0.4 for young children aged four and younger, and then increases linearly from ages four to 20, and equals one for adults 20 years and older.

Public consumption in health is calculated with administrative data from different sources. Public consumption in health relies on provincial/territorial government expenditure by age and sex from the Canadian Institute for Health Information. Age profiles of public consumption in education are estimated from the number of students enrolled in public elementary and secondary schools and from the number of students enrolled in post-secondary education. According to the NTA manual, public consumption other than health and education is allocated to individuals equally by age because it includes sovereign functions such as the police, justice, defense or public administration (United Nations 2013). Aggregates and age profiles for 2011 in France were produced by the French NTA team (d'Albis et al., 2017b) and are available on the website of the National Institute of Demographic Studies: ctn.site.ined.fr.

Estimates of 2011 age profiles of labor income and consumption are averages of males and females together in the Canadian and French population. As noted by Lee and Mason (2011a), these profiles reflect culture, and institutional and public policy features found in each country investigated. In the following section, we underline the differences regarding these features between Canada and France. The first profile we look at is labor income, followed by the consumption profile.

Comparison of labor income and consumption between the two countries

About the remarkable similarities of per capita labor income in Canada and in France

Labor income is the sum of labor earnings, employer contributions and self-employment labor income.[4] In Canada, labor income accounted for 60.9 percent of the gross domestic product (GDP) in 2011. Labor earnings is the most important component of labor income in Canada (75.2 percent), followed by self-employment labor income (13.4 percent) and employer contributions (11.4 percent).

Figure 4.1 reports labor income age profiles for both Canada and France in purchasing power parity (PPP) Canadian dollars. The figure demonstrates that per capita labor income profiles have similar shapes and are comparable in value terms at each age in the two countries, with two exceptions being between ages 35 and 45 and after age 55. Let's start by analyzing per capita labor income for age that covers 15 to 55 years old.

Note first that the per capita labor income increases and is almost equivalent from ages 15 to 35 in both countries. At 25 years old, the per capita labor income is equal to $31,298 in Canada and to $33,645 in France. At 35 years old, the gap is even smaller with $56,127 in Canada and $54,445 in France (3 percent difference).

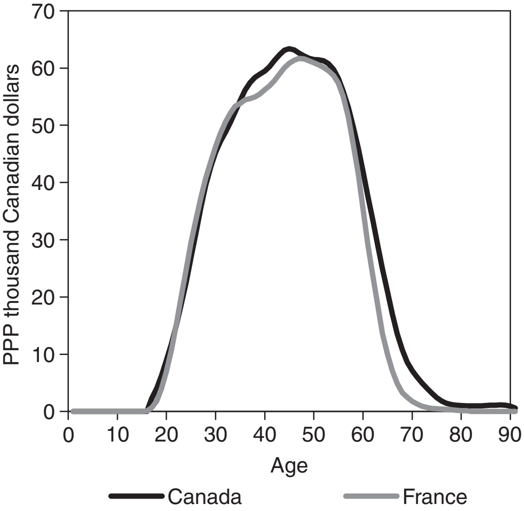


Figure 4.1 Per capita labor income age profiles in Canada and France for 2011.

Thereafter, between the ages of 35 and 45, per capita labor income diverges slightly between both countries. While labor income continues to increase in Canada, it remains relatively stable in France. The highest dissimilarity occurs at 38 years old, with a difference of \$3481 between Canada (\$58,906) and France (\$55,425). At 45 years old, the per capita level of labor income is equal to \$63,156 in Canada and \$61,387 in France.

Between 46 and 55 years old, labor income decreases slightly but is once again quite similar in both countries. At 46 years old, the difference between Canada (\$62,634) and France (\$61,689) is \$945, which is comparable to age 55 where the difference is \$879 between Canada (\$55,958) and France (\$55,079).

After 55 years old, labor income decreases promptly with age in both countries; however, it is worthwhile to observe that the difference in labor income between Canada and France increases significantly after age 55. At 60, 70 and 80 years old, labor income is respectively 29 percent, 354 percent and 760 percent higher in Canada than in France. This reflects greater labor participation rates of older workers in Canada. In 2011, there is an employment rate of 58.4 percent in Canada for ages 55 to 64 compared to just 41.4 percent in France. Although we cannot identify the exact cause of this significant disparity, we can certainly point out that Canada has more modest incentives for early retirement built into the pension system. As an illustration, public pension spending in Canada represents 4.3 percent of the GDP in 2011 but is as high as 13.4 percent in France (OECD, 2020a). Moreover, although there is no proof of this, it is possible that Canada's labor market is more open to older workers (as their salary is less structured by seniority) and/or that Canadians may have slower increase in demand for leisure at old ages than in France.

A higher level of consumption at all ages in Canada

Although per capita labor income profiles are remarkably similar in Canada and France, consumption differs significantly at each age in both countries.

Figure 4.2 reports the per capita amounts of total consumption (public and private) at each age in PPP Canadian dollars. First, note that in both countries, the slope moves upward with age. Hence, older individuals consume more than young and middle-age people; however, the consumption level in dollars in Canada deviates from the one in France. As for labor income above, we comment the total consumption age by age, starting with the youngest.

From zero to three years old, total consumption decreases in Canada and France. Consumption is much higher in Canada at birth with a level equal to $25,551 compared to $15,591 in France. Three years old is the only age at which consumption is higher in France ($17,644) than Canada ($16,034).

After age three, consumption increases in both countries up to the late teens and early 20s. The gap between Canada and France reaches a peak of $6607 at ten years old, with a total consumption equal to $31,912 in Canada and $25,305 in France.

Afterward, consumption follows a V-shaped curve up to the early 60s in both countries. As shown by d'Albis et al. (2017b), the V-shaped curve corresponds to the ages at which individuals are parents. They share their resources within their households with their children to fund children's consumption. At these ages, the difference between Canada and France varies between $6770 (24 years old) and $2748 (39 years old). At 45 years old, the per capita level of consumption is equal to $34,781 in Canada and $30,718 in France.

After age 60, consumption age profiles diverge substantially between Canada and France. At 64 years old, the difference between Canada and France is still relatively small. Total consumption is equal to $40,616 in Canada and $39,837 in France (a difference of $779); however, the difference increases thereafter to $3758 at 70 years old, $10,672 at 80 years old and $21,529 at 90 years old and more, which is the largest difference between both countries for all ages.

The evolution of the difference between Canada and France over the ages highlights a higher overall level of consumption in Canada, but the difference is not constant at each age. To further investigate the difference in the level consumption between both countries, we now proceed with a decomposition of total consumption into its private and public elements.

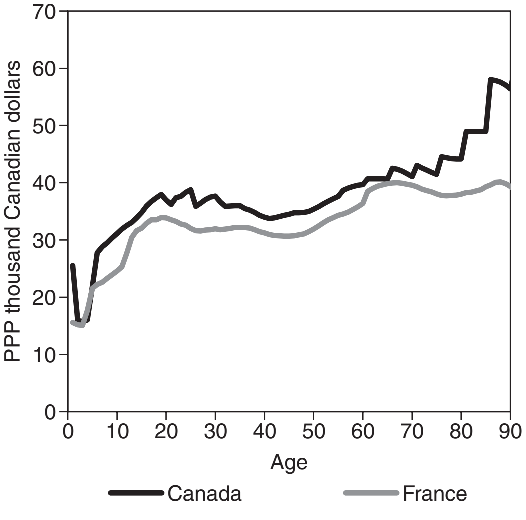


Figure 4.2 Per capita consumption age profiles in Canada and France for 2011.

The key role of private consumption and public health expenditures in Canada

Figures 4.3a and 4.3b introduce the per capita age profiles of consumption by separating the private and public consumption components between education, health and other consumption. Figure 4.3c investigates the difference in the level of consumption between both countries. We calculate the ratio of private consumption, public consumption and total consumption in Canada and France for all ages. Note that an identical consumption level of consumption in Canada and France implies that the ratio would be equal to one. The results reported in the three figures are striking.

First, public consumption is lower in Canada for middle-age individuals but higher for school-age individuals and older individuals, aged 75 and over. The highest level of public consumption is clearly due to the high level of public health consumption for older individuals in Canada. The ratio of per capita public health spending between Canada and France is equal to 1.15 at age 70 ($49,316 in Canada and $8069 in France) and to 2.25 at age 90 or more ($31,243 in Canada and $13,888 in France). Between ages 37 and 70, we find a larger level of public consumption in France. This reflects both the larger public consumption other than health and education that is higher in France than in Canada at each age, and the larger level of public health expenditures in France for the same age group.[5]

The most striking result is found in Figure 4.3c and refers to the ratio for private consumption. Between age 0 and age 90+, the ratio is remarkably stable in 2011. For all ages combined, on average, private consumption is 20.1 percent higher in Canada ($25,533) than in France ($21,264). The highest ratio of per capita private consumption is 1.28 for newborns ($10,366 in Canada and $8069 in France), whereas the lowest ratio is 1.12 at 69 years old ($29,950 in Canada and $26,714 in France).

The high level of private consumption in Canada can be explained by two differences between both countries. First, French people save much more than Canadians. In 2011, the net household saving rate was equal to 9.9 percent of the household disposable income in

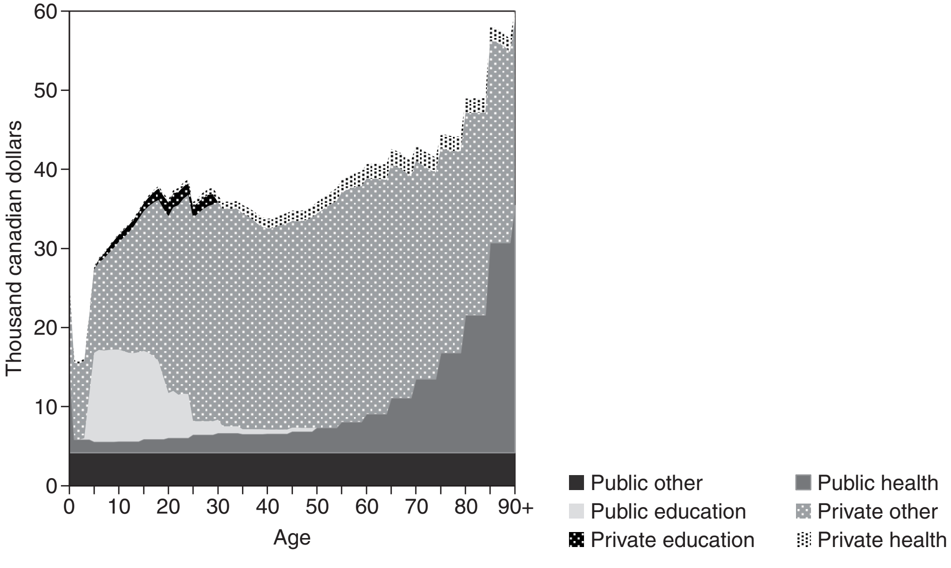
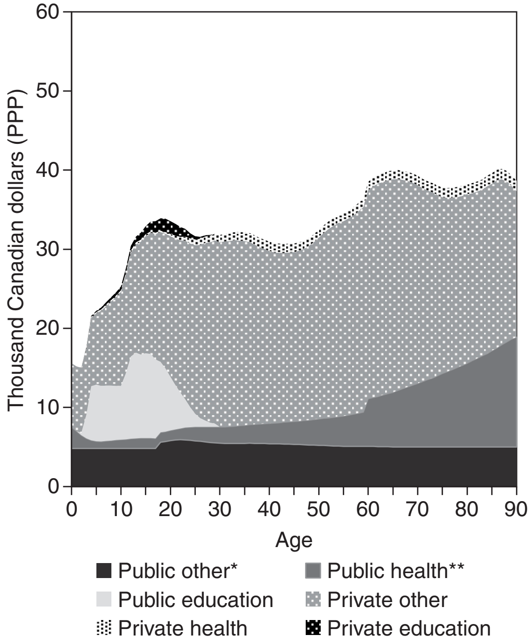


Figure 4.3a Canada.

Figure 4.3 Decomposition of per capita consumption age profiles in Canada and France for 2011.



* including Housing Benefits that are considered public consumption in France
** including Elder Care that is considered public consumption in France

Figure 4.3b France.

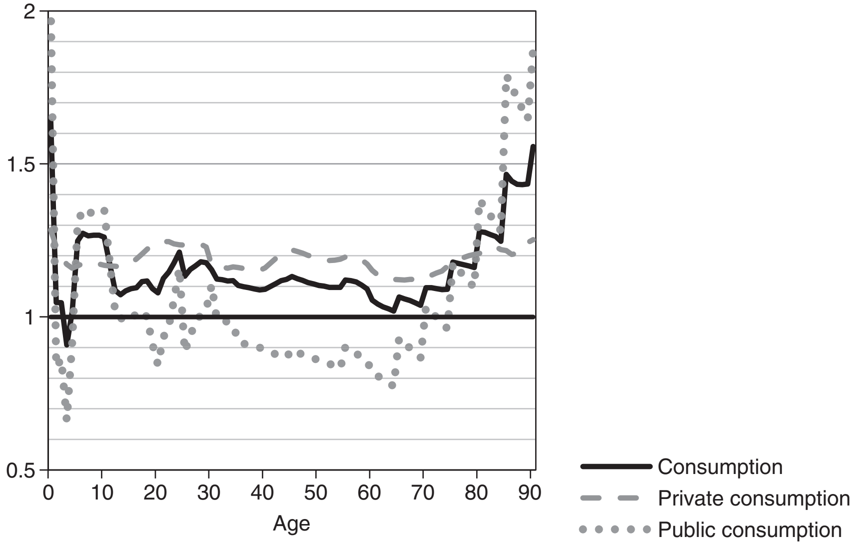


Figure 4.3c Ratio of per capita spending between Canada and France at each age from 0 to 90 and over, for 2011, in $CAD PPP.

France (OECD, 2020b). In Canada, the net household saving rate was equal to 4.4 percent. Therefore, Canadians dedicate a larger portion of their disposable income to consumption. This may reflect cultural differences regarding consumption but also easier access to credit in Canada as shown by the much higher level of household debt. Indeed, the OECD (2020c) reports that in 2011, the household debt with respect to disposable income was 169 percent in Canada but only 113 percent in France.

Conclusion and discussion

Comparing age profiles for labor income and consumption between Canada and France showed that the per capita labor income is very close at each age up to 55–60 years old in both countries, after which labor income is larger in Canada than in France. Despite a similar level of labor income revenue during most of the lifetime, total consumption is much higher at each age in Canada, due to two main differences. First, public health expenses increase significantly with age in Canada, while the rise of public health spending according to age is slower in France; however, the most striking result is the higher level of private consumption at almost each age in Canada. The difference reaches as much as 20.1 percent on average.

The increasing age profile of per capita consumption for 2011 plus the substantially larger level of consumption in Canada compared to France, despite similar labor incomes, should raise concerns regarding consumption in an ageing process. Indeed, we know that in 2011, the share of people aged 65 or more was equal to 14.4 percent in Canada, but 50 years later, Statistics Canada's projections indicate that the share of people aged 65 or more could reach 27.7 percent of the entire population. Consequently, if consumption behavior does not change, total consumption will increase substantially in Canada. Using NTA age profiles, this chapter shows that for Canada, the concern should be more about private consumption than public consumption.

Indeed, per capita public consumption in Canada is lower than in France for ages 31 to 69. For ages under 31, public consumption in Canada is sometimes larger and sometimes lower than in France, reflecting mostly different allocations of education for the two countries. It is as of age 70 that public consumption is much higher in Canada than in France, but we know that the pension system in Canada is sustainable and less demanding on Canadian governments than in France. The main difference in public consumption between both countries is the consumption of public healthcare services by older individuals.

Yet, although public health expenditures are particularly high among older Canadians, recent research conducted on the link between demography and health shows that population ageing is not the main factor explaining the rising costs of public health (Evans et al., 2001; Canadian Institute for Health Information, 2011). Also, health costs at death are an important driver of the total costs over a year. Thus, the decline in mortality rate at each age could postpone the health cost at very high ages. While public consumption seems reasonable in Canada compared to France for most ages, this is not the case for private consumption.

In fact, our study underscores that private consumption is especially high at almost each age in Canada. Assuming that the consumption behavior remains stable over the next few years in Canada and that the labor participation rate does not change much, the ability to finance total private consumption through total labor income will decline over time. One way to avoid this and to keep a relatively high level of private consumption at all ages would be to increase savings, which are very low in Canada, at least compared to France.

A higher saving rate would increase the asset income that actual workers will get once retired and would secure private consumption, assuming that the maintenance of public support systems in Canada will not deteriorate, as expected (see Denton and Spencer, 1997; and Evan et al., 2001). In other words, in the context of population ageing, NTA profiles suggest that public consumption does not seem extreme in Canada, at least on a comparative basis; however, NTA profiles show that private consumption is much higher in Canada than in France, even at old ages. Consequently, current behavior with respect to private consumption may well be challenged in the following years in the context of population ageing.

Notes

1 France and 2011 were chosen because of the availability of the database for comparison purposes. French profiles are available online at ctn.site.ined.fr/en/data/from 1979 to 2011. See d'Albis et al. (2017b) for a specific description of labor income and consumption age profiles from 1979 to 2011 in France.

2 Note that some aggregates, such as private transfer inflows and outflows, have no equivalent in national accounts. Aggregates for private transfers are thus calculated from the surveys and are readjusted on the net private transfers with the rest of the world (inflows from ROW – outflows to ROW). This is the only aggregate available for private transfers in the System of Nations Accounts.

3 Imputed rents are the value of the flow of services that home owners consume from their property. They are calculated in two steps using the Survey of Household Spending. First, we regress the value of rents paid by tenants on a set of variables, including the characteristics of the household, the characteristics of the dwelling (type of accommodation, year of construction, number of rooms, etc.) and the location (16 metropolitan areas and a subdivision of non-metropolitan areas with respect to the urban size). Then, we estimate the imputed rents of owner households according to the coefficients of the first regression.

4 The estimates exclude the value of time spent in home production and the value of non-market time spent rearing children, preparing meals, cleaning, providing care and completing other domestic tasks.

5 The high level of public health expenditure for older individuals in Canada is also observed by Donehower, Lee and Miller (2011) for the United States.

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5 Protection of the fundamental rights of older adults – methodological perspective of administrative and legal research

Anna Szafranek

This chapter refers to the following research methods used in the gerontological research:

- photographic method,
- individual case studies as well as multiple case studies,
- autobiographical method,
- focused interviews,
- research using the International Older Persons' Human Rights Index (IOPHRI).

Methodological conclusions:

1 While carrying out administrative and legal research on older adults, special attention should be paid to proper conceptualization of research, specifically to the selection of indicators, the ways of measuring them as well as to defining basic notions.
2 Qualitative methods are usually used to study older adults, which is why these methods are also used in the research into protection of their rights. An especially adequate tool seems to be a multiple case study, also called multiplace qualitative research.
3 As a research technique (in administrative and legal research) it is worth using an in-depth problem-centered interview and, as a research tool, a semi-structured interview.
4 An individual narrative in comparison with other research methods gives older adults a sense of security, and for lonely senior citizens is often one of the few forms of contacting the outside world, while in the case of research, for example, concerning violence, may serve as an informal therapy.
5 In selecting a research sample, it should be strongly emphasized that older adults (especially when it concerns today's generation of senior citizens, who have survived the war, the post-war period and communist rule – the example of East Europe) are one of the most heterogeneous groups as far as education is concerned. This means that improper choice of research sample or omitting this fact in the results analysis may be a misuse and may result in methodological mistakes, which would in turn lead to erroneous conclusions. In order to avoid the mistakes described above, cohort studies may be considered (taking into account appropriate criteria of selection).

Introduction

Contemporary society is characterized by global demographic dynamics, which bring about the necessity to adjust social policy and laws to the needs and expectations of older adults, whose number is systematically increasing. The ageing of society has not only demographical impact but also social, cultural, economic and legal impact. Therefore, gerontology as a science should be perceived from an interdisciplinary perspective and also from the point of view of gerontological research (Kijak and Szarota, 2013, p. 6). Thereby, one of the characteristics of contemporary science, including methodology, is interdisciplinarity. This is proven not only by plenty of national research but also reports from international research.

It needs to be emphasized that gerontology is defined within the category of interdisciplinary science of ageing and old age (Polak et al., 2007, pp. 51–53), which focuses on analyzing ageing and old age while taking into account optimal living conditions of older adults (Orzechowska, 1999) (in the demographic, social, economic, medical and legal aspects). The need for the analysis of these aspects of gerontology is strongly connected with the phenomenon of ageing societies, not only in Poland and Europe but also around the world. According to the forecasts, in 2050 every fifth inhabitant of Earth will be aged 60 years or more, while in 2150 it will concern every third person (Malec, 2008, p. 130) It needs to be mentioned that in the light of the data collected by the Polish Central Statistical Office (GUS), in 2015 in Poland the average life expectancy was 73.6 years for men and 81.6 years for women. In comparison with the data from the early 1990s, the female life expectancy increased by *circa* seven years, with six years for men; while in comparison with the year 2000, both men and women lived approximately four years longer. It is also forecast that the population of centenarians and people over 100 years will gradually increase (http://stat.gov.pl/infografiki-widzety/infografiki/infografika-osoby-starsze-w-wieku-100,41,1.html). Therefore, the need will arise to adjust current legislation and introduce new systemic solutions, for example in the field of social care and legislation concerning older adults. For the implementation of the abovementioned (example) regulations to be successful, it is necessary to conduct interdisciplinary research, which will not only diagnose the current situation but also for instance evaluate new pilotage legal solutions. Although so far interdisciplinarity has mainly been characteristic of medical, health and economic sciences, in view of the demographic changes and increasing social participation of older adults, it seems absolutely essential to develop the methodology of administrative and legal gerontological research. The aim of this chapter is to present the methodological bases in this area, good methodological practices in administrative and legal research concerning the legal rights of older adults, as well as the demands and recommendations concerning the implementation of such research.

The basics and new perspectives of gerontological research[1]

The literature on the subject emphasizes the fact that gerontology as a science has both learning and practical goals. Thereby, it studies the practical functioning of older adults in various aspects of social life, while remembering that the results should be used, and in many cases are already used, to create favorable living conditions and to solve multiple problems connected with ageing and old age from the social, economic, demographic, medical, educational and legal perspective (Orzechowska, 1999; Halicka and Halicki, 2014, pp. 139–156). Moreover, some researchers stress that gerontological research may not be separated from theory as this may result in methodological flaws, while others contend that the research findings may not be analyzed without taking into consideration theoretical bases (which are built around empiricism) (Hendricks, Applebaum and Kunkel, 2010, pp. 284–293).

The international literature on the subject lists the methods which are or should be used in gerontology more than in other disciplines. This suggests that gerontology as a science has partly developed a specific methodological approach. A very good example is “the photographic method”, which was used in the research into the perception of ageing in rural areas. It was additionally enriched by observation and in-depth interviews with individuals (Magilvy et al., 1992, pp. 253–257). It has also been noted that it would be advisable to apply focused research, for example research into living in social care homes carried out among their residents (Kydd et al., 2018, p. 232). However, when it comes to protecting the fundamental rights of older adults (which may be easily considered a sensitive issue), this method will not be applicable (for example due to the presence of strangers during focused interviews).

A crucial role in the research conducted among older adults is played by narrative (used in qualitative research). The narrative perspective is applied for example to research into the anthropology of ageing and the culture of ageing (Perkinson and Solimeo, 2014, pp. 101–107). Closely related to narrative is the autobiographical method (used especially in pedagogical research) (Duccio, 1999) and individual case studies as well as multiple case studies (Pilch, 2010).[2] Analysis of the literature on gerontological studies reveals that researchers use qualitative research more willingly than quantitative (with an exception of longitudinal research) (Putnam, 2018, pp. 127–128),[3] for instance, when analyzing the access of older adults to rural health services, researchers in New Zealand used methods which they described as a qualitative narrative gerontological approach, using semi-structured interviews (Neville et al., 2019, pp. 1–7).

In gerontological research concerning medical aspects, the object of the analysis was the purposefulness of using standardized questionnaires, pointing to their numerous advantages but also drawbacks (Bravell, Johansson and Finkel, 2018, p. 149). Such questionnaires cannot be applied to legal research as medical research is mostly based on facts (where completing standardized questionnaires basically does not pose serious problems), while legal research is based on opinions.

Nevertheless, it is worth remembering that in gerontology, as in other disciplines, flexibility and an interdisciplinary approach to research are crucial. That is because, depending on the research topic, various approaches and analyses can be combined, which gives the possibility of studying a complex problem from different perspectives (Cornwell, Marcum and Silverstein, 2015, pp. 87–90). Another widely discussed attribute in the area of designing and conducting gerontological research is transparency (Brown and Allison, 2018, p. 808). Putnam, apart from transparency in gerontological research, emphasizes the need for translating research results into practical solutions (2018, pp. 127–128). For example, the so-called method of deliberative dialogues is interesting. This bridges gerontological research with policy and practice, when integration of approaches and activities of various groups (academic circles, practitioners and decision-makers) enables sharing of knowledge and experience, and that means putting theory into practice – e.g., Canadian research into housing provision to senior citizens (Canham, Wada and Schwartz, 2017, p. 1076–1077).

Summing up, the following trends are discernible in contemporary gerontological research: interdisciplinarity, bridging theoretical, empirical and applicational approaches, as well as conducting research on the basis of theories which are especially selected and adjusted to the subject and goal of research – all these assumptions are met by administrative and legal research into the protection of fundamental rights of older adults.

Methodological connections and barriers between sociology and law

Methodological connections between sociology and law were indicated as long ago as in the works of Emile Durkheim, who said that law is a social fact exterior to the individual person and inseparably connected with an external constraint (2000, pp. 27–33). Sociological as well as legal and administrative sciences require precision; for example, in defining phenomena or in solving problems. Therefore, it seems right to refer to Durkheim's suggestion that all the above-mentioned sciences should "study only a group of phenomena previously defined by their common external characteristics and by this encompass in their studies all the phenomena which refer to the definition itself" (2000, p. 65). This quotation clearly emphasizes the necessity of applying precision to scientific (sociological and legal) research, as both these disciplines require it; however, in different dimensions. The aim of administrative and legal research encompasses both questions stemming from legal sciences and concerning for instance the sources of law, legal systems, the effectiveness of specific norms, but also questions arising from the point of view of social sciences devoted to the influence of specific regulations or norms on community life (Frieske, 2001, p. 8).

Although legal (or administrative and legal) research uses methods developed in sociology, in many cases they require certain modification (Ziembiński, 1975). Some of the social research methods can be fully applied to research on law, some only partially, and some are not applicable at all (Pieniążek and Stefaniuk, 2014, p. 122). It needs to be stressed that sociological and legal research is not possible in isolation from the current social, political, religious, ideological and economic situation (depending on the selected subject matter). Moreover, law is an instrument of the authority of the state, which is why the literature on the subject contends that. in the case of persons who are knowledgeable about the current legal system or clearly favor it, the questions about their opinion on the current system may raise suspicion as to the aim of the research as well as cause a sense of insecurity in respondents (Pieniążek and Stefaniuk, 2014, p. 122).[4]

A sense of insecurity may also appear in older adults during research concerning their fundamental rights. In a way, even a question: "Name your fundamental rights" may raise fear as respondents may not be aware of their rights. Consequently, they will possibly perceive such a question as an accusation of ignorance and as a result will resort to oversimplification (what is the aim of observing one's rights and extending their scope if older persons – the beneficiaries – have neither the knowledge about them nor the awareness of how to exercise them). Therefore, a sense of insecurity may be one of the obstacles to applying sociological methods to legal research (Pieniążek and Stefaniuk, 2014, pp. 122–123), including that concerning the protection of the rights of older adults. It seems that to some extent the problem may be eradicated, for instance by making every effort to keep questions in the research tool comprehensible (without such basic methodological mistakes as multiplication, false assumptions, questions raising insecurity in respondents) (Lutyńska, 1984).[5]

Another difficulty, especially in the case of older adults, is a specific intellectual tool used when discussing law. Some of the terminology concerning the protection of fundamental rights of older adults may not be understood or may require explanation and clarification on the part of the researcher. Therefore, although from the methodological point of view it may seem obvious, it is not always observed: conducting research among older adults without prior pilotage is a mistaken approach. In consequence, it appears that qualitative methods enabling immediate contact with respondents are more adequate for research into the protection of fundamental rights of older adults (which is going to be discussed below).

Operationalization of basic notions

A response to the demographic changes is the national administration performing different public tasks in the field of social care (Pszczyński, 2014, pp. 83–96) (including the rights of older adults). Consequently, research should include a legal perspective (concerning, for instance, research into the implementation and effectiveness of specific acts of law) and an administrative perspective (concerning, for instance, research into the effectiveness of the actions taken by law enforcement agencies), which are closely related. Moreover, the Center for the Study of Ageing points to the need for analysis of the link between institutional factors (a reference to administrative research) and socio-economic factors in the study of ageing (www.rand.org/well-being/social-and-behavioral-policy/centers/ageing/research.html).

Since this chapter concerns the methodological perspective, it does not discuss national or international documents dealing with the protection of rights of older adults;[6] it only quotes some of them in order to exemplify the rights of older adults which could be subject to analysis. It should be mentioned that a basic document containing a detailed catalog of human rights (to which every person is entitled, irrespective of their age) is the European Convention on Human Rights adopted in Rome on 4 November 1950. However, as Barbara Mikołajczyk notes, a real breakthrough came with an international document called the United Nations Principles for Older Persons adopted in 1991 because of its comprehensive approach to the situation of the elderly. The principles, which are guidelines for each country, are divided into the following groups: independence, participation, care, self-fulfillment and dignity (Mikołajczyk, 2012, p. 101).[7] The literature on the subject, however, points out that international protection of the rights of older adults does not receive enough attention and a comprehensive tool to help them and protect their rights has not yet been devised (Tonolo, 2018, pp. 107–120).

Bearing in mind the United Nations Principles for Older Persons, a group of Polish practitioners led by the Citizens' Rights Ombudsman prepared a human rights handbook addressed to older adults, which focused on the following four areas of crucial practical importance for them: the right to social welfare, the right to healthcare, the prohibition of torture and inhuman or degrading treatment and the right to respect for private and family life, home and correspondence (Bienasz et al., 2012, p. 18). The groups considered by the authors are tantamount to the UN guidelines for older adults.

In conclusion, one must refer to the thought of B. Mikołaczyk, who clearly stresses that global ageing is a huge social challenge, and to international opinion on the importance of protecting the rights of older adults (including the right to healthcare, which is tantamount to the area pointed to by the Polish Citizens' Rights Ombudsman).[8] Therefore, research into the protection of fundamental rights of older adults is urgently required, and its conclusions should yield improvement in the effectiveness of current legislation (including that concerning its implementation) (Mikołajczyk, 2019 pp. 1611–1638). However, this will be impossible without developing methodological bases for the research. Additionally, when looking into the literature on the subject of the rights of older adults, a deficit in research in this field is visible, although there are analyses of national or international legislation protecting the rights of the elderly. Moreover, while there are a lot of analyses of local/national legislation concerning the rights of older persons, similar research conducted internationally is still lacking (Doron, Cox and Spanier, 2019, pp. 625–634).

Good practices in the methodology of administrative and legal research into the protection of fundamental rights of older adults

As suggested above, law, as one of the social sciences, benefits from the achievements in sociology in its methodology. On this basis, it constructs elaborate research methods of analyzing structures, opinions or specific activities (legal research) as well as institutions (administrative research). Conducting administrative and legal research together, as a matter of principle, means they should complement each other and achieve a broader picture of the phenomenon in question.

Administrative and legal research (similar to other social research) may not be conducted in isolation from the political, economic and social situation in the research area.[9] That is why it is complicated to develop a universal research tool or to list conditions for selecting a research sample which could be applied internationally (without additional modifications). The International Older Persons' Human Rights Index (IOPHRI) is seeking to bridge this gap – using the research tool in question,[10] the research compared the legislation in six countries representing all the continents with their geographical, legal and cultural diversity, i.e., the United States, Ireland, South Africa, India, Chile and Australia (after having tested the tool in Austria). The authors testing the tool asked a crucial question: "Can the human rights of older persons be measured and compared?" (Doron, Cox and Spanier, 2019, p. 631). They also indicated important challenges in conducting research concerning older adults such as: (1) whether the research is conducted in federal countries or in not federal countries, (2) whether the research into the protection of fundamental rights of older adults is carried out with reference to legal regulations contained in specific acts of law, practical implementation of these principles "in real life" or the law laid out by courts, (3) the social and cultural differences between the countries and the social impact of law. The authors clearly concluded that the index requires more work, taking into account a broader social context of each country; however, a milestone achieved was proving the advisability of analyzing the protection of the older persons' rights. What's more, the link between the theoretical aspect of human rights (what the letter of the law says) and the opinions of senior citizens also calls for in-depth research (Doron, Cox and Spanier, 2019, pp. 631–633).

Furthermore, while referring to past research concerning protection of fundamental rights of older adults and applying good practices used in methodology, it is possible to formulate universal guidelines, which may be followed in conducting research in the subject area. This is presented below.

While carrying out administrative and legal research on older adults, special attention should be paid to proper conceptualization of research, specifically to the selection of indicators, the ways of measuring them as well as to defining basic notions. As C. Franfort-Nachmias and D. Nachmias stress, the key issue is to insure common intelligible language of communication between researchers and respondents (2001, p. 44). When it comes to research into the fundamental rights of older adults, the researcher needs to insure that respondents understand what the notion "fundamental rights" covers, which rights are being analyzed (if the analysis concerns their selection) and what the aim of this analysis is. According to E. Babbie, "an indicator is a sign of presence or absence of the concept being studied" (2007, p. 144). As an example, Babbie analyzes the notion of compassion, where he distinguishes such compassion indicators as visiting children's hospitals at Christmas or putting fledglings back into their nests (however, it is the researcher who forms a list of indicators based on his or her experience and the literature on the subject) (Babbie, 2007, p. 144). As for the fundamental rights of older adults, indicators may be defined by referring to the level of implementation of specific rights deriving from current acts of law.

Another pivotal issue is the selection of a research sample. It needs to be strongly emphasized that older adults (especially when it concerns today's generation of senior citizens, who have survived the war, the post-war period and communist rule) are one of the most heterogeneous groups as far as education is concerned. This means that an improper choice of a research sample or omitting this fact in the results analysis may result in methodological mistakes, which would in turn lead to erroneous conclusions. For instance, when studying old-age residents of social care homes and Third Age University students, the analysis of the results obtained from the perspective of one group only will most probably lead to mistaken conclusions. Although both groups consist of older adults (who thus satisfy the condition for being included in the research group), they may differ significantly when it comes to education. The Third Age University students as a rule will be better educated (which means more extensive knowledge and awareness of their rights and their protection) than social care home residents. In consequence, a statistical picture of the results obtained (for instance: high awareness of their rights among respondents) will be falsified – research will misinterpret the sources (research material obtained).

In order to avoid the mistakes described above, cohort studies may be considered[11] (for example, among older adults who within the last 12 months at least three times have attended Third Age University classes, or among older persons who within the last 12 months have reported infringement of their rights to the Polish Citizens' Rights Ombudsman).

As mentioned above, qualitative methods are usually used to study older adults, which is why these methods are also used in research into protection of their rights. An especially adequate tool seems to be a multiple case study, which allows for theoretical perception of the research problem as a group thanks to the analysis of specific cases. Robert Herriot and William Firestone call such a study multiplace qualitative research (Pawłowska, 2012, p. 270). It may be added that a useful technique could be an in-depth problem centered interview (Witzel, 2000). However, the most commonly used research tool (a conclusion derived from the articles on the subject) is a semi-structured interview.

An individual narrative in comparison with other research methods gives older adults a sense of security, and for lonely senior citizens is often one of the few forms of contacting the outside world, while in the case of research, for example, concerning violence, may serve as an informal therapy.[12] As S.E. Chase points out, a narrative is

> a retrospective meaning creation – shaping past events or ordering them. A narrative is also comprehension of one's own actions and the actions of others.… Differently from chronology, which places events in time, a narrative conveys the point of view of a narrator.… Apart from describing what happened, narratives express emotions, thoughts and interpretations.
>
> (2009, pp. 24–25)

Narratives enable each of the respondents to look at the subject matter subjectively, and discern similarities and differences in judgments and opinions (Chase, 2009, p. 25). This in turn will help to formulate recommendations concerning improvement in exercising specific statutory rights of older adults (this refers to ensuring applicability of good practices in conducting research). Moreover, as mentioned above, legal topics and terminology may be incomprehensible to old-age respondents. In such cases, researchers may adopt the role of an auxiliary voice – which is characteristic of Latino-American narratives (as opposed to the authoritative voice of the researcher (Chase, 2009, pp. 37–39), which may raise a sense of insecurity in old-age respondents, which is why it should be used only when justified and with utmost care), who will explain complex notions and at the same time focus on the narrator and his or her prominent role in the interview. Such an approach to respondents and the subject matter itself creates conditions for obtaining satisfactory results.

Conclusion

Conducting research into protection of fundamental rights of older adults is not the easiest of endeavors. Considering the need for adjusting research tools or selecting research samples to current social, cultural and legal conditions of a given country, it is difficult to formulate unequivocal guidelines for conducting such research. However, after analyzing available research, the literature on the subject and one's own experience as a researcher, it is possible to draw up a list of recommendations, which will facilitate construction of the research process in the present subject matter. Thus, the following conclusions can be drawn:

1. Conducting research (especially administrative and legal) requires an interdisciplinary approach and reference to specific theoretical approaches, which are crucial in the process of conceptualization, especially when specifying indicators.
2. Legal and administrative research concerning protection of fundamental rights of older adults should be designed while bearing in mind its application, i.e., putting the solutions into practice.
3. Legal and administrative research poses questions rooted in legal sciences, for instance those concerning the sources of law, legal systems, the effectiveness of specific norms, but also in social sciences focused on the impact of specific regulations or norms on collective life (Frieske, 2001, p. 8).
4. Administrative and legal research is not possible in isolation from current social, political, religious, ideological and economic circumstances (depending on the selected subject matter).
5. It appears that qualitative methods enabling immediate contact with respondents are more adequate for research into the protection of fundamental rights of older adults. An especially useful tool seems to be a multiple case study, which allows for theoretical perception of the research problem as a group thanks to the analysis of specific cases.
6. Research concerning protection of fundamental rights of older adults may be perceived as a sensitive issue, which is why it should be carried out with the use of an individual interview (focused research or diagnostic poll are not recommended), which allows for avoiding mistakes connected with respondents feeling insecure or an incomprehensible specialist intellectual tool.

Notes

1 For the purpose of this chapter, the selected perspectives on gerontological research were taken into account, which are characterized by an interdisciplinary and multiperspective approach as well as those which are significant for administrative and legal research on protection of the fundamental rights of older adults.

2 Gerontological research with the use of narratives provided by older adults was conducted as part of pedagogical research by, *inter alia*, J. Halicki (2010) and J. Maćkowicz (2015), or the sociological research of M. Halicka and her group (for example: Halicka, 2014; Halicka et al., 2017, 2016) and A. Szafranek (for example: Szafranek, 2014, 2016).

3 An example of longitudinal research is the research on the impact of sleep disturbance on depressive states, carried out among 3108 UK residents aged 65 years and over and 7527 Japan residents aged 65 years and over – see Cable et al. (2017) and see a list of other longitudinal research, available at: www.rand.org/well-being/social-and-behavioral-policy/centers/ageing/resources.html [Accessed 9 August 2019].

4 It needs to be emphasized, though, that the authors refer to questioning a group of business people on tax law – the questions concerning the purpose of specific regulations may raise fear of detecting tax fraud.

5 K. Lutyńska contends that one of the most common mistakes in designing research tools is formulating questions in a way that raises the feelings of insecurity in respondents.

6 The documents concerning protection of the rights of older adults are discussed in detail in the monograph by Mikołajczyk (2012) as well as in the article by Mégret (2011).

7 United Nations Principles for Older Persons (*Zasady działania ONZ na rzecz osób starszych*) are available at www.tus.org.pl/uploads/dokumenty/zasady_dzialania_onz_na_rzecz_osob_starszych.pdf [Accessed 7 August 2019].

8 In Poland, there is the Committee for Older Persons of the Citizens' Rights Ombudsman consisting of the representatives of various academic circles, also sociology and law, which proves the need for interdisciplinary cooperation in gerontological research.

9 A good example of linking research with social and political background is Africa, where in 2016 the African Union adopted the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa – which undoubtedly should be considered while designing research in the subject area. See: Chirwa and Rushwaya (2019).

10 The research tool is described in detail together with its application and findings in: Doron, Cox and Spanier (2019).

11 Detailed information on designing cohort studies among older adults can be found for example in the article by Kingston and Jagger (2018).

12 The conclusion of the Author, who in 2010–2011 carried out in-depth interviews among the residents of Podlasie social care homes concerning institutional violence, and in 2016 interviews with practitioners working with those who suffer domestic violence.

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6 The ethics of research on old age

Maria Łuszczyńska

Dealing with the ageing of societies not only makes it necessary to adapt medical, social and economic services to the needs of seniors but, above all, to broaden the research into and diagnosis of the needs of the oldest group of citizens. Research into ageing impacts all disciplines, from medicine and the biological sciences to economics, law and the social sciences – anywhere where seniors become the subjects of research.

This chapter considers ethical standards, as modified in response to the dynamic development of research into old age. The purpose of the text is to define ethical requirements regarding the acquisition of older people as respondents of research, particularly in relation to the researcher.

The chapter discusses the boundaries of such a researcher's knowledge and insights, data confidentiality and ways to provide respondents with anonymity and a sense of security, as well as issues arising when conducting research on sensitive issues in which a group of elderly people talk about their emotions, feelings, experiences, needs, motivations and privacy.

In light of developments in social research, various attempts are made to systematize the relationship between ethics and methodology.

Introduction

The extension of human life and improvement of its quality are becoming an indisputable fact, noticeable in practically all societies in which there is access to modern medical, rehabilitative and preventive solutions and in which the social, political and economic situation is conducive to supporting the elderly. Old age as a multidimensional phenomenon that affects ever wider social groups is becoming a reality. It should also be emphasized that old age treated as a multifaceted phenomenon – present in various areas of human activity, from the dimension of individual human life through the social, economic, political, medical, legal, cultural, educational and other dimensions – is extremely diverse.

The question of what kind of meaning will ultimately be assigned to old age depends on the individual trajectories of older people's lives, subjective political perspectives and individual ways of interpreting old age in the contexts of various disciplines of human knowledge. Old age is diverse – just like the people who, by belonging to a specific age group, become interpretative determinants for the phenomenon itself.

In this sense, both old age and older people may become the object of researchers' interest. In recent decades, there has been a huge increase in interest in research on old age and the elderly in very diverse research contexts (Uhlenberg, 2009). In virtually all countries of Northern and Western Europe, North America and Asia, scientific institutes operate and conduct active research, carrying out various types of scientific studies, including these pursued at the request of governments. An overview of global online resources has shown that around 300 scientific and governmental institutions – along with organizations that focus on the development and research of old-age phenomena as their main purpose – operate worldwide (http://info-centre.jenage.de/ageing/centres-and-institutes.html). The quantity and scope of interest in old age expressed in research are very high, and their main driver is the search for systematic solutions in dealing with the phenomenon of the global ageing of humanity.

Why is there such a large increase in interest in the subject of gerontology? It can be affirmed that due to the universality of this subject and the fact that sooner or later old age will apply to everyone, researchers are looking for answers to one general question in their studies: how can one experience old age well? This question is directly related to another issue, namely, how can one properly prepare oneself for old age? The very scope of these questions, and thus also of the answers obtained, is firmly embedded in ethical space, because when we ask about a "good" old age we mean a state in which our psychophysical condition, social relations, economic situation, legal status and educational activity guarantee us a dignified experience of old age – one that respects our rights, needs, autonomy, self-determination and individuality. Hence, every study – from one that searches for medication to insure longevity and conducts medical experiments, to psychological research defining a mental state or various disorders, to social research showing changes in roles, stereotypes or activities – is by nature ethical research. It is extremely important for gerontological researchers to realize how thoroughly their research should be thought out, in terms of respecting certain general ethical principles at every stage of the research.

An ethical perspective is present, regardless of the methodological perspective of the research discipline. Despite the fact that old age is subject to assessment by many disciplines and fields of science that apply various methodological approaches, the ethical premises of this research are common to all of them. Ethics in this sense has a meta-interdisciplinary dimension. Analyzing the detailed aspects of gerontology that can be engaged with ethical reflection on research into old age will be the main goal of this chapter.

Many references in this text will connect with the social dimension of research, but only because that field is largely developing reflection on the ethics of gerontological research, thanks to the tools that it has at its disposal. I am not asserting that medical or biological sciences do not refer to ethical thought when studying the ageing processes (Cash et al., 2009). On the contrary, they were the first fields – presumably in response to unethical experiments during and after World War II – to show concern for establishing ethical principles and norms in medical research; committees, bodies and ethical codes were thus established in connection with medical experiments on human beings. However, the ethical standards of medical research are insufficient for social research, and the development of ethical reflection (and a justification for such ethical reflection) belongs to the humanities and social sciences (Ramcharan and Cutcliffe 2001). Hence, references to codes of ethics with a social character appear in this chapter.

The purpose of this chapter is to deepen the awareness of the researcher – regardless of the field of research in which he or she works – of how deeply ethical reflection is rooted in methodological choices and of how much time should be spent on asking and resolving questions of an ethical nature before the researcher even begins research procedures. The chapter also attempts to analyze the researcher's relationship with the respondent from the perspective of ethicality, as well as to propose "decisive questions" on various ethical issues at specific stages of the research process relating to the elderly.

Ethics in academic research

The essence of scientific research is the systematic contribution to building verifiable scientific knowledge. Equally important in this process are the sources of knowledge, the way in which it is acquired and interpreted, and ethical reflection on the purposefulness of research and the research procedure itself. Ethical issues arise from the particulars of the problems analyzed in gerontological research and of the methods used to obtain accurate and reliable data.

Sources of ethical problems can be (1) the research problem itself (e.g., social stereotypes of the elderly, life expectancy, physical condition, mental disorders, intelligence determinants, new technologies supporting fitness, the level of fear of death, everyday life in care institutions or sexual activity); (2) the environment in which the research takes place (a hospital, social welfare home, university of the third age, family home, church organization or location); (3) research procedures and methods required by the study design that may adversely affect the study's participants or the results themselves (e.g., using an experimental method, employing concealed observation techniques or utilizing group interviews where the researcher must control the group process); (4) respondents themselves (e.g., people who are physically or mentally disabled or who are intimidated in a position of implied submission, such as residents of a social welfare home); (5) the type of data collected (e.g., personal, sensitive or confidential data); and (6) the relationship between the researcher and the research subject.

The ethics of scientific research should be understood as

> a certain specific, relatively distinct branch of normative ethics, which examines the ethical aspects of research activities performed in the context of science. The main task of this discipline is to establish and justify the rules which, from an ethical point of view, actors should observe. Within such rules – the principles of good research practice – I distinguish three groups: (1) rules regarding research reliability, (2) rules regarding fidelity to research participants, and (3) rules regarding the usefulness of the research results.
>
> (Galewicz, 2009)

Ethics is a science of morality, which in turn encompasses the practice of adhering to recommendations and realizing moral values. Thus, the debate on morality as a practice has an ethical dimension (Górniewicz, 2016). Research ethics can be a set of values and attitudes that scientists respect and adopt in order to incorporate moral norms and values into the research process. This applies not only to the research procedures themselves, but also to the way of dealing with the current thematic literature and of disseminating research in the form of scientific texts. It should be clearly realized that the commitment to comply with ethical rules is immanent in all scientific activities. Thus, one of the elements of establishing a research outfit is for a researcher to become familiar not only with the ethical requirements that apply to the particular research being pursued, but also those applying more broadly to all scientific activities.

Various codes and sets of ethical principles that set standards of conduct and indicate the consequences of non-compliance can provide a point of reference when considering the ethical context of research practices. In Poland, since 2012, the most general norms for ethical conduct in academic research are presented in the Code of Ethics for Researchers (KEPN), developed by the Committee for Ethics in Science of the Polish Academy of

Sciences (https://instytucja.pan.pl/index.php/kodeks-etyki-pracownika-naukowego). It was modeled on the European Code of Conduct for Research Integrity, a code published in 2010 (https://allea.org/code-of-conduct/) and developed by the European Science Foundation (ESF) and the All European Academies (ALLEA), which was intended as a benchmark for use in EU countries for creation of their own ethical codes. Shortly afterwards, the 2012 Sociologist's Code of Ethics was created in Poland (*Kodeks Etyki Socjologa*, approved by the general meeting of delegates of the Polish Sociological Association in March 2012: http://pts.org.pl/wp-content/uploads/2016/04/kodeks.pdf). Worldwide, guidelines for the norms and principles of ethical social research can be found in the Code of Ethics of the American Association for Public Opinion Research (AAPOR Code of Ethics: www.aapor.org/Standards-Ethics/AAPOR-Code-of-Ethics.aspx), created by the interdisciplinary association of researchers in the field of social sciences (sociologists, psychologists, political scientists); in the International Code on Market, Opinion and Social Research and Data Analytics, developed jointly by the International Chamber of Commerce (ICC) and ESOMAR, formerly the European Society for Opinion and Marketing (www.esomar.org/); in the International Code on Market and Social Research (http://ethics.iit.edu/ecodes/node/5178) which in Poland is obligatory for members of the Opinion Research Section of the Polish Sociological Association. In addition, research and academic institutions set up internal ethics committees and commissions, which in the context of these institutions deal with questions of the ethicality of individual research projects.

The fundamental premise of all these codes is their rooting in fundamental ethical principles, such as respect for human dignity and life in all its manifestations, truthfulness, honesty, responsibility and a recognition of the right to freedom of belief and to property. These principles are axionormative, i.e., their content is beyond dispute. Around these values, KEPN lists the following principles that directly result from specified values:

1. conscientiousness in presenting the goals and intentions of planned and conducted research;
2. credibility in conducting research, critique of one's own results;
3. objectivity, i.e., basing interpretations and conclusions solely on facts and verifiable data;
4. impartiality in the approach to the examined or presented problem;
5. independence from external influences on the execution of research;
6. openness in discussing one's own research with other scientists;
7. transparency in the collection, analysis and interpretation of data;
8. responsibility toward research participants and research subjects;
9. integrity in recognizing the scientific achievements of those who indeed deserve it;
10. caring for future generations of researchers and educating them in accepted ethical norms and standards;
11. courage in opposing views that are contrary to scientific knowledge and practices that are incompatible with the principles of scientific integrity (Code of Ethics for Research Workers, 2017).

Reflection on the need to introduce and enforce ethical standards in gerontological research derives primarily from the conviction that it is still a field of knowledge whose status is being shaped as we speak, which in the course of research and study is still developing methods and standards and also specifying problems and areas for research. The call to care for the ethicality of gerontological research is also linked with the broad theoretical postulate – which in Poland was first outlined in this form by Florian Znaniecki in 1919 – that all research and the conclusions resulting from it be based on the so-called “humanistic coefficient” (Znaniecki, 1919). It is a component of a wider trend, known as humanistic sociology.

The humanistic coefficient is understood as a particular methodological directive in the study of a given culture, which prompts the researcher to take into account the experience of people and their activities – the meanings or importance that the people being studied attribute to the examined objects in specific communities. According to Znaniecki, the sociologist should relate phenomena to empirical entities. The observation of social systems equipped with the humanistic coefficient is different from observing natural systems. Observing values should take into account the experience of the subjects in this process. In this context, there is no arbitrariness in applying a method; the world of values must be studied using the humanistic coefficient. The principle of the humanistic coefficient led Znaniecki to a new theoretical perspective that was innovative in comparison to existing research approaches, by incorporating the cultural aspect into social research. As applied to the human being, the humanistic coefficient opened up new possibilities for studying the cultural reflexivity of an individual and his or her cultural becoming (Hałas, 2010, pp. 145–146).

The postulate of being guided by the humanistic coefficient (on the basis of Znaniecki’s thought) does not encourage the adoption of a subjective perspective in research; it is a statement about something much more important – namely, that a person is the creator of values, as one who is a value himself or herself. Because a human being has value, he or she has both meaning and axiological importance, which is changeable and historically relative. In cultural becoming, the natural world of things can become transformed into values, but also vice versa – i.e., values can become things, when they present themselves as permanent and immutable meanings, given once and for all time. Such a process of reification of values can be observed in a world in which the declarative layer of the description of the world does not go hand in hand with action, as grounded in such declarations. The same can happen to values, which will “reflect” the researched reality in a certain guise when employed in research, including gerontological research.

In Florian Znaniecki’s theory of the humanistic coefficient, an individual constructs or reconstructs many cultural systems, including social systems, which are the source and material of his or her subjectivity. As one performing social roles, the individual can even be understood as a social system, but he or she is not closed within it. In this conception, culture as a source of subjectivity becomes a source of individual independence from social systems, insofar as the individual – as a center of action – learns, understands and participates in creating cultural systems. In this sense, it is an “open” subjectivity, if we can refer to Roman Ingarden’s thought (1987, p. 125).

Translating this into the area of the social sciences, if in light of the humanistic coefficient we take as the object of research the opinions of older people on a selected topic and consider these opinions important and sense-creating, then in order to analyze these opinions, they must be associated with motivations (i.e., tendencies to certain behaviors), attitudes (relatively persistent sentiments toward someone or something), social needs (conscious or unconscious aspirations resulting from situations and assimilated values), accepted and implemented social norms (spontaneously shaped prohibitions and dictates approved in a given environment) and values specific to a given community – tangible and intangible objects, to which people attach particular significance (Dyoniziak, 1997, p. 14).

What does the adoption of such a perspective mean for the ethics of gerontological research? Well, the recognition that the social reality is first and foremost as the respondents (and not the researchers) see it leads to a very careful building up of the research relationship with the respondents. It is advisable to use an objective-subjective approach in sociological research, i.e., a description, diagnosis and interpretation of the social world from the perspectives of both the researcher and the respondents. The researcher, wherever possible, must avoid valorizing the behaviors, feelings, opinions and attitudes of individuals, groups or entire communities. If this is not entirely possible for various reasons (e.g., methodological), the researcher must be open and honest toward the respondents. The emphasis on honest ethical reflection on the research relationship between the researcher and the elderly becomes a determinant of the entire research process in which all ethical considerations are subordinated to the good of the studied person. The researcher's goal, the research results and the interests of other parties involved in the research should stay at the background of the process. Hence, the measure for verifying the sense and ethical correctness of all research decisions is the categorical imperative of Kant – in which human dignity is a fundamental value and the use of the human being as an instrument is rejected, in accordance with the imperative's two premises: "Act only in accordance with that maxim through which you can at the same time will that it become a universal law" (G 4:421; cf. G 4:402) (Kant, 2002, p. 37) and "Act so that you use humanity, as much in your own person as in the person of every other, always at the same time as end and never merely as means" (G 4:429; cf. G 4:436) (Kant, 2002, pp. 46–47). Referring the theoretical perspectives and principles mentioned above to methodological considerations regarding gerontological research, it seems important to analyze some of them in more detail. In research on old age, what generates the most ethical difficulty is the responsibility to the participants of the study, as well as the need for objectivity, diligence and credibility in reflecting upon one's own assumptions and research results. The rest of this text will be dedicated to a deeper analysis of these principles in relation to the ordering of the research process.

Ethically relevant dimensions of research on old age

If one is looking for aspects of gerontological research in which ethics play a significant role, then it is necessary to differentiate several areas. The first thing to be subjected to ethical reflection should be the intentions of the researcher – and not only the initial ones that lead to the selection of the research problem, but also the later ones that decide the course of study and interpretation of its results. By intentions, I have in mind those factors that initially trigger the thought or emotion that leads the researcher to deal with a given research aspect. Every study starts with a certain intellectual spark or personal experience with or interest in specific issues. The researcher's life experience – undergoing situations that cause irritation, satisfaction, anxiety or trauma – can often contribute to the selection of research topics, as well as the need to study the thematic literature. This choice is always situated within a broader "axiological climate". The intentions to choose a topic should be subjected to ethical reflection, preferably in cooperation with and during joint discussions with specialists who can help the researcher decide whether the choice of the topic to be studied and the intentions behind it will not lead into a trap of distortion and will not cause the engaged researcher to fail to fulfill the requirement of objectivity.

Similarly careful analyses of one's intentions should be conducted at every stage of the research in which the researcher's subjectivity confronts the subjectivity or intersubjectivity of the information conduits, i.e., the research subjects. The discrepancies that then may be revealed may distort the course of the study itself, violate the research relationship and later affect the method of development or interpretation of the results.

When analyzing intentions, it is advisable to recognize possible discrepancies between what the researcher and a study's subject – and between what the study's implementer and commissioning party – consider important. These three spaces may not meet each other, remaining divergent throughout the planning and implementation of the study. The question of how to deal with this situation and what to decide with regard to the continuation of research and evaluation of the study's results is a question with an ethical character. Often, a thorough analysis of the interests, goals and values of each party that subjects these elements to an in-depth process of understanding makes the clues to these questions clearer and the answers simpler. Provided, of course, that one remembers the axionormative premises that underlie gerontological research.

The sphere of the research relationship between the researcher (or researchers) and the subjects – the elderly – is a very important axiological space. As respondents, older people belong to a group of persons "vulnerable to harm". It should be emphasized that this group is extremely diverse in terms of demographic and social features, such as education, place of residence, family situation, interests, social relations, health status, economic situation, level of activity, passions, life experience, social engagement and other features that distinguish members of the population of elderly persons from one another. Moreover, age – despite the common tendency to classify all older people as belonging to one age category – is increasingly a feature that differentiates the senior population. The situation will differ for a person who has just left the labor market, for a person who has been a pensioner for several years and maintains a relatively good level of independence, and for an elderly person who requires support and care because he or she is not fully independent (or is completely dependent). Elderly persons' vulnerability to harm is an inherent result of their psychological situation. Regardless of their actual mental condition and health, an objective common feature of this social group is a lesser or greater awareness of the fact that old age is the last stage of life – that after old age there is only death, and that this is an irreversible process. Different people cope with this awareness differently, but, regardless of this, it is a situation that can cause unexpected reactions, unpleasant emotions or even a worsening of one's health condition. Older people have a reduced degree of autonomy, when compared with the level of autonomy they enjoyed at earlier stages of their lives. It is often linked with their economic, social and health situation. Of course, there will also be exceptions, as for some people the situation of ageing will bring a positive experience; however, as a working hypothesis, it is assumed that, in general, at the levels of health, economic condition, or family and social relations (or from all of these perspectives), old age may reduce one's sense of independence from people, from things and from social support systems.

Older people who are subjects of social research are also susceptible to influence and manipulation. They tend not to reveal their situation to the same degree that they experience it; usually, this involves a tendency to present their perceptions, beliefs, desires and expectations as better than they are in reality. This can be illustrated by an example of research conducted in which older people were asked to assess their contacts with family; most of them rated them as great or very good. When asked about the frequency of such direct and personal contact (i.e., not by phone or email), they stated that it takes place once every three months, on average. The correlation showed that an assessment of contact as very good also occurred when such contact happened twice a year, on holidays. This example reveals the tendency of seniors to be wary in revealing their true assessment of their situation. While it can be assumed that some seniors are happy having such rare contact with their families, this tendency can be treated suspiciously before it becomes the norm.

Similarly, research with seniors who are permanently in care institutions where their fate depends on other people – family or staff – should be conducted with great caution and care. In such situations, the seniors will often have objections to revealing accurate information about themselves, fearing that it might be used against them. Health status, level of strength, stereotypes, limited or absent autonomy, cognitive impairment (associated with damage to the senses or mind) or the current overall state (mental, physical and emotional) may cause the respondents to collapse under the pressure of authority – which in their eyes may be represented by the researcher.

The research relationship between the researcher and the respondent should be – as is the case with groups of subjects "vulnerable to harm" – characterized by a high degree of acceptance of the respondent and by patience and openness, so as to eliminate existing stereotypes or superstitions (including in the researcher) about the senior population. The climate of the research relationship is supported by minimum requirements that the researcher must fulfill toward the respondent. When we analyze the ethical-methodological context of sociological research, we pay attention primarily to the research process, especially when the relationship between the researcher (or pollster) and the person who is the subject of the research is a face-to-face relationship. Above all, it is possible to point out six basic ethical principles, which, as closer analysis reveals, very often are not (or cannot be) fully applied, due to the particulars of the adopted method or research technique. These principles include:

1. the principle of voluntariness,
2. the principle of informed consent,
3. the principle of doing no harm (of not jeopardizing the subject),
4. the principle of anonymity,
5. the principle of confidentiality,
6. the principle of privacy,
7. the principle of truthfulness regarding the identity of the researcher, the purpose of the research, the institution conducting the research and the commissioner of the researcher.

The principle of *voluntariness* (expressing agreement to participate in the study) by the respondent should be based on a precise definition of what is the purpose of the study, what issues (including sensitive ones) will be raised in the study, what the course of the study will be and how the results will be used. Expressing consent based on the information possessed is absolutely essential in situations where the subjects are at risk. Research subjects must know that their participation in a study is completely voluntary, and they should receive full information about the benefits, rights, risks and dangers of their participation in the research beforehand. In principle, obtaining consent to participate in research not only respects the individual's right to self-determination; it transfers onto the respondent the responsibility for potential negative effects that the research might have for those participating in it. Expressing consent also reduces the legal responsibility of researchers, as it confirms the voluntary nature of the participation of subjects in the conducted research.

The concept of the *right to express informed consent* based on given information likewise arose from the acceptance of social norms, cultural values and legal regulations. Although the principle of obtaining the consent of potential subjects based on the information that they possess has gained wide acceptance, researchers may still have problems applying it. This is because in certain cases, researchers may not fully understand what it means for a person to be informed or how they can be sure that the person has understood the information provided to them. A problem may also arise due to the selection of information to be shared (or not shared) by the researcher, if, for example, the researcher wants to carry out an experiment that involves concealing from the respondent whether he or she is in the control group or experimental group.

The respondent's decision-making procedure comprises four aspects: competence, voluntariness, full information and understanding (Frankfort-Nachmias and Nachmias, 2001, pp. 94–95). The components of the consent procedure should include:

- fully explaining the procedure to be followed and of the purpose that it is supposed to achieve;
- describing the inconvenience that may arise and the extent of reasonably expected risk;
- describing reasonably expected benefits;
- disclosing appropriate alternative procedures that may be beneficial to the subject;
- providing responses to all questions regarding the research procedure;
- making it clear that the person making such a decision has a free choice and may at any time refuse to continue participating in the study without any negative consequences to himself or herself (Ethical Guidelines for Good Research Practice, 2011).

Another principle that applies in research relationships, especially in medical and psychological research, is the *principle of doing no harm* (of not jeopardizing the subject). It can be said that it is closely related to the two previous principles, and it applies to situations in which the participation of the respondent in the study has a highly experimental nature (for example, in the testing of a new drug or in a psychological experiment relating to sensitive issues, like the motivation for actions or experiences related to unpleasant emotions). After several widely known psychological and medical experiments (e.g., the experiments of Stanley Milgram from the 1960s, of Philip Zimbardo from 1971 or of Laud Humpreys from 1975), the principle of non-harm in such experiments became a foundation of protections in the face of study participants' lack of awareness knowledge.

The obligation to insure the *anonymity of respondents* and the obligation to insure the *confidentiality of collected data* are not mutually exclusive. They should be met at all costs, unless the researcher has come to a previous agreement with the subjects on these matters. Researchers insure anonymity by separating data about the identity of the subjects from the information that the individuals provide. A studied person is considered anonymous if the researcher or other people are unable to associate specific information with specific research subjects. Therefore, if information is provided anonymously – thereby entailing that the researcher will not be able to associate names with the obtained data – then the identity of the studied person remains secret, even when he or she has provided very personal information.

One of the easiest techniques to guarantee anonymity is not to ask for names or other information that could identify a person.

Persons participating in social science research are often assured that the information they provide will be kept confidential – i.e., information that identifies the respondents will not be made public. This is accomplished through the removal of identifying data, the introduction of broad categories for data (e.g., using the province instead of the city, the year of birth instead of the exact date of birth, or a profession instead of the name of a specific workplace).

An important principle in social research, especially in the context of the elderly, is the *principle of privacy*. It's possible to speak of this in three senses: (1) regarding the scope of collected data, when the data relates to issues from the private life of the respondent and, because they are private, expose the respondent to potential peril; (2) regarding the space for conducting the research, with the respondent deciding in what space (from fully private to fully public) his or her sense of privacy can be most fully guaranteed; and (3) regarding the scope of identifying personal data with information provided in the study; this aspect concerns the possibility of identifying personal data and linking it with the answers given by respondents. For example, information about income will remain private, if only the researcher has access to it. However, if such information (including the amount of earnings and names) is disclosed to third parties, then there is a violation of privacy.

The last of these principles concerns *disclosing the truth about the identity of the researcher, the purpose of the study, the institution conducting the research and the commissioner of the research*. This rule is often not respected in the case of marketing research or in studies based on undisclosed observation of participants. (Regarding ethical problems of participant observation, cf. Chomczyński, 2006.) If disclosing the identity of the researcher, the purpose of the study or the commissioner can distort the result of the study – and, in particular, have an impact on its effects – then researchers may decide not to provide the respondents with this data.

The abovementioned principles are canonical in building a research relationship with the respondent. This does not mean, however, that all researchers employ such a procedure in its entirety, as they often exclude some of its elements because they disrupt the results of their research. This is always a discretionary exclusion, and it places the researcher in the situation of an ethical dilemma.

In academic research – especially that in which the subject of the study is a person, potentially an elderly person – two rationales are usually in conflict: the good of the academic research and the good of the studied person (respondent). The basic ethical problem in social science research is that in many cases the interference in the psyche of the respondent (the examined person) can be as deep as in psychological research – with the difference being that both the researcher (sociologist) and the examined person are sometimes unaware of this.

While the principle of doing no harm to subjects is quite clearly defined by institutionalized rules whenever a study involves interference with the human body (in the biological sense) – such as in medical experiments (e.g., the person who is to undergo such an experiment should complete an informed consent form) or in psychological experiments (regarding interference in the human psyche), the scope of non-harm remains unspecified with regard to social science research. This is so because the consequences of questions and requests addressed to seniors as part of research are unknown, even if the research's goal itself is seemingly innocent (Walczak-Duraj, 2013). In such a situation, the consequences of participating in a study are unpredictable, and thus it is impossible to completely protect an elderly person from the effects of his or her participation in the research.

Therefore, in the context of the research relationship, it is worth asking yourself the following axiological questions to verify your approach:

- Is it justified to involve selected elderly people in the study?
- Is each respondent treated as subject? Do I see him/her as a human being or only as a data source?

- Is the respondent's perspective respected? Are differences that might arise respected, registered, heard?
- Has the research guaranteed all minimum rules of the research relationship: anonymity, confidentiality, privacy, voluntariness, openness?
- Does the given study have a chance to achieve its goal – which is to get to know the studied reality more broadly and then to improve the quality of life of people representing the studied population?
- Is the researcher the right person to carry out research on the given topic in the given group?
- Will research ultimately contribute to more than just developing the researcher's academic career?

On ethical elements in the research process

Another area around which it is possible to arrange axiological issues is the dimension corresponding to the course of the study. When undertaking research on old age, we are not always aware that ethical problems occur at every stage of the research process: first, at the stage of conceptualization, when we select a topic and define research groups; then at the stage of selecting methodology and research techniques and constructing research instruments – and then, after that, at the testing stage; at the stage of analyzing and interpreting data (with the problem of imposing the researcher's value system on the respondent's value system); and, finally, at the stage of publishing the developed and interpreted empirical material (Brzeziński, 2015). At each of these stages, ethical reflection is inevitable, if we want to achieve the general objectives of research – namely, to obtain maximally accurate, certain and general knowledge that is as straightforward as possible and has maximal information content (cf. Dąmbska, 1967; Jevons, 1960; Nagel, 1970; Such, 1972; Pilch, 1998). Thanks to such knowledge, it is possible to formulate laws of science and its regularity. In this sense, the methodological context is closely connected with the axiological context.

Below, we present an attempt to analyze selected ethical aspects in relation to the following stages of a study:

1 conceptualization
2 conducting the research
3 analyzing data
4 presenting the results.

Conceptualization

Conceptualization is the stage of research when the particular research topics are clarified and answers are given to the question of why the research should be performed at all. The reasonableness and sense of given research was discussed earlier in this chapter, and the questions raised there can be used at this stage. Planning for a study's funding sources is also a significant factor. In strictly academic research carried out at the request of an academic institution, the financial source as such is not a subject of controversy. Debate may arise when the research has a dual scientific and implementative nature, in accordance with current trends to encourage researchers to strengthen collaboration with a country's so-called "second sector" (i.e., the private sector). In such collaboration, the factor of expectation of financial profit may put researchers in a situation of ethical dilemmas between the expected profit of a company that commissions research and the good of the respondents. An example of such a dilemma may be a study that ultimately did not take place in Poland, regarding the reverse mortgage system. A certain banking consortium tried to introduce this instrument into its banks' offers, and it needed research not only to determine the scope of interest in this instrument among a group of older people but also to provide data on the seniors' precise health conditions and health habits; the research would also have tested a proposition to put seniors under the care of specific medical clinics at the point of entry into the reverse mortgage system. Such expectations seemed to the researchers to violate the well-being of the respondents and, as a result, the research was not conducted for ethical reasons.

At the stage of conceptualization, a choice is made regarding the study's type of participants, and if they are to be elderly people, then all observations made in this chapter about building a research relationship with senior respondents remain pertinent.

Other ethical decisions must be made when selecting research methods, others when designing research instruments and yet others when creating the language to be used in the research. It should be considered whether a chosen method is adequate in view not only of the study's purpose but also of the capacities of the respondents themselves. The same applies to the particular instruments composed for the given method. If the method, tool and language that we use are not adapted to the particulars of the respondents, then stereotyping or exclusionary tendencies will increase as a result of this research, because its results will show the respondents to, in some areas, fall short of certain hypotheses and expected results.

The same applies to the language used in the instruments created. If it is incomprehensible, stigmatizing, manipulative or unclear, then the results of the study will reflect similar characteristics, while the respondent, not the researcher, will be held responsible for the quality of the study.

Questions that are worth asking yourself at this stage of the research process regarding ethical reflection are:

- Is the chosen research method suitable for the abilities and particulars of the examined group?
- Is the language used in the research instrument understandable to respondents?
- Does implementation of the planned research procedure transgress the boundaries of intimacy?
- Does the survey assume voluntary participation of respondents?
- Can the process of the study cause any mental or emotional harm to respondents?

Conducting research/collecting data

The stage of data collection should be preceded by obtaining subjects' informed consent, as mentioned earlier. Informed consent may vary in scope for different researchers. It should include voluntariness of participation, the possibility of resigning from participation in the study at any stage and the possibility of withdrawing consent to use the data obtained. In order to obligate researchers to continually determine what effects their research work may have, ethical codes include provisions about the need to protect research participants from harmful consequences; importantly, even the consent given by study participants does not release researchers from this obligation.

An issue that is worth noting with regard to seniors is that they tend to too quickly agree or refuse to take part in a study. The challenge for the researcher is to convince a senior to listen to all of the information needed to make a decision about participation in the study, so that this consent is actually informed. Elderly people are prone to make decisions under the influence of emotions (anxiety or an eagerness to be supportive); therefore, this aspect of research associated with an awareness of participating in the study must be further elaborated by the researcher. The process of reaching informed consent ought to be carried out responsibly, and, while implementing it, the researcher cannot think only about his or her research interests but should, in a spirit of broader responsibility, care about achieving an autonomous decision by the elderly person.

Worthy of particular emphasis is the situation of examining elderly people whose disability or physical or mental illness prevents them from taking a fully independent decision to participate in the research. Often studies of such people involve participation of an intermediary, from whom the researcher may be unable to obtain information, if a subject is presumed to be uneager to have such information disclosed. This means that the rules for receiving informed consent should also be presented to all family members, employees and caregivers of the aforementioned social categories whose dependent seniors may be the subjects of a study.

Older adults who are in a situation of limited autonomy (e.g., because they are under the care of a family or in a care institution) largely decide to participate in the study based on how they perceive the researcher. If he or she is treated as an "outsider" or authority and – in addition – is conducting comprehensive research (e.g., of a subject's family or employees of the institution in which the senior is located), then information provided by a subject during the study might be distorted due to the fact that the researcher may be seen as "disloyal". Hence, the researcher's great challenge in this situation is the requirement of "double neutrality" (Borkowski, 2013, pp. 14–18) – an attitude in which the researcher in no way (not even the least suggestive) endorses any of the antagonistic parties.

Another issue that raises ethical controversies is the reliability of collected data in a situation where the respondent (the elderly person) manifests some kind of communication disorder. Such disorders do not have to be associated solely with cognitive impairment or poor senses. They can simply be associated with misunderstanding, uncertainty or taking on the role of a participant in the study. In this situation, the researcher has the task of ensuring the understanding of the respondent – repeating and clarifying questions in a patient manner – while remaining neutral and not taking shortcuts.

Difficulty in understanding the research scope expressed by research questions and tasks may give rise to a variety of feelings in the researcher – discouragement, impatience, boredom, fatigue, resignation, anger, nervousness and other sentiments. Contact with the elderly may lead the researcher into a confrontation with his or her own issues. On the one hand, contact with an elderly person generates openness on the part of the interlocutors as a reaction to the openness of the senior; on the other hand, however, it often inspires digressions, the telling of one's life story, and avoiding statements about the main topic. A certain tone of expression may cause various reactions in the researcher, especially if in the context of his or her research there is an awareness that this state of life may become the researcher's own, sooner or later. Confrontation with old age during the study may be personal, thus obscuring the research results and causing various feedback reactions, such as rebellion, anger and impatience.

It is a great challenge for the researcher to anticipate that such situations may take place and to prepare for them ahead of time. As part of this preparation, vast areas of education for old age are opening. Thus, another ethical issue to be decided by old-age researchers is to what extent the researchers themselves should be familiar with their own ageing process. To what extent can such "homework" regarding the passage of the time of one's own life protect the researcher from disruptions in the process of collecting data and from distortions in their interpretation?

Ethical questions worth asking at this stage of the research process include:

1. To what extent did the researcher insure the autonomy of the respondent when making decisions about participation in the study?
2. Does the course of the study protect the respondent's dignity? Does the researcher transgress the limits of influence, manipulation or the exertion of pressure?
3. Is there a climate of trust during the study? What else can be done to make the respondent trust more?
4. Has the researcher used manipulation, distortion or selective means of presenting information about the study to attract the participant?
5. How does the researcher deal with possible problems with understanding the respondent? Do these disorders have an impact on interpretive simplification, the way in which the study is conducted or the resignation of the researcher/respondent?
6. To what extent do the researcher's emotions toward the respondent influence the course of the study?
7. To what extent is old age as a research topic internal/external to the researcher?

Data analysis

The data analysis phase is preceded by transcription of collected research material (interviews, observations, video recordings, etc.) or encoding of quantitative data. In this phase of research, care should be taken regarding the quality of the records and decisions should be made about how the statements of the respondents will be recorded, especially if they do not express themselves consistently, precisely and eloquently. With regard to the expectation of research reliability, quotes from respondents' statements should be reproduced in the transcription literally, and then quoted in the same way in the next research stage, i.e., in the presentation of the collected material. However, a researcher's care for the way in which respondents are perceived more generally (beyond simply literal quotations) is an area in which the researcher has an influence on the social perception and image of the elderly – and this yields a dilemma that is indeed ethical in nature.

On the one hand, the reliability of the research material should be attentively and carefully considered. On the other hand, though, the researcher should be aware of the consequences of literal quotations of the respondents' statements.

Analysis of data entails not only its reliable reproduction in the course of transcription or encoding but also a way of interpreting the collected data. Interpretation may involve placing a respondent's statements and behaviors on a spectrum from being considered extremely abnormal to completely normal, and thus may become a source of (de)stigmatization. Respondents' statements can also be presented as manifesting an acceptable difference.

In this activity – the interpretation of a study's results – the distinct value systems of the researcher and the researched also may pose a problem. This is especially emphasized in a situation where the researcher represents a population of young, working people who are at a different stage of life from seniors. The clash with the differing perspective of older people may cause an overinterpretation or misinterpretation of seniors' statements in the broader context of their psychosocial situation and other semantic contexts.

This is the stage at which the researcher is the most independent in his or her analyses and is subject to a constant temptation to make distortions that are convenient for him or her. Therefore, during this process it is very important to have a consultative team that can act as a supervising body with regard to the facts that were collected in the stage of data collection.

At this stage of the research process, it's worth the researcher asking him- or herself the following ethical questions:

- Have the source data been recorded reliably and accurately?
- Is the interpretation of the results consistent with/contrary to the objectives of the study?
- What corrections have been made to the source data? What has been distorted? What was omitted? What significance do these modifications have for the whole picture?
- Do all the research conclusions reflect the facts/statements of the respondents?
- Have the conclusions been evaluated by independent consultants?
- In what areas are the conclusions of the study different from the researcher's beliefs?
- To what extent do the final conclusions surprise the researcher? Where does he or she as a person disagree with the conclusions drawn from the study? Do these areas of disagreement have their roots in the source data?

Presentation of results

After the research is completed and the results have been described, the time comes to present them to a wider audience. This is an important stage with regard a wide range of issues that are not directly visible to the subjects of study but which are extremely important from the perspective of ethical analysis of the material. At this stage, one should consider the impact of the acquired knowledge on the studied group and its social environment in the context of the months, years and decades to come. Information that has been analyzed, described and made public as so-called "neutral knowledge" produced in good faith may, at some point, begin to take on a life of its own, with all the twists and turns that you can imagine, including irreversible changes in and disintegration of the study population.

The first matter concerns the researcher's responsibility for the consequences of the publicly disclosed conclusions. The researcher is responsible for the conclusions drawn, the form of which should be as objective as possible and justified by the source data. The researcher is a co-creator of the cultural identity of the elderly, due to the fact that this social group rarely takes the stage to speak about its own affairs. It is as a result of such research that whom seniors are in our world and what social significance is given to them is determined.

Two types of description are possible – the first is reproducing what seniors say and do, how they work, what they do not do, what they do not like, etc. It is possible, after Maria Ossowska (1947, p. 1), to describe this approach as a descriptive perspective. The second type describes seniors as the protagonists of stories created by the historians studying them; they are situated within the definitions and meanings that we give to them. How the senior will be treated as a member of a wider community will depend on the perspective adopted by the researcher for telling the story; such a perspective might be described as valorizing. Being aware of which of the two perspectives a researcher is operating with while interpreting and presenting the results allows him or her to carry out research that is more or less socially engaged research, i.e., by participating in solving social problems, even at the price of giving up the quest for objectivity (which, after all, is often purported to be illusory). It is in the moment of drawing conclusions and presenting the results that the researcher settles for one of two general paradigms – objectivist vs engaged. In the latter, he or she can make moral assessments of the studied phenomenon without consequences. This research identification may occur in earlier stages of the research process, but it is only at the final stage that this attitude is expressed to the recipients of the research conclusions.

The main challenge associated with the publication of research results is protecting the elderly – i.e., the study's respondents – from the negative consequences of participating in the study at the hands of members of their social groups (for example, inhabitants of the same town, members of the same club or residents of the same care institution). Therefore, the presentation of the results should, like the acquisition of respondents for the study, comply with the principles of anonymity and privacy. Sometimes, in order to protect seniors, it is necessary to introduce fictionalization, which involves modifying personal data or the place of study in order to prevent recognition of the investigated person (Kubinowski, 2011, p. 350).

Another issue is the axiological impartiality of the researcher toward the reality described. The researcher is responsible not only for the moral course of the research procedures but also for the ideological perspective adopted, which affects the form of the final conclusions. It is worthwhile for the researcher to be aware of his or her subjectivity in perceiving and assessing the research situation and of his or her own impact on the content and course of the study, as well as the impact that the study exerts on the researcher himself or herself. This self-awareness can play an important role in the direct presentation of results during talks at conferences.

In the context of ethical considerations, the issue of the "moral entanglement of social facts" (Ostrowski, 2005, p. 169) should not be overlooked in the case of research into ethically and socially sensitive problems, which in relation to elderly people may concern their addictions, sex life, sexual orientation, attitudes toward violence and issues of sympathy toward, or dislike of, others. A decision must be made about which data to disclose and what to do with incomplete, unpopular and internally contradictory data.

At this stage of the research process, it's worth the researcher asking him- or herself the following ethical questions:

- What is the researcher's attitude – objectivist or engaged?
- What long-term effects will the research results have on the people studied?
- To what extent should data be fictionalized in order to protect respondents?
- To what extent are the presented results morally entangled? What issues should be clarified? What issues should be omitted for the good of the respondents?

Summary

Caring about ethics in research is an element that increases the quality of research (Flick, 2011). Some social researchers believe that a poorly planned research project is, by definition, unethical. However, there are those who suggest – especially in qualitative research – that at the design stage of a study, it is impossible to plan for and resolve all issues, whether methodological or ethical (Ramcharan and Cutcliffe 2001).

In research into old age, ethics is undoubtedly intended to protect all sides of a study – the commissioning authority, the executor and the one being studied, from abuse. Additionally, in the case of studying the elderly, ethics aims to protect them in their weakness, dependence and disability.

The researcher is confronted with the need to answer the question about the importance of the ethical dimension of research at each stage of a study. He or she must determine whether the study will touch on the perspective of objectivity (corresponding to the truth), the good of respondents (protection of dignity) or ensuring the quality of research in terms of its correctness. Or, perhaps, the usefulness of the research should be the primary goal?

Constraining the freedom of the respondents and acting against their best interests are behaviors that are undoubtedly unethical in the study of the elderly. Moreover, using respondents to achieve goals of the researchers that are not related to research or distorting research findings during their interpretation are unacceptable activities that place the given research outside the sphere of ethically acceptable procedures. In this sense, the ethical competence of the researcher is an integral part of substantive competence, and methodological reflection must be accompanied by ethical reflection.

There are several basic rules that can insure that research is ethically sound:

- An analysis of potential gains and losses, of benefits and burdens, on the part of the researcher and respondents should contribute to the decision whether to join the research or withdraw from it.
- Informed consent means that no one should take part in the research without knowing what it means and without being able to express a refusal; misleading respondents should thus be avoided. Moreover, in the case of the elderly, information about the study should be provided in a clear and transparent way, in addition to ensuring that this information is well understood.
- During and after research, privacy, confidentiality and anonymity should be guaranteed and strictly observed.
- The research relationship should be based on appropriate treatment of respondents as subjects, with kindness, openness and respect.
- Basing conclusions and interpretations on source data that are obtained with due accuracy (without manipulation, omissions, overinterpretation or other distortions) should be the guiding principle in the analysis and presentation of the research results.
- The researcher should be aware of his or her own beliefs, attitudes, views, needs and expectations in the context of the research and should decide whether he or she is proceeding with an objectivist or engaged approach, with all the methodological and ethical consequences of this choice.

The social, medical and human sciences are deeply immersed in reflection on the human being, and scientists are both observers and participants in the research process. Researchers are constantly interacting with a complex and demanding environment that influences their research decisions both formally and informally. One important way to deal with these impacts is by following ethical principles. We might allow the following quote to testify to the complexity of ethical reflection in old age research:

> It is the researcher's responsibility to act in an ethically acceptable manner, bearing in mind his own goals, his situation in the field, and the values and interests of the people involved. In other words, as researchers and at the same time recipients of research, we

> have to assess for ourselves what is right and what is undesirable in a given case. We should also be prepared to defend our decisions if they are questioned. We must understand that other people, despite our arguments, may have a different opinion that does not follow from some hidden motives. It is important that ethical issues are discussed in the public forum, as this will benefit researchers' awareness.
>
> (Hammersley and Atkinson, 2000, pp. 289–290)

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Part II

Research approaches to ageing

7 Co-design the ingenuity of ageing

A cultural model of ageing through design thinking

Yanki Lee

Through the lens of design and ingenuity, evidence was gathered on many important topics around ageing – from coping strategies by creative citizens to end-of-life, dementia and productive ageing – with the goal of investigating which new services, tools and solutions will best serve our future super ageing society. This chapter is a reflection by a design researcher referring to Participatory Action Research (PAR) Methodology.

The program co-designed design actions based on the ingenuity of ageing within a diverse community. It does not conform to the medical model based on ageing as a disease to be cured by experts. Neither does it conform entirely to the social model of ageing, even though social connectivity with others is recognized as very important. By focusing on design as a creative practice/discipline and, more importantly, design as a citizen's right, the Social Innovation Design Lab (SI.DLab) encouraged every aspect of daily life to become a holistic celebration of autonomy. The SI.DLab exemplifies the cultural model of ageing through three tactics (articulation, culture and tool-making), in which boundaries are moved and new perspectives for change are opened up.

The SI.DLab is a cross-generation program which put together over 1000 students to work together with more than 400 senior citizens on topics of end-of-life, dementia and productive ageing, for ageing innovative ideas for our future super aged society. This chapter focuses on how to encourage more efficient PAR projects with older adults as partners with real design research projects funded by government on capacity building between the years 2017 and 2019 in the city of Hong Kong, China.

Introduction

While a group of design researchers set up a series of cross-generational and co-creation projects addressing ageing innovation for our future, some fundamental questions arose: Who participates in design processes? Who are the co-creators? These *who* questions informed our first Social Innovation Design (SI.D) Lab, funded by the Hong Kong government as a capability building program to train creative citizens through design thinking.

Manzini (2015) described emerging forms of collaboration between design professionals and others, where new solutions are suggested and new meanings created. A new paradigm and practices emerge based on a more engaged, innovative and sustainable way of being in the world. He also raised the question of what are the role(s) of the designer when everyone designs? This question is aligned to the discussion around the role(s) of designers and the differing relationships between "designers" and "users". This whole narrative challenges the designer's role as the sole creator, artist and celebrity (Szebeko and Tan, 2010; Thackara, 2006; Valtonen, 2005).

Design research: designers vs users

Let's look at this relationship in more detail. Describing designers as having a democratic role is akin to the definition of design first set out by the Scandinavian design research collective, A.Telier, in a book entitled *Design Things* (Binder et al., 2011). This offers an innovative view of design research and practice, envisioning ways to combine creative design with a participatory approach, encompassing aesthetic and democratic practices and values.

Similarly, Slavin (2016) put together another classification to explore the relationship between "designers" and the "others". The first type is "design for users' participation" which is called User-Centred Design (UCD): "the centre from the designer's imagination of the system to the designer's imagination of the user of the system". Even though it challenges the heroic sensibility of the modern designer, it still perpetuates the clear roles between "designer" and "user".

Instead of "users" or those designing for use, the second type is promoting the concept of "designing for participation" which Slavin (2016) continued to refer to British architect, Cedric Price's Fun Palace, as an environment continually interacting and responding to people. It is a

> more provocative proposal that the essential role of its designer was to create a context for participation … designing for participation, but that design is a fundamentally participatory act, engaging systems that extend further than the constraints of individual (or even human) activity and imagination.
>
> (Slavin, 2016)

It is also important to involve users/citizens as partners in the process. This is why we referred to Design Thinking as the latest description of User/Human-Centred/Universal/Inclusive Design, as a practice, which has been promoted by business schools and adopted by different sectors in the past two decades. There are seven typical stages of Design Thinking:

1. empathize
2. define
3. ideate
4. prototype
5. test
6. evaluate
7. implement.

The latest model has progressed further still: design as participation is about how designers immerse themselves to become participants of the objects/systems/campaigns they create. This echoes an anti-disciplinary discourse (Ito, 2017) that indicates a new role for designers, i.e., "Designers as Participants". This is the approach we referred to when curating the SI.DLab. Here, we trained 1000+ young university students to immerse themselves in old age and then co-design with 400+ senior citizens on ageing innovation for our future selves in our city.

Participatory Action Research (PAR): investigator-driven vs user/citizen driven research

Since Design Research is still a very young discipline, we still refer to other more established disciplines such as Social Sciences Methodologies. According to Blair and Minkler (2009),

> Although gerontologists have increasingly incorporated in their practice participatory approaches that emphasize individual and community empowerment (Bernard, 2000; Levine and Greenlick, 1991; Ray, 2007; Ross et al., 2005), the involvement of older adults as partners in the research process itself is still relatively rare.

After studying ten Participatory Action Research (PAR) projects, they confirmed six established principles for PAR practice.[1] However, for this chapter, we would like to focus on five new remarks – although two still focus on why researchers do not conduct PAR but continue the more traditional investigator-driven gerontology methodology, i.e., (1) concerns about research rigor and the need for broadening the bandwidth of validity, and (2) personal investment (labor intensive) and delayed outcomes. In this chapter, we are concentrating on the three other remarks and have transformed them into three "tactics" for conducting more efficient PAR projects with older adults for our future super ageing society. Using our three design tactics from the SI.DLab on critical ageing topics, including end of life, dementia and productive ageing, we intend to discuss how PAR can offer an important complement to research methodologies despite operational challenges.

Tactic 1: articulating the ingenuity of ageing

Blair and Minkler's (2009) first remark to the practice of PAR is "Honouring the Life Experience of Elders". This aligned with the concept of "Ingenuity of Ageing" (Lee, 2012) and our first tactic is about how to articulate this ingenuity by linking different generations and professions to co-create a better future, and then come up with innovative and holistic ways to tackle ageing-related issues, which are "wicked problems" (Martin, 2007). As Laslett (1996, p. xi) stated, these are not social problems to be solved but instead "a unique experience for each individual".

We researched and defined three crucial social topics in ageing innovation and carefully curated them into briefs for our Social Innovation Design Projects (SI.DPs): (1) Fine Dying – co-creating designs to prototype new services that enable the elderly in need to worry less about their end of life issues and age gracefully, (2) Dementia Going – co-creating designs to prototype new perspectives enabling dementia patients to access communal areas and be more active within their community, (3) Productive Ageing – co-creating designs to prototype a new value system, empowering elderly groups to creatively contribute to society. Over the two-year funded period, we worked with four target groups (1000 tertiary students alongside 400 elderly people, six social issue experts and three design mentors). Together, we co-created over 800 Social Innovation ideas toward ageing innovation for the future of Hong Kong.

These cross-generational ideas were articulated into design insights for implementation. Our intention is not just introducing design thinking but making the design discipline a practical social tool to orchestrate social innovation. Instead of working toward a market-focus economy, we are advocating that design can also deliver processes for radical social change when developing services, systems and environments to support more sustainable lifestyles. More importantly, these processes bring different people together.

Case 1: Fine Dying – designing your own ritual movement

For our three SI.DPs, we looked at different life topics and tapped into the life experiences of elders in Hong Kong, using this information to innovate within social services. The most controversial one is the Fine Dying Project where we engaged over 100 elders enabling them to express their concerns on everything from the dying process to burial services.

Unlike medical or social service experts, who are working hard to insure a Good Death, we, a collective of researchers using design methodology and thinking to investigate new social practices, are advocating a different term we have coined: Fine Dying. The *Cambridge English Dictionary* defines Fine Dining as "a style of eating that usually takes place in expensive restaurants, where especially good food is served to people, often in a formal way", and usually with special care. In line with this, we refer to Fine Dying as the extent of care we can offer to all of the experiences that surround dying. It is about ongoing processes where Hong Kong citizens can co-investigate unexpected new possibilities for their own dying matters in our city. Recently, new ideas about death and dying are arising, such as green burial, body composting and new spaces for mourning and grieving. However, as a taboo subject, many new ideas cannot be implemented because of fixed social values.

On the other hand, there are still some traditions offering us the opportunity to embrace the dead: one of them is the Chinese practice of burning joss paper. Our belief is that the deceased have similar needs in the spirit world to those of the natural world. This is why a great variety of joss paper objects are produced for people to purchase and burn at funerals. These objects are used on ancestors' birthdays and during important holidays for deceased relatives so they may exist comfortably in the afterlife. The result of our Fine Dying study (Enable Foundation, 2017) was the concept of transition, moving from creating objects to rituals. Our aim is to transform the burial spaces and systems through changing the fundamentals. The first proposed solution was named, the Envelope, a one-off, ash scatterer for garden burial ceremonies. It was inspired by the life experiences of over 100 elders in Hong Kong and the procedure they expect from their dying process and burial rituals. These experiences were recorded and articulated into a series of aspirations toward their imagined Fine Dying experience in the city. From there we decided to select those focusing on garden burial, which is one of the green burial methods promoted by the Hong Kong government.

Tactic 2: designing a cultural model of ageing

The second remark for PAR practice is "Building Biodirectional Trust" which means enhancing trust by offering elders ownership of research. Instead of framing elders as passive subjects for research, the study pointed out that academic researchers should "become(s) facilitators and the linker of dialogue among the group of interest, aiming eventually for a collective identification, description, and analysis of specific problems, priorities, strengths and assets, and needs" (Averill, 2005).

In our case, we argue that ageing is a culture that should inspire younger people (Lee, 2012, 2017) and we intend to respond in creative ways to this statement: "Ageing in itself is not (just) a policy problem to be solved" (Bazalgette et al., 2011). As a team of design researchers, we believe that whilst public policymakers and social service sector experts are developing ways to solve ageing issues from medical and social perspectives, there should be room for creative disciplines such as design research to bring new contributions on ageing research and innovation. For us, the major role of design research is to take the concept of aged culture and use this everyday ingenuity to inspire design and innovation. Our goal is to have the public understand ageing as a culture and not as a burden.

To experiment and embrace with the “Cultural Model of Ageing”, we have to acknowledge both the traditional models – medical and social dimensions of ageing – and, in addition, attach more importance to capturing how older people tackle their own ageing issues. With better health and higher education and less physically demanding jobs available today, more mature people become active elders who can stay longer in the labor force. Government policy encourages companies to employ more mature workers. Additionally, active elders are keen to contribute more to the community and develop their own interests. They are demanding a new, inclusive service model.

Case 2: Dementia Going – embracing the dementia culture

The common ground of this model is to work with exciting social phenomena and develop new citizen-driven services models. Young and old citizens worked together to co-investigate possibilities for our cities. Since 2015, we were asked by a regional center for dementia to research, design and prototype a set of “empathy tools” to enable people to better understand the illness of dementia. From its launch in April 2016, the toolkit was rolled out for training across Hong Kong communities. The Design Thinking-Making project opened up a new way of viewing the culture of care. Design research as a new discipline could contribute to a new approach to aged culture as well as linking different generations and professions to co-create a better future and come up with innovative and holistic ways to tackle ageing-related matters.

This particular project shows the inherent potential in the concept of “culture of dementia”, which aims to change people’s perception of the condition. It tries to foreground how joy and love can have a place in the life of a person with dementia and how meaningful, humoristic and positive interactions can be omnipresent in daily life. By heralding this positive perspective, the research aims to inspire designers to develop more appropriate designs to address this mystery while other experts work on a cure. For example, could designers create a story-telling tool for carers to capture the patients’ happy moments? Can a tool help us to enter the “magical world” of dementia, to see things differently and create a different world after the experience?

These experiences inspired us to conduct the Dementia Going Study as part of the SI.DLab, where active senior citizens became mentors for young people on dementia. They advised on it as a medical situation and gave their caring experiences for those suffering from dementia. Young citizens also went into care homes to engage patients with dementia through collage making and went on to develop an engagement tool: “Dementia Stories: Happy Colouring”.

Carers of family members with dementia also co-designed a number of urban games with students to enhance public understanding of the different dementia symptoms. All these research actions were collated into the installation and intervention, “Dementia Home”. This experience was a home full of demented objects, which are tools, to aid visitors in their understanding of the dementia experience, demystifying this complex disease. Design and design research could also take the concept of aged culture or “culture of dementia” and use the ingenuity of everyday life that we believe could be captured and use this to inspire design and innovation.

Tactic 3: tool making with the young and old

The final and most important remark is the one about "Training Older Adults for their Roles in PAR" which is essential for the future development of more participatory methods for our common issues: ageing.

"Social innovation focuses attention on the ideas and solutions that create social value, as well as the processes through which they are generated, not just on individuals and organisations." This is a definition of Social Innovation from the Stanford Graduate School of Business (www.gsb.stanford.edu/faculty-research/centers-initiatives/csi/defining-social-innovation), and we used this as our anchor when designing the SI.DLab program. This is why we curated carefully the process: each SI.DP is a three-stage training module with the aim of strengthening the distinct capacity of our target. To do this we openly recruited tertiary students from different universities or higher education institutions in Hong Kong. Our goal was to train them to become enablers of social innovation through design. Each participating student was guided through a specially designed co-creation process. This began by enabling them to immerse themselves into their older selves and invite others to talk about ageing. Then their task was to design for their future selves based on their immersive experience.

Over 1000 students – who we treated as young citizens – went through this immersion process. The most common projections they communicated about their older selves were related to physical restrictions such as poor eyesight and loss of hearing. Dexterity was also a concern for their older self due to back pain or arthritis experiences in family members. Based on all these assumptions, many of them proposed medical or healthcare devices for their future selves. In order to prepare them to co-create with older generations, we also pushed them to define their current interests and hobbies, which could be developed into a version, which fits their needs. Many of the ideas for their future selves were unrealistic but full of imagination and aspiration. These ideas inspired interesting conversations with older people.

Between young and old citizens – Super-ageing Society means there is a greater need for public and statutory authorities to work with older people in planning future services in order to insure communities are fit for all ages, or in other words, "lifetime neighborhoods". We developed this concept through the practice of "inviting elderly people to become living experts in their society". Therefore, it is beyond empathy, which can be defined as "putting yourself into others' people shoes". Advocating for design research and social innovation, our approach is to immerse ourselves in the living reality of others, i.e., not just design *with* the others or design *as* the others. Putting ourselves into the process and eventually we become the beneficiaries of these projects.

Case 3: Productive Ageing – #AgeReady drills for all

The best example to explain this immersive concept should be our Productive Ageing study. What does "getting old" mean? How should we define senior citizens' productivity and contribution? We held a roundtable discussion with members from local social welfare organizations, academia and governmental departments, and realized that to tackle the issues of population ageing, the public must first learn what it means to embrace their old age and prepare for getting old. We hope more people from all ages can be inspired – learning what it means to get old, learn and prepare for our old age.

The outcomes evolved into a new concept, the OLD School, where people can learn how to age well together. We believe that every senior citizen with his or her valuable life experiences embodies learning material, which they can share with younger people. Through the co-creation workshops of "Productive Ageing", old and young participants explored the various meanings and attributes of getting old; from this, different learning tools were developed.

For the one-month prototyping within community, we developed four sets of learning tools for ageing well, entitled the DRILLS: #AgeReady tools and they were adopted into a community art space in a grassroots neighborhood to test how we can prepare for our future super-ageing society. For the next step, we will be working on Productive Ageing in Schools – "training for ageing" of the OLD School: training tools will be installed in primary/secondary schools and educational organizations creating dialog around ageing and forming new forms of life education.

Conclusion: design against ageism

> Robert Butler coined the term "ageism" in 1969 … he defined it as a combination of prejudicial attitudes toward older people, old age, and ageing itself; discriminatory practices against olders; and institutional practices and policies that perpetuate stereotypes about them.
>
> (Applewhite, 2016)

How can design as a discipline contribute a bold response with new approaches to the scale of demographic change, to perspectives of ageing and more importantly bring everyone together to see ageing as "our" issues? This chapter is a reflection by a design researcher referencing PAR Methodology: value co-creation through conducting a creative citizen program with the aim of building their capacities in order to embrace their own "ingenuity of ageing" as well as being inspired and join the co-creation.

Gradually a picture emerged of a group of ingenious people working and stimulating each other to tackle persistent myths about older people, a culturally based fear of ageing. It became clear that their unique situation of collective living has become an incubator for social innovation, with co-design and participatory design processes enabling greater individual choice and control.

Through the lens of ageing and ingenuity, evidence was gathered on many important topics around ageing – from cognitive impairments to coping strategies for chronic diseases – with the goal of investigating which new services, tools and solutions will best serve a future ageing society.

Let's co-design as the others do

> [T]he notion of annotated portfolios entails selecting a collection of designs, re-presenting them in an appropriate medium, and combining the design re-presentations with brief textual annotation. Gaver and Bowers characterize their proposal as a methodology for communicating design research, and more specifically, a methodology that is very familiar to designers as well as artists.
>
> (Gaver and Bowers, 2012)

This is what we trained our students/young citizens to do: putting together their investigation of specific topics (burial services, dementia engagement and an ageing model) and immersive experiences becoming their "annotated portfolios". They were guided through the process of following the Co-creation Manual that we designed for them. The materials proved to be useful resources when starting the ideating process with the older citizens.

Prototyping as civic education

Löwgren (2013) responded to Gaver and Bowers' notion of annotated portfolios as a way to communicate design research and he also elaborated the concept into "[t]he essence of research is to produce knowledge, and the essence of design is to produce artefact". Our counter explanation is that "the essence of design research is to produce knowledge through co-creating artefacts with multiple actors". The way we conduct our design research projects is to visualize and materialize social issues through design. As a capability training program, we design "tools" that train citizens to be "enablers" forming exchanges between the experienced and the inexperienced, between everyday tacit knowledge (of the elderly) and design knowledge (of the younger generation). This step of intervention is also sharing our research findings and it engages more people to join further investigation.

"It is just the beginning. In the future, we hope people can openly discuss their own solutions, not being held back by limitations", said Chi-Wing Lee, Director of Milk Design Hong Kong and design mentor of the Fine Dying Study (interview with author). This is the conclusion after his team delivered a series of designs for a garden burial ceremony. Unlike the average commercial design process, we believe the outcome of co-creation should be about an opening up of citizens' choices. Here, designers are one of the key collaborators.

Manzini and Margolin (2017) outlined four key areas that highlight the important convergence between democracy and design:

1 Design of Democracy – improving democratic processes and the institutions on which democracy is built.
2 Design for Democracy – enabling more people to participate in the democratic process, especially through the use of technology.
3 Design in Democracy – building access, openness and transparency into institutions in ways that assure equality and justice.
4 Design as Democracy – the practice of participatory design so that diverse actors can shape our present and future worlds in a fair and inclusive way.

Referring to this classification, we are proposing the extension of type 4 (Design as Democracy) into action, i.e., designing democracy where design researchers become initiators of the 5i process. Designers would curate the process but not lead it. Together, we co-created and co-presented spectrums of possibilities and we advocate citizens to design their own lives in a democratic society through democratizing design as a knowledge production methodology.

This democratization through design research enables more citizen participation and also creates a dialog platform, helping to design an open society collectively.

Note

1 Six Key Principles of PAR in Practice (Blair and Minkler, 2009):
  i PAR is Participatory and Facilitates Collaborative, Equitable Partnership in All Phases of the Research.
  ii PAR is Empowering.
  iii PAR is a CoLearning Process.
  iv PAR Contributes to Capacity Building and Systems Change.
  v PAR Balances Research and Action.
  vi PAR Involves a Long-term Process and a Commitment to Sustainability.

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8 The life course perspective in social gerontology

Barbara Szatur-Jaworska

In this chapter, the research perspective is understood as the cognizant subject's point of view, which consists in distinguishing a certain part from the scope of the complex research subject and describing it using specific terms. The life course perspective is such an understanding of a separate research perspective in social gerontology. Apart from the life course perspective, we can distinguish the life cycle perspective in social research. Both are important in social gerontology, yet, nowadays, the mainly developed perspective is life course research.

This chapter points to cognitive and practical values of social research of old age using the life course perspective. The methodological and conceptual limitations of conducting such studies are also discussed. Serious methodological challenges are posed by using dynamic research schemes and the specificity of the elderly as respondents.

Introduction

Changes that occur in the life of human beings with the lapse of time are of interest to various scientific disciplines, with theories based on various ontological, epistemological and methodological assumptions. Developmental psychology, which has created a vision of human development throughout one's life – including in old age – has an important role in the development of research on changes in human life. This is one of the fundamental assumptions of social gerontology that allows us to treat old age as a phase of life that is no worse than previous phases and that is characterized (just like other phases of life) by its internal dynamics. Social gerontology looks at old age in the context of the whole human life, using and developing theories created in sociology, psychology, demography, pedagogy, medicine and social policy. Scientists dealing with changes that take place in the timeline of people's lives determine the subject of their research using many terms: life cycle, life course, trajectory, life span, biography and others. Some use these terms interchangeably, but there are also those who seek different definitions for each one and associate them with different research perspectives. In social gerontology, as an interdisciplinary science, the co-existence and combination of different research perspectives is fully justified. It is similar to combining several research methods in a single project, the choice of which results from the adoption of specific theoretical assumptions.

Among the concepts mentioned in the introduction, I consider life cycle and life course to be fundamental for social gerontology. Each of these terms is fuzzy. Often, the authors do not give precise definitions and their interpretation is left to the readers' intuition. A short conceptualization of each of these concepts is therefore needed in order to provide a clear framework for further consideration.

The concept of the *life cycle* derives from the observation of natural phenomena, the most obvious example of which is the repetition of seasons. Researchers dealing with the biological cycle of human life focus on genetically programmed changes common for the whole species, which take place in the human body from conception to natural death. The term “life cycle” is also used as a theoretical category in social sciences. Changes in the life of a single person are described as linear, stadial or cyclic-phase (Brzezińska, 2000, pp. 61–98). In the life of the entire species, the changes take place cyclically, i.e., they repeat themselves. Researchers using the term “life cycle” assume that the changes they are interested in occur in a constant sequence, i.e., everyone goes through the same phases of life in the same order (Dobrowolska, 1992; Rysz-Kowalczyk, 1996). What is more, all people go through the same cycle (unless they died prematurely) and this sequence of phases is repeated in subsequent generations (cohorts). What is important, it is assumed that it is not possible to go back to the phase that has already been experienced once. Of course, the criteria for separating the phases of the cycle understood in this way are different in each theoretical concept. It is generally accepted that the basic structure of the life cycle is determined by the rhythm of biological changes, but individual psychological characteristics of people and the socio-cultural norms that vary in time and space overlap with this rhythm. In gerontological research, the term “life cycle” is used in the concepts of developmental psychology, economics, social policy science, demography and sociology. The ontological status of this concept is different, as it can be treated in three ways: (1) as a name of a real, objective process, (2) as a name of a socially produced, normative construction, (3) as a metaphor. A separate research perspective is being built around the life cycle category, which focuses on: typical (and even universal) changes, supra-individual specificity of particular life phases (described by such terms as psychosocial ego development (Erikson), intelligence development (Piaget), interpersonal competence development (Selman), developmental tasks (Haviqhurst) (cited after Brzezińska, Appelt and Ziółkowska, 2015, pp. 76–86), regularities in transitions between life phases, life cycle disturbances, phase deformations (Rysz-Kowalczyk, 1996), dependencies between consecutive phases, etc.

In connection with the blurring boundaries between the traditionally distinguished life phases (e.g., biological rejuvenation of the organism, learning as a developmental task assigned not only to childhood but also to other phases), the process described as deinstitutionalization and re-institutionalization of the life cycle and the growing scope of people’s freedom in shaping their individual destinies, the popularity of the *life course* category is growing in social sciences. Compared to “life cycle”, the concept more strongly exposes the historical variability of life scenarios and takes into account the diversity of transitional periods between life stages (Green, 2017, p. 22), although in some respects this category is described similarly to life cycle. “Life course” has many definitions in the world scientific literature. In my opinion, the definition of the Polish sociologist Danuta Dobrowolska is very useful for considerations in the field of social gerontology:

> I would describe the course of life as a sequence of human experiences and behaviours (including actions) related to specific situations in which a person finds himself from birth to death. They are conditioned both by the transformation of the organism and psyche of a given individual, as well as by changing external conditions in the broad sense of the word. … other people and their products also participate in the course of life of an individual.
>
> (Dobrowolska, 1992, p. 77)

The life course is divided into stages which, among other things, differ from the phases in the life cycle in that there is a – limited – possibility to return to a once experienced stage (e.g., after a long break it is possible to return to school, start a family again, give up work and after some time return to it). The concept of the life course, like the life cycle, sets out a specific research perspective.[1]

The aim of this chapter is to describe the life course perspective in social gerontology, to indicate its values and limitations in gerontological research and to characterize key empirical research patterns used in social research on old age and elderly people.

The life course perspective: a conceptualization

The life course perspective has been present in gerontological research for many years. Its ontological and epistemological assumptions are developed mainly by the sociology of the course of life (life course sociology)[2] and life span psychology.[3] Both these disciplines provide key theoretical assumptions to which both sociological and psychological research, pedagogical and economic research, social policy science, etc., are subordinate.

In determining the essence of the course of life, one should refer to Martin Kohli's analysis, which many years ago drew attention to the dual understanding in science of the category of life course: as a social construction and as a process of shaping human personality in the process of socialization (cited after Hajduk 2001, pp. 41–42).

Conceptualization of the course of life as a social construct assumes that it is a collection of social norms and principles, which are guarded by social institutions. These norms and principles determine how a person's life should proceed in order to properly serve society. In addition, they regulate the individual's relationship with his or her immediate and distant environment, law, religion, etc. They also regulate the individual's relationship with his or her surroundings, law, religion, etc. Individuals are expected to behave and make choices that are consistent with the social construct of the course of life.[4] There are many such social structures in every society, because they are different for women and men, for people belonging to different social groups or cultural traditions. As demonstrated by Jean-François Guillaume (2005), in our cultural circle, the life course pattern has been created for a very long time under the influence of the dominant role of men in society and the key importance of physical effort in the creation of material foundations of life.

The social construction of the course of life is characterized by researchers in different ways. For example, the Polish researcher Edward Hajduk wrote that it corresponds to "the concept of a series of social roles that a person undertakes and fulfils throughout his or her life" (2001, p. 48). In addition to social roles and the associated patterns of thematic biographies/careers/trajectories (educational, family, professional, etc.), the social construction of the course of life also takes into account the typical social environments in which people live (e.g., family, co-workers), sequence of roles and social environments, patterns of orientation (thanks to which the individual knows what biographical scenarios he or she potentially has to choose and whether these choices are in line with the desired state standard; social institutions that more or less influence the course of life) links between the stages of life (social age) and calendar age, and typical critical events (Hajduk, 2001, pp. 46–48). In the construction of the course of life, its stages are distinguished. Researchers indicate the following formal criteria that are used to distinguish life stages: (1) typicality (a high probability that units at a stage in one day will reach the expected, typical next stage); (2) sequencing (life stages occur according to a set order), (3) definite duration of the stage (during this time human life is not constant, each stage has its own dynamics),

(4) irreversibility of the transition from one stage to the next, (5) relative universality (social reorganization of life associated with entering a given stage is proposed to all individuals having access to it) (Lalive d'Epinay, Cavalli and Guilley, 2005, pp. 67–68).

Traditional life course structures have assumed a one-way transition from one social role to another (e.g., from student to employee, from employee to pensioner). This one-way street has now been questioned, as adults are expected, for example, to combine the role of an employee with that of a student (the idea of life-long learning) or pensioner and an employee, and to return to the previously performed and abandoned social roles (e.g., for a long time, experts have been discussing planning career breaks for upgrading or changing qualifications).

Social constructions of the life course can be treated as part of the culture of the society.[5] They are normative in nature. They are both the cause and effect of individuals' behaviors and attitudes. They are present in collective consciousness (as cultural messages, patterns of socially accepted behavior) and in individual consciousness (they reflect cultural patterns, but modified by personal aspirations, experiences, assessment of one's own social position, etc.). In the approach discussed here, the life course study concerns both the products of collective life and individual imaginations. The course of life and its stages are also treated in science as social representations (Roselli, 2015). The products of collective life to be researched are, for example, media messages, colloquial language, works of art, curricula. In the case of individual images concerning the preferred life patterns, sources of knowledge about them are statements from people, found (e.g., in diaries) or triggered (e.g., in interviews). In the research of the course of life understood as a social construction, the so-called qualitative methods are used first of all.

In the latter conceptualization, the life course is treated as an *empirically experienced process of biological, psychological and social changes*. Researchers using this conceptualization deal with actually implemented patterns of changes in the lives of individuals and cohorts. Such research is most characteristic of sociology, psychology and pedagogy, but also occurs in demography and social policy science. The life dynamics of specific persons and the cohorts created by them are examined, and the events, experiences, attitudes, ways of fulfilling social roles, the course of detailed careers/trajectories (e.g., educational, professional, familial) are examined. Researchers look for similarities and differences in the ways of shaping the lifetime. These methods depend on biological, psychological, situational (at different levels of social and economic life) and volitional factors. Biographical patterns functioning in social environments that are reference groups for an individual are also important. The course of life is therefore perceived as a result of various factors: individual, cultural, social, natural, economic and political. Researchers of the course of life analyze many aspects of human development in relation to various contextual factors. It is also assumed that the relationship between

> changes in the individuals and their socio-cultural environment, seen over time … is two-way in nature, which means that changes in the living environment of individuals trigger and/or sustain changes in their individual development plan, while the activity undertaken in many different areas directly or indirectly causes changes in this environment.
>
> (Brzezińska, Appelt and Ziółkowska, 2015, p. 15)

According to Susan McDaniel and Paul Bernard (2011, p. 2), the life course perspective consists of four basic analytical principles: (1) everyday human experiences create a trajectory that runs from birth to death; (2) the patterns of life course evolve in many interrelated spheres; (3) through social links, the individual's life course influences that of others; (4) life course is shaped by a variety of local and national contexts, and at the same time, these contexts are shaped by the life course of individuals. It is therefore important for a life course perspective to capture the interdependencies between the different dimensions of the individual's life, as well as to explore the interaction between the individual's life and the life of their loved ones. Analyses are conducted on a time axis with simultaneous consideration of the mutual interactions indicated here. As noted by Nancy Côté (2013: 184), the life course perspective allows us to capture social phenomena in the long term, placing the individuals, their representations, experiences, actions, at the center of the analysis. The author considers that the most appropriate conceptualization of the life course is treating it as a set of different trajectories (familial, professional, health-related, etc.).

Using a life course perspective (defined as an empirically observable process), researchers analyze what has already happened (describe and explain past events and their dynamics), diagnose the current stage of life of the respondents (cohorts) (often the subject of such research are moments of transition between life stages, events being potential turning points) and forecast how the current life course of the respondents and cohorts will affect their future fate. Furthermore, the subject of research can be life plans, which people make for themselves and for their close ones. The life course (as an empirically observable process) is therefore related to descriptive, diagnostic and prognostic research. It is also possible to conduct research that seeks to explain the cause and effect relationships between events that have occurred in different careers (e.g., the influence of professional biography on the family biography) and the relationship between the life course of various individuals. The subjects of observation are the individuals and their social environment (other individuals, family, institutions, etc.). Quantitative (e.g., surveys) and qualitative (e.g., biographical interviews) methods are used in research belonging to the current study discussed here.

Advantages and limitations of the life course perspective in gerontological research

In social gerontology, the first advantage of a life course perspective is the connection between the state in which an individual enters the phase of old age and the stages he or she has already experienced. The insight into the human past makes it possible to determine the underlying causes of the opportunities and limitations that arise in old age. The insight into the past of the ageing cohorts also allows us to formulate hypotheses on the relationship between their migration, educational, occupational, health-related and social biography (the extent to which welfare state institutions were used in the past) and the current diversity of the elderly population in terms of their life situation, lifestyle, views and expectations. For example, a small sample survey of poor elderly people (their main source of income was social assistance benefits) I carried out showed differences between women and men in terms of pathways to old age deprivation and strategies to deal with elderly people's poverty (Szatur-Jaworska, 2000).

Second, the application of a life course perspective is essential in research aimed at determining when old age begins and the resulting variability in the boundaries of old age. This is one of the fundamental questions of gerontology.

Third, the adoption of a life course perspective makes it possible to capture the patterns of variability in the course of the old age phase, track its dynamics, determine the timing of the occurrence of breakthrough moments typical of old age (e.g., in the PolSenior studies, we discovered that in Poland, women became single as a result of divorce or widowhood earlier than men; Szatur-Jaworska, 2014), capture the typical age ranges in which members of a given society enter particular stages of old age (from early to late old age).

Fourth, research conducted from the life course perspective makes it possible to determine to what extent the life course of older people – at earlier stages and in old age – is disturbed and distorted by institutional and situational factors of a systemic nature (e.g., unequal treatment of women and men, mass unemployment, chronic poverty), and to what extent it results from wrong decisions of people, their dysfunctional behaviors, etc. For example, such an analytical distinction can be made by studying processes such as social marginalization or premature loss of life independence on the basis of biographical materials and intersubjective sources. As Barbara Rysz-Kowalczyk writes,

> this property of the concept of the course of life is all the more valuable as radical social changes occur in a given historical period, which in a short time change the world of an individual so that the type of his earlier experiences and knowledge may prove to be useless and insufficient to meet the requirements of the previously chosen way of life.
>
> (2003, p. 140)

Fifth, the life course perspective allows us to reconstruct the individual biographies and social conditions in which people grew up and lived their adult lives. Thanks to it, we can create a multidimensional social history.

Sixth, the life course perspective is useful for political decision-makers, as the resulting image of the social situation better reflects the reality in which social actors functioned and function, which allows for the construction of a public policy better suited to their needs (MacDaniel and Bernard, 2011).

Seventh, the use of a life course perspective in research for political practice gives the opportunity to correct public policies when they are less and less in line with actual life course patterns in a given society. For example, the retirement of the *baby boom* generation is associated with a greater demand from older people for recreational, educational and cultural services than in the past.

Eighth, the observation of the life course of different cohorts allows us to change institutional and legal solutions in order to better adapt them to the new intergenerational relations. For example, the mass emigration of young people after Poland's accession to the European Union is causing a weakening of the care potential of families, which requires the development of services offered to the elderly by institutions.

Ninth, in the case of gerontological examinations, the joint work of a researcher and an elderly person on the production and evaluation of autobiographical material may play an important therapeutic and strengthening role. In gerontological psychology, attention is drawn to the important role of life recapitulation that should be done in old age.

As with any research perspective, the life course perspective is not free from limitations.

First of all, the study of changes that occur in a person's life or community over time requires long-term, repeated observation. Such research is costly, requires a great deal of organizational effort and a strong institutional base that guarantees the continuation of research in the long term.

Second, due to the limited possibilities of using experimental schemes in research, most of the claims concerning cause-and-effect relationships between the various variables studied remain hypotheses, as they are difficult to verify or falsify empirically.

Third, the subject of research: social constructions of the life course – empirical processes that make up the actual course of people's lives – is very complicated and multidimensional. This means that researchers quite arbitrarily reduce the study subject to the selected careers (trajectories) and transition moments. As a result, our knowledge about the life course is fragmented and it concerns different stages of life in different ways.

Fourth, in the two conceptualizations discussed above, life course is subject to an accelerated process of change, which means that the diagnoses prepared with a lot of effort become outdated relatively quickly.

Fifth, in the case of older people (due to cognitive disorders), the possibility of conducting research referring to memories is limited, and the state of health makes it difficult to obtain consent from respondents for participation in the research conducted in the form of interviews or questionnaires.

Key research schemes

There are numerous classifications of research patterns in social sciences. These classifications are based on a variety of criteria. Due to the criterion of manipulation, the independent variable is distinguished between experimental (laboratory or natural) and non-experimental (in developmental psychology it is also referred to as naturalistic-correlative) studies (Brzezińska, Appelt and Ziółkowska, 2015, p. 98). Due to a number of criteria considered together, quantitative and qualitative research is distinguished. Similarly, the division into the following types of research design is multi-criteria: experiment, case study, longitudinal design, cross-sectional design (de Vaus, 2007). Due to the role assigned to the passage of time in the study, cross-sectional studies (recording the values of variables and relationships between variables at one selected time) and dynamic studies (recording changes in time, serving to observe processes) are distinguished. The typologies of research in which a time variable is taken into account are numerous in the methodology of social sciences. In further deductions, I am going to use the typology used by Earl Babbie (2010, pp. 106–112), which distinguishes: cross-sectional studies,[6] longitudinal studies, approximating longitudinal studies. Since the ageing of individuals and the ageing of the population are processes that extend over time, have many determinants and take place at many levels, a special role in social gerontology is played by dynamic and near-dynamic research. These studies can use various strategies.[7] Within longitudinal studies,[8] Babbie distinguishes: trend study,[9] cohort study[10] and panel study.[11] Trend study (also called repeated cross-sectional studies) consists in carrying out, at certain intervals, several (a dozen or so) measurements of the researched phenomenon in the whole population (e.g., in the course of the national census) or in research samples from this population (e.g., samples of respondents drawn by public opinion polling centers). If it is a study on samples, they are drawn randomly or otherwise selected before each subsequent measurement (the survey wave). As a result of trend research, the direction of change can be determined using data from surveys, national censuses, official documents, etc. The cohorts study analyzes the changes over time in the selected categories of population. A cohort is a collection of people who have a connection to some important event, such as being born in the same year, getting married in the same period, retiring in the same year. In the scheme called cohort testing, a representative sample of the cohort is selected before each subsequent measurement. This study is a kind of accompanying cohort at different stages of its life and observing the changes taking place. The third type distinguished by Babbie is panel research, which consists in taking several measurements on the same research sample. Such a sample can be created according to different rules of selection. It may consist, for example, of persons belonging to one or more cohorts of interest to the researcher. In the basic version of the panel study, the sample selection is made only once – before the first survey is carried out – and in the subsequent measurements, the researcher returns to the same people. There are also varieties of panel tests in which the composition of the sample is subject to controlled changes (e.g., single panel design with replacement, rotating panel design; de Vaus, 2007, pp. 120–123). Panel research allows for the most insightful tracking of the directions of changes in the observed variables. Their weakness is the fact that in subsequent measurements – especially when they take place in several-year intervals – the number of dropouts decreases, because the respondents no longer want to participate in the survey, they leave, die. Moreover, multiple participation in research on the same subject may have an impact on the opinions and behaviors of research participants, thus influencing their responses to the research to some extent, and thus changing the results of the research.

Studies similar to this dynamic are those in which conclusions concerning changes occurring over time are drawn on the basis of one measurement (i.e., cross-sectional studies). They can be carried out using different strategies. In gerontological studies, the most frequently used are cross-sectional studies of different age groups (treated as representing different phases of the life cycle or different stages of life course) and retrospective studies (respondents are asked for information about their past and current situation; life story method is an example). The first of these strategies involves the risk of misinterpreting the differences between age groups resulting from the process of maturation/ageing of individuals. Retrospective research, in turn, is burdened with errors resulting from the unreliability of the memory of respondents, the desire to consciously falsify the past or to unconsciously modify memories (filtering memories through later experiences).

Research close to this dynamic – despite its numerous limitations – is often carried out because of its undoubted advantage; its short duration, lower costs, easier organization of research. Studies of this kind can provide very interesting hypotheses about the changes in the phenomena studied over time. However, more reliable knowledge of change is provided by dynamic research, in which, to a certain extent, researchers observe the evolution of change.

In the interpretation of the results of dynamic and near-dynamic studies, in which we search for the essence and regularity of changes associated with the ageing of people, we must be very careful. The observed changes in time, changes in life patterns or differences between age groups may have different causes, which researchers (e.g., de Vaus, 2007; Green, 2017) describe as: age effect, cohort (generation) effect, period effect. Determining which of these reasons is the most important is a difficult task. Its implementation makes it easier to combine different patterns of research in one research project and to cover different cohorts. For example, so-called sequential analysis combining longitudinal and cross-sectional studies (Brzezińska, 2000) is a research strategy that can capture the impact of cohort, age and period effects.

Conclusion

The adoption of a life course perspective in gerontological research is essential for a better understanding of old age as a stage in human life and an accurate diagnosis of the situation of people belonging to the older generation at a given time. This research perspective also has great potential for the development of human ageing theory and theory to explain changes in an ageing society. It has numerous cognitive and practical qualities. At the same time, it brings serious methodological challenges related to the use of dynamic research schemes and the specificity of the elderly as respondents.

Notes

1 For the purposes of social policy science, these two perspectives were described by B. Rysz-Kowalczyk (2003).

2 "A sociology of the life course focuses on patterns, trends and change through individuals' lives, and how historical, societal and political norm, situations and transformations impact on them" (Green, 2017, p. 26).

3

> Life span psychology has been described as the study of individual development (ontogenesis) – a lifelong adaptive process of acquisition, maintenance, transformation and attrition in psychological structures and functions.… Nature and nurture are combined but much attention is focused on individual differences relating to ability and personality. These are seen to have a biological basis and genetic foundation which cause age-related variations across the life span.
>
> (Green, 2017, p. 27)

4 As some researchers demonstrate, social actors do not mechanically adapt to the limitations and opportunities offered by the social system and cultural heritage, but rather "negotiate the available life course models" (Lalive d'Épinay et al., 2005).

5 I assume, after Piotr Sztompka, that

> culture is a network of meanings, produced by people, but for each of them separately external, inherited from generation to generation and historically changeable.… What distinguishes cultural meanings is their normative, obligatory character. Cultural meanings are values worthy of cultivating.
>
> (Sztompka, 2019, p. 21)

6 "A study based on observations representing a single point in time" (Babbie, 2010, p. 106).

7 A wider presentation on the topic is made by, among others: Koseła and Sułek (1986), Brzezińska (2000), de Vaus (2007), Brzezińska, Appelt and Ziółkowska (2015).

8 It should be noted that the concept of longitudinal study (research, design) occurs in the scientific literature in two meanings: broad – "a study design involving the collection of data at different points in time" (Babbie, 2010, p. 107) and narrow – as research conducted for subsequent measurements on the same samples (e.g., Brzezińska, 2000; de Vaus, 2007; Frątczak, 2014).

9 "A type of longitudinal study in which a given characteristic of some population is monitored over time" (Babbie, 2010, p. 107).

10 "A study in which some specific subpopulation, or cohort, is studied over time, although data may be collected from different members in each set of observations" (Babbie, 2010, p. 108).

11 "A type of longitudinal study, in which data are collected from the same set of people (the sample or panel) at several points in time" (Babbie, 2010, p. 109).

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9 Considerations when using longitudinal statistical models to study ageing

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Research methods
Longitudinal statistical models are presented to examine the ageing process. Approaches discussed include the latent growth curve model, multivariate latent growth curve model, latent growth curve model with a time-varying covariate, latent class analysis, growth mixture model, multi-state model and change point model.

Methodological lessons learned
This chapter highlights the increased access to longitudinal data sources and the variety of different longitudinal models of change available to researchers interested in ageing. These data sources and longitudinal models provide researchers with an opportunity to answer complex research questions related to ageing and within-person change. Researchers should devote efforts to choosing the data source and longitudinal model that matches most closely to their research questions because different models lead to different results.

Summary

In order to understand the ageing process, it is important that the same older adults are assessed at two or more occasions over time. Even though there has been an increase in longitudinal data and advances in statistical modelling, most research is still based on between-person differences rather than on within-person change. This chapter will discuss statistical models made possible with repeated measurements (e.g., latent growth curve model, growth mixture model) that are important for assessing changes that occur within older adults. Important considerations when using longitudinal statistical models will be discussed (e.g., using longitudinal data that matches your research question, gaining access to data, features of study design such as time elapsed between measurement occasions and number of occasions, comparison across countries). We hope this chapter will make it easier for researchers to use longitudinal approaches to their utmost potential.

Introduction

It is well known that the ageing process is complex, requiring an understanding of multiple biological, social, physical, neurological and psychological factors over an individual's lifetime. In order to understand the ageing process, it is important to examine how these numerous biopsychosocial factors change and interact over an extended period as the effect of these factors on the ageing process can take years to manifest. Looking at the effect of these factors at only one point in time only provides a snapshot of the ageing phenomenon. It fails to provide much needed information about the trajectories and transitions that older adults go through and its determinants.

The importance of understanding the complexity of various ageing phenomena has resulted in increased funding worldwide for large-scale longitudinal ageing studies that follow the same individuals over time (Woodard, 2017). These studies vary in the age of the targeted older adults (e.g., some studies follow individuals from birth to older adulthood, others start following individuals in older adulthood, and others specifically focus on the oldest age group), the number of repeated occasions available (e.g., some only include three time points and others include many more), the time intervals between studies (e.g., some collect information every year and others every three years) and the variables included (e.g., blood samples, psychological measures, neurological measures, cognitive measures); providing researchers with increased opportunities to select longitudinal studies that most closely answer their research questions. For example, a researcher interested in understanding the cognitive ageing process from normal cognitive ageing to dementia would want to select a study that follows older adults across numerous repeated waves of data collection over many years with valid measures of cognitive ageing and dementia.

This increase in longitudinal studies has also resulted in more procedures put in place that facilitate access to data (e.g., GAIIN, Gateway to ageing, DPUK). For example, numerous data sources can now be accessed at data centers or online with data request forms. The increased access to longitudinal studies has also led to an increase in research networks aimed at facilitating the integration of numerous longitudinal studies (e.g., Integrative Analysis of Longitudinal Studies of Ageing and Dementia). These networks make it easier for researchers to run statistical analysis across multiple longitudinal studies on ageing thus facilitating study replication and the examination of cross-cultural and cohort effects (Hofer and Piccinin, 2009, 2010). In addition, linkages between different data sources (e.g., national longitudinal studies, electronic medical records, long-term care data) is now also possible allowing researchers to complement their longitudinal studies with information that was not directly collected but that is important to understanding the ageing process.

This surge is longitudinal studies and the more recent ease of access to this data has also resulted in an increased use of longitudinal modeling approaches. Traditionally, psychological research has focused mostly on cross-sectional models that examine individual differences (between-person differences; e.g., how older adults of different ages differ from each other on cognitive functioning) rather than on longitudinal models that allow the examination of how individuals change over time (within-person change). More recently, researchers are requesting more longitudinal designs to better understand the within-person processes of ageing given that within-person research questions answered using cross-sectional designs can lead to biased results (Molenaar and Campbell, 2009).

Developments in advanced statistical models and computer software (e.g., Mplus, R, Mx) for the modeling of one or more variables collected over various time points allow researchers to answer complex research questions about ageing-related trajectories and the dynamic relationship between selected developmental processes. These models also allow researchers to examine the extent to which results based on cross-sectional designs align with those of longitudinal designs. These statistical advancements have resulted in more than one analytical technique to study longitudinal change (see Bollen and Curran, 2006; Duncan, Duncan and Strycker, 2006; Grimm, 2007; Hoffman, 2015; Muniz-Terrera et al., 2016; Singer and Willett, 2003) each of which can provide different insight into the trajectories of older adults. Using statistical techniques for longitudinal data (e.g., latent growth curve modeling and multilevel modeling) allows the identification of average trajectories of change (initial level and rate of change) and variability around the initial level and rate of change (interindividual heterogeneity) both of which are key in understanding the ageing process. The availability and complexity of these analytical techniques and the fact that new developments in the analysis of change are constantly evolving means that researchers must choose the most appropriate model even though they may not be aware of the different longitudinal models available to study ageing.

The purpose of this chapter is to provide researchers with an overview of longitudinal studies available to study ageing and review some of the longitudinal data approaches to studying the trajectories of ageing. This chapter is not meant as an exhaustive list of all longitudinal studies and data analysis methodologies but rather as an overview of some of these to highlight the range of studies available around the world and the various different longitudinal data approaches to analyze the data from these studies. More specifically, univariate and multivariate latent growth curve models, the latent growth curve models with a time-varying covariate, growth mixture models, change-point models and multi-state models will be discussed. These statistical models were chosen given their significance in understanding the trajectories and transitions of the ageing process. While there is overlap between many of these models, each still displays important distinctions which affect the research questions each can answer. We hope to provide readers with an understanding of the different statistical models and the research questions that can be answered by each of them.

Longitudinal studies

Before discussing the statistical models available to studying ageing trajectories, we felt it was important to highlight briefly some of the longitudinal studies available around the world. As mentioned in the introduction of this chapter, there has been an increase in accessibility of longitudinal studies on ageing worldwide (Woodard, 2017) and it is imperative that more researchers become aware of these data and their importance in further understanding the ageing process. These studies are imperative as cross-sectional studies only provide a snapshot of the lives of older adults. Some of the large-scale longitudinal studies on ageing include the Seattle Longitudinal Study (SLS), Baltimore Longitudinal Study of Ageing (BLSA), Victoria Longitudinal Study (VLS, Hultsch et al., 1998), English Longitudinal Study of Ageing (ELSA, Clemens et al., 2019), Origins of Variance in the Oldest-Old: Octogenarian Twins (OCTO-Twin, Johansson et al., 2004; McClearn et al., 1997), Survey of Health, Ageing and Retirement in Europe (SHARE, Borsch-Supan et al., 2013), Longitudinal Ageing Study Amsterdam (LASA; Hoogendijk et al., 2016; Huisman et al., 2011), Rush Memory and Ageing Project (MAP; Bennett et al., 2012; Bennett et al., 2005), Wisconsin Longitudinal Study (WLS, Hauser and Weir, 2010), Swedish Adoption/Twin Study of Ageing (Finkel and Pedersen, 2004; Pedersen, Lichtenstein and Svedberg, 2002), Canberra Longitudinal Study (Christensen et al., 2004) and Health and Retirement Study (HRS, Sonnega et al., 2014). This is a list of some of the longitudinal studies on ageing that are available, as an exhaustive list of all longitudinal studies was not the objective of this chapter.

Researchers interested in longitudinal studies are encouraged to examine these studies more closely to assess whether they would be appropriate for their research questions, as these studies all vary in the variables they measure, the number of repeated assessments they completed, the age range of participants, sample size and the time intervals between assessments. These are important to consider as they can have an impact on the interpretation of results. For example, a researcher interested in examining trajectories of people with dementia would not want to select a longitudinal study with repeated assessments at five-year intervals. Shorter data collection intervals would be needed to capture crucial information about dementia trajectories. Similarly, a researcher interested in trajectories of cognitive functioning would preferably want data for four or more repeated occasions in order to examine nonlinear trajectories.

In addition to these studies, researchers in the field of ageing should also consider other sources of longitudinal data such as administrative data. For example, in Canada, data from electronic medical records is available through the Canadian Primary Care Sentinel Surveillance Network (CPCSSN; http://cpcssn.ca/about-cpcssn/). There is also the InterRAI (www.interrai.org) data which has been adopted worldwide. For example, in Canada the InterRAI data is used in long-term care homes to assess demographic information and clinical and functional characteristics of residents (e.g., cognitive and physical function, psychosocial well-being, health conditions). Repeated assessments are done every three months for the duration of the resident’s stay in long-term care, making this data relevant to researchers interested in understanding the trajectories of people living in long-term care homes. For example, we used this data to examine the longitudinal relationship between dementia-related challenging behaviors (e.g., vocal disruption, physical aggression) and cognitive functioning in long-term care homes (Robitaille, Garcia and McIntosh, 2015).

Longitudinal data networks

Replication of longitudinal research is necessary to protect against uncritical acceptance of empirical results. Research findings and conclusions often vary across independent studies addressing the same topic. A number of reasons are possible for the discrepancies such as differences in measures, analysis and covariates used and cultural differences between populations. The wide variety of possible reasons for the discrepancies makes it difficult to untangle the real reason for the between-study variability. Longitudinal data networks make it easier for researchers to replicate longitudinal research across multiple studies. Using a coordinated analytical approach, researchers can take steps to insure a common protocol across all studies That is, the same statistical models (e.g., a multivariate latent growth curve model is used across all studies) can be used with the same variables (e.g., a Mini Mental State Examination (MMSE) and a measure of grip strength are used to examine the longitudinal relationship between cognitive and physical functioning across all studies) and covariates (e.g., age, gender, years of education are used across all studies) across multiple longitudinal studies. For examples of studies that have used a coordinated approach see, Brown et al. (2012), Duggan et al. (2019), Lindwall et al. (2012), Mitchell et al. (2012), Piccinin et al. (2013), Robitaille et al. (2018a) and Zammit et al. (2019).

Longitudinal data analysis networks include the Integrative Analysis of Longitudinal Studies of Ageing and Dementia (IALSA; www.maelstrom-research.org/mica/network/ialsa), Promoting Mental Well-being and Healthy Ageing in Cities (MINDMAP, Beenackers et al., 2018) and Ageing Trajectories of Health: Longitudinal Opportunities and Synergies (ATHLOS; http://athlosproject.eu/). Researchers interested in data harmonization or coordinated data analysis should also take a look at Maelstrom Research (www.maelstrom-research.org/). It provides access to an international team of experts in longitudinal data analysis, open-source software, harmonization platforms and free access to the

Maelstrom Catalogue (i.e., metadata catalog) which provides researchers with easy access to information about existing longitudinal research networks and a large number of longitudinal studies (e.g., study design, variables collected and whether bio specimens were collected, age of participants, number of data collection waves, country where data is collected).

Longitudinal statistical approaches

Throughout this section, we refer mostly to latent curve models, which are based on the structural equation modeling framework. However, for those who prefer multilevel analyses, multilevel models for longitudinal data in which observations are nested within individuals can also be used as both are equivalent (Hox, 2010).

Latent growth curve model

Latent growth curve models allow researchers to examine trajectories (i.e., intercept and slope) of repeated measures and examine the effect of various variables on these trajectories (Bollen and Curran, 2006; Curran, Obeidat and Losardo, 2010). For example, Piccinin et al. (2013) examined the association between age, sex and education with MMSE scores using a time in study latent growth models across six studies of ageing. That is, latent growth curve models allow researchers to examine mean trajectories (e.g., what is the average initial level of cognitive functioning and how does cognition change as a function of time) and the role of various variables (e.g., chronic conditions, education) on the intercept (e.g., levels of cognitive functioning at baseline) and the slope (e.g., rate of cognitive decline) to examine whether some older adults demonstrate more rapid decline compared to others. Latent growth curve models can either be linear, in which the rate of change is assumed to be constant across all repeated occasions, or nonlinear, in which a more complex rate of change (e.g., quadratic trajectory) is modeled. Researchers interested in modeling an ageing process that is expected to show accelerated or decelerated decline across time (e.g., memory) should model a nonlinear trajectory over time, although this will depend on the number of measuring occasions. In addition to using age or time in study as the time metric, latent growth curve models can also be used to model time to death and time to disease onset (e.g., Cadar et al., 2016).

Multivariate latent growth curve model (MLGC)

The MLGC model is an extension of the univariate growth curve model (Bollen and Curran, 2006; Curran, Obeidat and Losardo, 2010). It estimates the random trajectory of two variables (known to be correlated) simultaneously and examines how these correlate together over time. What makes this model interesting is that it allows for the examination of the correlation between the outcome's intercepts (intercept–intercept correlation), slopes (slope–slope correlation) and occasion-specific residuals (OSRs; OSR–OSR correlation). The slope–slope correlation examines whether people who decline more quickly than average on one variable (e.g., processing speed) also demonstrate a higher than average rate of decline for another variable (e.g., visual spatial ability). On the other hand, the OSR–OSR relationship is within-person, time-specific deviations/fluctuations around people's long-term developmental trends on some outcome (Hofer et al., 2009; Martin and Hofer, 2004). Therefore, this approach examines whether change for a specific individual at a specific occasion is associated with another variable at a matched occasion (Curran and Bauer, 2011; Hofer et al., 2009; Hoffman and Stawski, 2009). For example, it examines whether within-person variations from each individual's mean trajectory of processing speed is associated with occasion-specific residuals of the visual spatial ability measure.

While both approaches (slope–slope and OSR–OSR correlation) appear similar, they answer two rather different questions and relying on one approach over another can result in different conclusions about the relationship between both developmental variables (Hofer et al., 2009; Sliwinski and Mogle, 2008). Even though memory and social participation may both go up or down together at the overall trend level, they may not necessarily share the same transient deviations between shorter time intervals. To date, the majority of research has focused on associations between mean trajectories rather than relationships between occasion-specific residuals (Hofer et al., 2009).

In addition to providing estimates of the relationship between the intercepts, the slopes and the OSRs, this model also allows for the examination of the initial level and rate of change of each variable independently. Given that only correlations are estimated between both variables, estimating two independent univariate growth curve models would give identical results. See Muniz-Terrera et al. (2016), Praetorius Björk, Johansson and Hassing (2016), Robitaille, Garcia and McIntosh (2015), Robitaille et al. (2012) and Sliwinski, Hofer and Hall (2003) for papers where bivariate growth curve models were applied.

Another possibility is to estimate the structure of the MLGC model by regressing the slope of y on the slope of x and the intercept of y on the intercept of x (Bollen and Curran, 2006). For example, this model implies that changes in visual spatial ability may be explained by processing speed and therefore aligns more closely with the theoretical basis of the role of processing speed on cognitive ageing. Unlike the MLGC model which includes two outcome variables, this model includes a predictor and an outcome variable. The initial level and rate of change for visual spatial ability now accounts for what is explained by processing speed and is therefore no longer equivalent to results that would be obtained from a univariate latent growth curve model. Rather, the initial level and rate of change of visual spatial ability is net of the effect of processing speed. The initial level and rate of change of processing speed remains identical to the aforementioned model. For now, correlations are still included between the occasion-specific scores for the predictor and the outcome but as we will see in the next section, regressions can also be estimated.

Latent growth curve model with a time-varying covariate (TVC)

The latent growth curve model with a TVC is similar to the directional MLGC model in that only one outcome and one predictor variable is modeled and is therefore only pertinent to use in situations where there is some theoretical basis for having one variable predict the other. Unlike the directional MLGC model, the TVC model does not necessarily include a random slope for the TVC. That is, the predictor variable can be modeled as a variable that fluctuates over time rather than changing systematically over time.

In the TVC model, repeated measures of cognitive functioning are regressed on processing speed at each occasion to take into account the time-specific fluctuations of processing speed in explaining cognitive functioning (e.g., memory, visual spatial ability) above and beyond the changes predicted by the general growth trajectory. In addition, the intercept of the outcome variable (e.g., cognitive test) is regressed on the intercept of the TVC (e.g., processing speed) which provides between-person information and, most importantly, disaggregates within- and between-person effects. The intercept and rate of change of the outcome is also net of the effect of the TVC. That is, instead of controlling for the effect of the TVC (e.g., processing speed) at baseline only, the effect at each occasion is being controlled. Time-invariant predictors (e.g., initial age and sex) are interpreted somewhat differently in TVC models in that the role of initial age in predicting cognitive functioning is net of the effects of processing speed (Bollen and Curran, 2006).

Disaggregating both effects is especially important in order to avoid confounding both effects which could result in biased model estimates (Curran and Bauer, 2011; Hoffman, 2015; Hoffman and Stawski, 2009; Wang and Maxwell, 2015). Unlike time-invariant covariates which remain stable over occasions, time-varying covariates, such as processing speed, are variables that change over time. In addition to changing over time within the same individual, different individuals also have varying overall levels of the TVC when compared to others. For example, although processing speed is expected to decrease in older adults with ageing, some individuals inherently have higher levels of processing speed compared to others. Therefore, as time-varying covariates, in their raw form, typically contain both between-person and within-person sources of variance, it is essential to disaggregate these effects (Curran and Bauer, 2011; Curran et al., 2014; Hoffman and Stawski, 2009; Wang and Maxwell, 2015). In order to disentangle the within-person effect from the between-person effect, in addition to being included at the within-person level (level 1), processing speed is included at the between-person level (level 2) by including its random intercept in the model. The intercept of the outcome variable is then regressed on the TVC in order to extract information about the between-person effect of the TVC on the outcome. See Bielak etal. (2012), MacDonald et al. (2003) and Sliwinski and Buschke (1999, 2004) for examples where TVC models were applied to cognitive ageing research. An extension of this model would be to add a random slope to the TVC if it is believed that the TVC changes as a function of time/age. This would be very similar to the directional MLGC model with the additional prediction between occasion-specific predictor and matching occasion-specific outcome.

Latent class analysis (LCA) and growth mixture model (GMM)

Developments in the analysis of longitudinal data have resulted in recent studies focused on better understanding heterogeneity in the ageing-related trajectories. Two such developments, LCA and GMM, allow for the identification of different classes of individuals who cluster together thus identifying more than one trajectory within the population (Asparouhov and Muthén, 2014; Berlin, Parra and Williams, 2014; Grimm and Ram, 2009; Jung and Wickrama, 2008; Liu and Hancock, 2014; Muthén, 2004; Muthén and Shedden, 1999). Although the growth curve models mentioned above do evaluate heterogeneity, this approach goes further by examining whether sufficient heterogeneity exists to form different trajectories that group together into distinct classes. Unlike latent growth curve models, these models have an added latent categorical variable (also referred as a trajectory class variable) in order to model the potential unobserved subpopulation membership (Berli, Parra and Williams, 2014; Muthén, 2002, 2004; Muthén and Shedden, 1999). Therefore, LCA and GMM can be used to understand more precisely the trajectories of ageing-related processes beyond the average trends, thus providing opportunities for researchers not only to examine the role of predictors on the intercept and rate of change, but also examine the role of predictors on class membership.

An important distinction between LCA and GMM is that GMM models are more flexible than latent class models. That is, whereas the GMM model allows for variability on each intercept and slope, the LCA intercept and slope are fixed to zero, making the assumption that the trajectories within classes are homogeneous (Berlin, Parra and Williams, 2014; Muthén, 2004; Nagin, 1999). GMM provides estimates of the average trajectory (intercept and slope) and variation for older adults in each latent class (Berlin, Parra and Williams, 2014; Muthén, 2004, 2002; Muthén and Shedden, 1999). GMM provides information about the optimal number of classes and characteristics of each class including the mean intercept and slope, proportion of membership and significant predictors of class membership. The number of classes identified is based on an exploratory approach in that models are fit with increasing number of classes (e.g., one class, two classes, three classes and four classes). The number of classes is based on the fit of the models and the interpretability of the classes (i.e., BIC/AIC values, entropy values, Bayesian Information Criterion, bootstrap likelihood ratio test; Nylund, Asparouhov and Muthén, 2007). A number of studies have used GMM to explore the optimal number of classes for cognitive ageing (Proust and Jacqmin-Gadda, 2005; Small and Bäckman, 2007; Terrera, Brayne and Matthews, 2010; Hayden et al., 2011; Xie, Mayo and Koski, 2011). These studies suggest that different groups of trajectories might better explain change in cognitive functioning and that forcing everyone to fit within the average group might be misrepresentative.

More recently, some studies have modelled multivariate GMM (Robitaille et al., 2018a). Unlike the univariate GMM, the multivariate model includes two outcomes modeled simultaneously allowing for the additional possibility to examine the relationship between the two outcomes within each of the identified classes (e.g., cognition and grip strength). LCA and GMM have important clinical implications in that they can help predict which individuals are at increased risk of being in the low functioning classes.

Multi-state model (MSM)

Unlike the aforementioned models, multi-state modeling can be used to assess the transitions of older adults across different states such as health related processes of ageing (e.g., dementia, disease) and examine the role of risk factors on the transitions between states (van den Hout, 2017). These models are also referred to as multi-state survival models given that death is included as one of the states. Importantly, these models are flexible in the number of states that can be included and allow for the modeling of transitions even though the exact time of the transition (e.g., exact time of dementia diagnosis) is unknown (van den Hout, 2017). For example, Robitaille et al. (2018b) examined the role of education on transitions through cognitive states and death using a four-state model with State 1 defined as normal MMSE, State 2 as mild MMSE impairment, State 3 as severe MMSE impairment and State 4 defined as death. Robitaille et al. found that a higher level of education was associated with a lower risk of transitioning from normal MMSE to mild MMSE impairment but was not associated with the later transitions. This approach also allows for the estimation of overall and non-impaired life expectancies (van den Hout, 2017). For example, Robitaille et al. (2018b) found that those with higher levels of education and socio-economic status had longer non-impaired life expectancies but that no differences were found on overall life expectancies. Another paper that uses multi-state modeling is Kryscio et al. (2013). Unfortunately, multi-state models are only rarely used in the field of ageing even though the knowledge gained from these models can improve our understanding of risk factor to disease-related processes of ageing, potentially facilitating earlier detection for inclusion in preventative interventions.

Change point model

Change point models, a version of random effects (Laird and Ware, 1982) models that permit the identification of the onset of change in rate of decline, have recently become popular in ageing research (Hall et al., 2000; Johnson et al., 2009; Karr et al., 2018; Muniz-Terrera, 2015). They have been used to describe ageing related changes, and accelerated declines that occur in the proximity of death (terminal decline) and prior to the onset of disease. Although change point models can be used to model the onset of accelerated change in any area of research, much of the research literature has focused on accelerated change in cognitive function prior to dementia and death (Karr et al., 2018). In a seminal publication on cognitive ageing research, Hall et al. (2000) identified the onset of faster memory decline in preclinical dementia cases by fitting change point models using profile likelihood and Bayesian estimation. Following this publication, numerous research papers have been published that used change point models (Muniz-Terrera et al., 2013). For example, in an examination of the terminal decline hypothesis, Thorvaldsson et al. (2008) reported onsets of faster decline at 6.6 years before death for verbal ability, 7.8 years before death for spatial ability and 14.8 years for perceptual speed, and Muniz-Terrera et al. (2013) estimated the onset of faster decline at 7.7 years before death for global cognition scores. Most of these papers regarded the change point as a fixed effect, most in preclinical dementia or terminal decline investigations and that described change occurring in two linear phases with an abrupt change. The assumption that the change point is a fixed effect, that is, that all individuals transition from an initial phase of decline to a phase of faster decline at the same distance from death or dementia or age is without doubt, very strong and highly questionable given the observed heterogeneity of the ageing or disease process. More recently, a fewer publications, most of them using Bayesian estimation, have modelled the change point as a random effect (which is essential for identifying individuals for potential treatment) and some have relaxed the assumption of an abrupt change allowing for a transitional period between the two linear phases (Muniz Terrera, van den Hout and Matthews, 2011; Terrera et al., 2014). More researchers need to consider change point models in their study of the ageing process as these models can provide knowledge that can help to plan more timely interventions to delay decline.

Discussion

The purpose of this chapter was to highlight some considerations that should be taken into account when conducting longitudinal data analysis. As demonstrated, there are numerous data sources available and one cannot overestimate the importance in choosing a longitudinal study that meets your research needs. This chapter also emphasized the variety of different longitudinal models of change available to researchers interested in ageing and highlighted the distinction between these models. The sheer number of different models of change that are available and the variations in parameterization that are possible are making it difficult for researchers to use the best model for their research question. Researchers should devote efforts choosing the model that matches most closely to their research questions because different models lead to different results. Given the wide variety of longitudinal models available, it would be important for researchers to provide an explanation for why one model was chosen and provide a detailed description of the model specifications (e.g., fixed or individually varying time points). Advances in multivariate models of change are allowing researchers to answer complex questions of developmental change. We hope this chapter will make it easier for researchers to use these models to their utmost potential.

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10 Quantitative and qualitative interviews in older people research

Specificity and usability of the research tool[1]

Piotr Czekanowski

What is approximated in this chapter are the qualitative, quantitative and mixed research approaches, which are reflected in three related forms of interview, i.e., qualitative, quantitative and quantitative-qualitative interview (in the latter case in a form proposed by the author of the chapter). The first part of the text presents issues explaining why a large proportion of Polish researchers, especially those less experienced, approach the qualitative methods almost uncritically, underestimating or sometimes even negating the value of research carried out using quantitative techniques. Therefore, the chapter illustrates both the advantages of qualitative (unstructured) interview, such as the possibility of profound insight into the phenomena, as well as its limitations (small number, high impact of the researcher on the achieved results), and an analogous approach was applied to quantitative (structured) interview, where the possibility of testing numerous communities was considered to be an advantage, whereas the effects of the so-called flat empiricism were considered to be a limitation. The conclusion resulting from all the considerations is as follows: it is possible and advisable to go beyond the traditional dichotomy and construct a quantitative-qualitative (mixed) oral interview useful not only in gerontological research, where it finds particularly good application. Such a research technique combines the advantages of qualitative and quantitative interviews, which are usually designed and developed separately, thus allowing minimization of the degree of restrictions relating to them.

Introduction

Choosing the optimal research method[2] to diagnose how elderly people function, as well as those around them, is not a simple task. This is mainly due to the relatively large number of research approaches and techniques that can be used. Making the right choice by the researcher requires him or her to think deeply and consider many methodological issues to ultimately lead to the selection of the most appropriate solution. During such searches, we may encounter various dilemmas that make this choice difficult. They are often associated with the functioning of certain simplifications and generalizations about which of the research methods are by definition better and which are worse. I would like to analyze this issue on the example of the opposing qualitative and quantitative methods, which, in my opinion, are still juxtaposed as those which have a distinctly different “cognitive ability”. I undertake these considerations in order to propose an interview-related solution that can reconcile extreme visions as to what role “qualitative” and “quantitative” methods play in obtaining information from interviewees. Therefore, my considerations in this field can be related to the area of the more and more often presented ideas on the so-called mixed methods (methodologies, paradigms) (Creswell, 2013). I would like to add, however, that due to the nature and volume of this text, the solutions presented regarding the division of the two types of the interview proposed in the title of the text are mainly reduced to – using the terminology used by K. Konecki (2000, pp. 20–22) – its technical (neutral) dimension without going too deeply into the paradigmatic issues related to the creation and use of this technique.[3]

Quantitative and qualitative research – end of a dispute?

I start thinking about the research methods by discussing more general issues. Therefore, they do not refer solely to doing research of the elderly, because so far in the research focused on older adults, we have often used the methods also applied in other sociological or – more broadly – social research.

The issues regarding the division of the research methods into quantitative and qualitative ones have been arousing emotions for many years, constituting – as S. Kvale described it – a hot topic (2004, p. 77). This phenomenon occurs not only in sociology, but also in other sciences. Let the example of W.R. Shadish serve us as an example confirming this observation (1998, p. 3). At the end of the 1990s, this author expressed the certainty that if the members of the American Evaluation Association were to point to one issue, which in the last 20 years had been most often discussed and divided evaluators the most, they would point to quantitative and qualitative disputes. C. Trutkowski, citing the above words, makes the observation that currently the issue of using quantitative and qualitative methods does not entail the emergence of such theoretical divisions among researchers as it did before (2008, p. 127). A similar opinion seems to be shared by other authors, for example M. Halicka, who notes that nowadays the view that qualitative and quantitative research are not in opposition to each other is almost widespread and it is pointless to oppose them (2004, p. 62). However, my conviction regarding the dissemination of this view among some Polish scientists is different, although I cannot support it with any results from research in this field. However, reading various reports based on the results of diagnoses made, listening to numerous speeches at symposia, taking part in conference discussions (including the one that became the stimulus to initiate the project within which this book appears), teaching methodology of survey research or conducting talks on the subject of research methods used in social sciences (especially with those less experienced adepts of these sciences) I still notice a tendency to depreciate the so-called quantitative research, especially a structured interview, and glorification of so-called qualitative research, regardless of its type. These people seem to understand what is associated with the term “qualitative research” in a specific way – as noted by U. Flick (2011, p. 22). This specificity is expressed in treating qualitative research as a method that constitutes some new form of research constituting an alternative to – criticized especially in the 1960s and 1970s – quantitative research. This author, however, emphasizes that the research which today is referred to as qualitative has had a long tradition in many disciplines.

It is worth noting that such “oppositional” perception of qualitative and quantitative research is not a new phenomenon in the environment of Polish sociologists, especially those with shorter experience. This issue was raised many years ago by A. Sułek, noting that at the beginning of the 1970s global trends began to reach Poland, calling into question the pre-existing positivist social research paradigm. The author added that after some time the rapid influx of these new trends, such as ethnomethodology or symbolic interactionism, led to a situation in which “they became, *especially among the younger generation* [my emphasis], obligatory and gained the significance (again!) of ‘truly’ scientific approaches” (Sułek, 2002, p. 35).

Perhaps, therefore, the described situations indicating the predominance of qualitative methods over those of a quantitative nature, especially by researchers who are just beginning to try out or practically use the empirical methods of social sciences, are not accidental or coincidental. One may even be inclined to suppose that this situation indicates a certain tendency in this regard. Regardless of whether the observed trend occurs or not in reality, I do notice a one-sided approach to research by some students and scientists, who treat almost all quantitative diagnoses as cursory, shallow and thus of only survey value. It is therefore worth considering what are the potential causes of these types of attitudes. I believe that there are several main reasons conducive directly or indirectly to the emergence of the described situation, which I think include first of all:

Presenting in the mass media: mainly opinion poll results

Let us point out that in general perception, the survey (probably often identified with each type of an interview) can be associated especially, if not only, with opinion poll organizations diagnosing views of specific persons on a given subject, without going into the motivations conducive to the emergence of such and no other views of these people.[4] In the described situation, one may even risk the statement that by showing in the mass media mainly only one forms of sociological tools, i.e., that related to public opinion poll, the authors of news and journalistic broadcasts unintentionally lead to the fact that such a narrowed and simplified image of social research is recorded in the minds of the recipients of the media message.

Unfortunate terminology

Due to the popular associations of this terminology, and as a result quite a narrow and shallow way of understanding the terms “quality” and “quantity”, they can also in the case of social research lead to such understanding of the qualitative approach which will be perceived as something high class, i.e., something significant, and the quantitative approach as something massive, cursory, sometimes even primitive.

One-sided presentation of research methods due to specific methodological preferences of lecturers at universities

This one-sidedness resulting from too far-reaching, and sometimes even ideological, as M. Hammersley calls it, attitudes of the researchers are manifested mainly in that the weaknesses of quantitative methodology are exaggerated and the deficiencies of qualitative analysis are insufficiently outlined. In the event of such a situation, lecturers may promote incomplete knowledge among the participants of their classes about the advantages and limitations of both qualitative and quantitative research approaches (Hammersley, 1992, p. 163; Silverman, 2012, p. 64).

A clear advantage of the number of currently published publications devoted to qualitative research over those describing quantitative research

In recent years, a very large number of methodology books have appeared on the Polish publishing market, including many based on translations, but presenting mainly the issues of qualitative research. On the one hand, this large number of publications describing qualitative methods is a most advantageous phenomenon: on the other hand, however – which can be considered a paradox – such a significant number of them can even give the impression among some readers that the whole world of scholars is currently primarily interested in qualitative research, because those of a quantitative nature are less useful and therefore are in retreat.

Insufficient degree of research curiosity as well as independence and inquisitiveness in searching for reliable knowledge

One of the effects of this – let's call it – scientific immaturity is the existence in some academic environments of a kind of "fashion" for using qualitative methods in research. The inexperienced – in the broad sense of the word – researchers often think that these methods are relatively simple to use, and the issues of reliability and accuracy of measurement are of secondary importance. With this approach, every study is basically successful, because it does bring some results, which without an embarrassing restriction of even elementary standardization, can always "somehow" be interpreted. Therefore, we probably still come across supporters of Barney Glaser's approach cited below (1998, p. 254), whose recommendation was quoted by U. Flick in his work, assuming, however, that this stage in the development of qualitative research, in which researchers fully trusted their methods, is already over: "Trust grounded theory, it works fine, just do it and publish the results" (2011, p. 22).

Listing the main reasons that may be conducive to the occurrence of excessive simplifications in the understanding of the relationship between "quality" and "quantity" in relation to ongoing research, I ask myself whether it is possible to limit the force of their impact so that the image of quantitative research could become more reliable in the near future. I think that achieving this goal is somehow real, but probably only in the long term, and the activities associated with it are certainly not easy to implement. For example, it is difficult to change the established attitudes of researchers in the near future, enrich information programs with in-depth sociological analyses or encourage more young people to critically study methodological issues. Nevertheless, it is worth starting to look for solutions among those which are probably the simplest, i.e., the ones related to the language we use overall, not only with our academic contacts. Perhaps, for example, a departure from the use of the term "quantitative research" or the popularization of terms that in turn would replace the term "qualitative research", such as the hermeneutic, reconstructive or interpretative approach, which is cited by U. Flick (2012, p. 23)[5] or – which also comes to my mind – simply descriptive, it would change the described situation, thus limiting the perception of qualitative and quantitative methods in unjustified opposition.

Dilemmas encountered when choosing the right research approach

Once you are aware that quantitative and qualitative research should not be contrasted with each other, can you also clearly indicate which of these research approaches is better in specific types of research, including, in particular, gerontological research? I believe that it is impossible to give a generalized answer to such a question without specifying the particular purpose and object of the diagnosis we make, because each of the approaches used has its own individual advantages and specific limitations. I share in this respect the observation of B. Synak that, just as there is no single, valid theory of ageing, there is also no single, good research method. However, wanting to make it easier for the researcher to make the right choice, let's think about what potential restrictions we may encounter using both the so-called qualitative and quantitative methods (Synak, 1997, p. 20).

I begin a brief analysis of these issues with B. Synak's other thoughts. On the one hand, for many years he insisted that qualitative methods be used in Polish research on the elderly (1988, p. 30, 1997, p. 20); on the other hand, however, he indicated, referring also to other authors, numerous and significant features that may have a positive or negative impact on the implementation and development of the results from such research (1997, pp. 17–19). There is no doubt that proponents of qualitative methods used in various studies must take these issues into account, because of, for example:

- consequences of the possibility of freely creating an image of the studied phenomenon based on its subjective, sometimes selective, stereotypical or even biased perception (the reliability of the researcher);
- difficulties conditioned by the level of the ability to ask open-ended questions (the need to focus on the experience of the surveyed people) and the ability to create a favorable atmosphere to be able to respond freely;
- narrowing the scope of research, i.e., the size of the surveyed community or meeting places, to the number in which the researcher is able to participate;
- complications occurring during the presentation of the research results to diverse recipients related to convincing them that the diagnosis reflects the existing reality.

B. Synak's conclusion resulting from his more detailed analysis of the pros and limitations occurring in qualitative research presented in his cited article is as follows: "All in all, it should be said that qualitative research is more difficult than the empirical, quantitative approach; it requires better researcher preparation, greater responsibility, sensitivity and empathy. In gerontological research, the difficulties are even greater" (1997, p. 19). In my opinion, this thesis, which is probably worth in-depth discussion, should not lead to an over-simplistic conclusion that in such a case quantitative research is easy to implement and does not require appropriate methodical, substantive and ethical preparation, unless we mean – signaled by the aforementioned author in an earlier part of his argument (1997, p. 15) – flat empiricism. What is meant by it? In my opinion, this term may mean at least four situations, namely:

- creating research "from behind the desk", i.e., without sufficient knowledge of the researched issues, field conditions or the peculiarities of the subjects, with the exception of piloting (trial tests);
- lowering the level of necessary standardization, sometimes found in the work of multidisciplinary teams, which is the result of misunderstanding by some representatives of, for example, medical sciences, the need to clearly formulate questions and then posing them to interviewees in a unified way, which is required in structured interviews used in social sciences;
- the researcher's use in the interview only of closed-ended questions, if this is not substantively justified, and is motivated solely by the intention of easily and quickly obtaining information from the survey;
- developing research results in a way described by D. Caplowitz as crass empiricism, which is expressed in the fact that the researcher analyzes all data (counts all possible dependencies) before he thinks over and prepares a detailed table of contents on the basis of which he will create a research report (Caplowitz 1983, pp. 383–386).[6]

The examples presented above illustrating the occurrence of potentially numerous methodological difficulties that we may encounter when preparing and implementing both qualitative and quantitative research probably allow us to better understand why making decisions as to which of these research approaches will suit our competences and needs is not easy. Probably it was the occurrence of the dilemmas among researchers connected with the need to make the choice between either the qualitative or quantitative method, as well as the desire to limit the scope of the mentioned methodological difficulties, that contributed to the fact that nowadays we are increasingly encountering tendencies to combine quantitative and qualitative optics into a certain whole.[7] M. Halicka, for example, deals with the issue in detail (2004, pp. 62–69; see also Flick, 2011, pp. 153–177; Creswell, 2013). The search for further ideas in this area, one of which I present below, is therefore a good opportunity to go beyond the traditional dichotomy in order to work out – as stated by U. Flick using the thoughts of A. Tashakkori and C. Teddli – "a methodological third way" (Flick, 2012, p. 33; Tashakkori and Teddlie, 2003, p. IX).

Quantitative-qualitative interview and its characteristics[8]

I think that a very useful tool for a structured face-to-face interview is a well-prepared questionnaire. I am referring to the interview, which, generally speaking, combines the features of the so-called qualitative and quantitative interview because:

1 through the appropriate type and structure of the questions asked (and observations made) it allows us to investigate the phenomenon we are interested in as deeply as possible, which can be considered a qualitative element of the diagnosis made by means of this interview;
2 by examining a large number of members of a given community, it enables the creation of its overall image or gives the opportunity to compare the situation occurring between communities, groups or their representatives, which is a quantitative dimension of such a diagnosis.

Let's take a closer look at both of the indicated features of a quantitative-qualitative interview, thinking about whether and how one can combine the qualities of qualitative and quantitative interviews in one research technique, i.e., interviews usually perceived separately.[9] Bringing these issues closer, I want to emphasize that in the above sentence (as well as in other places in this chapter) I consciously use the terms such as "so-called" or "conventional" to make it clear that in my understanding of the content under the terms "quality" and "quantity" I treat them as two elements co-creating a specific and complementary whole. The justification for this approach can be found, for example, in the longer argument presented by J. Sztumski, who concludes by saying that there is no subject of empirical research that would be defined only in a qualitative or only in a quantitative manner (2010, p. 257). In my opinion, E. Babbie also approaches the issues related to the quality–quantity relation stating that

> each observation is qualitative at the beginning, regardless of whether it is experiencing someone's intelligence or placing the clue on a measurement scale, or the answer marked in the questionnaire. The nature of any of these things is not numerical or quantitative, but sometimes it is useful to give them this numerical form.
>
> (2007, p. 48)

Qualitative dimension

When it comes to the first of the distinguished features of the interview, i.e., the one related to the *questions* used to obtain information and expand knowledge, then the type of the interview is carefully matched both with open-ended questions, which are usually the heart of the unstructured or in-depth interview, i.e., those forms of interviews that are recognized as qualitative interviews, and with semi-open and closed-ended questions, associated mainly with standardized,[10] and therefore quantitative interviews. Of course, we will notice that combining (mixing) three types of questions in one questionnaire is not in itself anything new, but what is important in this case is – which seems obvious – a comprehensive concept of the research undertaken with a clearly defined goal that we intend to achieve through the coexistence of different types of questions, and this goal is – let us repeat – to investigate the issue that interests us as fully as possible. Therefore, despite the fact that in a combined quantitative and qualitative interview we usually do not use only open-ended questions, as is the case in the abovementioned unstructured interviews, the researcher using this type of interview largely sets the same goals as S. Kvale indicates in relation to a qualitative interview, stating that "a qualitative research interview tries to understand the world from the perspective of the interviewees, comprehend the meaning of human experience, discover the world of their life prior to scientific explanations" (2012, p. 19). In the interview form that I propose, in order to explore the depth of this more subjective, internal world of the interviewees, there appear open-ended, semi-open and closed-ended questions mixed up in various proportions, which often complement each other, thus encouraging the search for relevant content and additionally fulfilling the function of control questions.[11] In order to learn objectively about the feelings of the interviewees occurring "prior to" scientific diagnosis and not to lose the opportunity to find out what the respondents would really like to say themselves, the varied research tool proposed is not adopting certain preliminary assumptions or creating operational definitions based on the results of previously conducted research or as described in the literature on the subject. Therefore, in cases where we make certain assumptions in advance, the interview is not intended to impose on the interviewees the vision of the researcher, but to find out to what extent the researcher's concept, which was in no way even signaled to the interviewees, is reflected in their feelings.

In the combined quantitative-qualitative interview – as has already been indicated above – we treat observation as an element that complements its "qualitative" dimension, i.e., the one related to obtaining information important for the researcher. As in the case of other standardized oral interviews, we do not treat such observation as an independent research method, because it plays only a supplementary role in them. Although in quantitative research, as pointed out by D. Silverman (2012, pp. 39–40), observation is usually not considered an important method of data collection, because it is difficult to conduct observational study on some samples, in relation to the quantitative-qualitative interview, it can be assigned at least two important tasks:

- First, such observation is helpful in properly reading the verbal message addressed to us. In order to understand properly – as S. Gertsmann notes – what our interviewee is saying to us, the interviewer observes his behavior and interprets it immediately (Gertsmann, 1985, p. 182). The subject of observation – as the author writes further – is always a certain whole, which consists of both the statements of the examined person and his facial expression, pantomime or sound of the voice. To the benefits of the overall observation of the examined person, I include, for example, the opportunity to perceive the interlocutor's manifestations of his mood expressed during the interview, in the form of, for example, exasperation or amusement, which in turn can affect the nature of the answers given.

- Second, observation accompanying the interview enables obtaining additional information about the interviewee and his or her surroundings. By conducting the interview in a specific place, often at the interviewee's place, we have the opportunity to examine people in a certain way in their natural location, gaining some opportunity for the correct interpretation of the recognized phenomena, because they are embedded in a specific context. However, it is worth repeating over and over again that during an interview what we should assume is the perspective of the person being interviewed, and not our own, because the assessment of the observed reality from the perspective of the researcher may not coincide at all with the feelings of the examined person.

Focusing on the complementary role of observation in an interview, I would like to point out that the interviewer has the opportunity to save his or her observations in a place properly prepared in the questionnaire form called "Interviewer's Comments", based on the points – which is crucial – prepared in advance by the researcher. The questions addressed to the interviewer relate to such issues as the degree of understanding of individual questions by the interviewee, the interviewee's apparent attitude toward the interviewer or the presence of third parties during the interview. This is a fairly precise list of issues to which every interviewer is to draw attention during observations, which later allows preparation of, among others, some collective summaries. Therefore, these numerical sets of results from the observation carried out can be considered as another element that reflects the combination of qualitative and quantitative components in the interview, and for this reason I propose to treat it in this text as a kind of transition to presenting the "quantitative" dimensions of this interview. I will only add that, in my opinion, the role of these supplementary entries made by interviewers is often underestimated by researchers and may prove to be very important or even crucial, especially when it is necessary to make an auxiliary interpretation of the answers given or to assess their credibility.

Quantitative dimension

When it comes to the second of the features of the qualitative-quantitative interview listed at the beginning of the third section, i.e., the one that allows *the examination of numerous representatives of the communities we are interested in*, I do not see any contradiction in the fact that the so-called "qualitative" research intentions presented above, i.e., the ones that enable investigation of the complex social reality, could not be carried out by conducting this kind of interview with a large number of people.[12] I am convinced that this would facilitate the achievement of the goals referred to by U. Flick regarding qualitative methods: "All approaches seek regularity in meanings … allowing the researcher to formulate – more or less generalized – models, typology and theory as ways of describing and explaining social or psychological issues" (2012, p. 13). We should note that to a large extent J. Lutyński wanted to achieve similar goals by means of a questionnaire interview, though not by means of a qualitative interview, recognizing that it serves "to learn both about the behaviour and mental experiences, including opinions, as well as phenomena that very often constitute complex and diverse sets of both, such as human attitudes, norms of conduct, habits, etc." (1994, p. 152). E. Babbie sees these issues similarly, noting that surveys can be used for various purposes, i.e., descriptive, explanatory and exploratory (2007, p. 268).

When discussing the most important issues related to the so-called quantitative dimension of the research conducted on the basis of the quantitative-qualitative interview, it should be emphasized that in order to conduct such interviews (as well as other standardized oral interviews) we usually need carefully prepared *interviewers*. This situation is understandable because rarely is a researcher able to reach larger groups of interviewees alone. However, in the case of gerontological research there are two key and complementary, which I emphasize, requirements for interviewers. First, it would be desirable to have such interviewers who are proficient in the implementation of questionnaire interviews. This is a feature that probably is common for many of them, although it is worth remembering what, for example, S. Kvale draws attention to, that we learn interviewing skills mainly through practice (2012, p. 20). However, the second extremely important feature that characterizes the interviewers, which must go hand in hand with the first, is having reliable knowledge in the field of gerontology.[13] The specificity of research on advanced age people implies such combined requirements. What is this specificity? For example, there is a need to free yourself from the quite common stereotypical perception of older people in society,[14] or to be sensitive to the moral rules of the so-called previous era, complex health issues and extremely important ethical issues.

Just indicting how I imagine the model person conducting an interview with an older man (or on issues related to old age) I am aware that finding reliable interviewers with "dual" qualifications, i.e., equipped with methodological skills and gerontological knowledge, is not an easy task. For many years, what we have paid attention to and what we have been admonishing (Czekanowski, 1993, pp. 4–5, 6, 87), is the fact that unfortunately in Poland there has been no nationwide research center to date that would be specialized in, among others, conducting widely understood analyses and gerontological research, and which, in addition, would have at its disposal a network of interviewers optimally prepared for such research. In the current situation, it is mainly the duty and responsibility of the researchers who "equip" with the interviewers whose services we intend to use, at least with the most relevant knowledge related to ageing and old age or at least with the subject related to the research (this can be done by preparing supporting materials for them or indicating literature or relevant training). However, it is worth being aware that we do not always have the opportunity to prepare our own network of interviewers or even appropriate training in the field of gerontology of those interviewers that we will have at our disposal. In many cases, therefore, the authors of gerontological scientific projects commission interviews to various survey laboratories, which probably very rarely (if at all) have employees properly qualified to perform such tasks (in such situations, we try to establish substantive cooperation with them, although probably only exceptionally the opportunity arises). Needless to say, the occurrence of shortcomings in the interviewer's work is always highly inadvisable because – as we know – it is primarily the interviewers' professionalism that determines the degree of reliability of the research material collected during their contact with the interviewees.

Concluding the presentation of the general characteristics of the quantitative-qualitative interview as an attempt to combine the advantages of both the quantitative and qualitative interview, I will recall another observation by U. Flick (2012, p. 22). According to this author, the progressive development of qualitative research methods meant that the term "qualitative research" is treated more and more precisely because it has ceased to be "defined by negation – qualitative research is non-quantitative, non-standardized, etc. – but through a set of features specific for them". I think that using this line of reasoning, it can also be assumed that a structured interview is no longer just a non-qualitative interview, and therefore it can also be useful in in-depth recognition of the phenomena that are of interest to us. I assume that this departure from the extreme dichotomy already mentioned will lead to a situation in which we will increasingly improve also the interviews of the most universal nature possible, i.e., the ones that will combine conventional quantitative and qualitative features, previously perceived differently.

Conclusion

To sum up the considerations in this chapter, I would like to answer potential questions about why, in my opinion, the quantitative-qualitative interview is worth disseminating (and further improving), and why I propose its use in the research of older people.

Referring briefly to the first question, I think, which I have tried to prove by presenting numerous arguments, that such an interview combines the advantages often attributed only to qualitative interviews with those that distinguish a quantitative interview. Thanks to such integration, it is a complex research tool open in its intention, but closed in the form of a questionnaire, useful for detailed understanding of the broadly understood life situation of the interviewed. This type of an interview allows you to create a picture of larger communities and make comparisons that interest you. In addition, in the presence of the previously described polarization of positions regarding quantity and quality in social research, constructing one type of a relatively universal interview, i.e., containing both qualitative conventional features and meeting the so-called quantitative requirements, may nonetheless be the easiest solution to implement. I think that this relative simplicity will appear in the case of some researchers appearing to be more willing to understand each other and, as a result, to seek further ideas useful in diagnosing the functioning of individual members of our societies. However, I realize that this task is not easy to achieve and entails the need to decide on some, and not only methodological, compromises. In turn, when it comes to the answer to the second question, related to the usefulness of a quantitative-qualitative interview to diagnose the situation of elderly people, then we note that in surveys on older people we rarely have the opportunity to occupy them for longer periods of time (or reappear to use further research methods). This happens for a variety of reasons, even as a result of the progressive effects of various diseases limiting or even preventing further contact with such interviewees, or because of a lack of finance for a continuation of a survey. In the discussed situations, the proposed type of interview may be at least a substitute for the application of a classic recommendation to use as many research techniques as possible in a specific diagnosis, because thanks to this we gain the opportunity of multidirectional, and thus more complete recognition of the phenomena that interest us.

Notes

1 This text develops and revises ideas included in the chapter entitled Quantitative and Qualitative Approach: An Attempt to Go beyond the Traditional Dichotomy, from the book *Social Aspects of the Ageing Population in Poland: A Perspective of the Sociology of Old Age* (Czekanowski, 2012).

2 The terms: method, technique and research tool are used interchangeably in this chapter.

3 K. Konecki (2000), however, emphasizes that when applying the paradigmatic criterion, such a contradiction between qualitative and quantitative techniques may occur.

4 This perception of a standardized interview is part of J.-C. Kaufmann’s thoughts, who writes that this kind of an interview “reaches only one layer: superficial opinions that are directly available”, and thus can only be used – as he calls it – for surface analysis (2010, p. 29).

5 I would also like to add that analyzing terminological issues, U. Flick notes that in relation to qualitative research, one can sometimes come across terms such as “inquiry” instead of the commonly used “research” or even a situation where we do not use any of these terms, using instead the name “ethnography” for this type of research approach (2012, p. 23).

6 Probably J.-C. Kaufmann meant something similar writing about the need to combat “abstract empiricism” in relation to the production of raw data and methodological formalism (2010, p. 21).

7 S. Kvale draws attention to the fact that attempts to build bridges between qualitative and quantitative methods have not been very successful, and the conclusion of the debate or qualitative–quantitative dispute seems premature. According to this author, the research in social sciences is still dominated by a dual quantitative and qualitative concept, with the presence of quantitative sphere hegemony, though (Kvale, 2004, pp. 75–78).

8 Other names that I propose for this form of interview is an integrated, multidimensional, holistic, combined or mixed interview, although it is difficult to predict if any of these names could be popularized. The last of these terms, i.e., a mixed interview, is not the slickest term in Polish, among others because of its meaning, although it can be associated most easily with the so-called mixed methods.

9 Such a dichotomous understanding of both types of interviews is presented, for example, by D. Silverman. The author indicates that in the case of qualitative research, the interview is based on open-ended questions and is carried out on small samples. According to Silverman, “the important issue is ‘authenticity’ rather than reliability [of research]”. On the other hand, in the case of quantitative research, the interview serves survey purposes; it contains mainly closed-ended questions and is carried out on randomly selected samples from the whole population. According to Silverman, “the central methodological issue for quantitative researchers is the reliability of the interview scenario and the representativeness of the sample” (2012, pp. 39–40).

10 In Polish, the interview has various names, such as standardized, categorized, structured or questionnaire interview.

11 This complementary, and at the same time checking, function of closed-ended and open-ended questions worked very well in recognizing in elderly people such personal and subtle feelings as loneliness. In examining this phenomenon, a dozen or so closed-ended questions from the shortened version of the UCLA Loneliness Scale with those taken from the NUY Loneliness Scale, as well as open-ended questions concerning the causes leading to loneliness, experiences related to its feeling and ways of dealing with loneliness were used (Czekanowski, 1993).

12 According to E. Babbie “surveys are probably the best method available for those researchers who want to collect original data to describe a population too large to be observed directly” (2007, p. 268).

13 I confirmed my belief in the importance, or even necessity, of implementing the appropriate postulate, i.e., methodological and gerontological preparation of interviewers, after detailed familiarization with 1000 very extensive, 200-question interviews, which made up the Polish part of the European research carried out under the international EUROFAMCARE project dedicated to family carers of older people in Europe. As it turned out, these were the interviewers who were practicing nurses or social workers (i.e., those equipped with professional knowledge about the functioning of older people) who with greater understanding and, as a result, more accurately wrote down the answers to questions about, for example, the level of fitness, than, for example, graduates or PhD students of sociology, familiar especially with the general principles of doing research. In the cases discussed, therefore, we were dealing with a certain influence of interviewers on the results of the survey.

14 These stereotypes may concern not only interviewers but even researchers themselves. The confirmation of this observation can be found in the experience of Z. Woźniak from research on the oldest citizens from Poznań, who wrote:

> The strength of internalized stereotypes on old age in the early stages of socialisation may be testified by students of the Social Work Studies who persistently maintain opinions, full of anxiety and reserve, on the behavior and functioning of older people during the preparatory work for the research, – even though they previously had classes in geriatrics and gerontology. Only direct contact seriously violated their stereotypical image of older age and the life of an older man.
>
> (1997, p. 9)

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11 Conducting research on ageing in the space of sensitive issues – as exemplified by domestic violence against the elderly

Małgorzata Halicka and Jerzy Halicki

The chapter is devoted to problems related to conducting research on sensitive topics in a qualitative research paradigm. Polish literature lacks a precise definition of the term “sensitive topic”, which is more often referred to as a “difficult topic”. A sensitive topic that is presented in these considerations is violence against the elderly, with particular emphasis on elderly women. Under certain political conditions (e.g., in a totalitarian system) any research subject may become a sensitive topic. The researcher – in addition to their main role – can also support the elderly in seeking professional help. There were situations when the respondent expected help from us – the researchers. Expecting such actions is referred to in Polish literature as “incorrect identification of the researcher”. Knowledge from sources other than the interview may also be useful for a proper understanding of the research situation. These types of situations can be described as backstage phenomena and backstage knowledge. Satisfaction with the meeting and its effect in the form of an obtained interview are dependent on prudent empathy understood as dialog marked by patience, alertness, understanding and sensitivity (but not devoid of criticism?). Based on many years of research experience, we are convinced that the interview is in many cases a therapeutic procedure. Interviews can also take on an educational dimension. This occurs when the researcher delves into the personal micro-worlds and experiences of the subjects. This is accompanied by strong emotions that would not otherwise be revealed.

Introduction

There are subjects which are difficult to discuss even among friends. For example, it is not easy to tell others about violence experienced from a spouse. It is all the more difficult when this is chosen as a research subject. After all, in the context of research, we interact with strangers, who we expect to share their life experience, opinions and reflections.

The aim of this chapter is to present our thoughts on research into sensitive subjects. Our discussion will focus primarily on violence against the elderly. This subject is described as sensitive in literature (Renzetti and Lee, 1993; Dickson-Swift, James and Liamputtong, 2008; Elmir et al., 2011).

The authors of this chapter have conducted research together, but the interviews were conducted by one person. Therefore, some of the thoughts on specific situations will be described in third person singular.

Defining sensitive subjects

In English language literature one can find two categories describing the same problem: sensitive research and sensitive subjects. According to Joan Sieber and Liz Stanley

(1988), socially sensitive research is research defined as "studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research" (p. 49). Such a broad definition of sensitive research means that almost all social research may be described as sensitive (Dickson-Swift, James and Liamputtong, 2008). Sensitive research is usually described as research which is "intimate, discreditable or incriminating" (Renzetti and Lee, 1993, p. ix). Raymond Lee defines sensitive research as "research which potentially poses a substantial threat to those who are or have been involved in it" (1993, p. 4). This definition includes potential effects on both the subjects and the researchers. It is stressed that this take on the subject encourages research into the potential damage done to both the researchers and the subjects (Dickson-Swift, James and Liamputtong, 2008). It seems, however, that research into sensitive subjects may not lead to negative results only, but to positive ones too (Elmir et al., 2011).

Social research on sensitive subjects was initiated by sociologists from the Chicago school of sociology. Their research often concentrated around the family, friendship and the local community and often involved gaining access to the private lives of research subjects. According to M. Bulmer the researchers were not entirely aware of the methods they used, which allowed them to circumvent many methodological and ethical issues (Dickson-Swift, James and Liamputtong, 2008).

Following the social changes of the 1960s and 1970s issues began appearing which went hitherto unnoticed, described as "perceived sensitivity". Researchers started to delve into issues of sexual behaviors, domestic violence or alcoholism, which were considered taboo in the 1970s and associated with sensitive research. This period also saw the beginning of feminist research, which involves, primarily, attempting to understand the experience of women in relation to power, dominance, unequal relations between genders (Dickson-Swift, James and Liamputtong, 2008).

What in English literature is described as sensitive subjects, in Polish is often referred to as "difficult subjects". Trying to find a precise definition of "difficult subjects" in Polish scholarly literature is futile. M. Wojciechowska (2013, p. 245), writing about difficult issues has in mind "primarily those social issues which for various reasons research usually find difficult to access directly" [*przede wszystkim te zjawiska społeczne które z rożnych względów są na ogół trudno dostępne bezpośredniemu poznaniu badaczy*]. They fit – in the author's opinion – into apparent reality, but also function in the hidden realm, which is hard to access for researchers. Difficult issues, although not the easiest to observe directly, are all the more interesting for scholars because of that (Ślęzak, 2009). Marta Makowska (2013) describes difficult issues as thorny and in her work invokes the definition created by Clary Renzetti and Raymonda Lee. The broadest understanding of difficult issues was presented by Sylwia Męcwel (2012), who frames it as difficult problems, difficult research terrain and difficult methods. In her article she also invokes a wide range of literature implicitly and explicitly discussing "difficult" problems. The term "difficult subjects" is also often associated with the category of "hidden issues", which often comes up in literature and is understood as "social actions which are hidden by their subjects out of fear of sanctions" [*takie działania społeczne, które są przez podejmujące je podmioty ukrywane w obawie przed sankcją*] (Gurtowski and Waszewski, 2009, p. 168). The discussion of difficult subjects taken up in Polish scholarly literature concentrates on two areas: methodological (e.g., Przyłuska-Fiszer and Wójcik, 2009; Ślęzak, 2018) and ethical (e.g., Mizielińska et al., 2018; Izdebski and Łukaszek, 2018).

The reason why there are no broader efforts into defining the term “difficult issues” in our culture is – as it would seem – the use of this particular term. The word “difficult” is fairly obvious in its perception. It needs no further explanation in Polish. However, the perceptions of the word “sensitive” is different. Its meaning is blurry enough that it needs further narrowing.

Sensitive subjects will be exemplified by our experience derived from conducting empirical research on violence against the elderly, including elderly women. For those reasons we owe the readers a few sentences about the research on violence against the elderly. However, in order to go deeper into the problem we are interested in – that of conducting research into sensitive subjects – we will also draw on the experience and observations from other research areas.

Gerontological research into sensitive subjects, as exemplified by domestic violence

Abuses against the elderly have for many years not been seen as a social problem. First clinical descriptions of maltreatment of the elderly started appearing by the end of the 1930s (Bonnie and Wallace, 2003). From the mid-1950s abuses against the elderly started to be treated as a serious social issue. This was associated with changes in familial relations, which resulted in the elderly being less able to rely on the aid and support of their children and grandchildren (Anetzberger, 2008). Abuses against the elderly became a matter of public debate by the end of the 1970s and the early 1980s. The discussion was inspired by the publications of geriatrician R. Butler and sociologist S. Steinmetz. The former wrote in 1975 about the “abused elder syndrome”, while the latter was the author of the testimony made in front of the House Science and Technology Committee (USA), which was based on the results of the research that had been conducted in 1978 on the thus far neglected aspects of domestic violence (Anetzberger, 2008). As it was brought to attention in the 1970s the problem of violence against the elderly in the USA immediately began to be studied and explained, while the search ensued for solutions (Penhale, 2010).

In Europe, one of the first mentions of the subject was a letter to the editors of the *British Medical Journal*, written by a physician at the Southmed Hospital in Bristol, G. R. Burston, and published in 1975 (Burston, 1975). The problem started being treated seriously in Great Britain in 1988, although it had already been noticed in the 1970s (Penhale, 2010). In the 1980s in the USA and some European states research was undertaken into violence against the elderly and prevention (Lowenstein, 1995).

Currently, after over 30 years since systematic research into violence against the elderly started, one can confidently state that this very important issue has been treated with the appropriate seriousness by scholars and received significant attention in literature.

In Poland, the problem of violence against the elderly was not analyzed in many works in the twentieth century. It came up rarely and tangentially to other problems, such as intergenerational conflicts. Particular attention should be paid to the work of J. Piotrowski (1973) and B. Synak (1976). The first systematic research into the elderly as perpetrators and victims of pathological behaviors was conducted in Białystok at the turn of the 1980s and 1990s (Halicka, 1997, 1996, 1995).

Interest in violence against the elderly in Poland increased in the first decade of the twenty-first century. Various research methods were used. Research was done based on quantitative (Pędich, 2002) and qualitative methods (Orzechowska, 2000; Twardowska-Rajewska and Rajewska-de Mezer, 2007; Maćkowicz, 2015), as well as analysis of medical and nursing documentation (Rudnicka-Drożak and Latalski, 2006). Some of the research was also conducted as part of international research projects (Tobiasz-Adamczyk, 2009; Halicka and Halicki, 2010: Halicka et al., 2015, 2017). These publications contain a full literature overview on the subject of violence against the elderly in Poland.

Difficulties in conducting research into sensitive subjects concerning the elderly

One of the sensitive issues which will be treated as the point of reference for this work is domestic violence against the elderly. From the point of view of the empirical research done in this area it is a challenge for both the researcher and the subjects. We understand sensitive research as R. Lee does: as research which can potentially be a serious threat to those who are or were involved in it (Lee, 1993). By discussing the difficulties researchers face when conducting research of this type we will invoke – as was mentioned – mostly the issue of violence. However, this will not be the only point of reference for this work. To encourage readers to take an interest in the issues discussed in this work and the experience we have derived from our research, we will attempt to also reference other important and sensitive subjects. Following the thoughts of the aforementioned R. Lee, we agree with the author that as research is done into sensitive subjects there is potentially a risk in three areas. The first is the risk of invasiveness understood as intruding on the private, intimate world of the subject. Another type of threat is the risk of sanction should the research results be stigmatizing or aggravating, for example in the case of interviews with drug addicts and leaking sensitive information. The third potential risk is a political one, for example related to some social conflict (Lee, 1993). By characterizing sensitive research as that which is a potential threat, the author has in mind a threat which has its source in the studied problems. However, this definition cannot be applied to the specific socio-political situation in the studied geographical area. This is well illustrated by the following example. In 2005 we conducted interviews in the Republic of Belarus. The Belarusian researcher who was cooperating with us was unable to obtain permission to conduct the interviews from the authorities. Since we had the consent of the subjects, we decided to conduct research without the authorities' permission. This situation changes every subject into a sensitive one, because revealing the fact that the research was conducted would be a threat to both the researchers and the subjects.

Taking this into account we claim that some research into sensitive subjects will be more risky than others, while others may involve potential benefits to both the subject and interviewer. However, one should note that every person has a different private sphere, a different level of sensitivity. Furthermore, the perception of sensitive subjects depends largely on the culture in which one was brought up and identifies with, on their personal situation, their age, gender and finally on the interviewer. Below we will present our own experiences and difficulties we have encountered in conducting research into sensitive subjects.

Our own approach to research into sensitive subjects

The qualitative research into sensitive subjects which we have conducted in Poland over the years concentrated on various research areas. Over the last decade-and-a-half they focused on the problem of violence against the elderly. In our experience, this type of research is a challenge to both the researcher and the subject. Various situations demand scholars to enter different roles and there are no clear rules of conduct – the researchers make decisions and adopt strategies on their own. However, they must pay heed to methodological and ethical concerns. Responsible conduct requires scholars to face ethical questions, which result from face-to-face contact (Babbie, 2007).

The research situation may give rise to doubts, dilemmas and sometimes even a sense of guilt both in the scholar and the subject, but this type and character of empirical research, considering its subjects are the elderly, can also have a supportive, therapeutic character, especially for victims of domestic violence. Many of them lack expertise on the kinds of help and formal professional support they can receive. Aside from their main role, researchers may clearly and intelligibly explain to the elderly where and how they can gain access to professional, formal aid.

Conversations with research participants on sensitive subjects require skill, research and life experience, as well as the appropriate interview techniques, because studying problems such as violence may cause pain and discomfort to the victim. As a researcher one has the chance to not just observe, but also to participate in the biographical experience of the subjects. Elderly who experience violence, in particular women, can be considered a special category of research subjects. Their knowledge based on life experience is priceless. However, when it comes to sensitive subjects, there are usually strong emotions involved: shame, humiliation, sacrifice, fear for the future. Would a different form of conversation, maybe more informal, maybe more discreet, be better at managing the emotions of the subjects? According to Babbie, conducting interviews requires the skill of attentive listening and the ability to discreetly direct the conversation (Babbie, 2007).

Scholars of sensitive subjects should bear in mind the unintended consequences of their research. Research subjects may see researchers as a source of material gain, connections and prestige, which has nothing to do with the research process or objectives (Frankfort-Nachmias and Nachmias 2001). It happens occasionally that a person who falls victim to violence expects help from the scholars. In one of the interviews, which were part of our research, the interviewee expected help in finding temporary accommodation, so that she could move away from her abusive husband. Even after the study had ended she remained in contact with the interviewer, whom she asked repeatedly for help. In Polish scholarship such situations are referred to as false identification of the researcher (Borucka, 1992). We believe that false identification of the researcher is a peculiar way of finding help, maybe more confidential, discreet, maybe causes less shame to be brought on by the domestic violence and lack of expertise on how to deal with the situation. Such an attitude is characteristic of strong people, who are willing to fight for themselves, who take advantage of any chance to change their situation. However, our research indicates that women with this attitude are decidedly a minority.

Social workers who worked with us claimed that a sensitive interview delves into the personal traumas of the victim. Based on our extensive research experience we can state with some conviction that an interview can bring out old traumas for some people, but in other cases it may be quite therapeutic. For many people we talked to about the violence in their families the conversation caused gratitude for the meeting, where they could finally unburden themselves. We would like to note here the role that is played by the scholar in researching sensitive subjects. In the case of violence against women the researcher should be a woman, preferable married, middle-aged, with children, who has life experience. Her own life experience allows her to have a broader view of sensitive subjects. This was also noticed by other Polish scholars (Czekanowski, 2018).

Another thing we have noticed in our research is the problem of interpreting the collected data correctly. It would happen that a male police officer sided with the male perpetrator of violence. We present below an example of such a situation. A female victim of domestic violence noted the lack of reaction from the police officer when she accused her husband. The husband, a trained psychologist, manipulated others by spreading false information about his relations to his wife. To her surprise the police officer did not believe in her story, but was more likely to believe her husband and refused to open the so-called *Blue Card* procedure.[1] This procedure was only put into motion after a visit from a female officer who was standing in for the usual policeman. She believed in the victim's version of events. It turned out that the local officer was recently abandoned by his wife and was distrusting of a woman's statement. Therefore, in order to understand the situation correctly and undertake appropriate corrective actions one needs to obtain knowledge from sources other than an interview. This type of situation can be described as phenomena and knowledge from behind the scenes – a phrase which appears in Polish literature (Gurtowski and Waszewski, 2009). Obviously, from the point of view of a scholar the objective is to understand the micro-universe of the woman revealed through her narration. However, it is also important to be aware that the research should serve a greater purpose than just knowledge and understanding.

Conduct in empirical research into sensitive subjects

Since sensitive subjects can be associated with a significant risk to the participants of the research and cause intense emotions, such as sadness o embarrassment, one should tread carefully within the space of empirical research. A researcher's ability to build a relation with the participant and gain their trust is the basis for the research. We suggest that in sensitive cases one should be cautiously empathetic. Being overly rigorous is ill-advised.

Satisfaction with a meeting and its effect in the form of a successful interview is dependent on cautious empathy. As an example we can invoke one of the interviews we conducted with an elderly man who was dissatisfied with his life, as part of a research project on life satisfaction among the elderly. The co-author of the article tried to meet with the interviewee twice, with no success. Despite having arranged the date and time of the interview over the phone, the subject was not at home. She was only successful on her third attempt. The researcher, who was then visibly pregnant, was late for the meeting, even though she did not intend to. However, with the benefit of hindsight, she believes this was a positive thing. The man opened his door and, seeing a middle-aged pregnant woman, invited her in. Establishing a relationship was difficult at the beginning, the man was quiet, spoke in half-sentences, unwillingly. At first glance he seemed stone-faced, cold, reserved around others, unwilling to make contact, distrustful. However, as the conversation progressed his armor melted and a breakthrough happened after some 15–20 minutes. He was visibly moved, cried, and the researcher entered a new realm of difficult events and the man's traumatic experiences associated with them. Opening up, he entrusted many personal secrets to the researcher, which he had so far, as he claimed, not told to anyone. Heavily burdened by a difficult life, rarely smiling, very sensitive. At the end of the 4.5 hours of recorded conversation he expressed his happiness and gratitude for it. For the co-author of the presented work it was also an exceptional enriching, if difficult, experience. Although it seems that in this case one can talk about cautious empathy, it was nevertheless difficult for the researcher to distance herself from the subjective experience of the interviewee. If researchers become too involved in the life of the subjects, they may be moved by their personal problems and crises. This issue has to be acknowledged and faced (Babbie, 2007). In such cases researchers might themselves be traumatized, as was discussed by Dunkley and Whelan (2006).

The aforementioned personal experience of a research case indicates that haste is not advisable, if there is a possibility that the time of the interview may significantly increase. One should bear in mind that if the interviewee "opens up", is keen to talk and to make personal confessions, they become submerged in their autobiography and lose a sense of time, which is beyond their control in such situations. If the researcher does not hasten the speaker and reacts appropriately to the situation in a balanced and sensitive manner, they may obtain rich, valuable research material. For the interviewees talking about themselves and the chance to be heard is helpful and provides a sense of relief. From this extremely valuable interview we can draw more conclusions, that is, that it is good to be able by the end of one's life to express one's pain and burdens, and what has hitherto been kept secret. This is yet another reason why the study of sensitive subjects is necessary. When, after many years, we remember those that we once talked to, their memory is still alive and the emotions still vibrant. As a research task this was a difficult experience for us, but at the same time it enriched us not only as scholars but, more importantly, as people.

Another important step toward handling empirical research into sensitive subjects is patience and caution. If a participant is impatient with the interview or its subject, one should react delicately, carefully and with care, because one never knows what is the cause of such a reaction. Time to reflect is necessary. It becomes an ally to the relation between the scholar and the subject. Let us use as an example an interview, which we conducted with a woman with low life satisfaction. This was a very difficult but short interview, lasting only 45 minutes. She had communicative and interpersonal problems and was secretive, withdrawn, one could say she was not fully present at the interview. She was, as would later turn out, permanently traumatized, which was the result of wartime experiences, in particular the medical experiments Fascists conducted on her, which left her infertile. These experiments left permanent scars in her psyche. Psychologists claim that after suffering through a traumatizing experience, a person may experience dissociative symptoms, relive the event, avoid stimuli that remind them of the event, experience fear and have a limited capacity in social and professional life (Widera-Wysoczańska, 2011). Not all stories, even those told in detail and in depth, can be cathartic and bring relief. Everyone perceives and experiences events subjectively. The meaning that one associates with such situations depends on an individual's unique life history. Understanding somebody's life is being aware that it is separate from fate. It also involves reaching into the complicated network of connected factors, which lead to the uniqueness of everyone's life experience (Bauman, 2010). In these and similar cases one should strive to create the conditions allowing one to identify ways of avoiding permanently traumatizing the subject. However, if we are to find out about such situations regarding people at the end of their lives, one has to ask if this is indeed at all possible.

We would also like to pass on some of our reflections on the reliability of the obtained research material. There may be situations when conducting face-to-face research into sensitive areas turns out to be difficult for the subjects, who may be embarrassed by the interview. Our research experience also indicates that if appropriate research conditions are created, based on trust between the subject and the scholar, there is no risk of this happening. Furthermore, when starting research one should assume that if a person agreed to an interview, the information obtained from them will be true. We want to stress that elderly research participants are a specific category of subjects. Work with them is very rewarding:

they are humble, honest and seek relief in conversation. If there is a relation of trust during an interview, it can be a therapeutic, cleansing experience, which gives the interviewee a chance to express hidden negative emotions which have accumulated over years of often difficult, sensitive, embarrassing or traumatic personal experiences.

Another issue connected with conducting research into sensitive subjects is the question whether it is ethical to discuss certain subjects and expose an elderly to pain, bad memories and negative experiences. Based on our own experience as researchers studying social subjects involving the elderly, we claim that in some situations, such as permanent trauma, there may be a risk of further injury. However, in most cases, a return to the past and difficult memories is not an invasive threat, even though it delves into the personal and mysterious and releases emotions. The personality of the researchers is very important. If they respect the dignity of the subject and display expertise, if they do not force the conversation, there is little threat of injury. The elderly often need to talk. Negative emotions, which they (particularly women) have often been suppressing for years, influence their psychological health, which is often reflected in their everyday behaviors.

Another important reflection associated with studying difficult subjects relating to the elderly is that they are at the end of their lives and have a host of experiences. Considering their lives and its balance they may come to the conclusion that if they do nothing for themselves, or for a cause, they might never have the chance to do it. A female victim of violence may take steps toward freeing herself from her husband-tormentor. Agreeing to participate in research into sensitive subjects increases our understanding and may result in new social practices. The elderly who agree to an interview do this consciously, responsibly and honestly.

Another thread of research into sensitive subjects and its practices may relate to death and dying. It is hard to create a research relationship with a person experiencing a limited situation. We invoke with nostalgia and emotion the memories of one interviewee, who was, at the same time, aware of his slow passing and with a great will to live and hope for another meeting, which would allow him to save from oblivion that which was in his life valuable and precious – his memories. He was at peace with his mortality but also glad to be able to share his experiences before death. He felt the need to go back to his past, which he remembered in great detail. In terms of verbal communication this was a beautiful, lively, thrilling, enriching tale of a dying man. He also talked about his sickness and discussed issues of finality. He wanted to share at least a part of his life. We were waiting for another meeting, but death took him earlier. We never completed the interview, because he did not live to have another meeting. This was an exceptional interviewee, who was for the researcher not just a source of knowledge, but also education. In subject literature it is stressed that diving into the individual micro-worlds and experiences of the subjects may lead to deep emotional reactions, which might otherwise never come to light (Cowles, 1988).

Additional reflections derived from our research, which may also turn out to be useful to other scholars delving into qualitative research are related to the research team. If more than just the narration of a victim of violence is to be interpreted, but the whole situation of violence, it is good for the analysis to be conducted by a mixed gender team. In our case this helped us distinguish situations of violence from those of conflict.

We would also like to note that problems may arise associated with recording the information obtained in an interview. This may lead to resistance from the elderly. Our use of a voice recorder in our research caused certain reservations. We noticed this both in our research in Belarus and in Poland. Some women were willing to talk about the violence they were experiencing, but would not agree to recording the conversations, only allowing interviewers to take notes. This information was used as factual. This material was treated similarly to how the police treat evidence in an investigation.

We also have some thoughts on research methodology. In literature it is often written that sensitive subjects should be studied using qualitative methods. Does a problem stop being sensitive if quantitative methods are used? In our experience, for example, when young people talk about their alcohol consumption, some answers are clearly dishonest. It is different when they talk about alcohol consumption in their age group. Therefore, the way research questions are posed can also make an issue sensitive.

Conclusion

In order to learn about and understand social realities and various problems therein, it is necessary to undertake the study of sensitive subjects. We are aware that this is not an easy task, but it is necessary. We as scholars bear the responsibility for recognizing and understanding social realities. Sensitive research often relates to important, burning social issues.

Many years ago at one of our sociological conventions in Poland a renowned professor, Piotr Sztompka, entreated the participants to have the courage to take up difficult research subjects. It is with some satisfaction that we note today that this research is being done. And even though they are still small in scale, we believe that Polish scholars' scientific curiosity and courage to take up sensitive subjects will lead to both academic and utilitarian results. According to Antoni Sułek, social science is increasingly becoming an applied science – not just in planning and politics, but also in many areas of social practice. The author encourages sociologists and social scholars to have open minds and follow their "scientific conscience" (Sułek, 2002).

Note

1 In Poland the *Blue Card* procedure is opened by the police or social services in cases of domestic violence.

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12 Age(ing) and things – methodological perspectives

Carolin Kollewe

This chapter sketches the theoretical foundations for researching material things which arise from the social and cultural sciences. It offers a brief introduction to material culture studies and science and technology studies and presents approaches toward and findings on material things in gerontology. The chapter sets out how to investigate material objects and look into their meaning for age(ing) and their part in the constitution of age and ageing. To this end, it draws on the analysis of an object within the ethnographic study "TechnoCare". It reveals how material things co-produce age and ageing in a society which is making increasing use of assistive technology. Finally, the potential of such a focus in studying age and ageing is discussed.

The chapter demonstrates that studying material things can be used to pinpoint the role which objects play in constituting old age. This is possible if things are not merely examined as resources for older adults, or characterized only in terms of their function, but are also seen as participants in socio-material practices. This is precisely how associated societal issues and social implications can be addressed.

Introduction

Things are found everywhere, including in the lives of older adults. However, it is only in recent years that researchers of age and ageing have begun to study things in old age from a social and cultural science perspective (e.g., Twigg, 2013; Endter and Kienitz, 2017; Kollewe, 2017; Höppner and Urban, 2018; Alftberg, 2017). In the social and cultural sciences, by contrast, interest in things has greatly increased in recent decades in the course of the "material turn". A small number of studies on old age and ageing include these perspectives, often inspired by material culture studies and/or science and technology studies (STS). Studies of this kind analyze the role which things play in age(ing), how older adults interact with things and the role things play in "doing age".

This adds to the conventional perspectives adopted in gerontology. Until now gerontological research has mainly focused on social relationships and interactions between human beings. Although material objects have sometimes been taken into consideration, they have largely been seen as part of an environment which needed to be designed to give old people the highest possible quality of life. In contrast, recent gerontological research echoing the "material turn" has mostly been concerned with how age(ing) is produced in socio-material practices.

At the same time, this relatively small but growing interest in things in gerontological research raises the question of which methods can be used to collect data on objects and their meanings and how people and things interact. In gerontology and ageing studies, however, this debate on methods and methodology is still in its infancy. As yet, there are no works providing an overview of corresponding methods, or practical instructions for putting any such perspective into operation in actual research designs.

From a perspective informed by material cultures studies and STS, this chapter thus describes how objects and their role in the production of age(ing) can be studied, including the methods which can be applied. First, a short overview is provided of material culture studies and STS. Then some studies of material objects and their role in later life from a cultural and social science perspective are depicted. This is followed by a presentation of a methodological approach of how to investigate things as parts of socio-material practices, their materiality and meanings. Experiences and findings from an ethnographic case study named "TechnoCare" add a concrete dimension to this depiction. The example taken is a socio-technically networked, sensor-based system for monitoring older adults living in private households, mostly alone. Finally, there is a discussion both on the opportunities which the study of material things opens up for gerontological research, and on the challenges and limits it presents.

Material culture studies and science and technology studies

The interdisciplinary domain of material culture studies is a heterogeneous field of research linked by a focus on things as an important component of social life and of cultures (Tilley, 2006, p. 1). The researchers, mainly from cultural studies, are interested in dialectical relationships between people and things: what do people do with things and what do things do to people (Tilley, 2006, p. 4)? In the 1970s, influenced by structuralist and semiotic approaches, scholars of material culture studies began to intensively examine what things meant to people. Objects were often regarded as signs or symbols and treated as similar to language (Hahn, Eggert and Samida, 2014, p. 8). However, for some time now, objects are no longer viewed primarily as bearers of meaning; instead, their haptics and materiality are coming back into focus (cf. Hicks, 2010, p. 75f.). The question is now also asked of what things "do" (Hicks, 2010). Among other things, this involves linking approaches from hermeneutic phenomenology with elements from Latour's Actor-Network Theory (ANT), which emerged in the context of STS (Hicks, 2010). Currently, there are calls from the field of material culture studies for objects' various complex facets to be identified by viewing things from different perspectives, focusing on their ambiguities and contradictions (Hahn, 2018, p. 17).

Meanwhile, STS (e.g., see Felt et al., 2017) deals with the (natural) sciences and technology and how they come about in a societal context. Taking a social constructionist perspective, this starts out by establishing that technology is not neutral and objective, but instead an element of socio-cultural contexts and practices (Bijker and Law, 1997, pp. 3ff.). At the same time, technology requires or enables certain behaviors because preconceptions of users, of cultural norms and of values are inscribed into technology. Technology therefore affects people's behavior and, thus, in the long run, social structures and knowledge (Akrich, 1997, p. 207). Proponents of ANT called for the social constructionist perspective to be left behind (e.g., see Latour, 1995; Callon and Law, 1989). Adopting a relational perspective, for example, Latour advocates an approach which examines humans and non-humans (animals, artifacts etc.) in the same way. He sees objects as participants in actions, for example, by enabling, preventing, prescribing, authorizing or suggesting them (Latour, 2005, pp. 71ff., 83). Seen in this way, things have agency or are a constitutive element of a relationally understood agency.

Studying material things in old age from a social and cultural science perspective

Within the study of age(ing), some investigations have taken inspiration from material culture studies and STS. They explore the question of what role materiality – understood as things and sometimes also as bodies – plays in age(ing) and in the production of old age. These studies not only focus on the function which things serve and what they mean to older adults, but often also examine how people and things interact, and how things are embedded in societal discourses and ideals, e.g., that of anti-ageing.

This developing field within the study of age(ing) is sometimes known as "material gerontology" (Höppner and Urban, 2018). It is characterized by a variety of influences. For example, researchers take their lead from social constructionist paradigms, approaches based on the theory of practices, post-modernist theories and the perspectives of new materialism. This means that material gerontology takes on a different focus from, for example, the interdisciplinary field of environmental gerontology (e.g., see Lawton, 1977; Wahl and Oswald, 2010). Influenced by environmental psychology, for some decades now the latter field has delved into issues related to how people are connected to their environment in old age. The focus of such research has often been on (living) space. In recent years, new technologies have also aroused the interest of environmental gerontologists.

Studies falling under material gerontology deal, for example, with what objects mean to older adults and their construction of identity, e.g., using clothing (Twigg, 2013). Some authors explore the role which objects play in the context of care (e.g., van Hout, Pols and Willems, 2015; Artner et al., 2017). One example is an investigation into how things are sorted out when someone moves into a care institution (Depner, 2015). Research has also revealed how objects co-produce care in care institutions (Artner and Atzl, 2016; Depner, 2017; Artner, 2018). The importance of objects when caring for and supporting people with dementia has also been shown (e.g., Buse and Twigg, 2014; Depner and Kollewe, 2017). In addition, there are some studies on new technologies used in old age (e.g., remote monitoring technologies); influenced by STS, these focus on the relationship between technology and society. Studies of this kind have yielded insights into the social and societal implications of such technologies for the elderly and for shaping old age in society (e.g., Kollewe, 2017; Urban, 2017; Aceros, Pols and Domènech, 2015; Mortenson, Sixsmith and Woolrych, 2015; Mort, Roberts and Callen, 2013; Pols, 2012). They frequently examine power and aspects of domination. With their critical perspective grounded in basic research, studies of this nature have a different emphasis compared with mainstream applied and evaluation research, which primarily present technologies of this type as a solution to the challenges of demographic change.

Analyzing objects: methods

As set out above, the study of material things takes place in an interdisciplinary field and has emerged from widely differing starting points. Accordingly, the different disciplines that deal with material things (e.g., archaeology, social anthropology, art history, museum studies, sociology, psychology) have developed different methods for analyzing objects (cf. Hahn, Eggert and Samida, 2014). After all, different questions are in the foreground when analyzing a painting than, for example, when investigating how people and technology interact. Depending on their theoretical and methodological inclinations, researchers thus use different methods to collect and analyze data. In qualitative studies, for example, participant observation and interviews are frequently conducted. This data is then, for instance, used to create a "thick description" after Geertz, or analyzed based on ethnomethodological conversation analysis or grounded theory (cf. Depner, 2017, p. 208). While approaches of this type can be valuable to gather data on how people use things, and how people and things interact, most are not geared to investigating things in terms of their materiality (Depner, 2017). That requires approaches emerging, for example, from the way in which museum studies deal with objects. The description of an object, for instance, starts out from a thorough analysis of the item in question. Building on this, the context of the object is then considered.

The research questions differ depending on the research interest and the researchers' theoretical perspective. To paint a clearer picture of the different steps taken during object research, the methodological description is now followed by an illustrative case example. Following the example set by STS, the qualitative "TechnoCare"[1] study (Kollewe, 2017; Depner and Kollewe, 2017) explored the question of how care is produced involving assistive technologies. The study scrutinized the practices into which the objects in question – remote monitoring technologies – are integrated, and investigated the meanings ascribed to these objects by older adults, their relatives and social workers. It also took into account the societal context and the discourses into which the objects are integrated.

Investigating objects

As things cannot usually speak for or about themselves, the analysis of objects involves on one hand deriving information about the thing from its materiality and form, and on the other collecting information about the context in which it is or was used (Ludwig, 2011, p. 5f.). Objects are, after all, polysemic (Barthes, 1988 [1966]) and cannot simply be "read" to extract a single, clear meaning. This means that it has to be studied, for example, on how a thing is used and how it is integrated into an ensemble of objects. This is the only means of reconstructing whether and how a thing plays a role in practices and whether people attach a certain meaning to it.

How are things chosen for investigation?

Especially in the countries of the Global North, older adults are surrounded by a variety of objects – e.g., mobile phones or handbags – some of which they actively use. Which objects out of this large number of things are selected for closer examination in the context of research depends primarily on the researcher's question. For example, if the research interest is on care, then different objects play a role compared to an investigation into leisure activities. In addition to this, the specific researcher and her or his sensitivity to the relevance of certain objects affects the choice of thing (cf. Froschauer, 2009, p. 330). One approach which lends itself to deciding which objects should be examined more closely in their context is participant observation. When observing certain situations, researchers notice which objects are used, and which are not. Another approach is ethnographic discussion or qualitative interviews, which can be used to ascertain which objects people consider relevant for certain actions or processes; or which objects are ascribed meaning. Participant observation combined with ethnographic discussion is a particularly effective means of drawing researchers' attention to what are sometimes unexpected objects. However, alongside this inductive approach, it is also possible to proceed deductively. This means that a certain group of objects is already selected when developing the research question.

The description of an object

Following the selection, the original object in question is precisely examined and described. This includes the object's function, form, color, size, material, feel, date of production and any signs of wear and tear or texts written on it. Also, as things are rarely alone – they are usually part of an ensemble of things – the question must be asked how objects are or are not related to other things. This description is written down. The question is then asked of what conclusions can be drawn from this first descriptive step. Might the description offer an indication of usage practices, what the thing could mean, or any connections with other things and possibly discourses?

The object in its context

The next step is to reconstruct the context of an object. To this end, a record must be made of how the object is used in everyday life, e.g., using ethnographic methods such as participant observation, (ethnographic) interviews, photographs and videos. In other words, methods are used which have been tried and tested during research into objects (technological and otherwise) and work processes (e.g., cf. Knoblauch, 2009; Tilley, 2001). Moreover, written documents and images are analyzed which refer to the object in question (e.g., advertising material, public and political discourses). This can reveal how objects are connected to other things, or to various societal fields and topics such as economics or politics. It is recommended that a heterogeneous team interprets interviews and other documents to avoid any hasty assumptions being made about the objects' meanings and interpretations (cf. Froschauer, 2009, p. 332).

If there is a research interest in the different stages of an object, for example, from its production to its destruction, in the different ways it is used, the different meanings ascribed to it or the different ways in which it is evaluated, one method which can be used is to create an object biography (Kopytoff, 1986). This type of investigation of the different stages and contexts an object goes through has proven particularly useful with things used in various historical or societal contexts, such as historical or ethnographic objects integrated into museum collections.

One inspiring approach which can be used to analyze the relationships between people and objects, how things are integrated into practices and how they are interwoven with discourses is Adele Clarke's situational analysis (2012). This method adds postmodern perspectives to Glaser and Strauss's grounded theory (1967). For example, when analyzing situations, Clarke includes discourses, power relations and non-human actors, borrowing from Foucault and ANT. She combines the classical methods of grounded theory (such as coding empirical data and memoing) with the creation of various maps. The first maps are intended to depict important human and non-human elements of the research situation, for example. They also document discursive, historical, symbolic, cultural and political aspects. The goal is to analyze the relationships between the elements (Clarke, 2012, p. 38). The two subsequent maps are intended to determine social arenas and discursive positions (Clarke, 2012, *passim*). The idea is thus, for instance, to use a situational map to visualize not only the things but also the discourses connected to them, along with political and economic elements and socio-cultural aspects.

Case study: "TechnoCare"

The "TechnoCare" study at Heidelberg University (Germany), which was realized from 2014 to 2017, focused on the question of how care is organized using assistive technologies. Observations were made of how care is produced in an arrangement involving older adults, their relatives, the social services and technology. The study's specific example was two different activity monitoring devices, both of which are currently being introduced into older adults' households in Europe. These systems combine personal alarm pendants, already a very familiar concept, with various sensors which register movement. These sensors are designed to recognize whether there are "significant deviations" from what is considered a person's "normal" daily schedule. The device which I am focusing on here is designed to flag up a possible emergency (for a more detailed presentation of the study, see Kollewe, 2017). The following paragraphs outline a brief description of the object, which builds the foundations for a subsequent analysis of the object as part of practices and in relation to societal discourses.

Brief description of the monitoring device

The sensor-based monitoring system analyzed here consists in several things that are connected in a network:

1. a motion sensor,
2. a door sensor,
3. a base station connected to the Internet,
4. a computer,
5. a smartphone,
6. an app for the smartphone or the computer.

All of these are objects that were made at the beginning of the twenty-first century and are connected to each other via the Internet or radio waves. This description is only a very brief outline of the most important components.

The *motion sensor* consists of a white, square plastic box. On it there is a plastic hemisphere which looks like frosted glass, i.e., not transparent, but translucent. The motion sensor is placed in a central location in the person's flat where there is "normally" a lot of everyday movement, e.g., in the hall or living room. This sensor registers the movements of the person or people in the flat.

The *door sensor* consists of two small white, rectangular plastic boxes. These two parts are attached to the door frame and the door so that one is positioned directly over the other when the door is closed. This sensor records the door's movements, i.e., whether and when it opens or closes. One notable point is that the sensors are designed and installed so that they are as unobtrusive as possible to the observer: they are relatively small and white, so that they do not stand out against a light background.

The data collected by the *motion* and *door sensors* are sent to a *base station*. This little black box, reminiscent of an answering machine, is usually placed next to the telephone. From there, the data is sent via the Internet to a cloud, where it is processed and then visualized in the form of information. The information is then sent as a message to one or more previously nominated responders, for example a monitoring center and/or a relative.

The message arrives on the *computer* or *smartphone* if the corresponding program or *app* is installed there. The message consists of text and a symbol informing the recipient that there has been "activity" or "inactivity" in the flat where the sensors are located. The device indicates "activity" with a green smiley face. In contrast, a noticeably long period of "inactivity" is indicated with a yellow dot that has a large exclamation mark in the middle.

Figure 12.1 Door with motion sensor (left) and door sensor (right).

Source: Thomas Bruns, Berlin.

What information does this object description provide, for example, about the meanings ascribed to the monitoring device? Visualizations of the data collected by the monitoring device in the app indicate how "activity" or "inactivity" are understood and evaluated. The term 'activity' is used by the producers of the device synonymously with motion and is therefore understood as physical activity. "Inactivity" means that there "was no movement in the apartment" according to the information on the home page of the producer. Moreover, the system takes the category "inactivity" to be the opposite of "activity". The green smiley, which indicates "activity", is a sign of the positive evaluation associated with "activity". In contrast, the yellow dot that has an exclamation mark in the middle and indicates "inactivity" is used in our society usually when something needs attention.

The monitoring device in its context

Now that the function and materiality of the object has been described, the question arises of how it is used in everyday life. Technologies are, after all, part of practices, i.e., people use them in certain situations in everyday life (cf. Suchman et al., 1999). Seen from this perspective, to understand how a technology works, the question also needs to be asked of

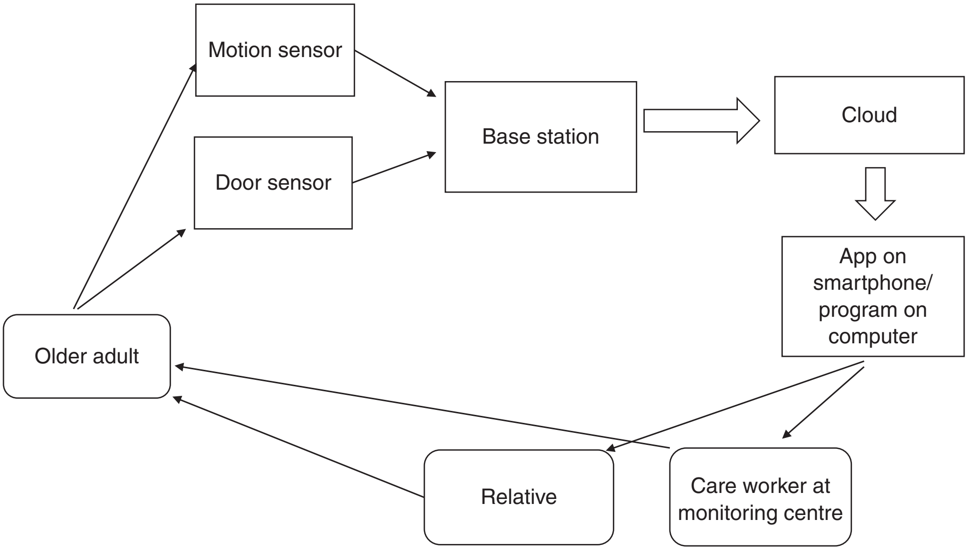

Figure 12.2 Schematic procedure of the sensor-based monitoring device.

what people do with it and, vice versa, what it might do to people. This involves studying or reconstructing the practices of which these technologies are an integral part (cf. Suchman et al., 1999; Marres, 2017, p. 46).

During my fieldwork, the sensor-based monitoring system described here was located in a total of five flats in an elective assisted living facility for the elderly in Germany. For this monitoring device to work, a "normal profile" and tolerances must be set up using a computer program. In other words, the operator defines when a person "normally" gets up and "normally" goes to bed. So that the system can recognize "significant deviations" from a person's normal profile, for example, if a person does not get out of bed in the morning, a tolerance is also set, e.g., of one hour. If no movement is detected in the flat within this defined time window, a message is sent to the nominated responders, e.g., a relative and a monitoring center. These responders are then expected to take appropriate action, starting out by contacting the person. If there appears to be an emergency, corresponding measures are to be taken.

As part of the "TechnoCare" study, several ethnographic interviews were conducted with the residents of the housing complex who were able to use the object analyzed here, along with interviews with their relatives and with people working for the social services involved. These social services workers were also accompanied and their activities watched by a participant observer. The interview transcripts and the reports on the participant observation were used to reconstruct whether and how the objects were used and what practices they were embedded in, if at all.

Echoing Clarke's suggestions, after some participant observation sessions and interviews, a situational map was created showing the different participants involved in the settings studied. Figure 12.4 is an initial visualization of the sensor-based monitoring device and shows that as well as the objects described here (sensors, smartphone, etc.), a large number of other objects, people and "invisible" participants are required for the sensor-based monitoring system to "run".

Figure 12.3 Smartphone with app. Thomas Bruns, Berlin.

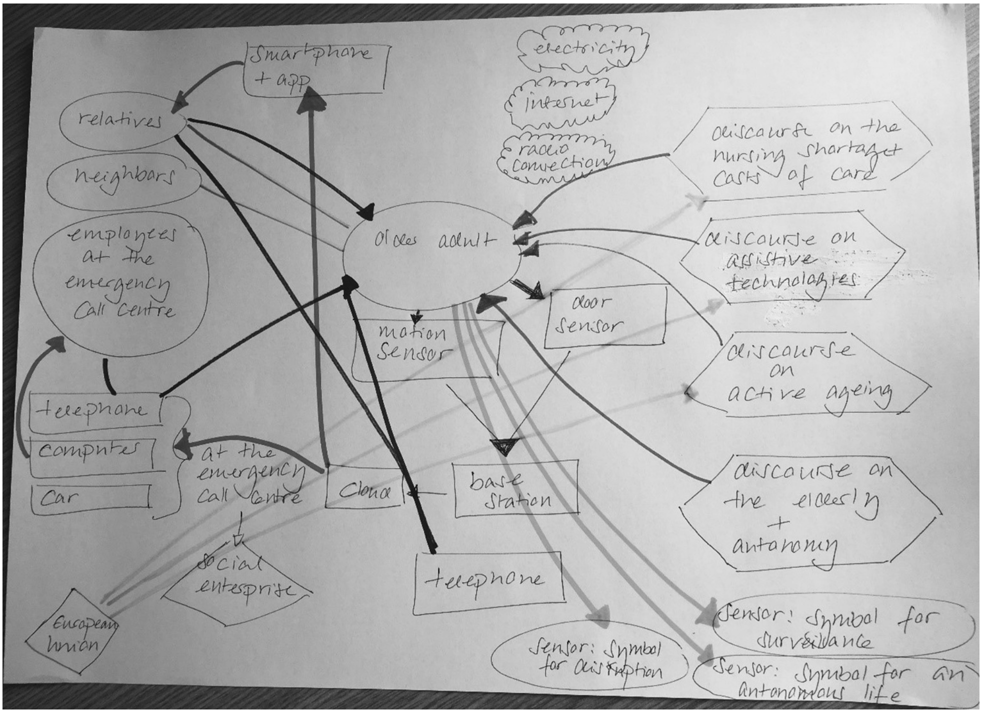

Figure 12.4 Relational analysis developed from the initial situational map.

The social service workers' car is required, for example, so that they can drive to a person's flat if they suspect an emergency. As another example, the technical system also depends on algorithms, radio transmitters and electricity. At the same time, the situational map shows which discourses and political and economic institutions are connected to the monitoring device which was studied. During the time in which the research was carried out, these discourses were on the care situation in Germany, active ageing and independence in old age. The situational map can be expanded or revised depending on what further findings emerge during the research.

The interviews and the participant observation revealed that people dealt with the technology in a wide range of ways: some residents did not want to use it as they did not (yet) see any need for it, or because they were afraid of being kept under surveillance. One resident was satisfied and felt safer with the system. Another resident, however, (Mrs Wolle) felt that her daily life was disrupted by the technology. It is specifically disruptions that clearly show how technology works and how it is integrated into daily life (Hörning, 2001, p. 96).

The case of Mrs Wolle

The empirical material on the case of Mrs Wolle reveals links between the activity monitoring device which she used, the resulting categorization of her movements by this technology as "activity" or "inactivity" and discourses about activity within gerontology and active society. Mrs Wolle moved into the assisted living facility with assistive technology devices when she was 86 in order to be nearer her daughter. It was important to her that the facility offered a wide variety of services for elderly individuals, which she took full advantage of. From chair aerobics to game afternoons, Mrs Wolle participated in many of the offerings.

In the interviews I had with her over a period of more than a year, she articulated that in her daily life the monitoring device installed in her apartment was disruptive. In one interview, she described the disruption she experienced and the strategies she had to deal with it as follows:

> And one time, I was doing fine but I got in bed at 11 a.m. I wasn't sleeping; I was just reading and lying down because I was afraid I would fall over. And at 4 or 4:30 in the afternoon, they called me: "Mrs Wolle, what's wrong? Can we help you?" Then I said, "No, why do you ask?" "Well, you haven't got up or moved around for four or five hours." And then I replied, "I'm doing fine", I said, 'that's not true, I have moved. It's nothing." Now we have extended the time frame [the tolerances of the device]. So that now usually when I go to bed at noon I sleep for two or two and a half hours until 2:30 or 3 p.m., … then after I've got up, at one hundred percent. Then I get up and go to the bathroom or somewhere else and then go back to bed. They take note of that somehow.
>
> (Interview April 2016)

Mrs Wolle reported in this interview that it had been a hot summer and her blood pressure was fluctuating a lot and as a result she had lain down frequently. She had fallen multiple times in the past, and she thought this would help prevent another fall. This practice of self-care – resting in bed and reading – was categorized by the device as an "inactivity" that had lasted too long. The monitoring center then contacted her to check if there might be an emergency. In our conversations, Mrs Wolle explained that she felt it was disruptive to continually get calls from the monitoring center during her afternoon naps or other times of rest. And in this particular summer, she reported that the calls sometimes came every other day. Apparently, her daily routine did not fit into the regular pattern that older adults were assumed to have and that the features of the device were based upon. To prevent such disruptions in her daily life, the settings in her profile were adjusted. In addition, after using the system for a year, Mrs Wolle developed a strategy to prevent unnecessary calls: if she planned to stay in bed for a longer period of time, she would simply make sure to get up briefly at some point. The motion sensors then registered her movement, and this was categorized as "activity". She was then able to take advantage of the new maximum allowed amount of time for "inactivity" and was able to again rest in bed.

As her daughter emphasized, Mrs Wolle had found a way to "manage" the device so that the way the device "ran" was not disrupted and it also did not cause any "disruptions" in Mrs Wolle's daily life. Her strategy consisted of intentionally moving in such a way that it would be recognized as movement by the sensors and categorized as "activity" by the device. This meant that she had to become "active" as defined by the technology and its inscribed categories of movement. It was only by becoming "active" in a certain way that she could enjoy peace and quiet. Mrs Wolle actually became "active" as a result of the technology – not only through maintaining several social contacts and taking part in a number of programs offered at her facility, but also through physical activity that was recognized by the technology as such. Mrs Wolle, who did not have the kind of regular daily routine that corresponded to the categories inscribed in the technology, had to adjust her life to the technology and manipulate it.

How can these co-produced forms of dealing with "activity" and "inactivity" be understood, when theory is brought in? In a certain way, Mrs Wolle can be said to have been manipulated and disciplined by the technology. As a result of using the device, she developed practices and integrated these into her daily routines. Building on Suchman (1994), who was inspired by Foucault, the categorization of Mrs Wolle's daily activities can be seen as a way to control and discipline Mrs Wolle. Yet the various descriptive and interpretative findings from object analysis within an encompassing ethnographic study also suggest that a closer look should be taken at how these socio-material practices are linked to wider societal issues and how they impact on these practices. Therefore, in the example, I asked how the concept of "activity" which is inscribed in the device related to discourses on activity in gerontology and active society. I will offer answers to this question in the following.

The concept of "activity" in gerontology and the activating welfare state

The term "activity" and the category associated with it are connected to needs-based approaches in nursing science such as "activities of daily living". But it is also connected to the term "activities" in the gerontological debate, which Katz (2000) focused on from a Foucauldian perspective. He has shown that "activity", understood in a very broad sense, has increased greatly in importance in gerontology since the 1960s (Havighurst, 1960). While disengagement theory (Cumming and Henry, 1961) conceived the role of older adults to be that of a retreat from society, activity theory emphasized the importance of activity for a satisfying and "successful" old age. Against the background of activity theory, the model of "active ageing" (WHO, 2002) was developed. This concept has proven influential in many areas of gerontological theory and practice, as well as in politics.

Approaches that emphasize the activities and resources of the elderly have helped work against the image of this age group as passive and having deficits (e.g., Walker, 2002). At the same time, according to critical voices (van Dyk and Lessenich, 2009; Denninger et al., 2014), the debate on active ageing is also in danger of overemphasizing activity and its importance for life satisfaction. As several critical gerontologists have shown, this can lead to a situation in which older adults are primarily viewed as needing to be activated, and then feel pressured into activity.

Alongside the meaning of "activity" in gerontological approaches and practical models, "activity" also represents a norm that pervades many of the social spheres in the activating welfare state, writes Lessenich (2013). People in an active society are required to be active and take responsibility for themselves. In this way, they are expected to contribute to social well-being (Lessenich, 2013, p. 121).

Adding this knowledge to the various analytical steps that were exemplified above, the following outcomes can be formulated based on a thorough engagement with things in ageing studies, and can be generalized to a certain degree. The case of Mrs Wolle offers evidence that discourses, ideals and images of older adults materialize in technologies. Assistive technologies contribute to the practices of individuals in old age and of society by suggesting that people should conform to certain behavior. A well-informed assumption would be that the newly generated, standardized data and information makes older adults more standardized and disciplined. As such, these technologies shape their lives in old age and the way in which they experience old age. Technologies such as the system investigated here should therefore be viewed not as neutral technical tools, as is frequently the case in most of the practical literature on assistive technologies, but as "normative actors" (Pols, 2010, p. 172).

Things in ageing research: possibilities and limits

To sum up, the argument here is that a focus on material objects informed by material culture studies and STS adds to our view of age(ing). As a result, it is no longer only interactions between human beings which are examined, and objects are no longer only understood as part of a purely physical environment. Instead, this method can be used to pinpoint the role which objects play in constituting old age. This is possible if things are not merely examined as resources for older adults, or characterized only in terms of their function, but are also seen as participants in socio-material practices. This is precisely how associated societal issues and social implications can be addressed based on solid foundations, i.e., on a precise analysis of socio-material practices.

There are various advantages to the method of analyzing objects in their context. Things are easily accessible for analysis, as they surround people almost everywhere (cf. Froschauer, 2009, p. 344). They sometimes also provide information about aspects which are difficult to examine in interviews (Froschauer, 2009), such as conflicts, if, for example, objects are ascribed different meanings or used in different ways. Objects can be used as a starting point for discussion during research. They are particularly important in historical research, as they survive the test of time and bear testimony to the past (Froschauer, 2009).

However, research into objects in their context poses many challenges due to their polysemy and polyvalence. The meanings and value of objects can undergo constant change. Without reconstructing the context and practices in which they are or were used, they are not easy to decode. Another challenge which arises is that objects often seem to be "invisible": people frequently use things "incidentally", without consciously thinking about it or paying continuous attention to them.[2] This can sometimes make it difficult to ask people about their relationship with things and the actions they carry out with those things. In cases of this kind, participant observation would appear to be an important means of observing the practices in which objects may be involved.

Objects such as the monitoring technologies which serve as an empirical example in this chapter co-constitute life in old age. Things bring order into people's lifeworlds (cf. Hahn, Eggert and Samida, 2014, p. 8) and give structure to work processes (Heath, Knoblauch and Luff, 2000). Conversely, this means that studying objects in their context and as a part of socio-material practices can help gain a better understanding of people's lifeworlds and working lives (see Hahn, Eggert and Samida, 2014, p. 8). In a society where people live a long time, and in which technical things, in particular, are gaining increasing significance for life in old age, it seems necessary to more closely examine the things and socio-material practices of old age, and thus gain a more comprehensive understanding of age(ing).

Notes

1 The study "TechnoCare" was part of the interdisciplinary research project "Objects of Care", which was funded by the German Federal Ministry of Science and Research from 2014 to 2017 (01UO1317A-D).

2 For the lack of attention paid to objects, see also Hahn (2018) and Depner (2017).

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13 The solo cross-national researcher of long-term care systems for older people

Henglien Lisa Chen

The main aim of this chapter is to fill a significant gap in the discussion of qualitative research methods and methodologies in cross-national comparisons, illustrated by the example of a three-nation study conducted by a solo researcher exploring the long-term care of the elderly. The study aims to shed light on several key issues – time and space, comparability, culture and language – involved in the practical implementation of cross-national qualitative research. Cross-national qualitative comparison is highly demanding and requires language skills, cultural understanding, resources and time to produce a rigorous comparative instrument and outcome. Key approaches that address challenges faced by solo researchers are careful attention to geographic location and flexible timetable and programs for the collection of data; use of multidisciplinary knowledge to address the complexity of the research topic; application of a multi-method and multi-layer approach in data collection and analysis; identification of the caring culture; and sensitivity to national as well as local language. The chapter concludes with an analysis of the added value provided by the activity of the solo researcher activity in cross-national qualitative research.

Introduction

Comparisons of long-term care provision for the elderly have been carried out since the 1990s. This testifies to a growing interest in gaining a salient international perspective on policy and practice in the field of care for elderly people and in increasing opportunities for learning about it. Such interest derives from welfare systems having to face the ageing of populations and looking abroad for evidence regarding effective policies and practical implementations. In conducting cross-national research on long-term care of the elderly, many researchers have relied on existing literature or secondary quantitative data to explore the provision and cost of care (e.g., Glendinning, 1998; Österle, 2001). Only a small number of countries were studied qualitatively, by a few researchers equipped with intimate knowledge of the countries under study, so that a concrete, well-defined issue could be investigated in two or more national contexts (e.g., Jani-Le Bris, 1993; Ungerson, 2004). Such scarcity is not surprising because this methodological approach presents serious challenges and requires the researcher to be able to interpret information across demographics and social issues, political and cultural differences, economic constraints, and the scope of welfare services. An overview of the extensive literature from the last three decades shows that, in general, cross-national qualitative research is rarely conducted by a solo researcher, with the exception of Zulauf's (1999) study on migration. Rather, it has been usually undertaken collaboratively by research teams based in the countries in question, contributing their substantial insider knowledge of the country in which they live. Intimate knowledge of the country by the researcher is vital for a qualitative cross-national study to be carried out successfully. Yet, the present chapter argues that cross-national qualitative research conducted by a solo researcher who has substantial knowledge of the studied countries may at the same time provide an insider and an outsider view that creates a different perspective. The main aim of the chapter is, therefore, to fill a significant gap in the discussion of research methods and methodologies in cross-national comparisons, by describing a three-nation study of long-term care for the elderly, conducted by a solo researcher. I am a native of Taiwan who has become a practitioner and researcher in England, with an additional family connection to the Netherlands. Such insider/outsider status not only provides me with the opportunity to investigate different realities, but also facilitates consideration of the researcher's distinctive and interactive roles in the process of truth seeking (Merton, 1972). Moreover, as cross-national comparison studies tend not to provide sufficient information regarding their methods, this chapter explores methods and methodologies in qualitative cross-national research conducted by a solo researcher. It reflects on the central challenges of time and space, comparability, as well as culture and language encountered in the research process, to illustrate this distinctive methodological approach to qualitative cross-national research. The discussion that follows draws on a cross-national study I completed for my PhD degree, in 2008. To my knowledge, it is still one of the few examples of cross-national comparisons conducted by a solo researcher. The objective of the comparison was to investigate the policy and practice of long-term care for elderly people in three countries.

Introducing the research project

The research, "Successful Ageing in Long-term Care", was a 79-month, part-time PhD project that included conceptual, empirical and statistical data regarding the long-term care of the elderly in England, the Netherlands and Taiwan. The three industrial countries studied have faced increasing demand for long-term care. In England (following the National Assistance Act 1948, the NHS and Community Care Act 1990 and Care Act 2014) and the Netherlands (following the AWBZ 1968, the WMO 2007 and the long-term care reform of 2015), long-term care of older people has been embedded in state welfare over a long period of time. By contrast, economic welfare in Taiwan has only recently caught up with the European standard, and only as of late, since the 1990s, did the state start to invest more in care for older people. Unlike England and the Netherlands, which have a tradition of strong social protection by the state, Taiwan placed the emphasis on family- and community-based care, as well as on increased numbers of workers and professionals employed in the care sectors (Walker and Wong, 2005). Each country presents a different type of welfare regime, as classified by Esping-Andersen (1990). The core of Esping-Anderson's analysis is based on the notion of "decommodification", which is an indication of good welfare provision. Decommodification "occurs when a service is rendered as a matter of right, when a person can maintain a livelihood without reliance on the market" (Esping-Andersen, 1990, p. 3). The author defines three regimes that can be summarized as follows: (a) a social-democratic system that provides universal welfare and is characterized by a strong decommodification and redistribution element; (b) a conservative/corporatist welfare system that supports the idea of class and status differentials, with minimal redistribution, where the benefit and welfare provisions are differentiated based on status; and (c) a liberal model that encourages a strong market-oriented welfare system for the middle and upper classes, has minimal decommodification, and provides a residual safety net for the poor. Of the three countries covered by the present study, England is liberal, encouraging a strong market-oriented welfare system, minimal decommodification and providing a residual safety net for the poor; the Netherlands is social-democratic, with universal state welfare provision, characterized by strong decommodification and retribution elements; and Taiwan is similar to Japan, in that it has a conservative familialist welfare regime, which supports the idea of class and status differentials, with minimal redistribution.

One principal aim of policies dealing with the ageing population in the three counties is to maintain elderly people in their own home for as long as possible. Nevertheless, both England and the Netherlands have found it difficult to sustain increases in state provision because of the significant economic effect of the necessary financing, whereas the Taiwanese government has found it necessary to provide expanded resources for its ageing population. Thus, the gap in responsibility between the state, individual and family is closing between the three countries. These similarities and differences mean that there is a potential for learning through cross-national comparative research (Doling, Finer and Maltby, 2005). Furthermore, by including Taiwan, the study filled an important gap in the comparison between Eastern and Western systems.

The study focused on exploring the quality of life of the elderly and the care they receive. I sought to understand how the systems supported their elderly and on what this capacity of each care system was based. Were some societies able to meet the needs of older people better than others? What were the successes and difficulties of each system in achieving better quality of long-term care? How could countries learn from one another in their search for solutions? The study provided an opportunity to broadly assess the three clearly different welfare systems, pointing out the complexity of comparison between countries with different funding issues, care market and care service patterns. I attempted to address the research questions by exploring the views and experiences of older people, extending the scope of the research to their families, care workers, care professionals, local administrators, service providers, civil servants and volunteer agency officials who had held care provision responsibilities. To minimize variation in the comparative research, the service users included in the sample were female, aged over 60, from the majority ethnic group and receiving formal care support. I chose to focus on women to reflect the demographic trend in the countries studied, because of women's more extended longevity compared to men's, and therefore, higher likelihood of them needing long-term care. To cover the widest possible range of provided services, in each country, five participants lived in their own home, two lived in nursing homes – and in England and Taiwan – two lived in residential care homes. Additionally, three (including one resident in the care hotel) lived in residential care type homes in the Netherlands. Of a total of 143 interviewees (48, 43 and 52 in England, the Netherlands and Taiwan, respectively), 28 elderly people were included in this study as shown in Table 13.1.

In the analysis that follows, the methodological challenges of space and time, comparability, culture and language are explored with reference to the position of the solo researcher.

Table 13.1 Numbers of interviewees in present research

Interviewees	*Number of interviews*			
	England	*Netherlands*	*Taiwan*	*Total*
Care recipients	9	10	9	28
Informal carers	6	1	3	10
Formal carers	5	9	9	23
Assessors	11	8	11	30
Service providers	10	7	8	25
Local administrators	4	4	6	14
National civil servants and NGOs	3	4	6	13
Total	48	43	52	143

Space and time

The geographic location of a study conducted in different countries, areas or cultures relevant to the aims of the research is important for both theoretical and methodological reasons (Tester, 1999). Research officially sponsored by countries is motivated primarily by the desire to promote and improve their own system. Often, effort has been limited by a methodology that focused on the most similar countries. Yet, comparing countries that are different from each other could also be informative, and learning social policy and practice from other countries is consistent with the phenomenon of globalization. Therefore, examining whether different welfare regimes – social democratic, conservative and liberal – deliver a different quality of care, as well as the questions of why and how the particular issues of quality of life in old age are more prominent in one country than in other are the main focus of this study.

It was important to insure that at the micro-level, the localities in each country were not in too dissimilar geographic areas, to provide relatively comparable research material. Therefore, both service users and providers in the sample were selected from midland districts, suburban localities at the edge of medium-sized cities. Suburban locations were chosen because cities may have other problems obfuscating the picture, and rural areas are not typical of the industrial countries studied. A further reason for excluding urban and rural areas was that the former would arguably attract more, and the latter fewer, formal and informal resources. The experiences of elderly people in these areas could be too extreme and not represent the situation in the country. I also excluded the areas where I used to live or work, to avoid a possible conflict of interest.

An adequate time span is crucial to allow for the comparative analysis of policy implementation and the outcomes for users and carers over a period of time, both the time frame of the empirical research itself and the time frame of provision of the researched service (Tester, 1999). My research design focused on service recipients who had been receiving care for over three months, because the three-month period is adopted by UK practitioner guidelines for reviews of social care provision (Department of Health, 2002). Therefore at least a three-month experience of care is necessary for an elderly individual to form an opinion about the care they are receiving. In addition, field work was carried out within a comparable time frame (roughly three months of the same year in each country), to capture the practice in the three countries at proximately the same points in time. All three countries have implemented important reforms regarding the long-term care of elderly people.

The policy changes created some tensions in practice, which were particularly strong in the Netherlands and England. This was one of the reasons that the fieldwork was difficult to time. In the Netherlands, it took four attempts to establish contact with the regional assessment offices, as such attempts were immediately turned down. In England, my application to carry out the fieldwork in one local authority in the Midlands took four months of negotiation, and eventually was turned down. The successful application with another local authority took two-and-a-half months to obtain approval, because of the complexity of research governance procedures. The extensive time required for obtaining research approval in England, in comparison with other countries, is a result of English research governance procedures, and has also been reported by Zulauf (1999). Thus, the sequencing of the research in time and space for a solo researcher working in a complex environment is a key challenge; it requires paying attention to the local research culture, and careful planning, to be able to start preparations for fieldwork as early as possible.

Many research projects have to meet a strict timeline. Care policy and practice, as well as the lengthy research approval process mentioned above resulted in an ever-present challenge of racing against time (Delva and Altman, 2010). Solo researchers face additional difficulties, given the extensive literature and secondary data research in the target countries that they must absorb, which at the time were undergoing various reforms in care for the elderly. Research design for every country needs to be comparable with the design of research for other countries, and it needs to be ready and operational as soon as possible. To increase communication efficiency, interviewees in every country need to be contacted electronically before traveling to the country. Thus, in planning a cross-national project, a solo researcher needs to take into account these aspects and be able to work using a "hurry up and wait" (Delva and Altman, 2001, p. 605) approach. Time slippage in one part of the study means reprioritizing the research tasks, as there is always work to be done elsewhere. One such example is to arrange interviews with the civil servants and senior officials in national non-governmental organizations (NGOs). My initial attempts to do so in England were unsuccessful, at the time when the rest of the interviews in this country had been completed. I decided to conduct fieldwork in the other two countries, while making further attempts to recruit the interviewees at the national level in England.

Comparability

The second and most common methodological challenge that arises in cross-national research, which may affect the reliability of research findings, is how to insure comparability. The challenges are considerable, given variations between political systems, social policies, institutional frameworks and underlining cultures in different countries (Clasen, 1999). Increasingly, comparative studies argue for combining quantitative and qualitative approaches, to detect various differences between the countries being studied (Bennett and Elman, 2006). The present study involved two key stages. The first stage consisted of discussing and analyzing quantitative data from public sources (i.e., the World Health Organization (WHO), the Organisation for Economic Co-operation and Development (OECD), Eurostat and national governments) and from the research literature, to assess the similarities and differences between demographic and social issues, the cultural and political differences shaping policy objectives, economic constraints and long-term care services (for further discussion, see Chen, 2010). The second stage utilized qualitative methods to facilitate a more detailed examination of data collected from statistical and literature reviews. The present section focuses primarily on the qualitative phases of the research.

The conceptual framework

Comparative analysis of long-term care may use the welfare system typologies, such as those proposed by Esping-Andersen (1990) and Abrahamson (1992), based mainly on social protection systems. The models and frameworks of Alber (1995) and of Attoneon and Sipilä (1996) further explore social care, which is an important constituent of long-term care in a comparative context. The various existing models and approaches contribute to our understanding of similarities and differences between welfare systems, but there is a need to build a conceptual framework specifically applicable to the study of long-term care for the elderly. Active Ageing (WHO, 2002) and Advancing Health and Well-Being into Old Age (IFSW, 2012) emphasize the importance of providing humanitarian assistance and adequate resources for care service programs, to insure that people are able to age with security and dignity, and continue to participate in community life. It is particularly important for those who are vulnerable and require support to achieve a good quality of life. The long-term care of elderly people is an extremely diverse concept, worthy of an in-depth and holistic look at the care systems being studied. The approaches underpinning this study, therefore, were based on multidisciplinary knowledge, derived from social policy (Doyal and Gough, 1991), the psychological concept of needs (Maslow, 1943) and the gerontological concept of successful ageing (Havighurst, 1961; Rowe and Kahn, 1997). Two aspects of a framework emerged: a theoretical one, derived from gerontology and psychology, suggesting that there are at least three components (care needs, social inclusion, and power and autonomy) that must be addressed for successful ageing to take place; and once concerning policy development and service delivery, certain elements of care delivery (such as partnership and resources) that need to be present if successful ageing is to be promoted.

Interview design

One of the cultural considerations in this project is the issue of power status of various interviewee groups within a country. Sohng (1994) has argued that many traditional empirical research methods are inherently biased in favor of the dominant social groups and fail to take into account the unique perspectives of vulnerable groups. Noticeably, within the field of health and social care, both practitioner and user knowledge have traditionally been marginalized (Cheston, Bender and Byatt, 2000; Beresford, 2003). This is one of the reasons why efforts have been made also to capture the perspective of diverse groups of respondents (i.e., care recipients and their relevant formal/informal carers and care professionals) on issues related to the quality of long-term care, and derived from the conceptual framework. To improve the balance of interests in each interviewed group, when framing the questions for the interview questionnaires, the valuation of different types of knowledge that different interviewee groups might contribute was taken into account. Several scholars (e.g., Lewis, 2001; Marsh et al., 2005) have provided an overview of the types of knowledge that should inform social care and practice:

- Organizational knowledge of governance and policies.
- Practitioner knowledge: personal, practice, and context-specific.
- User knowledge, with first-hand living experience and reflection on care.
- Research knowledge – the most “plausible” source but requiring a “broad church” interpretation.
- Community policy, with social and political drivers determining the issues of significance.

Such approaches offer no implied hierarchy of evidence, but rather, different types of knowledge are seen as suitable for differing purposes. As a result, six interview schedules were used in the fieldwork:

- The interviews with service recipients focused on how much they were involved with decisions about their care, what effect the services had on their lives, how they thought care services were meeting their needs and what should be included in the provision of long-term care services.
- To evaluate the contribution of informal and formal caregivers to the care system and to examine the process of long-term care from their perspective, two separate interview schedules were designed. The interviews were focused on how care affected the caregivers' individual welfare in the family and in society, how it may affect them in the future, what they considered to be important to them as caregivers, how much they had been involved with the assessment of the elderly individuals for whom they cared and what they thought was important for the long-term care of elderly people.
- Interviews with assessors explored how they put policy into practice, how eligibility criteria and the decision of the assessment system affected the care support the elderly received, how assessors worked in partnership with others, what they thought was the greatest challenge faced by those who provided elderly clients with long-term care and what could be done to insure these challenges were met.
- The aim of the interviews with service providers was to examine the process of care provision and management quality, to find out the state of their current staffing and financial situation, to find out their principal concerns and the quality of their relationship with service recipients, various professionals and other agencies.
- The interviews at the county level aimed to determine how the local authority implemented national policy, how the local authority insured that long-term care met local needs and how it met national targets, what the local authority thought were the important issues that needed to be addressed to improve long-term care for the elderly and what the local authority thought were the important issues that needed to be addressed by national government.
- The interviews with participants at the national level examined how long-term care policy was formed and implemented, how policy set standards of care and what the national influence on local practice was.

Although it may be argued that to fully represent the expertise of each interviewee group is one of the ways to improve participant inclusion, no research can claim to be 100 percent non-biased. Some of the complexities and challenges of comparative research that came into play derived from the cultural variation in gaining access to interviewee groups and in their responses, discussed below.

Choice of methodology for coding and analysis

Even an empirically rich comparative framework may produce poor findings if it is methodologically inconsistent and its objectives are unclear. To maximize the comparative reliability in the research findings across the countries studied, many cross-national researchers use multilingual teams applying multi-layer analysis to carry out the analytical work. For example, a European Union (EU) housing study (Quilgars et al.,

2009) focused specifically on the analysis of the individual countries studied by each team from the country of origin; subsequent comparative analysis was carried out by the leading research team. Nevertheless, the differences between countries in disciplinary and interdisciplinary approaches to analysis may result in differences in the application of the findings (Tester, 1999). Some relevant data may be filtered out or interpreted differently by researchers in an individual country before integrative analysis, which may compromise the validity of comparison. By contrast, a multi-layer analysis by one researcher in a cross-national analytical process arguably makes the methodological approach more consistent.

Thus, two layers of comparative analysis were employed in the present study. The first focuses on each interviewee group across the countries studied, then analyzes the themes shared by all the groups in the three countries. This layer provided fewer samples to consider at each step, allowing careful scrutiny of data at the first stage of the overall analysis, and preventing issues from being overlooked, as they might be when only a single layer is considered. In addition, multiple organizing approaches in the analysis of each layer were adopted by using Microsoft Excel to display relevant excerpts selected systematically, and by applying Becker's "sequential" methodology in the systematic coding and analysis of the interviews (Becker and Bryman, 2004), revealing certain thematic characteristics. Miles and Huberman (1994) have shown that table structures are powerful tools for data analysis. The advantage of using a template or code manual is that they may be more focused and time efficient than other organizing styles, such as editing and immersion/crystallization. Its disadvantage, however, is that when used alone, there is a potential for information to be overlooked (Crabtree and Miller, 1992). Displaying data in the maps and matrices (Dey, 1993) by using MindMan software at the third stage was another powerful means of discovering the relationships between categories, thus providing a visible way to explore possible links and associations between code-sorted segments of data. The software was used alongside Excel to reinforce and confirm the logical links between participants' views within and across the countries studied.

For a solo researcher, studying another long-term care system inevitably requires making some comparison with one's own or others with which one is familiar. To justify the findings, comparability in cross-national research is crucially important. In addition, certain supplementary mechanisms need to be put in place to prevent bias resulting from work in isolation. The present study sought to minimize bias by basing its conceptual framework on multidisciplinary theories, by inclusion of different types of knowledge that various interviewee groups were expected to contribute, and by adopting multi-methodology and multi-layer analysis. It is reasonable to question whether, given the researcher's potential biases, the multi-layer and multi-methodology analysis conducted by a situated solo researcher might nevertheless be flawed. Note, however, that a solo researcher project is not carried out in isolation. Proactive seeking of the opinions of other scholars, care recipients and care providers can significantly confirm or challenge the analysis performed by a solo researcher. In my research, first, I shared the early findings with all participants for feedback. Second, the research itself was evaluated annually by two university professors who were not supervising the project. Third, the ongoing research findings were presented and shared with scholars, elderly people and caregivers from the countries studied at nine international conferences and congresses. All confirmations and criticism were incorporated into the findings, providing further justification and affecting the overall analysis.

Culture

Cross-national comparisons benefit from a full appreciation of culture, such as language, values and attitudes (Van de Vijver and Leung, 1997). For the present study, an additional aspect of culture required special recognition: the culture of caring, including caring values, attitudes, systems and institutions. For this reason, single-person, cross-national studies that attempt to cover the full effect of policy implementation may be difficult to undertake, although, in this case, the researcher can claim to have cultural knowledge and experience, having lived in all three countries.

Gaining access: organic approach and snowball method

Recruiting participants was difficult and required a great deal of effort. As noted, the principle of the organic approach in this project presumed that interviewees who were the relevant care actors would have either a direct or indirect caring relationship with the included service recipients. One of the most practical methods of securing interviewees is through snowball sampling, which involves the personal recommendation of a contact (Arbert, 1993). Differences between the structure and operation of the care systems in each country, however, meant that participants could not be recruited in an identical fashion, but appropriate adjustments had to be made.

Taiwan, with its conservative welfare regime, places greater emphasis on private provision, therefore not all elderly service recipients are known to the government. Service providers, therefore, had to be involved in the process of recruitment. By contrast, in the social-democratic Netherlands, the vast majority of elderly service recipients are known to the government. At the same time, in that country there is a greater emphasis on privacy and rights of individuals, making a direct approach more difficult; therefore, an appeal had to be made to the general public in the community, by handing out leaflets inviting service recipients to contact the researcher. In England, social services identified the elderly who met the research criteria; assessors discussed the study with individuals who were potential interviewees, and passed details of those who had given consent to the researcher.

Differences in the care system also required different approaches to gain the cooperation of relevant authorities in each country. In England, where the local authority has the main responsibility for meeting the needs of care recipients, the research recruitment began with approaching local authority social services with responsibility for the care of older people. It then became possible to seek consent from participants at the local and national levels (center-to-bottom and top approach). In the Netherlands, with its pillar-like social structure and data protection regulations, many consultations took place between the researcher and various groups (bottom-to-top). In Taiwan, which has a strong hierarchical social structure, the strategy of obtaining approval at ministerial level was sufficient, and everything else then fell into place (top-to-bottom).

One limitation of the snowball method has to do with the power relations within the care system. In England and Taiwan, these can become more problematic in situations of a top/center-to-bottom approach. Some respondents may not turn down the interview because someone who has higher authority referred the researcher to them, and thus they do not wish to disappoint that person. The bottom-to-top approach in the Netherlands may have meant that recruited participants were more likely to be autonomous, and the elderly people volunteered without any pressure from other actors. Another potential limitation and difficulty of the snowball method is that it includes only individuals within a specific network of people, which may introduce a bias into the research findings (Arbert, 1993). In the case of this study, differences in the culture of caring affected the personal recommendations of contact and the final participant sample. There is little doubt that informal caregivers played a significant role in the care of their older relatives. Elderly individuals' perception of informal caregivers in the three countries, however, resulted in varying involvement of caregivers in the research. Access to informal caregivers was not always possible in England and the Netherlands because some English and Dutch elderly individuals saw themselves as being independent while receiving formal support, and therefore as not being dependent on their families. In Taiwan, some elderly people considered the research involvement as a burden on their family or informal caregiver, many of whom were working full time.

The organic approach to the recruitment and selection of interviewees from every level of the care system, to represent the care system as a whole, can be complex and difficult, especially in cross-national research. To meet the criteria, a complete cluster had to include a minimum of one service recipient, a formal or an informal caregiver, an assessor and a service provider. Although there was close cooperation with potential participants, some of the care recipients or their relevant caregivers refused to participate. Two elderly care recipients in England were too frail to be interviewed. In Taiwan, three care recipients were too frail to participate, and one assessor and one formal caregiver could not be contacted. The care recipients who were too frail to participate were either suffering from dementia or unable to communicate with the researcher for other reasons (e.g., one English service recipient was too distressed by having to sell her home). In the Netherlands, one care recipient who had given consent did not meet the research criteria, and four assessors could not be contacted. This was discovered at a later stage, and, as a result, 11 clusters could not be completed and 36 interviews had to be abandoned.

To represent the different structures of care systems and different individual needs of elderly people who received different levels of support in the three countries, the number of participants in each cluster could not be identical. The number of participants at the national level and the local administrators in the study (Table 13.1) reflected the level of public responsibility characteristic of the English care system, with fewer departments and NGOs than in the other two countries. In England and Taiwan, most of the service recipients had a regular, main, formal caregiver. This was not quite as often the case in the Netherlands, however. Although the original principle of interviewee selection was still maintained, it worked out a little differently in the Netherlands. When there was no one main caregiver, one was selected at random. The culture and political differences identified in this section suggest the complexities in identical versus equivalent comparison approaches to recruiting participants.

Interviewees' responses

One of the general difficulties of involving elderly people who receive long-term care in research is that they are likely to have experienced the effects of the loss of health, family and independence. In the case of formal/informal caregivers and assessors who provide front-line care, it was recognized that they too were in a vulnerable position. In many instances, they displayed some stress stemming from the demanding responsibilities of their role. It was important to allow time for interviewees to express their feelings and to insure that individual interviewees realized they were free to decline to take part or answer only certain questions, without any negative consequences.

As a result of seeking to take Eastern and Western cultural and political contexts into consideration, there was some variation in the responses. For example, the idea of a consent form worked well in England, but not in the Netherlands and Taiwan, because of different views of how agreement to participate in research should be expressed and presented. In the Netherlands, nearly all the interviewees saw their verbal agreement to participate in this research as equivalent to the signing of a consent form. In Taiwan, nearly all of the interviewees at local and municipal levels did not welcome, indeed were frightened by the offer of, a consent form. They saw the consent "form" as an official constraint on their voluntary contribution toward the research, and did not like to think of it as part of a government investigation. This difficulty was reduced by providing explanations and examples to the interviewees when required. The physical condition of the elderly (hearing, vision and cognition) affected the interviews to some degree, but this was minimized by the researcher's own experiences with older people as a social worker. Interviews lasted for an hour on average, with the exception of the interviews with the elderly. English and Dutch service recipients were expected to be less at ease because they were being interviewed by a foreigner. Yet, the length of the interviews suggests that Taiwanese elderly respondents were, in general, less forthcoming and more private than those in England and the Netherlands (approximately 30, 50 and 40 minutes, respectively).

Visual method

Whenever relevant for the study, photographs were taken to provide an additional perspective on the experience of care. Several anthropologists have stated that cultural products, such as visual materials, reflect social reality in various ways, and are among the best approaches to the illustration and elaboration of research findings (Albrecht, 1954; Alexander, 2008), especially when presenting cross-national, long-term care research to readers who are not always familiar with the countries studied. Visual methods, however, are still relatively uncommon in cross-national social policy and practice research because most research of this type has been conducted by social policy, health and social care scholars.

Cross-cultural studies, such as those of Dingwall, Tanaka and Minamikata (1991, cited in Chaplin, 1994, p. 195), which used visual images to compare parenthood in the UK and Japan, have argued that a comparison of images can be an effective general indicator of cultural differences, because images show a wealth of detail about the social situation they depict. The present study employed the strength of the visual image, which is information-rich, to draw attention to what is real and to contribute to the understanding of the everyday life of care by giving a more immediate and detailed account of people than is possible by a verbal description (Chaplin, 2002). In the present study, I used photographing as a visual recording method during the field research. The visual inventory was carefully classified and assisted me in reflecting on the views of the participants, especially of those who are disempowered by society. Nonetheless, visual materials, despite their potential, require that careful attention be paid to their interpretation. First, they are liable to create a problem of ambiguity, as different people may interpret them in different ways (Alexander, 2008). Second, photos can capture only a brief moment in time and a fraction of space. Third, consent needs to be obtained from the participants to be photographed, but if they are aware that a photo is being taken, it may affect their natural behavior.

Language

Last but not least are challenges related to the multi-linguistic competence of a solo researcher. Language can present a key obstacle to effective international comparison, because it is not merely a medium for communication, but part of a wider system reflecting institutions, thought processes, values and ideology. This could mean that the approach to a topic and its interpretations may differ according to the language of expression. Comparative analysis is rarely able to achieve exact linguistic equivalence in concepts. Definitions acceptable in one country may not be understood elsewhere. The aim must be to devise functional equivalents, which need further explanation for use in a comparative context (Tester, 1999). For instance, the term assessor refers to all the people who formally assess elderly individuals' needs for formal care, covering a range of occupations that can vary a great deal in the countries studied. These can include social workers employed by the local authority, nurses and occupational therapists in England; social workers, physiotherapists, nurses in a regional assessment office, and nurses and social workers from service providers in the Netherlands; nurses contracted by a local authority, and nurses, social workers, physiotherapists and nutritionists from service providers in Taiwan. Hence, the terminology used in each country and by each interviewee group became important and had to be considered carefully.

In a world of social science research where good language skills are a rare commodity (Ungerson, 1996), a much more common strategy is to put together research teams made of native speakers from the target countries. For an international project by a solo researcher to be successful, a certain level of linguistic and cultural affinity of the researcher with the respondents is essential (e.g., in the national languages and local dialects), in addition to assistance from professional interpreters and translators. It helps facilitate good working relationships with the participants and minimizes translation problems at the critical stage of data collection and transcription.

In the present study, several measures were adopted at the stage of formulating research questions to overcome the language barriers. First, regular visits to the target countries, related to the research topics, as well as reading the relevant literature in the language of origin, helped me gain a greater understanding of the variations in terminology used in each country. Second, the interviews covered the same questions translated into each of the languages used in the study, following a pilot study (conducted with 21 interviewees) in the three countries, with some ensuing adjustments made to insure that the interview questions were clear and covered comparable areas of concern in the three countries.

The process of interviewing further confirmed the credibility of the use of the language of origin. For example, although many of the Dutch interviewees were fluent speakers of English and the use of English could have greatly increased the accessibility of their views, many of them spoke in their first language when responding to nearly all the interview questions to address sensitive care-related issues. What added to the complexity of conducting the interviews, especially with the elderly in the Netherlands and Taiwan, was that local dialects and provincial languages were frequently used. As a solution in this study, when a problem of communication with Dutch elderly individuals arose, was to avail myself of additional support from a colleague. To prevent the problem of mistranslation and misinterpretation, verbatim interview transcripts in both the original language and English were performed by the solo researcher and professional transcribers in each country, to minimize the possible loss of nuance and culturally determined meaning (Ungerson, 1996).

Conclusion and implications

This chapter detailed the challenges and opportunities in conducting cross-national research in long-term care of older people by a solo researcher using qualitative methods, which has been rarely been carried out or discussed. Qualitative cross-national comparisons have the potential to provide valuable analytical insights into a range of outstanding long-term care problems and to facilitate a deeper understanding of care policies and their implementation. This chapter provided support for such work by demonstrating the benefits and feasibility of conducting qualitative comparative research by a solo researcher, in view of the fact that cross-national studies are lacking because of the challenges in their practical implementation. It offers examples of facing the challenges in study design and data collection and analysis, based on the experience of solo cross-national research of the long-term care for elderly populations. As in any research, it is important that theory and data correlate, and that issues of validity, reliability and ethical considerations be addressed. The need for comparability is an additional aspect (Tester, 1999). A rigorous cross-national comparison research demands extensive language skills, cultural understanding, resources and time. To achieve the research aim, it was essential for the researcher to collect the information about the relative effects of different actions on actual welfare outcomes in different countries. Some of the difficulties could be addressed by understanding the contexts in which comparisons were made. Empirical research conducted by a solo researcher helped maximize the consistency of data collected cross-nationally. The determination of equivalence in the fieldwork was insured by great attention paid to careful and detailed planning, based on continuity, reflection and adaptability. A delicate balance was required between sensitivity to these complex issues and ensuring, at the same time, that the project moved along without falling behind on important comparability criteria. Multiple methods in the overall analysis helped obtain consistent and systematic results, and avoid methodological pitfalls. More research is needed on ethical issues concerning a broader range of vulnerable elderly people, such as those with multiple health problems, and those who are caregivers. The ethical approval process varies across the countries studied, and lead times are especially protracted in England; researchers should consider this when planning their research.

In conclusion, the solo research experience presented in this chapter indicates that the challenges of cross-national research carried out without national research teams in the target countries can be successfully addressed. Indeed, in some respects, a single researcher working cross-nationally may overcome some of the challenges in cross-national research more broadly, thus contributing added value to the research process.

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Part III

Implementation as the main purpose of ageing research

14 Current challenges in ageing population health intervention research

Illustration with the case of the SoBeezy program

Linda Cambon, François Alla and Karine Pérès

In this chapter, we develop issues and methodological aspects of health intervention research in the ageing field. These deal with the complexity of interventions inviting understanding of how these interventions work and can be transferred into another context or scaled up. We illustrate these words with the example of a concrete research project, named SoBeezy.

More precisely, we develop the idea that approaches and research methods have to integrate new research objects, to allow an explicit theoretical hypothesis underlying the levers used within the intervention (designing the theory) and to anticipate the constraints in implementing the innovation into the routine (designing the viability study), with the aim of facilitating the transfer of innovation into practice and to transform organizations.

Introduction

In the context of the rapid ageing of the population, ageing in the best possible conditions has progressively become a major challenge for all societies worldwide. The new demographic transition combined with increasing life expectancies, now realized late in life, raises the issues of health conditions, living conditions, organization of the welfare and health systems and, consequently, of the medical and social costs of ageing.

To face these challenges, we must transform our system and develop and implement innovations, particularly organizational innovations at all levels of care through population health intervention research (PHIR). Developing PHIR in the ageing field raises the following questions: how do we assess these innovative models and interventions considering their complexity, and integrating, at the same time, (i) their efficacy, (ii) the conditions of efficacy and (iii) the conditions of transferability and scalability?

In this chapter, we propose providing methodological insights for PHIR and to illustrate them by a concrete research project, named SoBeezy, in order to answer these questions.

Supporting ageing, an innovation challenge

In a context of the rapid ageing of the population, ageing in the best possible conditions has progressively become a major challenge for all societies worldwide. According to the World Population Ageing 2017 report, in 2050, two billion people will be aged 60 and older, i.e., more than 21 percent of the world's population, but with great differences by countries (United Nations Department of Economic and Social Affairs, 2017): from around 7 percent in Western Africa countries to more than 40 percent in some European and Asian countries (Italy, Greece, Spain, Portugal, Japan, Hong Kong, Taiwan, Republic of Korea and Singapore). The new demographic transition combined with increasing life expectancies, now realized late in life, raises the issues of health conditions, living conditions, organization of welfare and health systems and, consequently, of the medical and social costs of ageing. Indeed, this expected rapid ageing of the population raises concerns about increasing prevalence and incidence of age-related diseases, of chronic illnesses, of polypathology and of all the consequences in terms of dependency and loss of autonomy, both for elderly people and their caregivers.

According to the bio-medical approach of ageing, pathologies are clearly the "gateway" into the ageing process. Prevention is obviously the first level of levers to activate, which is already conducted in classical prevention strategies (with physical activity, diet, tobacco and adequate medical management and care). However, it is now well established that other factors than solely health factors significantly contribute to well-ageing. Defined as contextual factors, they play a significant role in the ageing process (WHO 2019), modulating the impact of disease on people's lives, playing either the role of positive or aggravating factors. Among these potential factors, promising results could be obtained with psychosocial factors; as yet largely underestimated in usual prevention strategies. Among them, combating loneliness and social isolation, and restoring feelings of usefulness to others and self-esteem could be interesting to experiment. Indeed, feelings of loneliness and social isolation have been identified as a real scourge of modern life. With increasing prevalence and incidence over the last decades, they have been recognized as risk factors of poorer quality of life, unhealthy behavior and lifestyle (Shankar et al., 2011; Schrempft et al., 2019; Kharicha et al., 2007), of chronic diseases (depression, anxiety, cardiovascular, Alzheimer's disease) (Valtorta et al., 2016; Grande et al., 2018; Domènech-Abella et al., 2019), dependency (Kharicha et al., 2007) and premature death (Rubin 2017; Tabue Teguo et al., 2016; Tanskanen and Anttila, 2016). In the same way, feelings of uselessness to others, which often appears after the transition to retirement and exacerbates with age, also has a deleterious impact on self-esteem, quality of life, lifestyle, health and even mortality (Gruenewald et al., 2007, 2009; Levy, 2003; Gu, Brown and Qiu, 2016; Okamoto and Tanaka, 2004). Focusing on these levers, an intervention research (IR) approach should be implemented to assess the potential impacts that could be expected on healthy ageing and helping elders staying at home as long as possible in good conditions. Indeed, "ageing in place"[1] has clearly become the priority goal of all ageing policies.

Hence, to increase the chance to meet the challenges of ageing populations, we must transform our system and develop and implement innovations, particularly organizational innovations at all levels of care (Alla and Cambon, 2017): to identify research-based and field-based interventions and organizations; to understand what works, how it works, in which context, in which populations and with what impact and effectiveness at both societal and individual level; and to explain the transfer of innovative models into public decisions and practices are the objects of PHIR.

Developing ageing intervention research

PHIR has been defined as "the science of solutions" (Potvin, Pettcrew and Cohen, 2014), complementary to the science of problems (i.e., study of health determinants). Especially in ageing intervention research (AIR), this calls for several observations. The first is that these solutions are diverse. They could include prevention programs, such as falls prevention programs, or technological innovations, such as a remote fall detection monitoring system. They could also refer to organizational innovations as a specific care pathway, or policies such as an elderly plan or social welfare. The second is that PHIR is an operational science, since one of the goals of research is the use of its results by field practitioners and policymakers. This involves taking into account the future transferability and scaling of results in practice and in decision-making (Cambon et al., 2012). This transferability should not be considered *post hoc* but integrated into the research process itself, challenging perspectives and methods of research (Alla and Cambon, 2017). Indeed, because public health interventions are complex (MRC, 2012), with their results depending on the interaction between the intervention and its context (Cambon, Terral and Alla, 2019), an effective intervention in a given context (especially an experimental one) may not be transferable or scalable.

So, developing PHIR in the ageing field raises the following question: how do we assess these innovative models and interventions considering their complexity, and integrating, at the same time (i) their efficacy, (ii) the conditions of efficacy and (iii) the conditions of transferability and scalability. In this chapter, we propose to provide methodological insights for AIR and to illustrate them by a concrete research project, named SoBeezy, in order to answer these questions.

The SoBeezy project: an innovative program on ageing

SoBeezy is a large-scale solidarity network based on a digital intelligent platform. Connecting all the resources of a territory, the SoBeezy program aims at facilitating and improving the lives of the most vulnerable people, mainly elderly persons and people living with disabilities. The system proposes solutions to face the main social and material difficulties in activities of daily living and promotes social participation through activities and experience sharing. Whatever the age, gender, socio-professional category, disabilities or diseases, everyone can contribute to the platform, thus restoring feelings of usefulness to others and reducing loneliness. Indeed, beyond the direct benefits expected for the beneficiaries of the services, we assumed that the opportunity given to everyone to contribute to the system allows tackling the sense of uselessness that strikes many elderly people and to give back meaning to life.

In addition to the intergenerational citizen mobilization and contribution, the SoBeezy system relies on all local resources and is organized as a network hub. It includes SoBeezy citizens and different stakeholders of a territory: the municipality and their social services, health and social professionals, other professionals and associations (charities, sports, cultural and leisure associations). This hub design combined with a powerful algorithm guarantees the optimal answer to the expressed needs of the SoBeezy users.

The SoBeezy platform is available on all digital devices: smartphone, tablet and computer. Nevertheless, given the still frequent digital divide in the targeted population, a specific effort has been undertaken to give universal access to the proposed technology. To do so, a specific voice assistant has been developed to facilitate the expression of a need by elderly people, vocally (e.g., “I am looking for someone to … take me to the “doctor” or “to share a walk” or “to play cards”). In addition, the SoBeezy device also proposes several options to facilitate daily life such as an easy-to use digital calendar, video call, weather, radio, emergency numbers. Thanks to the high usability and accessibility of the device, the SoBeezy voice assistant aims at decreasing apprehensions and fears about technology usage and finally at reducing the digital divide in the elderly population.

Initially designed to meet the specific needs of the elderly population, the SoBeezy program finally also meets other population needs, such as people living with disabilities, particularly struck by the scourge of loneliness and feelings of uselessness and also confronted with activity limitations in daily life. To meet the public health and social cohesion challenges of ageing, the SoBeezy program is innovative in many ways:

- Development: co-constructed with elderly users and local stakeholders and partners in charge of the elderly population, the SoBeezy program proposes appropriate solutions to face difficulties and meet the real needs in daily life.
- Levers: SoBeezy targets psychosocial factors less investigated than health factors in usual prevention programs.
- Hypothesis: people who contribute to the platform may have personal benefits in terms of loneliness reduction, reduced feelings of usefulness, gaining meaning out of life, and great encounters and interactions.
- Technology: SoBeezy gives a social utility to technological innovations. With the SoBeezy voice assistant, digitally excluded people could benefit from the network, which is really innovative among the huge amount of technologies currently available.
- Organization: SoBeezy involves and centralizes all the resources of a territory: citizens, professionals and associations.
- Evaluation: a rigorous IR strategy will be conducted to assess the impact and effectiveness of the program on well-ageing.

The effectiveness of AIR

Hawe and Potvin (2009) described three “myths” of IR, among them: IR is just about intervention effects, is only about controlled trials and controlled interventions. According to them, many different types of study design can actually be used and build evidence but some studies failed because of over-control from researchers on the form of the interventions. Cambon, Terral and Alla (2019) highlight that although public health has historically favored experimental designs because of their internal validity allowing causal attribution, some ethical, technical or legal constraints in PHIR still exist (Tarquinio et al., 2015; Cambon, Terral and Alla, 2019). Some adaptations could be provided to fit with the complexity of interventions. A range of methods could be used successively, or combined at various steps of the evaluation approach (Minary et al., 2019). Among these designs, the most frequently used (Grande et al., 2018) are trial adaptations, quasi-experimental and observational studies, realistic evaluation and other case studies. In short, the aim of the trials’ adaptations is to bring them closer to “real life”, mainly pragmatic and cluster trials (the latter being also suitable for collective interventions). Quasi-experimental methods (before-and-after design and/or with control group design), observational studies and more generally natural experiments, have the advantage of a stronger external validity than experimental methods, at the cost of a decrease in internal validity. They are sometimes the only ones that can be used (for example, for policy evaluation, which is non-randomizable in nature). Finally, realistic evaluation (Pawson and Tilley, 1997) comes from another scientific paradigm derived from the social sciences. The principle is to explore mechanisms that are activated by the intervention to produce its effects in a given context using mixed methods. Realistic evaluation can provide an explanation on how an intervention functions and in what circumstances (Pawson and Tilley, 1997).

Thus, no “universal” design can be proposed for evaluation of population health intervention, but a range of methods can be used according to the nature of the intervention evaluated and the objective and the context of the evaluation (Grande et al., 2018).

To illustrate this, in the case of the SoBeezy program, the evaluation protocol has been notably designed to (i) evaluate the use of the device, in terms of acceptability, accessibility, usability and user experience, (ii) assess the impact on well-ageing in terms of feelings of loneliness, sense of usefulness, self-esteem, quality of life, social participation, dependency and healthcare consumption.

The general framework of the research is a prospective pragmatic quasi-experimental study (i.e., an intervention population and a control population with no randomization), involving a cohort of 1000 SoBeezy users recruited in three cities, initially aged 60 years and older, all volunteers to use the platform and to participate to the research. Figure 14.1 illustrates this data collection in steps 1, 2 and 4 (cf. Figure 14.1). The choice of a cluster (i.e., the city) is linked to the collective nature of the intervention, that of a quasi-experimental rather than experimental design, mainly because the preparation and implementation of the intervention required a strong investment from the communities and their representatives. Randomization was not socially acceptable. In addition, the number of voluntary sites was too small and heterogeneous for this randomization to have been effective. Outcomes data (loneliness, sense of usefulness, self-esteem, quality of life, social participation, dependency and healthcare consumption) will be collected at home by a specially trained psychologist at baseline and after 12 months of intervention (step 1 in Figure 14.1). Complementary data will be collected from the SoBeezy device in the ecological context of home and after extraction from the medico-administrative claims datasets. Comparative analyses will be conducted according to different strategies, first, among the SoBeezy users themselves with a before–after design (e.g., in terms of loneliness, feeling of usefulness, dependency). Moreover, two additional comparative analyses will be conducted using specific control groups (step 2 in Figure 14.1). The first, specifically focused on the impact on loneliness, will be conducted comparing two groups of older adults suffering from loneliness: the intervention group of 200 subjects issued from the SoBeezy cohort and the control group including 200 comparable elderly subjects recruited in non-SoBeezy territories. The second approach will consist of a comparison of the short-, mid- and long-term evolution of the SoBeezy-group compared to the general elderly population using the claims data. These two groups will be compared in terms of healthcare utilization (step 4 in Figure 14.1): drugs consumption (with a specific focus on psychotropic drugs), paramedical and medical care use, chronic diseases, hospitalization data, dependency (using a claims-based algorithm) and mortality.

Hence, the efficacy evaluation of SoBeezy was conceived with pragmatic, feasible and rigorous (control groups) approaches in order to allow the implementation and use of the SoBeezy platform during 12 months and the collection of data. Indeed, the SoBeezy project is an alternative design to randomized control trials with a quasi-experimental design embedded in a cohort study.

The conditions of effectiveness of AIR

In the last 20 years, the number of technological innovations, devices, robots and platforms addressing the issues of assistance, surveillance and prevention for the elderly has dramatically soared. Yet very few of them have been able to prove their effectiveness; some do not meet real needs, others encounter usage-related barriers. But for a large majority of them, conclusions were limited due to the lack of a rigorous intervention research strategy, including processes and mechanisms studies. Such technologies are promising to improve the

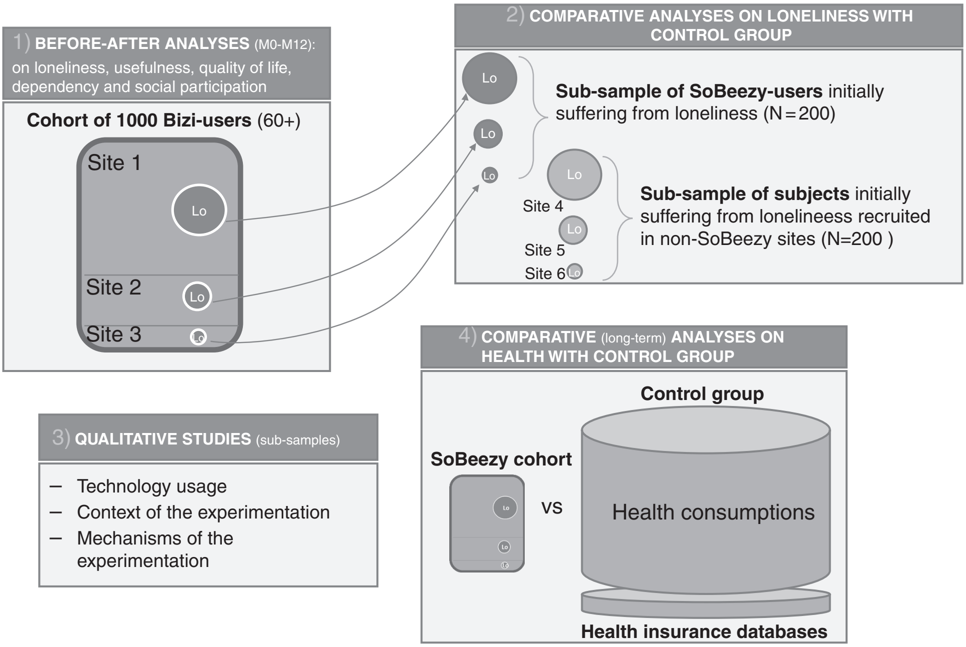

Figure 14.1 Data collection in the SoBeezy program.

well-being of elderly people living at home. However, the lack of high-quality and in-depth studies clearly limits the opportunities of transferability and scaling up (Moore et al., 2015; Marasinghe, Lapitan and Ross, 2015; Chen and Schultz 2016), yet these are crucial for policymakers. Indeed, beyond the feasibility aspects of trials evocated before, efficacy-focused studies (as experimental or quasi-experimental studies) have, if they are used solely, a drawback: they are “blind” to the contextual elements, which influence outcomes. Their potential efficacy may well be demonstrated, but their transferability is weak. And, it becomes a major issue as intervention research is supposed to inform policy and practice (Tarquinio et al., 2015). We talk about the evaluation of a “black box”. Yet, the “black box” has to be opened in order to understand how an intervention is effective and how it may be transferred elsewhere. It is about understanding of the conditions of effectiveness. These are the components of intervention, the processes used to implement it, the mechanisms triggered by it and the contextual elements likely influencing the results. Indeed, PHIR, as well as AIR, has to be considered with the complexity perspective of organizational research (as health service research), leading to integrating clearly the context (Hawe, Shiell and Riley, 2004) as co-producing the effects by interactions with interventional components. Some authors as Pawson and Tilley (1997) consider that results in complex intervention are actually derived from configurations between contextual parameters including intervention (C) producing mechanisms (M), which in turn produce outcomes (O). The realistic evaluation framework they have conceived aims to assess these CMO configurations in order to open the black box and answer the following question: for whom and in which conditions does the intervention work? In this respect, Cambon, Terral and Alla (2019) have argued that another major myth of PHIR is the willingness to distinguish arbitrarily intervention from context. They advocate that the complexity has to be assumed and propose a new definition of the object of public health studies – the "interventional system" – which includes interventional, contextual components (Shiell, Hawe and Gold, 2008) and the mechanisms triggered, these last considered as the key elements of this interventional system.

In this way, another challenge in AIR could be the understanding of these mechanisms and the ways they are produced. It involves tracking (*in-itinere*) in process evaluation the mechanisms as they are hypothesized and as they emerge, expected or not, during implementation. It leads to rethinking the evaluation approach and methods, exploring the interventional system as different from the sum of its (interventional or contextual) parts by a contributive analysis (Mayne, 2001). Process evaluation is the point of any guidelines for helping the researcher to take into account these questions and consider this complexity (Moore et al., 2015; Craig et al., 2018). One way to assess process evaluation is theory-driven evaluations (Alla and Cambon, 2017), solely performed or complementary with trials, because they use this contributive understanding of an intervention through mechanistic interpretation focusing on the exploration of causal chains. In theory-driven evaluations, the causal combinations of components are hypothesized by combining scientific evidence and the expertise of practitioners and researchers. The hypothetical system is then tested empirically. If this is conclusive, evidence therefore exists of contribution, and causal inferences can be made. Two main categories of theory-driven evaluations can be distinguished: realist evaluation and theories of change (Blamey and Mackenzie, 2007). In both cases and in an interventional system perspective, context and interventional components have to be equally considered in the analyses.

In the case of SoBeezy study, the understanding of mechanisms is the reason why a third objective has been added: analyze the intervention processes, context and mechanisms that lead to the results obtained. Indeed, the SoBeezy program is a complex intervention, which can be highly influenced by contextual elements. The SoBeezy system relies on different actors (citizens, professionals and associations), concerned directly or indirectly with the elderly population. This multiplicity of partners, which is one of the main strengths of the program, also represents a complexity to evaluate. The efficacy of the system will largely depend on the level of involvement of the different partners; a level which can vary between territories according to local policies, to the dynamism of the associational network, to the involvement of professionals and to the sweep of citizen mobilization. Moreover, other contextual elements can also influence the results. Thus, the choice has been made to experiment with SoBeezy in three pilot territories (three cities of south-western France) very different in terms of number of inhabitants (from 6800 to 62,000), proportion of elderly people (22 percent to 41 percent), population density (67 to 1580 inhabitants/km^2), urban or rural areas, medical and paramedical demography, access to transport, and services and digital coverage. All these parameters may influence the obtained results of the intervention. Moreover, the general objective of the SoBeezy program is to favor well-ageing and ageing at home in good conditions. To do so, five mechanisms are targeted by the program, and hence studied (cf. Figure 14.2).

- *Loneliness and social isolation*. With more than 20 percent of the elderly population affected by loneliness and, given its deleterious impact on quality of life and health, the SoBeezy program first proposes visits at home by citizens or trained volunteers from associations already involved in the battle against loneliness. Another less direct way to tackle loneliness, probably less stigmatizing, is the experiences and activities sharing component of the SoBeezy program. Finally, being personally involved in the

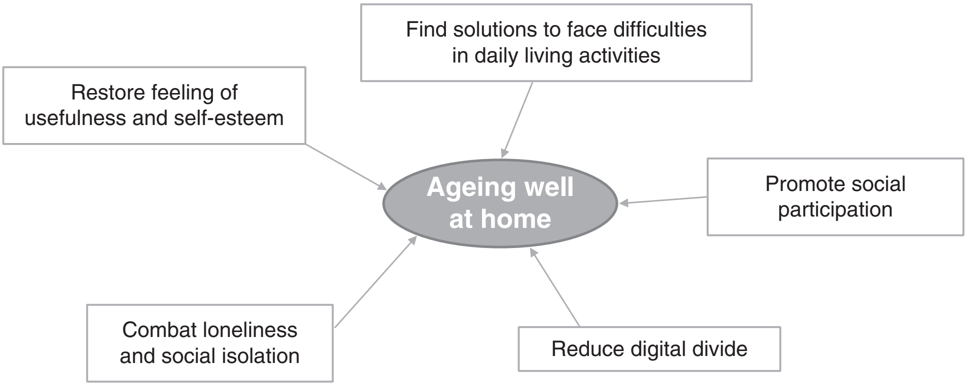

Figure 14.2 SoBeezy mechanisms of effect.

system for other people and belonging to the SoBeezy community should also contribute to reducing loneliness and isolation.

- *Feelings of usefulness and self-esteem*. With ageing, the retirement period (sometimes associated with loss of social status and "daily life routine destructuring"), loss of spouse, relatives and friends, diseases and disabilities etc., feelings of uselessness and loss of self-esteem often occur and worsen with age. The SoBeezy program gives the opportunity to everyone to get involved for other people, as a helping hand, a sympathetic ear and an encouraging and caring smile for persons struggling with loneliness, dependency and illness.
- *Facing difficulties in activities of daily living*. Such limitations can jeopardize the chance of staying at home, especially for people living alone. Thanks to local large resources referenced and centralized in the SoBeezy Hub, the platform will be able to identify the optimal answer to meet the needs of the SoBeezy users. Based on previous studies, the services proposed by the system should cover the main needs of the elderly people: transportation, shopping, punctual aid for housekeeping and gardening, digital training, assistance for administrative tasks (mainly now digitalized) and pet sitting and care. Some services will be either provided by citizens and volunteers (freely), or by professionals (paid) when specific skills are required or when no free solutions are found by the platform.
- *Social participation***.** In the last years of life, most of us are concerned by diseases and disabilities. On this basis, instead of considering successful ageing as the absence of diseases, well-ageing could be considered as living with preserved social participation despite disease and functional limitations. This goal will rely on all the local actors and partners of the territory (municipality and associations), as well as on all the social activities proposed by the SoBeezy community.
- *Digital divide*. All administrative tasks are becoming digitalized at a steady pace. Consequently, being digitally excluded starts to become a real social disadvantage. Given the high frequency of digital divide in the current generation of elderly people, the SoBeezy system provides volunteer digital trainers and easy-to use technological devices to reduce fear, apprehension, aversion to technologies and to give universal access to technologies and to the Internet.

To analyze both contextual elements and mechanisms, we will perform a realistic evaluation embedded in the efficacy design. Concretely, qualitative studies to analyze technology usage, the context and the mechanisms of the experimentation have been added to the efficacy study described above. This qualitative investigation will be conducted through non-structured and semi-structured interviews with all stakeholders and older people involved in the intervention group. The aim is to figure out the combinations of recurrent CMOs in the intervention group in the three towns in order to answer these questions: (i) Through which mechanisms does the SoBeezy system produce some results (M-O)? (ii) What key elements of the SoBeezy system are the most effective (C-O)? (ii) What key elements of the implementation of the SoBeezy system are the most effective (C-O)? (iv) What are the factors that depend on people's and environments' characteristics which influence the mechanisms triggered and the effects (C-M-O)? This data collection is illustrated, complementary to the others in Figure 14.1 in step 2 (cf. Figure 14.1).

Hence, complementary to the efficacy evaluation, this complementary study will contribute to understand in which conditions the SoBeezy platform is effective: which components of the interventional system – population and stakeholders, implementation, external, internal to the platform characteristics – and through which mechanisms are they effective?

Considering transferability and scalability in AIR

Despite this methodological development, PHIR remains undersized and the findings are not always used by decision-makers and practitioners for many reasons. One of them is that the knowledge produced is not always adapted or usable because it does not take adequate account of real-world circumstances. To avoid this, the production of knowledge has to be made with an interacting framework, including all stakeholders and their points of view, in order to verify that the intervention can be routinized in a real-life context. We talk about viability analysis (Chen, 2010), which has been considered an essential prerequisite in PHIR, and hence in AIR. Indeed, in a perspective of use, what is the point of analyzing the effectiveness of an intervention in an experimental context that is not a real-life one without first ensuring that if it is effective, it will be transferable in real life? Chen (2010) recommends addressing the "viability validity" of an intervention as the first step in an evaluation process. He has defined this concept as "the extent to which an evaluation provides evidence that an intervention is successful in the real world", referring to the practical, affordable, suitable, evaluable and helpful aspects of an intervention in the real world. In other terms, it refers to the way an intervention fits with the context, especially answering stakeholders' needs and interests. According to Chen, without a viability assessment, we risk addressing the efficacy of an "off ground" intervention that cannot be transferred to another context or scaled up. The proposal is to use an integrative validity approach, first proceeding to a viability study, second performing an effectiveness study considering the real conditions of implementation and last (and if necessary) conducting an efficacy study or directly proceeding to dissemination. Practically, if the intervention is research based, this viability analysis should be integrated into the objectives of a pilot study in addition to its classical objectives (Thabane et al., 2019) in research-design program evaluation in order to prepare as best as possible both trial and intervention by reporting essential information to transfer or scale up the intervention. If the intervention is field based, it is by nature adapted to the context, conceived with local and routine resources. This kind of intervention is likely more transferrable than the others. We talk about natural experiment designs (Craig et al., 2012); because the intervention is not conceived and implement by researchers, the research is added second to evaluate the ongoing field intervention. In this case the viability study aims to understand the possible adaptations of the "intervention prototype" by assessing its "key functions" (Hawe, Shiell and Riley, 2004). The key functions are basic elements considered as key to producing an effect, for example an intervention's theoretical processes ("key functions") which have to be distinguished from structural and contingent parameters (Hawe, Shiell and Riley, 2004). In both cases, research- or field-based interventions, the aim is to understand how and under what conditions intervention components could fit with routine conditions, answer different stakeholders needs and be able to be adapted in another context or resources scale up.

The SoBeezy program is the second case evocated: a field-based program. But, given the complexity of the SoBeezy organization and the potentially important influence of the contextual factors (due to the heterogeneity between territories in terms of needs, dynamism and mobilization of each partner), the transferability issue remains a major point. It is the reason why (i) technological and organizational pre-tests have been made with 35 elderly users living at home and in retirement homes, (ii) they have been tested in real conditions of use, (iii) they have been implemented at a city scale. The whole city is potentially exposed to the SoBeezy program and each person (citizen, volunteer or professional) represents a potential resource to the system. Thanks to the diversity of the three pilot sites, a specific analysis of the special influence of the contextual factors on the impact and efficacy of the intervention will be conducted, which will provide crucial data in a perspective of transferability to another context and scaling up. Data will be collected by the same interviews performed in realistic evaluation, mentioned above, in order to answer these both questions: What are the elements to be considered when transferring this intervention in other contexts: preparatory modalities, resources, types of professionals involved, culture, etc.? Which adaptations have been made in the implementation in the three contexts in terms of resources, costs, modalities of implementation? This viability assessment aims to provide essential data to consider the relevance of efficacy evaluation. Indeed, an intervention could be effective but unfeasible or unwilling for cultural, ethical reasons for example. Conducted in a decision perspective, it provides information about what is really feasible, adaptable and scalable in the SoBeezy concept. Hence, the viability study, imbedded in the realistic evaluation, becomes a complement to the efficacy evaluation. Mechanisms, process and viability data collection contribute to provide some recommendations to implement and scale up SoBeezy. This involves a global and complete approach of ageing, a multidisciplinary strategy will be implemented, with both quantitative and qualitative approaches and several disciplines represented: epidemiology, public health, psychology, sociology, cognitics, economy, computer science and statistics. Admittedly, the research becomes more complex! But it also becomes a source of more learning in a perspective of decision and change of practices. It fits more the complexity of the intervention itself.

Conclusion

To conclude, PHIR, and especially AIR, is a question of perspectives, moving concepts, approaches and research methods by the integration of new concepts such as context, mechanisms, viability and theory. This means doing research differently, based on interdisciplinarity and involving the different stakeholders in order (i) to make explicit the theoretical hypothesis underlying the levers used within the intervention (designing the theory), (ii) to anticipate the constraints in implementing the innovation into routine (designing the viability study) with the aim of facilitating the transfer of innovation into practice and transform the organizations. Considering, as such, the complexity of ageing intervention could contribute to change and improve the welfare and health systems to face the current challenges arising from the ageing of the population.

Note

1 "Ageing in place" is defined by the Centers for Disease Control and Prevention as "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level" (www.cdc.gov).

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15 Supporting empowerment of elderly persons with multiple chronic conditions

Evidence for sustainable practice improvement

Elise Verot and Alexandra Lelia Dima

We have reviewed four main directions in which research methods are evolving in France to sustain effective change at multiple levels, and given examples of methods and studies that could be considered as good starting points for future research.

1. Health sciences need to evolve toward interdisciplinarity and build bridges between clinical research, social sciences and health services research.
2. Researchers need to set priorities together with all stakeholders, especially the patients themselves, and engage them at all times of the research cycle, from study design to dissemination and long-term implementation of results.
3. Hierarchies of evidence need to give way to valuing and integrating multiple types of data and research findings produced by quantitative, qualitative and mixed methods.
4. Research needs to be planned proactively to insure successful implementation in clinical practice.

The transformation of healthcare services to address the needs of the elderly with multiple pathologies in France requires advancing in these four research directions, in line with international developments and the specific needs and cultural context of health and ageing in our country.

Introduction

Providing healthcare for an ageing population is a current challenge in France, as worldwide. In 2017, 19 percent of the population living in France was aged 65 or over (INSEE, 2017). In the next 40 years, the number of people aged 75 or over will reach 11.9 million people, more than double that in 2007 (Haute Autorité de Santé (HAS), 2015a). Over 60 percent of these elderly persons live with two or more chronic conditions (Bähler et al., 2015) and need to be constantly and actively involved in efforts to maintain autonomy and health. Loss of autonomy and functional decline is costly for the individual and puts pressure on the limited resources of healthcare systems. For example, in France, the cost of dependency was estimated at $23.7 billion in 2011 (or 1.1 percent of GDP) (Péres et al., 2017). Thus, a major challenge for public health in France is to improve health services to this increasing user group and maintain healthy and independent living in old age.

The French national health authorities acknowledge the challenge of chronic illness and the need to adapt health service delivery to the demographic, epidemiologic and societal changes facing us. The current health strategy (2018–2022) aims to transform the healthcare system toward comprehensive prevention, equal access to care, ensuring quality across the care continuum and user-centered care (French Ministry of Health and Solidarity, 2018). For preventing loss of autonomy, the strategy recommends focusing on changing representations of ageing, raising awareness among healthcare professionals (HCPs) and the elderly of the importance of healthy ageing, promoting social participation, healthy eating and physical activity, and reorganizing services to improve screening and care of the most vulnerable users, especially by moving service provision closer to the living environment and strengthening primary care and social services. This transformation is supported by a strong commitment to continuous quality improvement processes which involve users and insure effective knowledge transfer. An emphasis is placed on the need to focus in initial and continuous HCP training on several competences such as understanding patients' perspectives, adopting multi-professional teamwork values and working in closer collaboration with other professions, as well as to update competences in line with the newest research evidence and clinical practice recommendations. To sustain this systemic change, health services research in France needs an equally transformative change toward a more interdisciplinary and participative approach in closer connection to training and practice.

Current developments in France are aligned to changes occurring internationally. More specifically, many countries have been promoting stronger links between practice, training and evidence and continuous quality improvement, together with building efficient digital infrastructures to support this process. This new paradigm is now known as the "Learning Health System" (LHS) (Friedman et al., 2015; Smith et al., 2012). Following the example of other sectors which have managed to create rapid cycles of knowledge generation and transfer to transform practice, the LHS has been proposed as an answer to the traditional approach to healthcare research, which was criticized as slow and with limited impact on clinical practice. The LHS represents a vision of healthcare where data and knowledge are generated continuously as output of routine care and feedback into service improvement via learning processes at different levels of the system. Beyond the technical challenge of implementing the tools to support this transformation (such as e-health platforms for data collection and sharing), advancing toward an LHS requires new ways of producing research evidence and integrating it into healthcare professional training and practice. Knowledge produced within separate disciplines using selected expertise and single methodologies will likely continue to play a role. However, answering urgent societal challenges requires an inclusive interdisciplinary approach that involves all stakeholders (patients, HCPs, policymakers, etc.), uses multiple methods and types of evidence, and works toward efficient implementation in routine practice.

In this chapter, we present an overview of the transformations that have started taking place in the last years in clinical practice, training and research in France and discuss examples of methods and studies locally and internationally. We highlight the value of using such methods in developing programs to support elderly patients with multiple chronic conditions maintain their autonomy and quality of life.

Healthcare for elderly patients with multiple chronic conditions: evolving practice and training

Addressing the complex needs of elderly patients involves effective coordination of primary and secondary care, medical and social care, and the full continuum of preventive to palliative care. Improving elderly care engages therefore the whole health system and is particularly difficult to achieve. In France, care delivery has been adapted in recent years to address more efficiently the needs of this age group. The French National Authority for Health (HAS) has highlighted the high prevalence of polypathology in the elderly population and issued practical recommendations for its management in primary care (HAS, 2015b). These recommendations target persons over 75 years old at all autonomy levels and rely on an interprofessional approach coordinated by General Practitioners (GPs) aiming for patient empowerment and self-management support, continuity of care and personalized care plans. A notable feature of the HAS guidelines for managing polypathology is the focus on collaboration between professional stakeholders, users' associations and institutional partners (HAS, 2015b).

Interprofessionality is a key feature (and challenge) of other similar recent system-level initiatives promoted by French health authorities. Several national programs have been piloted to improve the care of these users. Some of them do not perform as well as expected, while others have led to a definite change in roles and professional identities, allowing real cooperation between the different primary care professionals.

- ASALEE (a team-based primary care initiative) is an experimental program created in 2004 to improve the management of chronic diseases in the community. In a recent review, Fournier, Bourgeois and Naiditch (2018) noted a heterogeneity of practices. In some regions, this system has generated a paradigm shift in the provision of care; practices have changed, from an approach of individual and prescriptive care management to a paradigm of care based on multidisciplinarity and patient education (Fournier, Bourgeois and Naiditch, 2018). Thus, individual care practices of participating HCPs have evolved toward multi-professional teamwork.
- Another initiative started in 2008, the MAIA (method of action for integrating support and home care services for supporting autonomy) aims to improve care coordination for people aged 60 and older suffering from Alzheimer's disease or neurodegenerative diseases. More specifically, it aims to integrate support and care services by involving professionals and caregivers who support people aged 60 and over who are losing their independence. The purpose of this method is to prevent discontinuity of care, insure that complex situations are adequately managed, implement case management and support the elderly in living in their own homes for as long as possible in the best conditions (CNSA, 2018). At present, local MAIA programs cover 98 percent of French territory. Yet, a recent MAIA assessment report warns that by remaining strictly associated with MAIA, the patients' care pathways are less efficient and can lead to competition between actors or overlapping public policy actions (CNSA, 2017).
- PAERPA (Health pathway for elderly people) is a pilot program in France launched in 2014 in several regions to improve integrated care for older people aged 75 years and older, aiming to support this target group in maintaining autonomy and living at home (Ministère de la santé et des solidarités, 2016). Its role is to strengthen home care, improve coordination of service providers and interventions, secure hospital discharge, avoid unnecessary hospitalizations and insure better use of medications. An initial evaluation showed limited progress, as the non-PAERPA regions obtained results similar to the PAERPA regions, in particular for cumulative length of hospital stay and 30-day rehospitalizations (Op et al., 2018). The authors conclude that such initiatives could only be effective if the professionals involved are ready to change their practices, which is a key barrier to consider (Op et al., 2018).

Thus, a common obstacle to these initiatives aimed at improving healthcare for elderly people with multiple chronic conditions is changing HCPs' practices toward a more collaborative and preventive approach.

In this context of increased pluriprofessionality and change of responsibilities along the care continuum, an overhaul of paramedical and medical training is being implemented. For example, the nursing profession is changing rapidly. Some research training programs are now specific to nurses and other allied health professionals. Since 2019, the Advanced Nurse Practitioner profession is structured within universities and officially recognized at a national level. Paramedical training now includes university-level courses, with the Bachelor's–Master's–Doctorate pathway becoming available. This new organization will facilitate transferability of knowledge from research into current practice, for a better performance of care and support. In the same time, initial efforts are being made toward interprofessional education in order to develop competences of interprofessional practice between medical and paramedical professions. Several recent innovations in teaching have also been implemented to develop HCPs' communication and patient involvement skills, in particular by involving patients in teaching and introducing Medical Humanities courses in initial HCP training (Aires et al., 2018; Fiquet et al., 2015). If sustained in the long term, these initiatives have the potential to empower the healthcare workforce to realize the necessary system changes planned at national level.

What research we need to improve care of elderly patients with multiple chronic conditions?

Despite setting clear directions for change, the French health authorities recognize the lack of knowledge to realize the vision of evidence-based practice (EBP) in service improvement (HAS, 2015a). Even in healthcare and public health domains where abundant scientific evidence has been generated, traditional methods leave a significant gap between research and practice and need to be replaced by a more integrative and pluralistic view of evidence and practice improvement (Glasgow and Emmons, 2006). In research on elderly care, due to the complexity of the system changes mentioned above, several elements need to be considered to produce EBP. First, health sciences need to evolve toward interdisciplinarity and build bridges between clinical research, social sciences and health services research. Second, researchers need to set priorities together with all stakeholders, especially the patients themselves, and engage them at all times of the research cycle, from study design to dissemination and long-term implementation of results. Third, hierarchies of evidence need to give way to valuing and integrating multiple types of data and research findings produced by quantitative, qualitative and mixed methods. Fourth, research needs to be planned proactively to insure successful implementation in clinical practice. Initial steps have been made on these four fronts in France in the last years. We describe them below and give examples of research topics and studies to illustrate the value of these approaches.

Interdisciplinarity: the role of social sciences in health services research

There is increasing awareness in health sciences research that, for medical innovations to be transferred in clinical practice and effectively improve health of citizens, numerous disciplines need to be involved. Moreover, improving and maintaining health is not only a matter of providing effective therapeutic agents or technology, but a complex interplay of human interactions addressing physical, psychological, social and environmental influences on the well-being of individuals and groups. Generating evidence for better clinical practice is therefore necessarily interdisciplinary. It is now widely acknowledged that implementing new practices and/or changing existing practices within an organization or a system requires changing individual and collective behaviors (Atkins et al., 2017). Behavioral sciences, and social sciences in general, are therefore increasingly integrated in health services research to support system change in France and internationally. Moreover, given the breadth of services and professions involved in supporting autonomy and health in the elderly, realizing change in services for this population requires not only a focus on individual and organizational behaviors, but also a profound restructuring of how older age and patient–provider relationships are perceived by society at large. Thus, the national health strategy considers changing representations of ageing and health, as well as roles and responsibilities for maintaining health, as key priorities for the near future. On these two topics, social science research has an important contribution.

Ageism is found both at the institutional and individual level and appears to be omnipresent in our modern society; elderly people are commonly stereotyped as “lonely, depressed, incompetent, asexual, intellectually rigid, sickly and senile” and they expect to be confronted with such stereotypes in medical consultations (Macrae, 2018). Health sociologists, elderly advocates and the elderly themselves have been denouncing the high prevalence of ageism in healthcare for several decades (Greene et al., 1986). HCPs may be more likely than the general public to develop negative attitudes toward ageing, as they commonly encounter elderly people suffering from chronic disease while “healthy” older people are generally not part of their active patient list (Greene et al., 1986). Three decades of research on the phenomenon indicate that HCP attitudes toward older adults have not changed substantially (Macrae, 2018). An interview-based survey of French adults aged 60 years or over indicated that 38 percent of respondents considered that French society perceives the elderly rather negatively, explained this perception by a lack of respect and support and many expressed themselves self-stereotyping (Macia, Chapuis-Lucciani and Boetsch, 2007). These perceptions were not related to respondents’ socio-demographic characteristics such as age, gender, level of education, marital status, living at home or in nursing home, or their autonomy in daily activities. Moreover, respondents reporting age stereotypes tended to report worse subjective health status, which was also strongly associated with dependency and education level. In an experimental study, French older adults exposed to negative age stereotypes were less willing to take risks, reported lower subjective health and extraversion, felt more lonely and requested more help compared to those exposed to neutral or positive stereotypes (Coudin and Alexopoulos, 2010). These results strongly suggest that dependency in old age is also a result of ageism, and a change in mentalities at a societal level, as well as specific training to HCPs to adopt positive representations of ageing and improve their communication skills, should be part of the efforts toward improving quality of life and autonomy in the elderly.

Changing attitudes on ageing toward a more positive discourse that describes the elderly as active, resourceful, socially connected individuals can be considered as part of a more general trend of shifting responsibilities toward self-care, as health services are restructured from a focus on acute care in highly specialized hospitals toward chronic care in the community. As length of hospital stays decreases, patients are required to navigate complex care pathways that involve many providers in the territory and take an active role in their care. By contrast, the hospital culture traditionally positions the patient in a passive role in relation to HCPs involved in their care; promoting new ways of interaction consistent with chronic care, such as the introduction in 2009 of Therapeutic Patient Education in France, has required sustained efforts in changing representations of all actors involved (Obertelli et al., 2015). Support for empowerment and patient-centered care are terms commonly used to represent an approach to healthcare in which patients are supported to participate in choosing, planning and implementing their treatment depending on their needs, preferences and individual situation. This approach is already used in common practice in many countries, yet it is not yet widely implemented in France (Härter et al., 2017). Patient participation has increased in recent years throughout Europe, particularly for younger people and those suffering from chronic conditions; however, the term is still commonly understood as following treatment recommendations within a more traditional paternalistic patient–provider relationship, shared decision-making is perceived by many as time-consuming and a potential source of conflict, patient–provider communication skills are limited, and many HCPs and patients find it difficult to share responsibilities for health-related goals and choices (Commission européenne, 2012). In France, the current organization of nursing care tends to maintain a paternalistic and prescriptive way of care regarding patients suffering from chronic diseases (Verot et al., 2019).

To date, social science research on this topic in France has been mainly limited to observational and descriptive studies, both qualitative and quantitative. We can identify therefore a strong need for this research to be followed up with interventions for enacting change in clinical practice, whether media campaigns for encouraging positive ageing attitudes, initial and continuous training for HCPs and allied professions on reinforcing perceptions of the elderly as resourceful, or individual or group interventions to support attitude and behavior change in the elderly themselves, in healthcare facilities or in the community. While many such initiatives are currently promoted by public and associative organizations, accompanying them with appropriate research and evaluation would increase efficiency in the long term by building the necessary evidence base.

Engaging older adults in the co-construction of healthcare services and research

Engaging stakeholders in the transformation of healthcare systems has been promoted lately in many countries, on both ethical and operational grounds, and in close connection with the patient empowerment movement described above. A realist synthesis performed by a Canadian team aiming to engage frail older adults and their caregivers in this research has identified numerous frameworks used in different contexts to describe how, why and where engagement takes place (McNeil et al., 2016). They integrated these frameworks into a program theory for engagement of older adults, which consists of five steps. Briefly, they propose that, for effective engagement, investigators need to (1) identify and address environment-specific constraints and opportunities, such as policy documents, organizational support, and adapting location and timing of meetings to age-related challenges, (2) know the characteristics and preferences of the target group and plan to insure diversity and meet expectations, (3) establish relationships by being flexible and encourage informal open exchanges, (4) build these relationships sustainably based on shared objectives for research and planning and regular co-evaluation of the engagement strategies; and (5) insure smooth transition between projects by providing sufficient and accessible information for continued engagement. This structured process enables participants to choose their desired level of engagement based on long-term relations of trust with investigators.

While this methodology has been formalized primarily in the United Kingdom, Canada and the United States, it has strong similarities with the use of community-based participative research in healthcare (Demange, Henry and Preau, 2012). This approach was developed in France in the last three decades particularly in relation to research initiatives from community-based organizations mobilized against the HIV/AIDS epidemics and expanded to other health conditions and specific user groups. It gives a central role to partnerships between research participants, researchers and policymakers to produce knowledge that is more relevant, timely, efficient and ethical. Several large-scale online initiatives to engage healthcare users and the general public such as Seintinelles (Bauquier, Pannard and Préau, 2017) and ComPaRe (Tran et al., 2019) have helped prioritize research questions and boost research participation. At policy level, the voice of patients, many of them elderly with multiple chronic conditions, are heard via the involvement of patient associations. However, as detailed by McNeil et al. (2016), older adults require adaptations of these methods for effective engagement, particularly to address practical constraints and achieve real integration of needs and expertise at all stages of a research or practice improvement project.

One example of research on methodology development for patient engagement is a study conducted in primary care by a Canadian team (Haesebaert et al., n.d.). The researchers aimed to develop and test a six-session (12-month) protocol for involving users in practice improvement initiatives following a participatory action research cycle (EQUIPPS) consisting of four steps: setting priorities (reflect), planning relevant actions given the local context and influencing factors (plan), implementing these actions (act) and assessing impact on practices (observe). This process was followed by a team of 12 patients/caregivers, one HCP (GP or nurse) and one manager, to insure representation of relevant stakeholders in this particular setting. Feasibility was assessed in terms of process, resources, management and research using both quantitative data. Pilot work has evaluated EQUIPPS as a feasible framework for such contexts and could be further adapted to French primary or secondary care settings.

Thus, while an approach specific to elderly populations is still to be developed in France, several elements exist in work with other user groups and can be adapted to research with elderly persons. Following the Canadian examples, successful implementation of this patient engagement resides in a systematic process of building and maintaining long-term relationships.

Mixed methods: qualitative and quantitative evidence for understanding and changing practice

Researchers have been using quantitative and qualitative methods for decades, yet the mixed-method methodology has only recently been formalized and presented as a standalone research paradigm (Burke Johnson, Onwuegbuzie and Turner, 2015; Creswell and Plano Clark, 2011). Quantitative and qualitative research have often been described as opposites in more traditional views of research as a source of disciplinary expertise, but in the context of increasing interdisciplinarity and stakeholder dialog mixed-methods research has gained traction. The need for understanding both quantitatively and qualitatively the experience of care from the perspective of all actors involved becomes even more prominent in ageing research, given the complex network of contributors in health and social care that requires particular attention to both personal experience and interactions, and population level phenomena. Numerous design options are available to structure data collection, analysis and interpretation either consecutively (sequential, transformative and multiphase designs) or simultaneously (convergent and embedded designs) (Creswell and Plano Clark, 2011). The distinguishing feature of mixed-methods research is that, instead of concatenating results, it combines different elements (which can be data, viewpoints, methods) in order to amplify understanding (Burke Johnson, Onwuegbuzie and Turner, 2015). Thus, they are particularly appropriate for accompanying change on multiple levels.

One inevitable change for healthcare systems is adapting to increasingly prevalent technology. In research with older adults, telemedicine and home care technology requires substantial testing for best results as often technology represents a barrier in accessing care. A research program involving mixed methods has been developing in France around the use and acceptability of Social Assistive Robots (SAR) for the elderly and their careers. A mixed-methods study using survey and focus group data investigated acceptability by three potential user groups – persons with cognitive impairment, informal caregivers and healthy older adults – of several SAR designs and use scenarios (Pino et al., 2015). Combining qualitative and quantitative data (e.g., by comparing the proportion of occurrences of relevant themes in the three groups), the authors were able to also point to different priorities, such as increased usability concerns from caregivers, and rejection of human-like SARs by healthy elderly but not by other groups. Another study by the same team used a Living Lab set-up to assess actual interactions with a SAR via questionnaires, interviews, usability-performance measures and focus group methods (Wu et al., 2014). This approached allowed researchers to capture a range of conflicting attitudes and beliefs about SAR use: on one hand perceived ease of use and amusement, yet on the other low intention to use and perceived usefulness, as well as barriers related to stigmatization and ethical/societal issues. Developing technology that provides long-term benefits and is sustainably integrated in patient care requires further testing with other actors in the healthcare ecosystem and obtaining multiple types of evidence throughout development and implementation. Mixed-methods approaches are particularly appropriate for this type of applied research.

While methodological literature on mixed methods is still limited in France, examples of their application in various healthcare domains are increasing, including studies with older adults. As with patient engagement protocols, conducting such research needs to take into account the specificities of this population by adapting quantitative and qualitative data collection to their preferences and practical constraints. Careful project planning needs to be based on solid theory and prior evidence at design stage, and expectations of participants appropriately managed throughout the whole process of developing and piloting of care innovations.

Implementation science: producing evidence fit for practice

Implementation science is a new discipline that emerged from criticisms regarding the lack of impact of research evidence on clinical practice. It aims to facilitate the transfer of new research knowledge in routine practice by understanding the clinical context of knowledge utilization and identifying and addressing barriers to uptake of evidence-supported tools and practices. Implementation science has been enriched with theoretical approaches to address different implementation challenges and has produced its own theoretical frameworks or models (Nilsen, 2015). In an international survey conducted among 223 researchers, more than 100 different implementation theories were reported to be used, from different disciplines: implementation science, health behavior, organizational behavior, sociology and management. Choosing among all these different models could be confusing for research teams, therefore the authors propose a list of criteria that researchers could use to make and justify their theory choices, while acknowledging the possibly limited benefit of prescriptive guidance given the diversity of scientific objectives and priorities (Birken et al., 2017).

To insure successful and sustainable deployment of evidence-based quality improvement initiatives, it is essential to understand the barriers and facilitators associated with the relevant behaviors (Curtis et al., 2017). The Theoretical Domains Framework (TDF) is a framework increasingly used by research teams worldwide (Birken et al., 2017) and helps identify barriers and facilitators for behavior change, including the transfer of EBP in routine practice (Cane, O'Connor and Michie, 2012; Michie et al., 2005). Linked to the COM-B model and the Behaviour Change Wheel (BCW), it can also be used to address barriers to interprofessional practice (Atkins et al., 2017). The initial TDF version consists of 12 theoretical domains grouping numerous behavioral determinants (Glasper and Rees, 2016): (1) knowledge, (2) skills, (3) social/professional role and identity, (4) beliefs about abilities, (5) beliefs about consequences, (6) motivation and goals, (7) memory, attention and decision processes, (8) social context and resources, (9) social influences, (10) emotional regulation, (11) behavioral regulation and (12) nature of behavior (Michie et al., 2005). These domains can be further condensed into three sources of behavior forming the more recent COM-B model, which stipulates that human behavior (B) results from the interaction between personal physical and psychological abilities (C), to exploit social and environmental opportunities (O) through reflective and automatic motivation (M) (Alexander, Brijnath and Mazza, 2014). Each TDF domain can be mapped onto one component of the COM-B model, which can be used to further structure and simplify the classification of behavior determinants and link to relevant actions at different moments in the research process. Based on a review of 19 intervention frameworks, the BCW was built around the three components of the COM-B and proposes several intervention functions and policy categories for intervention developers to consider in order to insure the best implementation of the change of practices envisaged (Michie, Atkins and West, 2014). It specifies theoretical links between nine functions (e.g., education, environmental restructuring, enablement) and seven policy categories (e.g., service provision, guidelines, environmental/social planning) which intervention developers can choose to act upon the behavior determinants previously mapped on the TDF and COM-B.

In France, implementation science is beginning to develop. For example, the TDF and its associated tools, the COM-B and BCW, have proven useful in a quality improvement initiative we are currently conducting on patient empowerment in an oncology context. In chronic disease, patient empowerment has been a key goal for several years. Specifically in oncology, the importance of long-term self-management by patients and their daily decision-making regarding their treatment, physical activity or diet are major concerns in the management and support of patients (Casalino, 2005; Lorig et al., 2001). An assessment tool measuring patient empowerment is being prepared for deployment in routine oncology nurse practice at several hospital sites. Nurses would use this tool to adapt the management of, and thus provide tailored support for, patient empowerment. To insure a good fit with the current routine care processes, we conducted a preliminary study to understand the social representations of HCPs involved in cancer care toward patient empowerment and the possible use of this tool. (Verot et al., 2019) Thus, a qualitative study was carried out in three cancer treatment centers representative of the cancer treatment offer in the territory.

The 12 TDF domains represented the basis of our interview guide as we aimed to understand EBP implementation issues during semi-structured interviews with physicians, nurses, psychologists and nutritionists involved in the care of patients undergoing cancer treatment. We followed published recommendations regarding the analysis of TDF-generated data for studying implementation issues (Atkins et al., 2017) and performed two analyses using Nvivo 11 pro (QSR international). The first analysis was deductive; it consisted of reading the participants' responses, assessing their relevance to the definitions of the domains and then assigning them to one or more domains. This analysis aimed to identify the determinants to map on the COM-B model and the BCW in a following stage in order to adapt the tool implementation to the clinical context. The second analysis was an inductive one, consisting of analyzing the same data to find out more about the representations of the professionals interviewed. Using the TDF enabled us to identify three major domains that were perceived by participants as having a major influence on the implementation of new nursing practices: "Environmental and contextual resources", "Social influences" and "Beliefs about consequences". These results indicated that implementing these practices must address barriers categorized under these three domains, all of which corresponding to the COM-B reflective motivation component. Thus, we subsequently used the COM-B model and the BCW to design and deliver a short course tailored to the caregivers involved and the context of their practice. This course now incorporates the intervention categories recommended by the BCW to counter the barriers inherent in the three domains, including an education component, a persuasion and incentivization component, followed by a practical training phase.

The TDF proved effective in collecting a broad range of representations within an acceptable timeframe for HCP practice (Godin, 2012), which is important particularly given the limited time HCPs can allocate to research. Our example highlights the need and usefulness of taking a theoretical framework such as TDF linked to the COM-B model and the BCW to detect obstacles and facilitators to the transfer of EBP in routine care practice. This makes it possible to design a tailored intervention to insure better acceptability of new care protocols deployed in nursing practice. Changing individual and collective behaviors is best prepared using implementation science methods as presented above, in order to guarantee good conditions for deployment of new practices and to promote their adoption and sustainability. Although to our knowledge such methods have not yet been used in service improvement programs targeting specifically the elderly, we expect their use to increase in the next years.

Summary and conclusions

In relation to the recent developments in healthcare practice and training, we have reviewed four main directions in which research methods are evolving in France and internationally to sustain effective change at multiple levels and given examples of methods and studies that could be considered as good starting points for future research. Interdisciplinarity is increasingly valued, in particular social science approaches to understanding societal perceptions of ageing and empowerment. Multiple stakeholder engagement frameworks have been proposed and applied to elderly healthcare users worldwide and need to be adapted and implemented in French research and practice. Mixed-methods designs are increasingly being applied in order to combine different types of complementary evidence for developing new care protocols and tools. Implementation science is emerging as a rich set of practical tools for generating evidence that can guide organizational change processes at different levels of the healthcare system. The transformation of healthcare services to address the needs of the elderly with multiple pathologies in France requires advancing in these four research directions, in line with international developments and the specific needs and cultural context of health and ageing in our country.

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16 Promotion of physical activity among older adults

Is social marketing an effective method?

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Social marketing is "the adaptation of commercial marketing technologies to programs designed to influence the voluntary behavior of target audiences to improve their personal welfare and that of the society". Social marketing is one of the most widely used methods for promoting behaviors that benefit the health of the population. That social marketing is effective has been proven in certain interventions and certain populations, such as smoking prevention as well as obesity prevention among young people. Although this method has shown its value in other contexts, its use and evaluation in getting seniors to take part in regular physical activity (PA) remains limited. This chapter presents a literature review conducted to identify interventions using the social marketing method to promote PA among elderly people. Our aim was to analyze whether social marketing can have potential to promote PA among elderly people.

As shown in this literature review, social marketing may have the potential to be effective for promoting PA among seniors. However, further research is needed since the studies we identified are not amenable to meta-analysis.

Introduction

Population ageing is the result of a falling birth rate and a rising life expectancy. Between 2015 and 2050, global projections show that the proportion of over 60-year-olds in world population should rise from 12 to 22 percent, representing nearly two billion people (World Health Organization, 2018).

Although increasing our life expectancy is important for humanity, so too is preserving functional autonomy to maintain a certain quality of life and manage health resources (Lau, Ohinmaa and Johnson, 2011).

Falls are the primary cause of death among over 65s, affecting one in three people in this age group (Gillespie et al., 2012). Physical activity (PA) represents the most effective method for preventing falls among older citizens (Gillespie et al., 2012; Grossman et al., 2018) while PA interventions focusing on balance are the most effective way of preventing loss of autonomy among older adults living at home (Liu-Ambrose et al., 2019; Sherrington et al., 2017).

However, though there is now agreement that PA is effective in practice, there are many barriers to participation (Hughes et al., 2005; Schutzer and Graves, 2004). Indeed, several such barriers exist among the elderly, such as a belief of no longer being able to participate because of a loss of physical capacity, an image of sport as being for young, healthy people, and poor awareness of the tailored activities on offer. That is why, all in all, only a small number of older adults participate in PA for fall prevention (Bongue et al., 2016).

Social marketing is one of the most widely used methods for promoting behaviors that benefit the health of the population (Gallopel-Morvan, 2014). That social marketing is effective has been proven in certain interventions and certain populations, such as smoking prevention as well as obesity prevention among young people (Stead et al., 2007). As regards PA, authors have identified a number of effective techniques for promoting it among older adults (Zubala et al., 2017). One of these is social marketing, which involves “the adaptation of commercial marketing technologies to programs designed to influence the voluntary behavior of target audiences to improve their personal welfare and that of the society” (Andreasen, 1995). The social marketing method is based on seven criteria. These are the aim of the intervention, analysis of the target audience, segmentation, exchange, marketing mix, competition and assessment (Hastings and Domegan, 2017).

Although this method has shown its value in other contexts, its use and evaluation in getting older adults to take part in regular PA remains limited (Fujihira et al., 2015). Our aim was to conduct a systematic literature review on the use and potential effectiveness of social marketing in interventions to promote PA among over 60-year-olds.

Method

We analyzed social marketing interventions aiming to increase PA among over 60-year-olds whose results were published in French or English in peer-reviewed journals between January 2008 and July 2019.

Web of Science, MEDLINE and EBSCOhost were the three databases analyzed. The keywords used were: physical + activit* or exercis* *and* intervention* or Randomized Controlled Trial or trial or evaluation or campaign* or program* or study or studies *and* social marketing.

Papers were selected for analysis if the interventions presented used some or all of the social marketing approach as defined by researchers in the field (French and Gordon, 2015; Hastings and Domegan, 2017; Lee and Kotler, 2016). Specifically:

- Behavioral change was the primary objective of the intervention (i.e., increase PA).
- Qualitative and/or quantitative studies were conducted on the target audiences to better understand their characteristics, habits and needs.
- The target audience was segmented based on various criteria (sex, social background, etc.) and specific interventions were offered to the segments identified.
- The exchange concept was implemented. In other words, in return for changing behavior, individuals were offered “benefits” and advantages to motivate them to take part in more PA, for example a financial or material reward in line with an indicator of change.
- The marketing mix was implemented on the ground, i.e., commercial marketing tools were used to achieve the objectives of promoting PA. There are five such tools: Influencers (work with partners on the ground, like associations, companies), Behavior (recommend and facilitate the adoption of the behavior), Cost (offer financial support mechanisms to combat financial and/or psychological barriers to adopting the behavior), Ease of Access (facilitate access to services or products that enable a change in the target behavior), and Communication (promote the behavior through the use of communication tools) (Gallopel-Morvan, 2014).

- A competitor analysis was performed (and factored into the program) to identify any issues that could hinder the adoption of the proposed change to increase PA, for example the existence of other organizations and/or competing programs.
- An assessment of the program.

The interventions selected in our paper had to have implemented at least four of the seven benchmark criteria of social marketing identified by researchers in the field. The exclusion criteria were: papers that did not use the social marketing approach, interventions aimed at children and adults under 60, and interventions that did not target PA.

All papers were compiled using Zotero 5.0.73. Their titles and abstracts were then studied. In the end, of 505 documents selected from the databases, only eight met our chosen criteria, to which one additional paper meeting the inclusion criteria was added (see Appendix 3). These nine papers corresponded to six interventions.

Results

Of the six interventions selected, five (DiGuiseppi et al., 2014; Kamada et al., 2018; Varma et al., 2016; Wilson et al., 2015; Withall, Jago and Fox, 2012) had a positive effect on participants, increasing participation in the activities offered and/or increasing the level of PA. One study was not assessed (Newton et al., 2015).

Of the studies selected, two specifically targeted over 60-year-olds (DiGuiseppi et al., 2014; Varma et al., 2016) whereas the others segmented the population into subcategories, one of which was over 60-year-olds.

Behavioral objective. The five interventions that had a positive effect on PA developed programs oriented toward specific goals. Carolyn DiGuiseppi et al. (2014) aimed to increase the attractiveness of balance classes for over 60-year-olds in selected churches. Dawn Wilson et al. (2015) aimed to improve the social and physical environment of low-income African-American communities in the study area, specifically via the promotion of walking. Janet Withall et al. (2012) conducted a study that aimed to increase recruitment and adherence in a PA program in a low-income area. Masamitsu Kamada et al. (2018) aimed to increase the proportion of people aged 40 to 79 participating in aerobic, flexibility and/or muscle-strengthening activities in Unnan, Japan. Lastly, Vijay Varma et al. (2016) aimed to increase walking levels among over 60-year-olds recruited as volunteers into public schools in the US city of Baltimore.

Population analysis. The five interventions conducted interview-based market studies to define the needs, barriers, etc., of the population. Withall et al. (2012) employed a mixed method, using a questionnaire to assess people's motivation to take part in group PA along with group interviews.

Segmentation. Of the five interventions that had a positive effect, three reported the use of segmentation. In the study by Withall et al. (2012), the segmentation criterion was sex. The target population mainly comprised women educated on the benefits of PA. The intervention focused on reducing barriers such as the fear of going to an activity alone. In the study by Wilson et al. (2014), two of the main segmentation criteria were being African-American and being aged over 18 years old. Lastly, in the study by Kamada et al. (2018), the researchers used a model to determine a primary communication target segment. Women aged 60 to 79 years were the primary target of their study.

Exchange. The five interventions implemented the exchange concept by using incentives. In the study by DiGuiseppi et al. (2014), participants received $5 if they took part in the classes on offer, while the leaders of the churches involved in the program received gift cards worth $55 to thank them for their churches' participation. The church leaders were tasked with facilitating the transmission of messages and communications to the study's target audience. Withall et al. (2012) offered the first six weeks of sessions free of charge in their intervention, after which the price rose to £1 per session. A low price was used to attract low-income individuals to the sessions. In the study by Wilson et al. (2015), participants received a $20 gift card for each assessment period as well as a $40 gift card for the assessment at 24 months. Lastly, in the study by Varma et al. (2016), participants received financial compensation for the time they volunteered as well as $25 for taking part in an assessment and $10 for a telephone interview.

Marketing mix. The five interventions used the marketing mix principles to set up their program. For example, in the intervention by DiGuiseppi et al. (2014), the "product" was a fall prevention class, while the communication involved distributing flyers or newsletters promoting these classes. They selected churches as their location to facilitate access to the target audience, and the cost of the classes was $20. Cost is one of the psychological barriers to taking part in PA, but it is important to remember that this cost includes more than just the admission fee. It also includes the number of sessions, their frequency and the distance from home, not to mention the fear of falling or aggravating existing pain. To reduce these barriers to their program, the classes of DiGuiseppi et al. were conducted in a "safe, comfortable environment", with regular classes on offer at times suited to the intervention's target audience.

Competition. The intervention by DiGuiseppi et al. (2014) was the only one that identified a facility that competed with their program. That facility was a wellness center offering exercise programs for over 60-year-olds.

Assessment. Of the interventions that had a positive impact on changing PA habits, that of Wilson et al. (2015) assessed participation data and psychosocial data from participants at baseline as well as at 12, 18 and 24 months after the intervention. They revealed that uptake was higher among PATH trial participants who received information on the PA program. Walking attendance was greater among these participants than among those who received no information. Over a period of nine months, the number of walkers rose from 40 to 400 per month in the social marketing intervention group (Wilson et al., 2015).

Withall et al. (2012) showed that enrollment in the different PA classes (dance, gym and balance sessions) had increased since the start of the program, that attendance levels were steady and that adherence was good.

Varma et al. (2016) reported an increase in walking among women in the social marketing intervention group, with their daily step counts rising by a mean of 1500.

Kamada et al. (2018) showed that their intervention increased the level of each type of PA promoted in their target population. That was a five-year study, with the first positive results having appeared progressively over a period of several years.

DiGuiseppi et al. (2014) aimed to assess class participation and information retention by participants. Their intervention showed that the program implemented in the churches succeeded in motivating older adults to join PA classes. The participants were also more likely to remember information about fall prevention.

Table A4.1 (Appendix 4) shows an assessment of the use of the seven social marketing benchmark criteria as defined by researchers in social marketing. None of the six interventions selected for this literature review implemented the entire social marketing approach. In other words, none met all of the seven criteria presented above. Four of the six interventions employed six of the criteria (DiGuiseppi et al., 2014; Kamada et al., 2015, 2013;

Wilson et al., 2015; Withall et al., 2012), one intervention employed five (Varma et al., 2016) and one employed four (Newton et al., 2015).

Discussion and conclusion

This systematic literature review aimed to ascertain whether using social marketing in interventions to promote PA among over 60-year-olds was useful for improving the effectiveness of programs. Our study shows that social marketing has the potential to be effective in promoting PA among older adults. Our results are in line with those in the literature (Baril and Paquette, 2016; Fujihira et al., 2015). So far, very few studies have been published on this topic. In fact, only nine papers representing six interventions were identified in the scientific databases. Of these six, five concluded that social marketing was useful for promoting PA among the elderly. The five studies that reported a positive assessment of their programs believed their success to be mainly due to three factors, specifically: the use of social marketing techniques through the implementation of a number of criteria; the funding of the activities, which made it possible to tackle financial barriers; and the building of social ties between participants in the programs, which provided them with support and interaction. For instance, Varma et al. (2016) suggest that walking levels increased among women because they were taking part in a new voluntary activity. Kamada et al. (2013, 2015) state that their studies did not succeed in demonstrating an increase in PA levels at one and three years because the program's approach was not comprehensive enough. For that reason, they suggested that a strategy of modifying the environment by improving the public transport system and building facilities specifically for PA could facilitate the meeting of recommended PA levels. And yet at five years after the launch of the study, Kamada et al. (2018) showed that their intervention had had a positive effect. The study by Newton et al. (2015) has not yet been analyzed.

The interventions identified in our systematic review all used the marketing mix and its "4Ps": Price, Place, Promotion and Product. The 4Ps represent a group of operational areas for which strategies need to be developed. However, there is currently debate. For instance, Gallopel-Morvan (2019) believes that the 4Ps may be more suited to commercial than non-commercial marketing. Instead, they advance five criteria (Influencers, Behavior, Cost, Ease of Access and Communication) potentially more suited to social marketing and behavioral change.

It is difficult to say whether social marketing is useful in promoting PA among older adults since none of the six interventions selected used the entire approach (i.e., all seven benchmark criteria). Yet Haruka Fujihira et al. (2015) showed that the more a program uses the social marketing benchmark criteria defined by A.R. Andreasen (1995), the more it becomes effective at changing the behavioral habits of target audiences. Literature reviews such as those by Carins and Sharyn Rundle-Thiele (2014), Pang, Kubacki and Rundle-Thiele (2017) and Stead et al. (2007) have classed social marketing interventions according to the same benchmark criteria as Andreasen, and have reported similar findings to those of Fujihira et al. (2015). Hence further studies that implement the seven benchmark criteria identified in this literature review are needed to assess the potential effectiveness of this technique of social marketing.

Additionally, the papers that we selected in this review comprise certain limitations in terms of assessment method, group heterogeneity and contamination risk. The assessment models chosen preclude any definite direct attribution of the positive results to any one part of the intervention or any combination of activities. In a number of studies, discrepancies between the intervention and control groups interfered with the assessment of change between them. Withall et al. (2012) suggested that the groups had differences (particularly in terms of age and ethnic origin) which prevented them from making direct comparisons during the assessment. Kamada et al. (2015) thought that the results of their study were contaminated because the control group may have been exposed to the social marketing campaign developed for the intervention group. This may have been due to the geographical proximity of the groups and word-of-mouth. What's more, the criteria selected for assessing the prevention programs were not always the same, making it difficult to compare the interventions, or were insufficient to measure effectiveness. For instance, in the study by Withall et al. (2012), the criteria only gauged PA program participation, without measuring PA levels, PA intensity or biological markers.

Different age groups (children, adults, older adults) have specific characteristics and guidelines in terms of public health and necessitate that separate social marketing interventions be designed for each one. Given both the paucity of studies on using social marketing principles to promote PA in older adults as well as the lack of conclusive evidence in those studies, it may be wondered whether the use of social marketing is appropriate in the geriatric population, particularly where PA is concerned (Fujihira et al., 2015).

Demographic projections show that the population of over 60-year-olds may represent nearly two billion people between now and 2050 (World Health Organization, 2018). Since PA has been identified as one of the effective interventions for healthy ageing (Lamboy et al., 2018) and since a large proportion of older adults are not active enough, targeted social marketing programs could help prevent numerous health problems associated with inactivity (Fujihira et al., 2015; Taylor, 2014). As shown in this literature review, social marketing may have the potential to be effective for promoting PA among older adults. However, further research is needed since the studies we identified are not amenable to meta-analysis. This is because the heterogeneity of the backgrounds of the studies selected along with the differing measures of their results render the standard methods of meta-analysis impracticable.

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17 Preserving autonomy and quality of life of the elderly

The contribution of French gerontopoles

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This chapter is based on a double qualitative methodology since it consists of both a review of the scientific literature and institutional texts as well as interviews with key players of the French gerontopoles and local structures working in the field of ageing of the population. Interviewing key players of gerontopoles allowed us to obtain a general view of these structures, while the local structures gave us a vision that is more specific to each territory and more critical of these new organizations. The semi-structured interviews, which were conducted with an interview guide based on the literature review, clearly identified theoretical approaches and feedback from the field. They were transcribed and analyzed in their entirety.

The review of the literature allowed us to identify the issue of the ageing of the population as well as the various policy areas developed in France to respond to this demographic transition. We were therefore interested in the 2015 law "adapting the society to ageing", which led to the creation of the gerontopoles.

The purpose of this chapter is to present and understand the functioning of French gerontopoles, their missions and their organization to identify representations related to these structures.

Introduction

Effectively managing the ageing of our population, providing home care services for people made vulnerable by ageing and improving the quality of life of our elderly is a major public health challenge. The spectacular increase in life expectancy seen lately has led to a growing number of people reaching very old age (Champio et al., 2018). By 2050,[1] the number of dependent elderly will have doubled according to the worst case estimations of the Libault Report (2019), and with this looming disaster, doubts are raised concerning institutional capacity to handle the demand, as well as families' ability to afford care. Building awareness of this evolution among our society's agents proves to be essential if we are to help make people conscious of this demographic transition and offer our elderly a better quality of life. Among the French, life expectancy is growing, while the age at which health deteriorates is remaining the same, only slightly increasing (INSEE, 2019); De Lapasse, 2018). The care provided for dependent elderly in institutions (nursing homes, sheltered accommodation) is rarely preferred by the elderly, who most often express desires to stay at home, within their social community and cultural surroundings. The choice to remain at home is initially left to the person concerned,[2] yet is also influenced by factors governed by politics. As early as 1962, for example, the Laroque Commission Report revealed growing poverty among the elderly and identified "home care" as a factor that could encourage and bolster a “third life stage of active, independent, and participatory living” (translation; Grand, 2016). Public healthcare policies (French law relating to social and medical-social institutions [1975]; *rapport vieillir demain* [ageing tomorrow] [1980]; Defferre Law [1982]; *Allocation Personnalisé d’Autonomie* [the French autonomous living benefit scheme] [2001] …) progressively took the lead in ageing issues so as to improve how the elderly are treated and help insure healthier ageing at home. With the arrival of the 1980s, there came recognition of unofficial care, the role of family and friend carers, and a will to support them. It was not until 2015 that the *loi d’adaptation de la société au vieillissement* (French Act on adapting society to an ageing population) (ASV) was made public, instigating a number of care services to be implemented, as designed to anticipate loss of autonomy, adapt society to ageing and accompany those suffering from loss of autonomy. This Act aimed “to enable all to benefit from the best possible social, economic, and healthcare conditions, for as long as possible, as life expectancy increases” (translation; ASV Act, 2015).

This demographic evolution was thus accompanied by economic, societal and scientific transitions requiring the participation of different regional bodies working in the field of

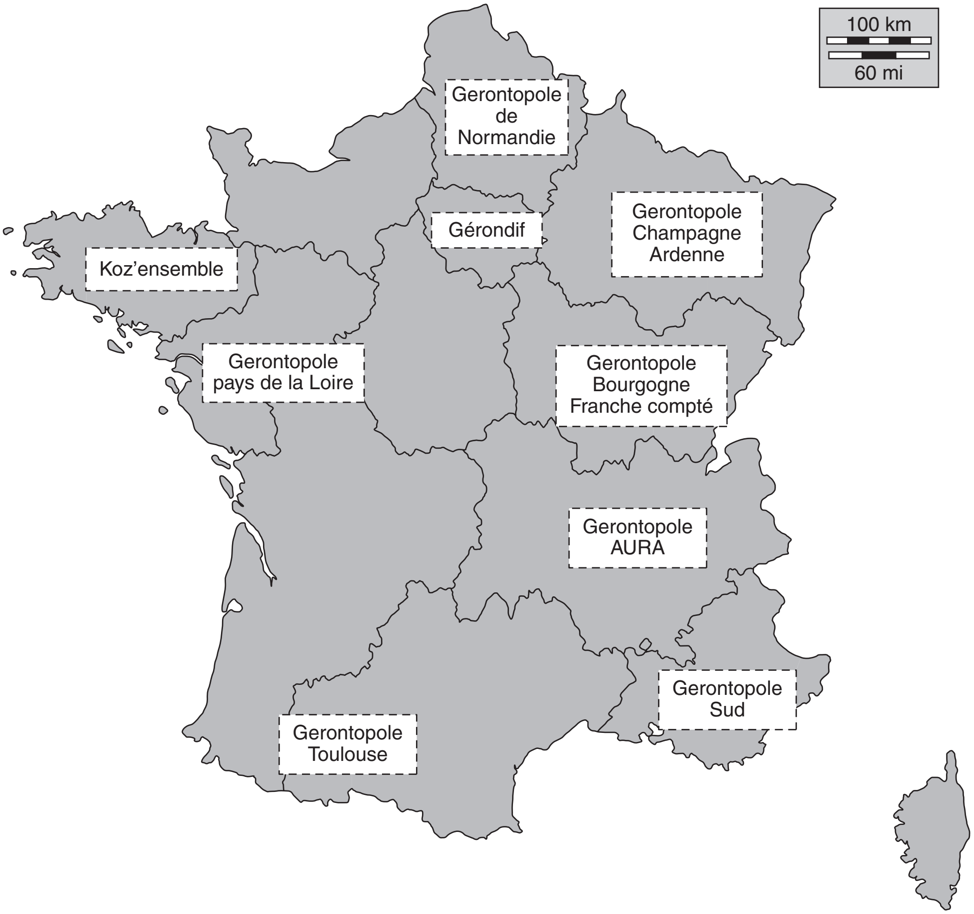

Figure 17.1 The gerontopoles of France.

the elderly. The creation in France of gerontology-dedicated clusters, called "gerontopoles",[3] was in order to respond to this need, "to develop all necessary services allowing to 'avoid the avoidable' in ageing and implement services to treat frailty and maintain elderly autonomy: early detection and management of frailty in the elderly/prevention of age-related disease and loss of autonomy" (Gonthier, Achour and Geffroy, 2015, translation).

Numbering nine centers in total in 2019,[4] these gerontopoles are designed to facilitate sharing of experience, research and innovation relating to ageing, while reducing social and territorial healthcare inequalities. Their mission is

> to bring together and galvanize action on ageing among professionals working in research, healthcare (hospitals, city institutions, medical-social centers …), training, and business. They seek to facilitate the transfer of research and technological development ("silver economy") to age-related healthcare, medical-social management, and services.
>
> (translation; ASV Act, 2015)

The gerontopoles thus have a dual purpose: (1) to improve the quality of life of the elderly; (2) act as an information and excellence pipeline for all regional professionals working with this population.

While the French gerontopoles all aim to provide solutions to this issue of the current demographic evolution, notably by implementing preventative, educational and promotional actions for healthy ageing, great disparities are nonetheless observed in terms of their internal organization and development. The French government has had no hand in choosing finance sources or controlling specific operations. As a result, each French gerontopole operates differently, with varying scopes and organizational structures. This leads to the emergence of location-specific particularities: some gerontopoles are more focused on medical approaches, others on the silver economy and yet others on social matters.

This chapter aims to identify the strategic orientations of French gerontopoles considering local specificities, along with public healthcare policies. We have asked the following questions: how can a gerontopole best benefit French society? By reducing social and local healthcare inequalities? By improving the quality of life of the elderly and reducing healthcare costs through improvement in service quality? Finally, to what extent are these gerontology clusters innovative and able to be activated for research?

Methodology

With the aim of being as representative as possible of the missions, role and place of French gerontopoles, we opted to combine an analysis of the scientific literature and institutional texts with a qualitative analysis of the key players of these gerontopoles. We conducted 12 semi-directive interviews over four months (2019) with seven representatives of six different French gerontopoles,[5] as well as regional-local professionals (five).[6] By focusing on the AURA gerontopole's activity, we were able to investigate the local system's dynamics, as well as the existing collaborations/partnerships among all different players. The interviews lasted from 40 to 60 minutes, conducted face to face (seven) or by telephone (five), and were then fully transcribed each time. The subjects discussed were the presentation of the structure (organization, financing, concrete actions), level of cooperation and coordination, and place of the gerontopole within the local ecosystem. Our interview analysis enabled us to identify the specificities of each studied gerontopole, the actions they were all committed to, and the local dynamics of each in terms of services promoting healthy ageing and elderly health, both on a social and research level.

Results

In order to improve the quality of life of our most elderly, the French gerontopoles were designed as part of a societal effort in the midst of a great demographic change, requiring a great number of different professionals to work together (hospital employees, human and social science researchers, professionals working in gerontology, communities and users, etc.), as well as to galvanize research and teaching that helps advance understanding of ageing and anticipate the related needs. What we were to find out was that despite having common goals, each studied gerontopole took a different stance vis-à-vis their social environment and in terms of the local particularities and dynamics.

Creating the gerontopoles: galvanizing social action in the midst of demographic evolution

In our Western societies, ageing is accepted as long as retired life can be led with a minimum of autonomy while links with society can be maintained. In France today, however, most frail elderly have been found to suffer from increased years spent incapacitated, along with severe isolation. With ageing necessarily comes frailty and chronic diseases, causing functional decline. The ability to live autonomously is reduced, and, little by little, dependent living becomes inevitable. As underlined by Gonthier, Achour and Geffroy (2015), developing living options near services and city-centers, while adapting public and private spaces to the needs of the elderly, could also contribute to helping them keep interacting with society while also benefitting from adapted and safe living conditions. Of all the isolated elderly, only 56 percent live in a town with over 100,000 inhabitants (Fondation de France, 2016). We need to find new solutions or alternatives in terms of living conditions, even though the elderly concerned are themselves resistant to change. Taking inspiration from the hotline-based direct-admissions service currently being tested in the geriatric wards of several French regions, we should also perhaps rethink how the elderly are managed when attending hospitals. In 2017, two out of five people aged 80 years or over were hospitalized, with the majority involving emergency care. Yet, there is no longer any doubt about the negative consequences of going through emergency care: malnutrition and weight loss, depression, disorientation and loss of autonomy, nosocomial infection transmission, sensory loss and confusion, risk of immobilization and so on. Being transferred from GP clinics to hospitals or ambulance transfers have proven to be traumatizing and should be anticipated by local professionals in order to improve how the elderly are taken care of when losing autonomy or approaching end of life.

These issues are of extreme relevance for the French National Solidarity Fund for Autonomy (*Caisse Nationale de Solidarité pour l'Autonomie, CNSA*); preventing loss of autonomy, promoting healthy active lifestyles (balanced diet, physical activity, stress management, anti-smoking measures …), and early detection of at-risk populations are all essential public health matters that require mobilizing many healthcare professionals. As clusters designed to preserve elderly autonomy, the gerontopoles are just one part of a new raft of political actions being implemented: transforming healthcare services to better adapt to at-home users, simplifying healthcare pathways for those suffering from several chronic diseases and in situations complicated by isolation or autonomy loss, multiplying local services on the ground (keeping nearby shops open, adapting individual accommodation, ensuring availability of public transport and so on). The main goal is to help people age in a healthy way and encourage elderly citizens to stay active within society.

Gerontopoles: encouraging collaboration and cooperation between all key players

The quest for efficacy involves developing partner networks while also encouraging a collective effort for prevention among all professionals involved in gerontology, from family and friend carers to retirement community workers (volunteers), complementary social protection organizations, in-home nurses, healthcare professionals and community associations, and also businesses and start-ups invested in combatting ageing issues. Nevertheless, achieving good cooperation and collaboration among these different, widely contrasting groups is not an easy task and requires effective interaction and even, at times, negotiation. The quotes, below, are from interviews with representatives of gerontopoles.

> These professionals are sometimes different, have never met each other, and evolve in worlds that have never overlapped.… We do manage to overcome this using communication techniques.
>
> (translation; PGI, Director, gerontopole 2015)

> In "healthy ageing" actions, there are so many different participants, and it is imperative they work
>
> (administrative Koz'series, age of the gerontopole 2015)

The institutions remain isolated from each other due to the great diversity in their competences and expertise, the multiple and varying types of actions they perform, as well as the inherent issues in how the French healthcare system is structured in separate silos. Reports have also revealed the presence of other obstacles, such as project financing or time schedules that differ from institution to institution, as well as difficulties doing collaborative work with the highly diverse professionals working in this field.

> The finance factor is a major obstacle. For me, the greatest hurdle is financing projects and the necessary time, yes time, too.… Some can bring in financing, others are more in research; depending on their legal status, they can be leader, contributor, financer, or other.
>
> (Pays de la Loire gerontopole, CEO, gerontopole 2010)

> It's about time and scheduling, especially when it comes to the silver economy, where, obviously, there are of course economic agents working off very short deadlines while institutional bodies, of support, are looking at longer time scales.
>
> (PGI, Director, senior manager of gerontopole 2015).

> So this means that while it's true that each professional is strong in his field, what we find the most challenging is working in what you could call a transdisciplinary way. That is what is very complicated, actually; working in gerontology really requires teamwork, meaning medicine, psychology, sociology, economy, and even politics working together.
>
> (AURA Gerontopole, Medical Vice-President, gerontopole 2015).

Still, all the gerontopoles are in agreement that collaboration on common goals is both necessary and demanded. Collaborative working also helps provide a better, more tailored response to needs; it means being able to surround yourself with new competences and knowledge, and uniting efforts for financing and projects.

> I believe that it is by taking a wider view, involving all different professionals around the table, that we can progress.… If everyone works alone in isolation, we can only partially respond to needs … these agents have a great need to share knowledge with each other, and these institutions offer no space for just such sharing on population ageing, they have neither the means nor the expertise to make advances in the fiel.
>
> (administrative Koz'series, age of gerontopole 2015)

> We have professionals who really complement each other; however, we realize that what is so difficult is the transdisciplinary approach. Obviously, it works well if it is well designed from the start, with a solid structure where everyone knows exactly why they are there, what they will be able to get out of it.… It's quite a win-win situation, and after the project, you adjust, you adapt; it's never a straight line to the top.
>
> (AURA gerontopole, vice medical director, gerontopole 2015)

Collaboration works most effectively when there are shared interests. The gerontopoles evoke real diversity and represent the value of a hub of expertise and knowledge. As for the institutions, they add value to all actions on the ground and local projects working to improve people's well-being, while businesses benefit from these areas that are ideal for experimentation, accelerating their projects (use surveys, for example). What motivates and benefits some can be different from others, though the goal is always the same: to improve the quality of life of our elderly.

> The gerontopole will be the representation of what the local professionals need, that's why it's a truly collaborative product enriched by our annual action plan.… We take our lead from the needs of the professionals involved, on whichever subjects they particularly want to develop, and we are above all highly pragmatic; we chose this associative mode in order to be more agile, as reactive as possible. Our real winning asset is when we are able to offer flexibility to our partners.
>
> (Director of the Gérond'if île de France gerontopole, gerontopole 2014)

> Whatever their profession, be they medico-social professionals, economists or other, they all come for the expertise of our technical team, that's for sure! Then the facilitation and acceleration of their projects is very clear … and some even see it as a long-term partnership, strategically so for some when they need to show financers or deciders that they are truly part of a collaborative dynamic.
>
> (PGI, Director, age of gerontopole 2015)

> We collaborate when we have a shared goal, nobody is naive enough to think otherwise. It enables us to have intelligent exchange, enriched collaborations, it's essential to fully understand the specificities of each player.
>
> (PGI, Director, age of gerontopole 2015)

Bringing together different professionals on the same projects and encouraging collaborative and cooperative work proves to be a goal for which the gerontopoles are particularly adept. Faced with the diversity of those working in the ageing field and the great number of services out there, coordination is essential for developing new healthy ageing policies that are adapted to the population's needs. The gerontopoles thus act as mediators for preventative and healthy ageing actions and as central components to bringing all the different players together.

> There are so many different professionals, procedures, and diverse pathways, if we are to succeed in creating a healthy ageing policy, I believe we really have to work together, the field of ageing is so vast: from social to medical, involving carers, treatments … I share the belief that we (the gerontopole) exist today because there was a void that needed filling, we identified the needs that required all of us to fulfil, not alone but together.
>
> (Koz'ensemble Manager, gerontopole 2015)

> We are here to mediate, as third-party agents on the front lines to detect any issues on either side.
>
> (PGI, Director, gerontopole 2015)

The gerontopoles are faced with a complex challenge: bringing together professionals who differ considerably in terms of competences, activities and even culture into the same shared mission requires demanding levels of collaboration and cooperation.

Gerontopoles: centers of excellence and innovation with boundless research ambition

The gerontopoles were created following the example of the French cancer-dedicated hubs named *canceropoles*[7] and represent new types of research clusters aimed at developing projects in the fields of life expectancy and ageing through encouraging multidisciplinary methods and multi-professional structures. As veritable centers of excellence, they are spaces that invite innovation, acting to stave off elderly dependency and age-related conditions, while recognizing the value of human and social science approaches. The research focuses of the gerontopoles, as defined by the ASV Act, are subjects relating to "normal and pathological ageing" (translation; ASV Act), life expectancy, neuroscience and cognitive function, quality of life and loss of autonomy. Preventing dependency and detecting those most frail nevertheless remain foremost in the gerontopoles' missions (Gonthier, Achour and Geffroy, 2015), with the determination to apply scientific results to public health policy.

> Scientific results can have an influence over policies of action for the elderly.
>
> (PGI, Director, gerontopole 2015)

To achieve this, the gerontopoles benefit from collaboration with university hospital physicians and researchers working on ageing, healthcare quality, the consequences of chronic disease and loss of autonomy.

> Our strength is in our consultations for each project: We have groups of experts that equate to steering committees, expert committees.
>
> (Director of the Bourgogne gerontopole in Franche Comté)

> Like every gerontopole, we are a center of scientific expertise, with over 200 regional professionals working here, from local community groups to start-ups, healthcare institutions, and even user representatives. We have two major focuses: training, and research. Yes, it is to support healthy ageing alongside all different professionals, we are not with the elderly in their day-to-day care, our objective is to be innovative and to support innovation across the region.
>
> (Pays de la Loire gerontopole, CEO, gerontopole 2010)

> We have also set up a scientific council chaired by one of the creative minds behind the gerontology services of Rouen university hospitals in order to encourage scientific expertise.
>
> (Seine Estuaire Normandie gerontopole, President, gerontopole 2017)

They include think tanks (scientific council, expert committee) that analyze the appropriateness of projects in terms of ethics, pedagogy and science, working independently with realistic evaluation. Each gerontopole is, therefore, by definition, a research entity.

Applied research and support for social and technological innovation

Applied research and advances in home automation are more and more sought after in the management and support of frail elderly individuals. Yet, these innovative tools need to be truly assimilated by the elderly themselves in order for them to become part of their everyday lives. It is essential to build awareness among the general public and professionals about the different technical aids that are available, ensuring they fulfill the needs assessed before their implementation. The gerontopoles thus organize this essential collaborative process between physicians and industry workers. They provide support and information on the users' needs to the industry professionals who call upon their advice, while offering areas for experimentation where they can develop new products and concepts. The AURA gerontopole, for example, publishes calls for experiments with the aim of supporting leaders of innovative regional projects.

> Four projects are being supported by the AURA gerontopole in 2019: evaluation of the healthy-ageing commissions organized by the local Saint Etienne association (OSPA) and support for two experiments on inciting regular, adapted physical activity in nursing homes, as well as projects conducted in the city's public areas involving innovative tailor-made solutions and our support of a stroke-prevention program in pharmacies using electronic boxes to record risk factors.
>
> (Project leader, Auvergne Rhône-Alpes gerontopole)

In these cases, the innovations that receive support are often technical, although they can be social and organizational. Still, in the current climate where residences are being requisitioned to avoid hospitalizations, to respond as best as possible to shortages in institutions, as well as to the desires of the elderly themselves, technological innovations can offer more comfort and safety, along with leisure activities and distractions, not to mention the possibility of keeping in contact with family and friends. This kind of set up evokes ideas of a healthcare ecosystem for the home, encouraging research into global approaches centered on the individual and care pathways that are less confusing and traumatizing. Digital and automated home solutions in this context represent tools capable of rethinking the entire hospital-centered organization we have today, getting rid of barriers between healthcare and medico-social fields, between city GPs or other local centers and hospitals. On the other hand, at-home treatment and management often necessitates technical devices that must also insure increased safety. The most commonly used are those for detecting falls and geolocation technology, although many more solutions are being developed every day, such as the smart walking cane, walking sensors, smart watches/bracelets and so on. Supervising and regulating use of these technical devices and innovations offered to subjects is essential to guarantee the tools provide the appropriate solutions, and are adapted to needs. The gerontopoles, in addition to their functional link with industry, support and advise businesses in order to help them better understand and empathize with the expectations and needs of the elderly, while also creating new tools adapted to their needs. The gerontopoles thus have a responsibility and mission to encourage innovation, experimenting in real-life contexts then distributing and highlighting the value of these innovations across their entire region. This is why the Gérond’if gerontopole (Ile de France) qualifies its studies in the field of innovation as “gerontotechnologie”. With the advantage of their great experiments and research into the conditions of old age (particularly regarding Alzheimer’s disease), Gérond’if promotes research, innovation and evaluation in the fields of geriatric medicine and gerontology.

> Another group that previously defined its role as to highlight the value of research to industry and since then has transformed into silver economy technology and innovation, it’s all gerontotechnology.
>
> (Gérond’if Ile de France gerontopole, Director, gerontopole 2014)

> Our vision is to galvanize action on ageing among all those working in research, healthcare, training, and business.… We conduct evaluations of projects and studies, measuring the innovation’s acceptability and influence on quality of life for the elderly, carers, and the professionals surrounding them.
>
> (Senior Executive Vice-President of Gérond’if)

Real-life experiments: the methodology of a living laboratory

The relevance of finding a balance between technological innovation and the human factor involves looking closely at how solutions are applied. These studies on device use are opportunities for the gerontopoles, enabling them to insist on the need to include the elderly subjects, their carers and their nurses in both the development and evaluation of the innovations offered to them so as to insure they fulfill their needs. The recent report by Dominique Libault (2019) on the conference on old age and autonomy (*Grand âge et Autonomie*), delivered to the Health Ministry on 28 March 2019, confirms this trend. It validates using preventative healthcare approaches, which aim to work so that signs of frailty in elderly subjects must be detected very early so as to reduce the risk of loss of autonomy. While these matters have in the past not been prioritized by public health policies, change appears to be afoot. The report goes on to state that France is in the midst of a changing environment that must not be ignored and should be thought about in a careful and precise way so that innovations are accepted by those who will use them. Based on surveys among inhabitants, the Libault report underlines the key role of users as participants in their own healthcare pathway, which enables the real needs of citizens to be identified. For this, the AURA gerontopole adopts a living laboratory methodology centered on autonomy and healthy ageing "Autonomie et Bien vieillir",[8] aimed at creating new economic solutions to support innovations that fulfill the needs of the elderly. The elderly are thus at the heart of innovation:

> We conduct many qualitative studies on technology use among users and residents, feasibility studies, real-life experimentations, and focus groups, too, to place innovation at the heart of a collective process involving all professionals of this field: engineers, but also the patients themselves, of course, sometimes friend and family carers, and professional carers too.
>
> (Project leader, AURA gerontopole)

Other gerontopoles create teams of users (elderly, family or friend carers, and professional carers) to work within the actual expert committees of the gerontopoles with the aim of getting their participation in the design and evaluation of new products and services.

> We have created specific teams of elderly subjects to work on the issue.… They are present (as user representatives) in governance meetings, decisive committees, and strategic committees that assemble users and financers of the entire cluster.… In addition, they are present in the committees, in the expert groups for projects, without exception of course, as well as in the research programs.
>
> (Koz'ensemble Manager, gerontopole 2015)

> It is the heart and soul, so much so that, in fact in September you'll see it in our marketing, we have launched a club for local users, they will meet regularly to discuss essential issues, it was their own idea to meet in order to be more effective and really work together. Supporting and debating on innovations of the future and the issues they are facing right now.
>
> (Pays de la Loire gerontopole, CEO, gerontopole 2010)

The gerontopoles: centers for teaching and training

In the form of scientific conferences and seminars, talks for the general public or even regional themed days for professional carers, patients and their families, researchers, professionals of the social sector, students, journalists, business leaders or politicians, the gerontopoles offer local educational opportunities of all shapes and sizes, accessible to everyone in their local area. The majority of these events are spread out to reach people locally as much as possible in order to spread good practices and promote good treatment. Often interactive, these educational programs usually cover multiple disciplines. Sometimes, an academic university course is linked with themed days or organized seminars. One of the priorities is to offer better training and support for family and friend carers, as they play a key role in how many age-related conditions are managed and coped with (Alzheimer's, Parkinson's, cancer …). Realizing this, the pays de la Loire gerontopole has created a "carer school", while the Normandy organization puts on a cycle of conferences all year round. The Bourgogne Franche-Comté gerontopole has designed a multidisciplinary follow-up of a cohort of unofficial carers with the aim of better identifying the needs and expectations of those caring for patients suffering from chronic disease.

> We take a real stance of engineering in training, or you could say of engineering design, it's training courses that don't yet exist, to respond to the needs of our members.
>
> (Director of Bourgogne Franche Comté gerontopole)

> Yes, there's lots of work to do, they [the at-home carers] are on the front lines of healthy ageing, yet when you look at what is provided for them, the training and services, it's not much, it's incredible. There's lots of progress to be made in training courses. We can bit by bit improve their practices, make them more professional, help them, offer them more security in their jobs, teach them to detect problems, anticipate problems. There is real work to do. All that means we must try to improve this training, and this is the kind of work that can be carried out by the gerontopoles.
>
> (AURA gerontopole, Medical Vice-President, gerontopole 2015)

The gerontopoles: local specificities guaranteeing approaches adapted to the elderly

The gerontopoles have some points in common (research, innovation, training, professional collaboration), yet each region has its own particularities, resulting from the local background of each gerontology institution and the research focuses chosen by the different professionals working on ageing. In the beginning, our gerontopoles were made up of regional initiatives carrying out activities with the potential to contribute to clinical research and innovation. In Toulouse, for example, significant research was conducted into Alzheimer's disease and malnutrition; in the pays de la Loire region, research was focused on adapting local organization and services to ageing; in Bourgogne, it was on fall prevention and ethics; in Auvergne-Rhône-Alpes on the field of first aid (via GPs as well as paramedics and family and friend carers of the elderly) and human and social sciences through the study of patient pathways and real-life experiments. As centers for learning and training on professions linked to life expectancy, as well as being hubs of research and specialist expertise, not to mention spaces for exchange of knowledge and excellence, the gerontopoles are at times similar to permanent exhibition centers.

Beyond the research focuses and training courses, the associative organizations themselves even vary from one gerontopole to another, from the social and cultural environment, the establishment's size and number of employees (from all voluntary to 67 employees), to the financing source (ARS, INSERM, private health insurance …) and different local partners (see Appendix 2).

> We have annual subscriptions with high fees of 80 euros for associations to 500 euros for large groups, though as a result there are not many … the committee members are legal entities, which means that these are real authoritative bodies that have a role to play, in governance, mediation, and decision-making, but … on the other hand do not even have any creative potential, as for this we have representatives from specific deliberating bodies.
>
> (PGI, Director, gerontopole 2015)

> The idea is to have each of the 7 founding members taking turns to preside. We currently have 70 subscribing members, including institutions, public and private businesses, healthcare professionals, health services, and of course those affected by the issue of ageing – it's no small number. At our gerontopole, we have also kept the structure very small in terms of staff, for example at the moment there is one person who is director, secretary, and project manager. She does it all! We have an executive committee where all the agents take an active role.
>
> (Seine Estuaire Normandie gerontopole, President, gerontopole 2017)

The influence of the ARS, regional councils, health insurance companies and universities on each gerontopole varies widely, and can hamper operations. In Bourgogne Franche-Comté, for example, the gerontopole has to coordinate with two different administrative regions with contrasting backgrounds and local conditions.

> This is also what makes us so strong: we are all ready to collaborate in koz'ensemble – we don't have any paid employees and it is precisely this role we are lacking.
>
> (Koz'ensemble Manager, gerontopole 2015)

The gerontopoles built themselves progressively, developing collaborations within their regions, and doing so without extensive finance from the state, unlike the *canceropoles* and AIDS centers. While there are disparities, reports evoke the possible collaborations that could emerge among different French gerontopoles:

> What you need to understand is that each locality has its particularities, all those working in French gerontopoles are focused on the same dominant issue: the impact of ageing on the future of our society, the risk of frailty associated with ageing, and how to prevent it in order to enable the elderly to have better quality of life. There are thus different approaches, yet which are highly complementary, hence the great interest in coming together in the future.
>
> (Novella, Hospimédia, 2014)

Conclusion

Geriatric medicine is a scientific field that spreads beyond the hospital and health sector in order to support healthy and high-quality ageing and prevent dependence. The clusters of gerontology, a.k.a. the gerontopoles, work to deal with the new demand of elderly people living at home, which is growing in terms of quality and quantity. The goals are to improve support for the elderly through more effective research that involves multiple fields in collaboration and can be directly applied in order to improve quality of life at home or in nursing homes. Unifying competences and projects, mobilizing and bringing together all professionals working in gerontology, creating a closely knit network involving both state and private players, both to their advantage and that of the patients – these are the main priorities of the gerontopoles.

The gerontopoles stimulate clinical practices and research. They provide their expertise to centers of learning, leading to better-adapted and appropriate practices being passed along in the medico-social fields as well as to the general public. They also offer industry results that validate and add value to their products, proving their reliability and acceptability. A great majority of the French elderly prefer to be able to remain at home in their old age. As a result, more and more innovations are required to improve individual services, encouraging and enabling social links to be maintained in safety, using many technological advances. The gerontopoles thus enable the elderly to live at home while still having access to diagnostic tools, innovations and treatment research.

The creation of gerontopoles has also created a hub of exchange, deliberation, advice and action, involving greater numbers of decision-makers, all within reasonable budgets in order that the old-age stage of life benefits social progress and techniques. This co-construction model is founded on the participation of researchers, professionals working in healthcare and local policy makers (community organizations and industry), enabling partners from widely different cultures and backgrounds to be engaged and mobilized, creating a region-wide network united for prevention of dependence and the study of ageing.

The gerontopoles similarly improve how we approach and think about organizing our local healthcare structures and create coherent training across the region. There are particularities to each locality and differences in organizations depending on location and environmental context (local-specific issues, cultural anchoring, local economics …). We see this diversity as an asset to the gerontopoles, as they work in harmony with all implicated local professionals, relying on the local competences and expertise and responding to the needs and desires of the elderly in consideration of their surroundings and lifestyle.

Notes

1 In 2060 one-third of the French population will be over 60 years (Libault, 2019). In 2030, one out of two will be over 50 years (De Lapasse, 2018). Yet, it is the growth in people aged over 75 years that is the most significant: their numbers will triple, while that of people over 85 years will quadruple by 2040 (De Lapasse, 2018).

2 Ninety percent of the French population prefer remaining at home (summary of the state report of the French Court of Audit; Chambre Régionale et Territoriale des comptes, cours des comptes 2016).

3 The term “gerontopole” was employed for the first time in 2005 by Professor Pierre Pfitzenmeyer (Dijon university hospitals) to mobilize and bring together the driving forces of research and development to focus on new practices, services and products (Gonthier, Achour and Geffroy, 2015).

4 The French gerontopoles were only recently created, the first appearing in Toulouse in 2007. Since then, these hubs have progressively spread throughout France: the Bourgogne Franche Comté pole of gerontology and innovation and the Pays de la Loire gerontopole (2010), the AURA gerontopole (2014), Koz’ensemble and the Champagne-Ardennes gerontopole (2015), Gérondif (2016), the Normandy gerontopole (2016) and the Sud gerontopole (2019).

5 We were able to ask representatives of the following gerontopoles: Pôle Gérontologique et d’Innovation de Bourgogne Franche-Comté, Gérond’if, Gérontopôle de Normandie, Koz’ensemble, Gérontopôle Pays de la Loire and Gérontopôle AURA (Appendix 1).

6 The interviews were conducted with representatives of two gerontology centers, of Forez and vallée du Gier, the Office Villeurbannaise des Personnes Agées et des Retraités (OVPAR), Isère Gérontologie and a representative of the Autonomy committee of the ARS.

7 Galvanized by the French cancer plan of 2003–2007, the cancer-specific hubs (*canceropoles*) were created to improve the quality of management of patients, develop shared solutions, and support research, promoting the transfer of academic findings into clinical and industrial applications. The *canceropoles* insure the promotion of scientific excellence, highlight the value of interdisciplinary collaboration and remove obstacles between researchers, physicians and industry.

8 So-called living laboratories promote innovative practices, providing real fields of experimentation, access to cohorts (with support from the university hospitals), methods and tools, mobilizing multidisciplinary approaches in the fields of autonomy and healthy ageing (anthropology, economy, ethics, geriatrics, general medicine, sociology, urbanism, etc.). The elderly are themselves participants, contributing to the construction of their own lifestyle and conditions.

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18 Measuring caregivers' perceived work-based stress in nursing homes for the elderly – a concept considering residents suffering from dementia

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Research aim: to emphasize that a suitable research concept is required to analyze "the extent to which a certain care concept counteracts subjectively perceived stressors during everyday care and support".

Methods used: summative evaluation design – more precisely, a semi-experimental design with a control group and an experimental group, collecting data at two waves ("before and after" measurements). It permits the simultaneous evaluation of the experimental group (in which a new concept is introduced) in one or more care homes and the control group (in which the specific concept is not implemented) in comparable care homes. Changes over time can thus be studied under controlled conditions.

Lessons learned: the implementation of a care concept in nursing homes depends on the people involved, from the management to the caregivers. Even if the background conditions (e.g., legal regulations) and the characteristics of the home or the organization running it (e.g., mission statements) are identical, the way in which this type of concept is dealt with personally evidently plays a key role in its effect, or at least this is the only explanation for the identified differences. Moreover, the initial starting point is important when measuring the effect of a new concept. The level of improvement (as in a positive effect) will be minimal when a high level of caregiver motivation, or of nursing and care, is already reached, before a new concept is introduced.

Introduction

Caregivers in nursing homes for the elderly are currently facing changes to their nursing tasks. This is due on one hand to rising life expectancies and societal change, which is giving rise to individualization, changing family structures and rising female employment rates. Subsequently, there is rising demand for professional nursing services, which increasingly fall under the remit of public-sector or private providers (Glaser and Höge 2005). On the other hand, the proportion of elderly people with dementia is rising ever higher. Estimates by the Austrian Ministry of Health and Women's Affairs suggest that 115,000 to 130,000 people living in Austria currently suffer from some form of dementia (Bundesministerium für Frauen und Gesundheit, 2017). According to projections, by 2050 that number will have increased to 260,000 people with dementia (Höfler et al., 2015). These developments are also altering the population structure in nursing homes, creating new challenges for caregivers. The amount of care required is constantly rising as residents are entering homes at an older age, with higher support needs and frequently, as described, advanced dementia; longer life expectancies mean that they are also staying there longer (Engels and Mehlan, 2008). Today, people suffering from dementia already make up the largest group of elderly people living in homes, which has a considerable effect on everyday life there. There are also different expectations of what comprises "good care". The trend is shifting from functional "keep them warm, fed and clean" care toward full-service care and support, taking into account users' quality of life (Leichsenring, Schulmann and Gasior, 2015). Providing care and support, especially for dementia sufferers, is a challenging task which requires caregivers to display a great deal of specialist knowledge, physical abilities and, above all, social and emotional skills (Dietrich et al., 2015; Glaser and Höge, 2005; Engels and Mehlan, 2008; Zimber, Rudolf and Teufel, 2001).

People suffering from dementia thus need more intensive support and care than those who only need care due to their physical condition (Höfler et al., 2015). The law states that the minimum number of caregivers required must be based on the average number of residents per care level (Oö. *Alten- und Pflegeheimverordnung* [Upper Austrian Care Home Ordinance], 1996). In Austria, there are seven levels of care, based on the amount of care required per month. For dementia sufferers, since 2009 an additional 25 hours per month have been factored in as extended care needs (Pensionsversicherungsanstalt, 2017). According to the Austrian Dementia Report, however, the levels of care do not adequately reflect the intensive degree of care required for dementia sufferers, and the additional workload is currently not taken into sufficient account in nurse–patient ratios (Höfler et al., 2015). As a result, work-based stress in homes is rising along with the proportion of dementia sufferers. For this reason, care concepts are required which not only meet the needs of such residents in care homes, but also reduce the stress affecting caregivers and nurses.

A research project was carried out to examine how successful such concepts are; its findings form the basis of this piece. The focus was on the caregivers' and nurses' subjective perception of stressors, the subjective results of that stress and any consequences affecting their health and career. One point is clear: a suitable concept is required to analyze the extent to which a certain care concept counteracts subjectively perceived stressors during everyday care and support. The goals of this type of survey are to:

- record subjectively perceived work-based stress among caregivers and nurses looking after residents suffering from dementia;
- take background conditions into account;
- determine the factors influencing the perceived level of stress; and
- compare the findings based on various care concepts.

On this basis, we developed a theoretical model (the second section of the chapter), the theoretical framework of which is presented before – building upon this – we go into further detail on the measurement concept and thus on the operationalization (the third section of the chapter). Finally, the findings are summarized and possible limitations indicated.

Concept for recording perceived work-related stress in an experimental group and a control group

Where the aim is to compare different nursing and care concepts to identify differences in people's subjective perception of work-related stressors, a summative evaluation design should be selected. Where, as in this case, the intention is to evaluate the effect of introducing a new concept, an experimental design is required: a simple comparison of perceived work-based stress among different care homes would be inadequate. A semi-experimental design with a control group and an experimental group, collecting data in at least two waves ("before and after" measurements) serves this purpose. It permits the simultaneous evaluation of the experimental group (in which a new concept is introduced) in one or more care homes and the control group (in which the specific concept is not implemented) in comparable care homes. Changes over time can thus be studied under controlled conditions.

The first step is always to select the experimental and control homes. As well as featuring comparable care concepts, these should also have similar background conditions, especially with regard to:

- the number of residents in proportion to the number of full-time equivalent caregivers,
- the availability of care and nursing services (short-term care, all-day care, etc.),
- the building (age of the building, whether or not people can withdraw into their own private areas, etc.).

A research design that meets the needs of the above project requires a combination of qualitative and quantitative surveys studying different actors. This combination of methods (triangulation) enables researchers to make the most of each approach's advantages while at the same time compensating for its disadvantages. The research design's different approaches insure that the sometimes varied viewpoints of different actors, nursing managers, psychologists and caregivers can be taken into account.

On this basis, this type of research design is made up of several stages (Figure 18.1), as described in further detail below.

The first stage is an exploratory preliminary study in the form of qualitative expert interviews or focus groups. These are used to record the subjectively perceived background conditions and various work-based stressors, discuss the factors which increase and reduce work-based stressors and note their consequences. For this purpose, guidelines were developed (see Appendix 1). The findings thus obtained not only provide a comprehensive insight into the current situation but also serve as the basis for developing (or refining) the quantitative survey instrument (see Appendix 1). In other words, a quantitative questionnaire was developed to measure impacts, based on the theoretical model (see Figure 18.2, below) and taking into account the qualitative findings. This questionnaire must still be validated for further use.

During the second stage, the quantitative questionnaire is tested. This can be done using a pre-test with staff in nursing and care facilities who are comparable to the control and experimental groups, to find out whether any adaptations are necessary.

In the third stage, a standardized assessment of the current situation is carried out, i.e., a survey of caregivers and nursing staff in "Wave 1" (before the implementation of a new concept). A whole-population survey (asking all staff) is advised if there are not many staff at each institution. In the fourth stage, the standardized impact assessment is carried out: a survey in Wave 2 (roughly one year after the implementation of a new concept in the experimental homes). This ends with the validation of the findings, e.g., in the form of a findings workshop.

Figure 18.1 Research design.

Theoretical framework and measurement concept

Theoretical model

Based on the modified stress-strain concept (Metz and Rothe, 2017), a theoretical model was developed to measure the influences upon and consequences of subjectively perceived work-based stressors among people working in nursing and care. This took into account the subjective evaluations and assessments of working conditions and situations, and whether and to what extent people saw themselves as individually capable of coping with these situations and circumstances (see Figure 18.2).

Validation of the findings

Similarly to the stress-strain concept, the theoretical model is based on external influences which (may) affect the working person. In the theoretical model (Figure 18.2), these external influences are located in the background conditions of the nursing and care facility (A) or in the staff's subjective perception thereof (B).

People's subjective perception of the background conditions and stressors (D) are influenced by personal characteristics. It is assumed that on one hand personal characteristics (C1) and on the other hand personal resources (C2) play a role in people's perception of working conditions and work-based stressors. Meanwhile, various consequences for their health and career (E) may indicate that the stress has repercussions. Below is a description of the concept used to measure these dimensions.

Measurement concept

In the field of nursing and care for elderly people, when the topic of dementia sufferers comes up, the two issues highlighted are, first, information about the symptoms of dementia, support schemes and services, and, second, the quality of nursing and care (see Höfler et al., 2015; Juraszovich et al., 2015). Work on dementia frequently focuses on the development and implementation of nursing interventions designed to improve the dementia sufferers' situation, e.g., reminiscence work, Snoezelen environments, dementia care mapping (DCM), "understanding diagnostics" and assessment tools (Palm et al., 2013). As far as we are aware, as yet there have been no studies concentrating on the specific working conditions and work-based stressors in dementia nursing and care. For this reason, we examined general models for measuring work-based stressors and studies in the context of residential care for the elderly.

In the following, the individual dimensions of the theoretical model are described and set out as operationalized for the research project. This includes outlines of findings from other studies and results of the exploratory preliminary study which played a role in the development of the theoretical model.

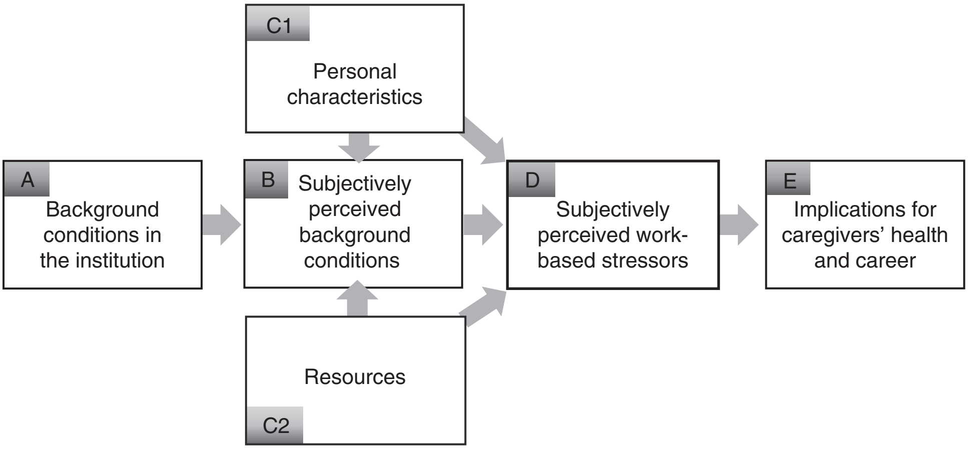

Figure 18.2 Theoretical model of subjectively perceived work-based stressors.

Implications for caregivers' health and career (E)

During the project, because of the interest in the nurses' and caregivers' subjective perceptions, the subjective consequences of the stress were investigated and operationalized as implications for their health and career. Evaluations in the context of nursing and care for the elderly come up with the following consequences of stress on an individual level: somatization, back pain, emotional or mental exhaustion, job dissatisfaction and a lack of intrinsic motivation, fearfulness, depression, social dysfunction, reactive distancing, irritation and aversion to clients (Dietrich, Kirch and Rößler, 2014; Glaser and Höge, 2005; Maier and Kälin, 2015; Ziegler et al., 2016; Zimber, Rudolf and Teufel, 2001). During the qualitative surveys, the topic was also addressed of the psychological or social burden increasing while the physical burden tends to become less important.

In other words, work-based stressors can affect the state of people's physical, mental and/or social condition. They can have an effect on their ability to work and identify with their job (see Table 18.1).

Subjectively perceived work-based stressors (D)

The stressful situations recognized by Glaser, Lampert and Weigl (2008) include organizational stressors (problems caused by absences, staffing changes, etc.), social stressors (stressful work with colleagues, superiors, residents and relatives), resident-related stressors (stress caused by demented, dying, depressed residents), being rushed, being given contradictory tasks or tasks outside one's field of responsibility, being uninformed, work being interrupted and an unfavorable working environment (physical spaces, noise, lighting, long distances to travel, etc.) (see also Becker and Prümper, 2016; Brunner and Jenull, 2009; Dietrich, Kirch and Rößler, 2014; Dietrich et al., 2015; Engels and Mehlan, 2008; Glaser and Höge 2005; Ziegler et al., 2016; Zimber, Rudolf and Teufel, 2001). Meyer-Kühling, Wendelstein and Pantel (2015) point to another aspect, namely the different perceptions of collaboration between the nurses and doctors.

Accordingly, the exploratory preliminary study addressed the subject of stress caused by work with residents suffering from dementia (frustration, despair, making monotonous noises, constantly demanding attention, retrogenesis, the urge to wander, confusing day and night, mental illness and addictions), work with relatives (insufficient knowledge about dementia symptoms, differing expectations with regard to care and nursing, insufficient appreciation of work done, conflict among relatives), and internal and external collaboration. Other perceived sources of stress included conflict among residents of the kind which occurs frequently when residents with or without dementia live in close spatial proximity. The interviews and focus group also showed that the care home staff frequently felt rushed. A lack of time and low staffing levels were seen as the main cause of stress in their daily work, as dementia sufferers in particular require more time for care and nursing.

Based on the above findings, the indicators for work-based stressors derived for the research project were office management, work with residents suffering from dementia, interaction among residents, work with relatives and internal and external collaboration (see Table 18.1).

To assess the level of perceived work-based stress in the field of office management, the study gathered data on perceptions of being rushed in nursing and care, on work being interrupted, the feeling of not having enough time to respond to residents' wishes and needs which could otherwise be fulfilled, and the perceived fairness of how tasks were distributed.

Table 18.1 Dimensions, indicators and example items

Area	*Dimension*	*Indicators*	*Example items*
Implications (E)	Toll on health	Social, mental, physical toll	Looking back on the last 3 working weeks, how much of a toll do you feel your work took on your health? … social stress (social contacts, relationships, conflicts etc.)
	Identification with work	Choosing same job and thoughts of career change	If you could go back in time, would you choose your current occupation again?
	Ability to work	Ability for future professional practice	Can you imagine still being able do your job in 5 years' time?
Subjectively perceived work-based stressors (D)	Office management	Task distribution, being rushed, intensity vs. interruptions, lack of time	During the last 3 working weeks, how often have you felt rushed in your daily work?
	Work with residents	Psychological impairment, challenging behaviors, activities, communication among dementia sufferers	Please now think about the following behaviors which occur when working with dementia sufferers. I find … challenging behaviors (constantly demanding attention, uncooperative behavior …) very stressful to not at all stressful.
	Interaction among residents	Conflict among residents caused by certain behaviors found in dementia sufferers	How often do you find the following types of interaction among residents stressful (e.g. including among residents suffering and not suffering from dementia)? Conflict due to psychological impairments (depression, panic attacks, paranoid ideas …)
	Work with relatives	Insufficient knowledge, false expectations, lack of appreciation, family conflicts among relatives	Please now think about the following aspects of working with relatives of dementia sufferers. To me, … false or unfulfillable expectations are very to not at all stressful.
	Internal and external collaboration	Effectiveness of collaboration with superiors, colleagues and outsiders	How often do you find working with others to be stressful? Specifically, with … direct superiors

continued

Table 18.1 Continued

Area		*Dimension*	*Indicators*	*Example items*
Subjectively perceived background conditions (B)	Tasks/content	Confrontation with dementia	Proportion of dementia patients, work in the field of dementia	Thinking of all the residents you take care of, how high would you say is the proportion of dementia sufferers?
		Residents’ behaviour	Frequency of mental impairment, challenging behaviors, activities, communication among dementia sufferers	How often do the following aspects occur in residents suffering from dementia? Challenging behaviors (constant demand for attention, aggressive behavior, uncooperative behaviour …)
		Work as enriching	Enjoying work, drawing strength from work, feeling of enrichment	I really enjoy work.
		Opportunities to be creative	Variety, self-determination	The work I do when nursing and caring for dementia sufferers is: varied – monotonous (5-step scale)
		Coping requirements	Coping during day or night shift activity, strength	I cope well with daily nursing and care for residents during the day. I draw strength from my work.
	Organization	Time management	Planning shifts and holidays	My wishes and needs are considered as far as possible when making up the duty roster.
		Allocation of work	Information, suitability of assigned activities, too many or too few demands made	Looking back on the last 3 working weeks, how often … … were you given all the information you needed to do your job well?
		Sphere of responsibility	Taking on responsibility, task assignment	Looking back on the last 3 working weeks, how often … … did you feel you had been given too much responsibility?
		Working environment	Suitability of the physical space, equipment and subjective well-being	The premises’ physical spaces (living areas, corridors, rooms, the garden, etc.) are well suited to work with dementia sufferers.

		Training and CPD	Sufficient selection	There is a sufficient selection of training and CPD schemes available.
	Atmosphere	Leadership culture	Transparent expectations, appreciation, support, participation, leadership style	I know exactly what she/he expects of me regarding my work.
		Atmosphere among staff	Support, collaboration, getting on together	If necessary, I get help and support from my colleagues.
		Interdisciplinary collaboration	Collaboration with external occupational groups	Members of other occupational groups come to me for my specialist knowledge in nursing/care.
Pers. characteristics (C1)		Demographic characteristics	Age, gender, mother tongue	I am ___ years old.
		Occupational characteristics	Working hours, occupational group, years of service	I have been working in nursing and care for elderly people for about __ years.
		Salary	Appropriateness of pay	My salary is appropriate.
Resources (C2)		Care concept	Institution's care concept, seen as a resource (evaluation of professionalism, practices and supportive schemes for dementia sufferers)	Thinking about your daily work nursing and caring for residents suffering from dementia, how helpful are the following aspects for you? … the institution's care concept.
		Professional resources	Training, work experience, validation approach, internal and external CPD	… internal and external CPD attended (e.g. lectures, workshops, seminars).
		Occupational resources	Supervision, team discussion, discussion with colleagues	… discussion among colleagues in the institution.
		Leisure as a resource	Team activities, recreation/relaxation in free time	… recreation/relaxation in free time.

To assess perceived work-based stress, the study also took into account the extent to which challenges were experienced as stressful in the specific case of nursing and care for residents suffering from dementia (depression, panic attacks or paranoid ideas, challenging behaviors and activities such as constantly demanding attention, refusing to cooperate, the urge to wander about, confusing day and night, lack of drive and demanding communication such as constantly repeating things or making monotonous noises). Mental disorders and specific behaviors specific to dementia sufferers are also often the cause of conflict among residents, which can be stressful for caregivers and nurses. The aim was to make the perceived work-based stress measurable, including stress during work with relatives (see above), internal collaboration (with superiors and colleagues) and external collaboration (with members of external occupational groups).

Subjectively perceived background conditions (B)

During the explorative preliminary study carried out for the project described above, stressful situations were sometimes connected to organizational aspects, physical spaces or the working atmosphere. Long shifts, for example, can play a role in whether certain behaviors in residents are perceived as stressful, if caregivers are exposed to them for hours on end. The roster and holiday planning can be adjusted to reduce the stress. Other important background situations addressed are the staff's scope for action and decision-making and whether they are given an appropriate level of responsibility. Other relevant aspects which emerged were the level of appreciation the management show the staff, and the working atmosphere. Last but not least, the premises or architecture of the institution can make everyday life with dementia sufferers easier or more difficult (long corridors, lifts with glass walls, an open-plan support center with no private areas, etc.). Whether or not the building makes people feel at ease is an important factor not only for the residents but also for the staff.

Based on this, the dimensions developed during the operationalization process were allocated to three areas: working tasks/content, office management and working atmosphere. Under working tasks/content, data was gathered on how strongly staff felt confronted with dementia, whether they felt equal to the requirements of their job, whether they saw their work as enriching and whether they were given opportunities to be creative. The indicators under office management include a needs-based roster and holiday planning, whether work and responsibility are suitably allocated and the amount of training and continuous personal development on offer. The working atmosphere was operationalized via the dimensions of the leadership culture (transparent expectations, leadership style, appreciation, support and involvement by direct superiors), the atmosphere among staff (support, collaboration, how well they get on) and interdisciplinary collaboration with external occupational groups (see Table 18.1).

Personal characteristics and resources (C)

Various studies (Becker and Prümper, 2016; Glaser and Höge 2005; Ziegler et al., 2016; Zimber, Rudolf and Teufel, 2001) compare the requirements and stress experienced in nursing with the resources which are available. The resources which are available play an important role in coping with requirements and stress. Resources may be found in terms of the organization (scope for action, opportunities to influence the way work is allocated, whether staff can plan and allocate work independently, feedback from superiors), the social environment (positive atmosphere, effective communication with colleagues, superiors and residents) and the individuals themselves (professional skills, social skills, organizational skills and personal skills).

In the exploratory preliminary study, emphasis was placed on the fact that people working (or wanting to work) in nursing and care for dementia sufferers require well-developed social skills and a "stable" personality. Professional training and internal and external CPD were considered to be of great importance. Training in validation was often brought up as central to everyday communication and dealing with residents suffering from dementia. Other resources mentioned were supervision and a good working atmosphere, and leisure activities (i.e., a successful work–life balance) were attributed a key role in combating stress and stressful situations in everyday working life.

On this basis, the potentially relevant resources used in the theoretical model which was developed were the institution's care concept, professional resources (training, work experience, validation approach, internal and external CPD), occupational resources (supervision, team discussions, discussion with colleagues) and leisure time as an occupational resource (team activities, recreation/relaxation during free time). The personal characteristics on which data was gathered included on one hand demographic characteristics (gender and age), and on the other hand occupational characteristics (working hours, occupational group, years of service) and perceived appropriateness of pay (see Table 18.1).

Measuring instruments: establishing dimensions and testing reliability

As mentioned above, guidelines were developed for the qualitative preliminary study (see Appendix 1). Their content, and that of the quantitative questionnaire based on the findings, reflect the model of subjectively perceived work-based stressors (see Table 18.2). Statistically, the individual dimensions were based on exploratory factor analysis (e.g., see Brachinger and Ost, 1996). To check the internal consistency (reliability) of the scales, Cronbach's alpha was calculated. The analyses were carried out using SPSS (IBM SPSS Statistics 24).

Table 18.2 offers an overview of the dimensions established and their internal consistency, which is satisfactory apart from three aspects ("collaboration", "sphere of responsibility" and "professional resources"). For the sake of completeness, individual items are also listed. For details see also Table 18.1.

Conclusion

The work-based stressors affecting caregivers in nursing homes are a subject of increasing public discussion due to the rising number of residents suffering from multiple morbidities or dementia. Data from a repeated survey of caregivers in Austrian nursing homes were studied to analyze how caregivers actually subjectively perceive work-based stressors and what factors cause this. Particular attention was paid to the effect of having a defined care concept. To analyze the influencing factors, a theoretical causal model was developed taking into account multiple factors at different levels. The correspondingly high level of complexity posed a challenge, not only when analyzing the data, but also when presenting the findings. One aspect which became clear was that with such complex models in particular, appropriate methodological knowledge is a must (especially for analyzing data over time).

Moreover, the complexity of the identified causes and effects made them difficult for the research commissioners to follow, raising the question of whether knowledge can be transferred from empirical studies to (care) practice.

Table 18.2 Individual items and established dimensions, including explained variance, Cronbach's alpha

Area		*Dimensions*	*Number of items*	*Explained variance (%)*	*Cronbach's alpha*
Implications for health and career		Toll on health	3	–	–
		Identification with work	2	75.22	0.641
		Ability to work	1	–	–
Subjectively perceived work-based stressors		Office management	4	67.39	0.838
		Work with residents	4	69.65	0.849
		Interaction between residents	4	74.34	0.883
		Work with relatives	4	58.85	0.764
		Collaboration	4	52.41	0.525
Subjectively perceived background conditions	Tasks/content	Confrontation with dementia	2	–	–
		Frequency of residents' behavior	4	70.17	0.853
		Work as enriching	3	63.33	0.706
		Opportunities to be creative	2	70.70	0.582
		Coping	2	82.22	0.783
		Requirements	2	–	–
	Organization	Time management	2	81.91	0.778
		Allocation of work	3	52.98	0.548
		Sphere of responsibility	2	60.60	0.349
		Working environment	3	64.93	0.723
		Training and CPD	1	–	–
	Working atmosphere	Leadership culture	5	73.64	0.908
		Atmosphere among staff	4	76.52	0.894
		Interdisciplinary collaboration	3	–	–
Person		Demographics	3	–	–
		Occupational characteristics	3	–	–
		Salary	1	–	–
Resources		Care concept[a]	3	–	–
		Professional resources	4	48.35	0.635
		Occupational resources	3	61.98	0.667
		Leisure as a resource	2	–	–

Notes

The findings are based on the data from the second survey ($n = 131$). Two filter questions were used (confrontation with dementia, language skills) which were not considered separately. Four open-ended questions were not taken into account in this overview.

[a] In addition, questions were asked about six items specific to the care concept, which must be adapted to the care concept used.

Cronbach's alpha increases, *ceteris paribus*, along with the number of items (e.g. see Tavakol and Dennick, 2011). Some of the scales used comprised only two to three items. Accordingly, on scales with up to three items the internal consistency was tolerated as (just) acceptable at values of roughly 0.4 to 0.5, and considered good at 0.6 to 0.7, and very good from 0.8 and higher.

The sometimes rather low questionnaire response rate suggests that caregivers are only willing to take part in surveys of this kind to a limited extent. When it comes to putting the model into empirical practice, this can be especially problematic if they drop out at one of the two waves ("panel mortality"). However, an interval of six months between the two waves has proven effective, the maximum recommended interval being one year. In retrospect, three waves would be ideal to calculate the effects optimally. It would not be recommendable, in contrast, to include nursing homes in the study which implement more than two different care concepts. In the case described here, six nursing homes were studied, using two concepts (three homes per concept). An analysis of the long-term effects of one specific care concept on perceived work-based stress among caregivers remains an almost impossible undertaking, among other things due to staff turnover.

There is no doubt that the implementation of a care concept in nursing homes depends on the people involved, from the management to the caregivers. Even if the background conditions (e.g., legal regulations) and the characteristics of the home or the organization running it (e.g., mission statements) are identical, the way in which this type of concept is dealt with personally evidently plays a key role in its effect, or at least this is the only explanation for the identified differences. Another aspect which is important when measuring the effect is the initial starting point. In homes which start out with a high level of caregiver motivation, or of nursing and care, before a new concept is introduced, the level of improvement (as in a positive effect) will be minimal compared with other homes.

Finally, it can be said that the theoretical model for empirically assessing subjectively perceived work-based stressors among caregivers can generally be effectively transferred to other countries. This is mainly true of their subjective assessment of work-based stress, whereas in the case of basic structural conditions (staff qualifications, labor law, etc.), country-specific features must be taken into account.

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19 Application of the five-phase model for dyadic analysis in qualitative research to relationships between older Israeli bereaved mothers and their daughters-in-law

Einav Segev and Yael Hochman

The chapter presents an application of the five-step qualitative methodological model for dyadic analysis to relationships in families of older people. The chapter describes a five-phase model for dyadic analysis and demonstrates the phases of analysis in a study dealing with the relationships between older bereaved mothers and their daughters-in-law (widows). The chapter includes a discussion of the benefits of applying the model in studies dealing with relationships in families of older people in a variety of situations. The model provides a solution to the methodological gap concerning the topic of relationships in families of older people in the research literature, and discusses the ethical and methodological challenges facing researchers who use this model to investigate relationships in families of older people. The conclusion derived from the application of the dyadic analysis model is that the model allows a systemic perspective that expands the understanding of relationships in families of older people. The analysis enables a growing understanding that begins in the first phase, with the individual and subjective perceptions of older people, extraction of the different perceptions of the two interviewees regarding their relationship in the second phase, expansion to the understanding of the relationships in the family as a whole and between the key characters in the relationship in the third phase. The fourth phase, the abductive one, provides new theoretical insights about the family through a dialog between the theory and the analysis. Finally, in the last phase, the model makes possible an overall understanding of the families that participated in the study, and its products may help social workers who assist older people and their families plan appropriate interventions that may improve and preserve family relationships.

Introduction

Owing to the increase in life expectancy, the importance of dealing with the relationships of older people with their families has increased. Demographic changes affect relationships in multigenerational families, which have become common with increased longevity and must deal with illness, dependence and loss over many years. In most cases, the family serves as the primary source of support for older people (Parker, Mills and Abbey, 2008; Piercy, 2010).

Studies about older people indicate that relationships in old age are important for their mental well-being. Loneliness of older people has been found to be related to their mental well-being. Studies show the association between loneliness and the development of depressive symptoms (Cacioppo et al., 2006), and that loneliness is a risk factor for the mortality of older people (Litwin and Shiovitz-Ezra, 2006; Shiovitz-Ezra and Ayalon, 2010). Studies have examined various types of social networks, and have shown the importance of family relationships for the mental well-being of older people (Litwin and Shiovitz-Ezra, 2010; Park et al., 2013). At the same time, studies have shown the importance of examining the quality of the relationships and the interaction between older people and their families, with emphasis on relationships with spouses and children, which have been demonstrated to affect the mental well-being of older people (Holtfreter, Reisig and Turanovic, 2017; Santini et al., 2015; Zhang and Lu, 2019).

Family relationships depend on various components, such as family values, cultural norms, the older person's level of functioning, age and gender, as well as the psychological characteristics of family members, previous family relationships and the family tradition of division of roles. All these create a mosaic that influences family relationships and functioning (Piercy, 2010).

Despite the centrality and importance of the relationships between older people and their families, most studies that have investigated these relationships have been conducted from an individual-developmental perspective (Blieszner, 2006). Little reference has been made in the research literature to intergenerational family history in the family and the quality of intergenerational relationships in old age. Most of the research literature deals with the primary caregivers and with the support of older people (Whitbeck, Hoyt and Tyler, 2001), with the complexity of emotional relationships in the family, differences in family structures, interdependences between roles, rules in the family, and patterns and outcomes of care for older people within the family setting (Silverstein and Giarrusso, 2010). Studies that have investigated the provision of support by families to older people have focused on the older person as the recipient of family support. There is now an understanding that the provision of support by older people to younger generations is just as important, and therefore it is essential to examine in depth the relationships in families of older people, and the support that older people provide and receive in the family (Gierveld and Dykstra, 2008).

In a review of the research literature on ageing and family life (Silverstein and Giarrusso, 2010), the authors addressed the methodology used in most of the studies conducted on this topic. According to them, studies on relationships in the ageing family were based primarily on quantitative methodologies, large-scale sampling and statistical innovation. They argued that qualitative methodology and thick descriptions of micro-family environments are needed for a deep understanding of relationships in the ageing family, to discover the frameworks that older people and their families use to negotiate the gap between expectations and behaviors related to family help and support, tensions between dependence and independence, and more. The research literature on the families of older people also tends to be differentiated based on the relationships that are being explored, such as relationships between spouses, relationships of older people with their adult children and more. Thus, a holistic methodology that examines comprehensively the relationships in the families of older people is needed but missing. Dynamic models are essential for understanding why and how relationships in the families of old people change over time in response to normative and abnormal events (Silverstein and Giarrusso, 2010).

In the area of mourning and bereavement, there is also a lack of research literature that examines post-loss intergenerational relationships, and the development of relationships over time in light of changes taking place in each family member and in the family as a system. Although it is well recognized that bereavement is a "family affair" (Stroebe and Schut, 2015; Stroebe, Schut and Boener, 2013) that affects all members of the family and their relationships, bereavement theory and research have focused primarily on *individual grief*, with insufficient attention to the effect of a death and loss on the *family* as a relational system (Breen et al., 2018; Stroebe et al., 2013; Walsh and McGoldrick, 2013). Studies that adopt a systemic approach to understanding bereavement place greater emphasis on the nuclear family than on the family of origin of the deceased as a unit of investigation. These studies examined mainly the coping of bereaved parents (Bar-Nadav and Rubin, 2016), widows (Barak and Leichtentritt, 2015; Griese, Burns and Farro, 2018), and the relationship between bereaved parents and their other children (the siblings of the deceased) (Malkinson and Bar-Tur, 2005). The relationship between the nuclear family and the extended family following loss, specifically the relationships between the in-laws, remain understudied.

Research has stressed the important role of the son/husband in the relational dynamic between mothers-in-law and daughters-in-law (Rittenour and Kellas, 2015). Despite this centrality of the son/husband in the relations between the mother-in-law and the daughter-in-law, and in ensuring the continuity of the relationship (Morr-Serewicz, 2014; Rittenour, 2012), there are almost no studies on the implications of the absence of the son/husband following loss on the shaping of the relationship between mothers-in-law and daughters-in-law both in the short term, close to the loss of the son/husband, and in the long term, when the bereaved mothers reach old age.

Given the importance of examining the intergenerational relations in families of older people, the need arises for a methodological model for qualitative data analysis that would assist in examining these relationships and make possible data analysis in qualitative research dealing with these issues. The purpose of the present chapter is to fill this gap with methodological analysis methods in qualitative studies dealing with relationships in families of older people. In this chapter, we demonstrate the application of the model we developed for qualitative analysis of family dyads to study relationships in bereaved families in Israel, where the dyads included older bereaved mothers and their daughters-in-law (their sons' widows).

Sample research: relations between older bereaved Israeli mothers and their daughters-in-law (widows)

We demonstrate the application of the model through a dyadic analysis of the relationship between older people and their families in a qualitative research conducted in the phenomenological tradition (Starks and Brown Trinidad, 2007). The purpose of the study was to understand the participants' perception of the relationship dynamics between mothers-in-law (older bereaved mothers) and their daughters-in-law (widows) following the loss of their son/husband. In this chapter, we present an analysis of three dyads, from three families, which are part of a broader study investigating relations between older bereaved Israeli mothers and their daughters-in-law. In each family, the older bereaved mother and her daughter-in-law (her son's widow) were interviewed. Both women in the dyad were aware of the fact that their counterpart was also interviewed.

The study population included ten bereaved mothers and ten widows whose sons/husbands died while serving in the Israeli military, the police or the security forces. The participants were identified by social workers in the Family and Commemoration Department of the Ministry of Defense, and were interviewed in 2018. The sons/husbands lost their lives between 2000 and 2010. At the time of the interviews, the widows' age ranged between 44 and 51 years, and that of the bereaved mothers' between 73 and 87 years. All the interviewees were Jewish. Most women lived in cities in the southern part of the country and in geographic proximity to one another.

In the following section, we present the analysis of three dyads, which were the only dyads of women from the same family in the sample of the broader study; all other interviewees in that sample belonged to different families, and therefore could not be included in this analysis.

Data collection

Semi-structured in-depth interviews were conducted to understand the subjective experience of the mother-in-law/daughter-in-law relationship as perceived by the interviewees, and the dynamics of the evolving relationship between the women. To this end, an interview guide was drafted. The interviewees were asked a broad opening question about family relationships, especially about the relationship between the mother-in-law and the daughter-in-law. Subsequently, additional questions were asked about the relationship, for example: "Tell me about the time you met your daughter-in-law/mother-in-law, and the relationship between you at that time", and "Tell me about your relationship with your daughter-in-law/mother-in-law since the loss."

The interviews were conducted by three veteran social workers (12–30 years of practical experience with bereaved families, with an average of 24 years), with significant experience working with older bereaved mothers and widows as part of their clinical work. None of the social workers who conducted the interviews worked directly with the interviewee as part of their job. The interviews were conducted in the homes of the participants, and lasted on average from one hour to an hour and a half. All the interviews were recorded and transcribed verbatim.

Data analysis

Analysis of the relationship between bereaved mothers and their widowed daughters-in-law, illustrated below, relies on the five-phase model of dyadic analysis (Hochman, Segev and Levinger, 2019). This application of the model for the study of older people is relevant in cases when (a) the research question is aimed at investigating the relationship of the older family member with one of the family members, or with the entire family, sharing a common experience and reality, and (b) when investigating the research question, for ethical or epistemological considerations, the researchers collect data separately from the older person and one of the family members about their relationship or about relationships within the family as a whole. This type of data collection makes possible a holistic understanding of family relationships that affect the lives of the older member, which cannot be understood by interviewing the older person alone.

According to the model (Hochman, Segev and Levinger, 2019) the analysis of interviews collected from family members includes five main steps that were conceptualized in accordance with Bronfenbrenner's (1979) ecological systems theory. The first phase, *microanalysis*, included an inductive thematic analysis of the subjective perception or experience of the phenomenon, to understand how each participant experienced and perceived the phenomenon, and the meaning they attach to it in their subjective accounts. To this end, each individual narrative was analyzed to identify units of meaning arising from each interview separately. Next, we searched for repeated patterns of meaning that emerged from the various interviews. The second phase included a *dyadic analysis*, where the units of analysis were the dyads. We examined the themes that emerged from each dyad and assessed the overlaps and contrasts between the individual narratives at the descriptive and interpretive levels. Our aim was to reach an understanding of the shared dyad reality by reconstructing a relationship narrative that describes the way in which each individual perceives the other in the dyad, and how each of them perceives the relationship as a whole. The third phase, *exoanalysis of the family narrative*, explores the dynamics of family relationships through the dyadic perspective. In this phase, the focus is on the family narrative, on the relational dynamics within the family as one unit. Each member of the dyad, and the dyad as a unit, account for the systemic understanding of "a web of family relationships that was larger than the dyadic relationships" (Hochman, Segev and Levinger, 2019, p. 9). The fourth phase*, abductive top-down analysis of meaning making*, aims to develop a systemic meaning and understanding of the insights gained in earlier phases regarding family dynamics, to shed new theoretical light on the data through continual dialog between the data and existing theories. The fifth phase, *a cross-family analysis*, produces a holistic understanding of all the families as one group, including the similarities and differences between them.

Ethical considerations

The study was approved by the Ethics Committee of the School of Social Work at Sapir Academic College. Each participant signed an informed consent form. Privacy and confidentiality were strictly observed, and all identifying details were obscured. No information obtained in the interviews was transferred to the social workers handling the participants' cases. The interviewees received a detailed explanation from the interviewers about the purpose of the research, its importance and the protection of the confidentiality of the participants' personal information.

Five phases of analysis of in-depth interviews with multiple family members

Below we explain and illustrate each of the phases of the model, based on the analysis performed at each phase of the study, to illustrate the implementation of the model and the outcomes of each phase, as well as their contribution to the understanding gained about the relationships in the family of the older person.

Illustration of phase 1

In the first phase of the analysis, we examined the subjective significance of the loss of son/husband for the participant, both for the bereaved mother and the widow. Separate analysis of each interview revealed that all the participants described the loss as a traumatic event, difficult to cope with, whose significance received different meaning for bereaved mothers and widows. The older bereaved mothers described that, alongside coping with mourning for the son, a process in itself too difficult to bear, they had to deal with additional loss and deterioration in their physical and cognitive function, which further encumbered and challenged the ongoing grieving process. Sophie said: "When my son was killed everything was fresh. Now I have forgotten many things, so much time has passed. I didn't believe that I would live so many years after his death." Shula, another bereaved mother, said:

> My hearing is not good anymore, I have many problems at my age, I am forgetful, I want to talk, I know what I want to say but the words don't come out, but the pain is there and it will remain.

It also became evident that bereaved mothers faced new losses of family and close friends who passed away:

> I have lost a child for life, and it is very, very difficult, I can no longer go out, so I have conversations with a social worker in my house.… My brother passed away recently and it's getting harder and harder.

Finally, during the interviews, the bereaved mothers often mentioned their age as a factor that makes it difficult for them to cope with the loss and with family difficulties.

Unlike the bereaved mothers, who were preoccupied with their present subjective experiences in their old age, the widows noted their difficult coping in the past, when they became widowed, and were caring for young children. For example, Anna described the loss as a young woman, caring for a small child who was orphaned from his father:

> I won't lie, after he was killed I didn't want to live. I was only 24, with a small child.… Some people find a solution in alcohol and drugs, but I wasn't like this, and I said, how would it help if the child lost his mother too?

In the interviews, the widows describe the children as a motivation for continuing to live. Noa said:

> You realize you must go on living, there's no choice. You have a choice of going into depression and drug therapy, or standing on your feet and saying, there's nothing to do, we have to go on living for the children.

Sarah said:

> You think about the children and think about yourself, what do I do and how will I cope. I had many difficulties and many thoughts, I was confused. I feel that I had a life before and a life after. When my husband died half my strength was gone.

Another theme that emerged from the widows' interviews touched on loneliness and the social stigma that manifested itself in distancing and labeling on the part of society, which they endured for many years. Noa said:

> I would talk about my difficulties and they would say, so what if you're a widow, don't make yourself out to be helpless. They didn't understand what it means to raise children without a father when you're 32 years old.

This stigma was also evident to partners. Noa related: "Some people think widowhood is a contagious disease, some men I went out with were frightened by the word widow. On one hand pity, on the other hand it frightens them." Anna said: "I felt very alone, I didn't want to, I didn't want to phone and cry, and I felt caution on the part of everybody, as if they were telling me 'how would you feel, we have spouses and everything?' "

In sum, the first phase of the analysis highlighted the difference and uniqueness in the subjective personal experiences of older bereaved mothers and of their widowed daughters-in-law. Each woman appeared to be preoccupied with the concerns and struggles associated with the phase of life in which she found herself, ascribing a different meaning to the struggle with grief: the widows focused more on the period following the loss, whereas the mothers spoke about the loss in the context of their own old age.

Illustration of phase 2

In the second phase of the analysis, we examined how the older bereaved mother and the widowed daughter-in-law perceive their relationship over the years, from the time of the loss to the present. In their descriptions, alongside similarities in the perception of the relationship, contradictions emerged, as well as information that expanded our perception of the relationship between the two women, which helped to broaden the perspective of the delicate and fragile dynamics between bereaved mothers and their daughters-in-law. Thus, we obtained a picture from two perspectives on the relationship, as perceived by both parties.

Similarity and overlap can be found in the dyad in which one of the bereaved mothers, Sophie, described the deterioration of her relationship with her daughter-in-law after the latter met a new partner:

> When she first started to go out with her second husband it was very difficult for me. When I walked into the apartment and saw an army uniform I almost fainted. I told her, you're joining a new family, and it isn't ours.

Her daughter-in-law, Anna, described the distancing and the difficulty in their relationship when her second husband moved into the picture:

> The truth is that the relationship went somewhat sour once I had a partner and I remarried … I was very much afraid of her reaction, I was afraid it would ruin our relationship, and when she found out, there was a period when they took it very hard.

The analysis at this phase made possible a rich understanding of the complexity of the relationship in each dyad of a bereaved old mother and a daughter-in-law.

Alongside the similarities presented above, contradictions were also found between the perceptions of the women. For example, Sarah described the present relationship between her and her mother-in-law, after they were reconciled: "Today, my mother-in-law respects me very much, to this day she calls me 'my daughter-in-law.' My mother-in-law is a kiss and a hug; we're really in good relations." By contrast, the bereaved mother, Dalia, describes a more complex picture: "I'll tell you the truth, I concede to her but I don't forgive. Because she cursed my son, I will not forgive her in my life." Dalia described the gap between how she feels about her daughter-in-law's behavior and her own easygoing appearance: "We meet, laugh, talk as if nothing happened. What I feel inside me is something else, and what you must show outwardly is something else." Sarah, her daughter-in-law, described the forgiveness and her present relationship with her mother-in-law as close and loving: "I love my mother-in-law and I maintain excellent relations with her. She has always loved me and done things for me and pampered me."

Thus, implementing dyadic analysis made it possible to understand the relationship described by both sides beyond the descriptive level. We found similarities in some of the descriptions of conflicts and reconciliations between members of the dyads, and, at the same time, difficulty on the part of the bereaved mothers to fully forgive their daughters-in-law. Our findings show that in addition to recognizing support, help and mutual respect, bereaved mothers placed blame on their daughters-in-law, which resulted in conflict or disconnect between them. This understanding was obtained from the combined analysis of the two interviews, and would not have been possible without it.

Illustration of phase 3

In this phase, we examined the dynamics of the entire family from the perspective of the bereaved mother and widowed daughter-in-law dyad. Each participant in the dyad described the network of family relationships, which is more extensive than the relationship between the two of them, and which has affected their relationship over the years. Thus, we obtained information on family dynamics from a dual and broad perspective. In this phase, we identified similarities in the depiction of key family figures by each member of the dyad, including the father-in-law, the children/grandchildren, the siblings of the deceased son/husband and the parents of the widow/daughter-in-law. We also obtained descriptions of key family events, and similar expressions. Thus, we were able to achieve a broader understanding of the network of relationships in the older bereaved mother's family, facilitated by memories, descriptions of family history and family stories.

In addition, at this phase, the information obtained on the family history of pre-loss and post-loss relationships included a description of other family members and of their roles in the relationship between the older bereaved mother and the daughter-in-law. In all the dyads, we found that the key figures and the central motives for preserving the relationship between the bereaved mother and the daughter-in-law were the children/grandchildren. For example, one of the older bereaved mothers, Shula, described the role of her grandson in the reconciliation between her and her daughter-in-law after seven years of disconnect: "The child caused our reconciliation … He wanted us all to come to his bar mitzvah, refused to celebrate without us, and we all came and then we were reconciled." Her daughter-in-law, Noa, provided a similar account of the role of the son/grandson in the reconciliation between them:

> After we haven't spoken for seven years, it was my son's bar mitzvah, and the poor kid felt in the middle; on one hand he was in touch with my mother-in-law and wanted his grandmother to be at the party, and on the other hand, I wasn't talking to her and I didn't know how I would invite her with all this conflict. In the end my mother called and invited her, and at first she didn't want to, but finally my sister-in-law persuaded her: there's no way out of it, we must do it for the sake of the child. And they really came, and there was a lot of crying and was very difficult. They brought presents to the child, and that's how we were reconciled.

Participants provided information not only about specific figures but also concerning the general dynamics of the family. Periods perceived by them as times of distancing and disconnection between family members were described alongside periods of reconciliation and closeness. For example, in one of the dyads, the older bereaved mother, Dalia, described the change in family relationships from close and cohesive to remote, following the loss of the son:

> Before the disaster we were a happy family, a good one, there's nothing to say. We were together, and all the time enjoyed life together, until this trouble came and since everything has been destroyed, the whole family was destroyed, everyone lives for himself, no more no less.

Her daughter-in-law, Sarah, described the relationship in the family after the loss as follows:

> That period was difficult for the whole family. This blow crushed them and me as well, a distance was created, arguments started in the family. From people who were supportive and generous, loved and respected each other, we became disconnected and remote.

Thus, we obtained information from two different perspectives about relationships in the family as a whole. In most cases, the descriptions of family dynamics were quite similar. In some cases, one perspective expanded our understanding and the picture that emerged about family relationships. In most cases, similar references were made by both women to key events and turning points in family relationships, such as bar mitzvah, funeral, the period after the loss, etc. This information was necessary for understanding the relationships in the family as a whole, and not merely between the older bereaved mother and the daughter-in-law.

Illustration of phase 4

In this phase, abductive analysis made it possible to make the transition from the inductive understanding that we obtained from the older bereaved mothers and their daughters-in-law to a systemic understanding of the way in which they experienced the shared family reality, through a continual dialog between the theory and the data analyzed in the previous phases.

In the present case, we chose to analyze the relationships in each family based on the McMaster model (Epstein et al., 1993; Miller et al., 2000), which is used by family counselors to assess family functioning in six areas: (a) problem solving, (b) communication, (c) roles, (d) emotional response, (e) emotional involvement and (f) behavior control. The McMaster model is by nature systemic, and made it possible for us to make the transition to a systemic level of meaning, which is what was needed to conceptualize the relational dynamics and ascribe meaning to the family dynamics, as they emerged in the previous phase.

Because of limited space, we demonstrate below the analysis of family dynamics based on two of the six dimensions of the McMaster model, communication and roles, as expressed by a bereaved mother and her daughter-in-law. Dahlia, an older bereaved mother, described communication in the family as an act of concession and forbearance, she being the one who makes the concessions and shows restraint, demanding it also of her daughters, the widow’s sisters-in-law:

> When I used to sit at the table and we all sit together, and she says something to one of the kids or something, I don’t get involved, I pretend I don’t even exist. They talk, and I see one of my girls wants say something, and I tell them “girls come to me”. I go with them to the kitchen and tell them: “Don’t say a word to her about what she said, no matter what she said, don’t answer her, because if you answer her a fight is going to break out, and who’s going to pay the price? Only I, who won’t see the grandchildren.”

The widow, Sarah, described the same pattern of communication from her point of view:

> We have a good relationship, we meet, talk. It's not self-understood that every time my sisters-in-law see me, they come and hug me and tell me "how are things", and still call me sister-in-law. They understand that it doesn't pay to spoil things because in the end it's the kids who will be hurt, not me. That's what got them to make peace and show love and pamper and talk.

Examining the relationship from the point of view of the division of roles in the family reveals that in the presence of mutual respect and good relations, the older bereaved mother and her spouse (if he is alive) are assisted by the younger daughter-in-law in various functional areas such as transportation, shopping, repairs in the home, etc. At times of disconnection and separation, they are deprived of these functions. On her part, the grandmother plays an important and significant role in the lives of the children/grandchildren, as Noa, one of the daughters-in-law, said:

> If I can help, I help her. Often I take her to the doctor, or if there is a bereaved mothers' day, I take her. And it doesn't go without saying that she's taken by her daughter-in-law because her daughters have no time, this is not supposed to happen. She is an 82-year-old woman, and very active. For every remembrance day I took her and also brought her back.

She went on to say: "She's a very warm, pampering woman, buys gifts for the children on birthdays, calls them all the time and worries about them. She cooks and exerts herself for them, she does everything for them." The bereaved mother, Shula, said:

> Our relationship today is excellent. She helps me a lot, I can't complain.… When I'm sick she comes and helps, calls. Helps me a lot. She gives of herself, cooks and brings me food, and overall she's okay … with me and the children.

She adds: "Even when we were not on speaking terms, I was constantly available for the children. Would take them for a walk, take them out, pamper them, feed them. Until they are grown, they come and I pamper them."

Illustration of phase 5

In the final phase of the study, we conducted a cross-family analysis to expand our understanding of the similarities and differences between the three dyads. Its purpose was to obtain a view of all the families as one group, and to find connections between the different themes and the patterns of relations in the different families. This was intended to achieve a fuller understanding of the dynamics and processes of development of the relationship between the older mothers and their daughters-in-law, and, overall, of the relationships in the entire family.

Based on the understandings gained for each family in the earlier phases of the analysis, we identified three patterns of connection that were found in the various families who participated in the study. We referred to these patterns as (a) narrow bridge over turbulent waters (Dalia and Sarah), (b) break and forgiveness (Noa and Shula) and (c) the war over the connection (Sophie and Anna).

In the family in which we identified the pattern of connection in general, and between the daughter-in-law and the older bereaved mother in particular, as a bridge over turbulent waters, we found many difficulties in family communication and in the relationship between the two women, since the time the daughter-in-law joined the family. Similar perceptions were described by both participants. These complex relationships led to a break and prevented meetings between the grandmother and with the grandchildren for several years. Following this break, the two seemed to have succeeded, with the help of the family (the daughter-in-law's parents, brothers-in-law and sisters-in-law) to reconcile. But the phases of analysis indicated gaps and differences in the perception of the connection today: whereas the daughter-in-law described reconciliation and a loving family, the bereaved mother described resentment, inability to forgive and continual restrained behavior and concessions on her part to be able to see her grandchildren. The restrained communication, full of obstacles, and the non-reciprocal division of roles revealed in phase 4 exacerbated the fragile nature of this pattern of relationships.

In the second type of family, development of the relationship appears to have shifted from bad to better, after relations of mutual respect in the past, described by the two women in the dyad, have suffered from a turbulent and difficult conflict that led to a seven-year break following the death of the son/husband. But the turning point, which was mediated by the son/grandson, has led to mutual forgiveness, warm and open communication, and mutually supportive and helping roles.

In the third type of family, despite difficulties experienced and described by the two women from the beginning, they reported a mutual decision not to give up on the relationship for the sake of the son/grandson. The description is one of struggle of each woman with her own emotions, with the age differentials and with developmental tasks they were facing to preserve the relationship, of mutual help and support roles over the years, without breakdowns, even during difficult periods.

Discussion and conclusions

In the present chapter, we demonstrated an application of a data analysis model in qualitative research appropriate for examining various issues relating to relationships in the ageing family. This model allows analysis of data derived from interviews with older people and at least one other family member. We illustrated an analysis of interviews of bereaved mothers and their daughters-in-law with a view to examining the dynamics of the relationship between them after the loss of their son/husband, and the relationships in the entire family following the loss.

In light of the paucity of qualitative studies examining relationships in the ageing family in general and intergenerational relationships in particular (Silverstein and Giarrusso, 2010), the present chapter offers a methodology for qualitative data analysis in studies aimed at investigating relationships in the families of older people. The model implemented in this chapter is that of the five phases of dyadic analysis (Hochman, Segev and Levinger, 2019). These phases were detailed and illustrated to show that this methodological model can be used to study relationships in the families of older people. The model makes possible a holistic and systemic understanding of how older bereaved mothers and their family members perceive and construct family relationships and experience a shared family reality (Reczek, 2014).

The chapter proposes a way of using qualitative methodology that allows in-depth study of issues related to relationships in the families of older people, and provides a holistic understanding of relationships in families of older people in a variety of normative and non-normative situations. The model can help explain and interpret information about family experiences in a range of ageing-related situations, such as older people in need of nursing assistance from family members; older people and families dealing with various family crises, stress, and trauma situations; and older people who have become widowed.

The first three phases of the analysis were inductive. The first phase, which focused on the subjective experiences of the research participants, highlighted the diversity and uniqueness of personal experiences and of the perception of loss at various developmental stages in the life cycle: old age and young adulthood. Because the two women are at different developmental stages, their grieving processes are different. This is consistent with the research literature on the subject of the mourning of widows and bereaved parents, which indicates that the mourning of bereaved parents is an ongoing process, whereas that of the widows is tempered with passing time. A few years after the loss, widows begin to recover, are better able to accept the loss, restore their lives and usually return to normal daily functioning (Blackburn, Greenberg and Boss, 1987; McCrae and Costa, 1993).

In the second phase, we expanded the perspective regarding the different conceptions of the relationship between the two women, and how each perceives the other. The dyadic analysis of the interviews revealed gaps and contradictions, together with overlaps and parallels in the narratives of the old bereaved mothers and their daughters-in-law. Such understanding of the complexity of the relationships would not have been possible without the analysis of the two interviews as one dyadic unit. In the third phase of the analysis, we expanded our perspective regarding the key figures involved in the relationships formed between the older bereaved mothers and their daughters-in-law, and of the relationships in the family as a whole. The fourth, abductive phase helped the conceptualization of research findings by providing new theoretical understandings of family relationships through a continual dialog between the data and the theory (Timmermans and Tavory, 2012). The McMaster model, whose purpose is to examine family functioning, which we used in the fourth phase, served as an organizing interpretative framework for the units of meaning that emerged in the first three phases of the analysis. Thus, we achieved a systemic understanding of various dimensions of the relationship between the older bereaved mothers and their daughters-in-law, and of the functioning of the family as a whole following the loss. The fifth phase allowed for a broader understanding of different relationship patterns in different families.

Alongside the methodological contribution of the implementation of this model, the products of the analysis have implications for the practice of social workers and family caregivers working with bereaved and multi-generational families where the bereaved mother is of old age. The findings provide a systemic understanding of relationships in families under their care, and may form the basis for planning family interventions with the entire family. These interventions should be based on an understanding of the common reality shared by the older people and their families.

Implementation of the five-phase model for dyadic analysis must address several challenges. The first is to integrate the socio-cultural element to which the family belongs, and address those elements, as for example, the perception of loss in a given culture, the place of the older person in the family from the perspective of that culture and the social affiliation of the family. Another challenge has to do with the fact that the model is based on data collection in separate interviews. On one hand, this allows each family member to openly express her views about her experiences, but on the other, it presents ethical challenges during the data collection phase, such as the dilemma whether to inform the interviewees that their family member also participates in the study (Taylor and De Vocht, 2011). Other challenges arise at the time of reporting the findings, when various issues may surface, including aspects of the family that have not been mentioned, exposure of which has the potential to harm one or both interviewees and exacerbate an already fragile relationship in the family.

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Part IV

Older adults as the source of knowledge

20 Older people as peer researchers in ageing research

Nuisance or necessity?

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Through a critical lens, this chapter draws on methodological considerations in the involvement of older people in research about themselves and discusses the promises and pitfalls. It first draws upon the conception and rationale of using participatory peer research method in ageing research, and then focuses on how the principles are operationalized, highlighting the strategic risks and dilemmas. The relevant practical and methodological challenges/dilemmas are discussed with critical analyses in the current practices of the participatory research method, including the operationalization of participation, the conflicts of experiential knowledge and scientific knowledge, impacts on research quality, commitments of peer researchers and ethical considerations. Some exemplars of gerontological research carried out with older adults are used to illustrate how and to what extent this approach has been utilized.

Introduction

Most of the knowledge on ageing and the lives of older people in social science is based on research conducted by academia and professionals across various disciplines by universities, government and service providers. Social scientists and academic researchers determine the scope of research, set the primary research questions, choose the research method/design, collect primary data, interpret the information and translate the results into actions, practices or criteria. Traditionally, the role older people play during this process is as research subjects whose life-world and behaviors are investigated by scientists or researchers. For instance, older people are usually interviewed by researchers on their lives and experiences; they are asked to complete paper-and-pencil questionnaires; or they are consulted on the quality of services or products as users. There is a distinct boundary and power imbalance in the investigation process between researchers and research subjects.

A growing body of studies, however, are involving older adults as co-researchers in the study of ageing – a participatory peer research method. As described by Glanz and Neikrug (1997), “Those who are intended to benefit from the research should be involved from its inception in the formulation of research agenda and conceptualization of the research questions and design, as well as its implementation”. Critical questions are immediately raised: In what kind of research activities and to what extent should older people be involved? Who should shape the research agenda and carry out the research? What are the roles of older people and academic researchers? What is the impact on the research process and validity of involving lay older people as research partners? How should the ethical and practical issues and risks of using this method be managed? While there are many various strands to the discussion, many gerontologists are hesitant to embrace this method, because there has yet to be a coherent and systematic framework and very few models of good practice on which to draw.

Through a critical lens, this chapter draws on methodological considerations in the involvement of older people in research about themselves and discusses the promises and pitfalls. It first draws upon the conception and rationale of using the participatory peer research method in ageing research, and then focuses on how the principles are operationalized, highlighting the strategic risks and dilemmas. The relevant practical and methodological challenges/dilemmas are discussed with critical analyses in the current practices of the participatory research method, including the operationalization of participation, the conflicts of experiential knowledge and scientific knowledge, impacts on research quality, commitments of peer researchers and ethical considerations. Some exemplars of gerontological research carried out with older adults are used to illustrate how and to what extent this approach has been utilized.

What is participatory peer research?

Peer researchers (or co-researchers) refers to members of the research target group (i.e., older people) who adopt the role of active researchers during the research process and construction of knowledge. "Peer" is understood more as the involvement of people who are under study but not professional researchers. This research method is also often called "participatory research", "participatory action research", "cooperative inquiry", "community-based participatory research" or "citizen science".

Professional researchers work *with* the people being studied, rather than *to*, *about* or *on* them as research subjects (Heron, 1996). Classical research participants are no longer passive subjects of these studies, but are active contributors working alongside academic researchers in knowledge production and transformation. In this instance, traditional participants have the potential to control the research agenda, and they are the ones who analyze and reflect on the information and data generated. Participants act as research partners to identify and reflect on issues that affect their lives and identify potential solutions to make positive change. This approach goes beyond the traditional practices of inquiry by engaging in collaborative relationships with people under study.

Why involve older adults as peer researchers?

The frustrating results of many health and social care interventions or dissatisfaction with technological products have been attributed to lack of user involvement in planning, implementation and evaluation processes (Chen and Chan, 2013; Guta, Flicker and Roche, 2013). The exclusion of older people in research also reinforces ageism and creates a vast gap in geriatric knowledge production and transformation. Researchers, service providers and policymakers have increasingly stressed the importance and necessity of user engagement to adapt research questions and geriatric services and products to meet the needs of older people (Baldwin et al., 2018; Bindels et al., 2014). They have articulated that knowledge on ageing should be conducted from the perspective of older people who are immediately concerned with the issue, rather than solely through the lens of young and middle-aged gerontologists.

Participatory research in ageing aims to produce new and local geriatric knowledge and services through collaboration with older people. Older people are enabled to construct their own paths to knowledge in ageing. The older researchers are themselves aged and ageing, thus they can bring important "insider" standpoints, skills and knowledge, and their personal experiences of ageing to gerontological research. They also have a strong research commitment, particularly if it means becoming politically active, more socially connected and contributing to tangible community change (Buffel, 2018). They can better empathize with the target group, which they belong to, and allow for developing emotional connection and understanding, thus enhancing the quality of research data obtained (Baldwin et al., 2018; Littlechild, Tanner and Hall, 2015).

Knowledge and actions on ageing could be enriched by a dialog based on older peers' interpretations and understanding of their lives and experiences (Benjamin-Thomas et al., 2018). A growing number of studies presented that peer researchers may help to understand complex health and social issues in gerontology, as well as to promote individual and community capacity building (Gutman et al., 2014; Littlechild, Tanner and Hall, 2015). Engaging participants in research is also a central concept in narrowing the gulf between knowledge and its application, and enforcing evidence-based policy at the local level. Research findings disseminated by peer researchers are more powerful in enabling or compelling service providers (Israel et al., 1998).

Extending the ownership of research to the people whom it concerns enacts empowerment. Older people are usually bypassed by the mainstream participatory research community. Studies found that older people are willing to express themselves and contribute directly and proactively in the research process, which gives them the opportunity to continue their existing social roles (Blair and Minkler, 2009; Munn-Giddings et al., 2016). This approach also has the potential to challenge ageism and to access the views of older people, whose interests are often ignored or rejected and undervalued. As suggested by Walker (2007), "As a matter of human rights, older people have a right to be consulted about research that is being conducted on them." Enabling older people's engagement in research fosters their autonomy and active citizenship; their knowledge and ability is reconstructed in a process of understanding and empowerment (Munn-Giddings et al., 2016).

Co-research with older people in the research process

Operationalization of participation

When gerontological research is conducted *with* or *by* older persons who are affected by the issue being studied, the methodological question arises as to what degree or in which activities they should, or must, be involved; and therefore, when they should be a part of the research process. Many scholars suggest that older adults should have opportunities to engage as co-researchers in diverse aspects of and probably in all phases of gerontological research, including the definition of the problems, conceptualization, data collecting and analysis, disseminating and publication findings and transformation of the knowledge into practice and informing change (Israel et al., 1998).

However, in reality, this does not take place to the degree that the researchers would have expected. There is a hierarchy of current involvement of older people in research in practice; as Walker (2007) posited, a continuum between consumerism and empowerment. The former is described as a "tokenistic approach" by Littlechild, Tanner and Hall (2015), in which older people have little influence over the research agenda. In some practice, there is little immersion of older people into the research process. Most commonly, they are viewed as research informants or advisors among several to be "consulted", for example, as interview participants or via focus groups (Chojenta et al., 2018).

By contrast, there are also some exemplars illustrated that give older people co-ownership in various stages of the research process, including taking leading roles in problem identification and conceptualization (Kong, 2018), data collection and analysis (Baker and Wang, 2006; Bindels et al., 2014; Doyle and Timonen, 2010; Gutman et al., 2014). Thus, they advance action change resulting from research, report writing or full engagement as co-researchers (Bindels et al., 2014; Buffel, 2018; Littlechild, Tanner and Hall, 2015; Tanner, 2012).

Baker and Wang (2006) discussed the utility of the Photovoice technique as a participatory method, which enables older adults to collect and analyze data for themselves in assessing pain experiences in the United States. In their study, older people used cameras to photograph their daily realities with written narratives, so as to construct their knowledge of chronic pain. In a gerontechnology infusion education project in Hong Kong, older people were intensively involved in co-planning and co-executing educational activities alongside academic researchers in bringing gerontology into university educational activities (GIE-CAMPUS Project). Older people also acted as interviewers for the evaluation of a gerontological social work course (Gutman et al., 2014). A study on developing age-friendly communities in the United Kingdom illustrated the potential for older people trained as co-researchers to take leading roles in all phases of the research process (Buffel, 2018). Given this role, older people are considered to be equal stakeholders in research on ageing, and they have equal opportunities to contribute in any way that is suitable for the research process. Negotiation and agreements on the degree of engagement between peer researchers and academic researchers were observed in the study of Bindels et al. (2014), in which peer researchers were given the autonomy to participate in research activities of their choosing.

Empowerment

A participatory peer research method emphasizes empowerment, creating conditions in which older adults can obtain a sense of control and involvement in decision-making. By adopting the peer-led research approach in gerontology, older people shift their roles from being research subjects into creators of knowledge about ageing. The new role can also give them a sense of purpose, increase their knowledge and skills, improve self-confidence, develop social networks and enrich their lives (Baldwin et al., 2018; Littlechild, Tanner and Hall, 2015). Peers are empowered through co-ownership of the research process, identifying issues related to them, and initiating possible solutions to make practice or policy changes (Gutman et al., 2014).

This approach shifts the participation of academic researchers and research subjects, calling for rethinking the power distribution between the two (Carey, 2019). By employing a peer research approach, the professional researcher acts as a facilitator or enabler to help peers undertaking research. It is common in practice for different value preferences, with regard to decisions, to lead to conflicts between research partners. Developing nonhierarchical and empowering relationships as well as establishing common goals and operation norms among the academic researchers, peer researchers and other community stakeholders, are crucial in encouraging collaborative participation and avoiding potential conflicts (Israel et al., 1998).

It has not been the intent of this chapter to suggest that active engagement throughout the entire research process is the best approach for participatory peer research. Doyle and Timonen (2010) questioned the full participation by older people in all aspects of the research process; instead, they observed that sharing of knowledge, rather than research tasks, through entire phases of the research is more appealing to older people. Similar arguments have been put forward by Baldwin et al. (2018) and Mey and van Hoven (2019), who suggest that not all older peers are willing to work intensely during all stages of the research process. They are often more eager to be involved in translation and modifying the findings that could create change.

Many structural and sociopolitical barriers exist in involving older people in different stages of research, including poor health, lack of research skill capacity, and limited time and resources (Benjamin-Thomas et al., 2018; Carey, 2019). Degrees of participation also depend on the resources available within the research budgets. Participatory peer research is more time consuming, costly and demanding compared to traditional research methods. These factors include the researcher's time for training and reflection, negotiating the new roles and relationships, and payments and expenses to peer researchers. If funding and time frames are limited, it is difficult to intensively involve peer researchers, and if done, it would probably result in tokenism.

Practical challenges in application of peer research methodology

The fundamental principle of not treating those researched as subjects, but rather as research partners and giving subjects equal rights as professional researchers in knowledge inquiry, gives rise to a number of challenges and dilemmas.

The knowledge of peer researchers

From a methodological perspective, the involvement of subjects as peer researchers has several advantages and disadvantages, each of which has to be carefully considered. One major advantage is that peer researchers are immediately affected by the issue under study, and they should have common experiences in the research field, i.e., in gerontological research. Since the research involves age and ageing, they are more sensitive to research data and should be able to understand the data distinctively.

An apparent dilemma inherent in participatory peer research becomes visible here. Participatory research aims, in particular, to involve people who have traditionally been excluded from mainstream research in the co-production of knowledge and, by so doing, enhance empowerment. However, it is questionable whether this disadvantaged and isolated group would understand various research methodological procedures and have the competencies required in the research process, such as data collection, analysis and dissemination. In the study of Littlechild, Tanner and Hall (2015), in which senior peers co-led interviews with people with dementia, academic researchers commented that peer researchers did not always have the skill to pick up on significant issues or pursue probes. As a result, the interviews drifted away from the central themes, and the obtained data was not sufficient to answer the research questions.

In order to support older people as research partners, extensive investment is required in building up capacities and competencies, which may include training and reflective meetings in research skills, linguistic competencies, communicative skills in dealing with groups and critical awareness of the roles and power dynamic between professional researchers, peer researchers and research groups (Buffel, 2018; Gutman et al., 2014). However, questions arose regarding the issue of peer researchers becoming professionalized. Glanz and Neikrug (1997) clarified that peer researchers were not going to be trained as professional research technicians, interviewers, statisticians or experts in research methodology. Some peer researchers rejected training, because they considered this as detracting from their lay role (Baldwin et al., 2018).

By contrast, the primary aim of participatory research is to enable marginalized groups to allow their voices to be heard. What counts is that peer researchers bring their everyday experiential knowledge (knowledge of the local region, language, cultural habits and experience with ageing in general) as well as their ability into the research process (Munn-Giddings et al., 2016). It has to be addressed that this experiential knowledge fosters new and distinctive perspectives and insights for academic researchers; it also helps them to triangulate the results, so as to better understand research findings, as different perspectives are negotiated and linked to each other. Blending experiential knowledge from peer researchers with the scientific knowledge from academic researchers achieves a mutual co-learning process for both parties (Bergold and Thomas, 2012; Bindels et al., 2014). All participants are known subjects who bring convergent and divergent perspectives into the knowledge production process.

Research quality

Research conducted by non-academic lay people is regularly challenged as to its validity, reliability and objectivity (Israel et al., 1998; Mey and van Hoven, 2019). Participatory methods introduce the peer researcher's first-hand experiential knowledge of the field into the research process. However, this information and views could be very personal and subjective. The question has to be addressed that different groups have developed different knowledge in the area under study (Bergold and Thomas, 2012). Subjectivity in research is a concern of many academic researchers. Some scientists believe that the peer researchers introduce subjective elements into research, which distorts the results and threatens the result quality.

Is result quality compromised by employing peer researchers? This discussion has been put forward in the paradigm of scientific research. The positivist paradigm, which emphasizes objective knowledge that is separate from the knower, is dominant in academia. However, researchers utilizing the peer researcher method need to be aware that this approach challenges the traditional positivistic subject–object dualism and addresses the researchers and research subjects as all knowers. The relationships between them are crucial in the knowledge production process (Benjamin-Thomas et al., 2018; Bergold and Thomas, 2012). Therefore, traditional quantitatively oriented objectivity, validity and reliability are neither appropriate nor adequate for participatory peer research.

Involvement of peer researchers in social science research tends to reflect the constructive and interpretive paradigm and bottom-up approach. The peer research model is based on established and shared characteristics, common points of reference, experimental knowledge and the potential to communicate and relate to research participants more closely (Mey and van Hoven, 2019). Peer researchers provide meaningful and informed insight into the experience of ageing, and thus facilitate data gathering (Littlechild, Tanner and Hall, 2015). In a study conducted by Tanner (2012), older people with dementia were involved as peer researchers and research participants. The author found the shared identify of being with someone with dementia helpful in creating a relaxed and non-threatening climate and strengthening the emotional connection with participants, thus enhancing the interview process and enriching the data obtained. In this circumstance, the involvement of peer researchers can produce better quality and more "grounded" data (Harding, Whitfield and Stillwell, 2010).

This can be seen from the fact that the participatory peer research approach is more enjoyed and acceptable in qualitative studies. Traditional academic researchers change from an extractive and analytic approach to a more collaborative and democratic means of involvement of those being studied. Explicitly and continuously engaging in dialogs and self-reflections for both peer researcher and academic researchers is underlined, in particular reflection on such aspects as how their subjective views impinge on the research.

Ethical considerations

The participatory peer research approach emphasizes self-empowerment and reduces social inequalities. A few researchers critically noted that this approach might run the risk of creating a further divide between the peer researchers and those underprivileged groups, and "unwittingly contribute to forms of disempowerment for more excluded groups" (Buffel, 2018; Littlechild, Tanner and Hall, 2015).

The fact that peer researchers who decided to participate in conducting ageing studies were those in relatively good health, socially active, educated and with professional positions is, perhaps, the group that needs empowering the least. Additionally, peer researchers participated in the recruitment of participants using their own social networks, and were, therefore, more likely to recruit people with similar social economic demographic characteristics. Those marginalized groups (in particular people from racial and minority ethical background and older adults with mental and physical disabilities) are in a very poor position to work alongside with academic researchers or to initiate such a research themselves (Bergold and Thomas, 2012). This situation must be called into question because it might reinforce the line and reproduce inequalities between the peer researchers and their older client, i.e., older adults being researched.

Another ethical challenge in equality lies in the recognition for contribution. Research on ageing was usually funded by universities, governments or community organizations, in which professional researchers receive remuneration for their work. However, in many cases, the peer researchers are engaged as volunteers and receive travel allowance or direct expenses, but are expected to make their knowledge and contribution available free of charge (Bergold and Thomas, 2012). Does this mean that older people have lower expectations and a willingness to invest time and effort for no monetary gain? Does it reflect a power imbalance, because the contributions from academic researchers and peer researchers were not recognized equally? Doyle and Timonen (2010) were concerned about this shortcoming, and thought it might reflect broader social inequalities and ageist stereotypes of older people. It is a practical challenge for researchers to operationalize and achieve equality among all research partners and insure all team members are valued for the work they contribute. Direct remuneration for peer researchers is observed in many current studies (Buffel, 2018; Gutman et al., 2014), but this might be constrained by the agreement with funding bodies.

Commitments of the peers

Practical difficulties are attached to maintaining the interest and commitment of the peer researchers. Attrition rates of peer researchers were mentioned in previous studies. A number of authors commented that older people were motivated to be involved in research on ageing, because they are interested in seeing how the results will be translated into action and promoting changes in services or policies, but not for the sake of conducting research (Buffel, 2018; Littlechild, Tanner and Hall, 2015). Expectations and division of labor for peer researchers and professional researchers are not as expected for each other. Sustainability is also a challenge. Many current research projects are short term with limited funding. If further funding is not forthcoming, peer researchers might feel frustrated about not being able to fully utilize their newly developed skills.

In the gerontological infusion project in Hong Kong (GIE-CAMPUS Project), academic researchers reflected that it was difficult to maintain the continuous interests of all senior peers in various tasks. In their volunteer pool of 50 older adults, there were a few active members, while the remainder were relatively hesitant and passive; drop-outs were observed as well. Furthermore, there are several barriers identified by previous studies that inhibit older people to commit to research activities. Older people might have physical limitations, personal health problems, transportation difficulties, lack of competence and other commitments (such as caring for a spouse or grandchildren) that limit their capability in attending regular meetings, training and performing research tasks (Baldwin et al., 2018; Fudge, Wolfe and McKevitt, 2007; Gutman et al., 2014).

Matching people's skills, capacities and motivation with appropriate research tasks and roles is critical in the early stages of research. Degrees of participation should always be adjusted to the particular and changing needs and capacities of those involved (Bindels et al., 2014; Mey and van Hoven, 2019). Additionally, it was necessary for academic researchers to maintain contact with peers, even in fallow periods such as participants' recruitment, to establish comfortable and nonhierarchical relationships and provide necessary support, including resources, training and briefings. It is a journey that requires open, flexible, sensitive, responsive and adaptive qualities from a researcher.

Summary

We conclude that although the participatory peer research method in gerontological research is full of challenges, it offers an important complement to traditional investigator-driven research. This approach adds layers of complexity to the research process, including power redistribution, variations in operationalization of participation, additional time and resources and conflicts among different stakeholders, whereby it is viewed as a nuisance. Considerable variations are involved when using older people in empirical gerontological research, which might due to a lack of a paradigmatic and theoretical framework that can inform and guide ethical and coherent practices. Additionally, it is not clear how this approach altered the research process or outcomes, because formal evaluation to quantify and assess the impact is still to be undertaken. Notwithstanding, participatory peer research has undoubtedly helped in creating inclusive, equitable and responsive research. In addition, it serves to enact empowerment at the individual and community levels. One can positively state that involvement of older people in ageing research is a necessity, not a nuisance.

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21 Including participants who cannot communicate in research on ageing?

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This chapter focuses on participant selection in research, in particular the involvement of older adults with communication challenges. With the ageing of the population and the increased prevalence of chronic health conditions such as stroke and dementia, a significant number of older individuals are left with difficulties that impair their ability to communicate or to engage in conversations. This has a profound impact on how researchers include them in research. Indeed, limited communication poses challenges not only for obtaining informed consent but also for engagement in surveys, interviews, focus groups or even in responding to surveys. The exclusion of this group of older adults has a wide impact because policymakers are relying on studies from which the most affected individuals have either been excluded or not properly included. In the chapter, the authors explore the ethico-legal and practical challenges facing researchers who consider the inclusion of this group of older adults in their protocols. A number of best practices are offered to researchers, institutional review boards and granting agencies with the aim of better responding to the need for increased participation while ensuring protection from harm and exploitation.

Introduction

Our complex ability to communicate and use language is one of humankind's most distinguishing characteristics. From as early as our days of living in caves, communication, through pictures, speech and, later, writing, has been an integral part of our lives. It connects us with others, it allows us to do the things that give us meaning and it helps us find safe places to live. Therefore, it is not surprising to find that communicative abilities affect quality of life. In no demographic group is the impact of communication disorders more evident than in the older population, where many health conditions such as stroke or dementia are associated with resulting problems in exchanging information. Communication is complex and how it affects lives depends greatly on the elements of communication that are needed to respond to the individual's needs. Even at the societal level, the emphasis we have placed on pictures, reading, writing or speaking has changed over time as well as what we have preferred as a means of expression from poems to emojis (McCulloch, 2019). Consequently, someone who cannot write would likely choose conversation over email and someone with limitations in expressing themselves verbally might do better with writing. The effect of living with a communication difficulty is not homogeneous. Hence, learning more about the lived experiences of individuals who struggle to communicate and learning about how they can adapt to societal demands is of paramount importance to public policy. Unfortunately, because of the inherent difficulties associated with including people with communication disorders in research protocols, we know less about the impact of communication disorders as compared to other functional limitations. For instance, how does a stroke with resulting language impairment differ in terms of impact on quality of life from a stroke that does not result in language impairment? How do these outcomes compare with the quality of life of those who live with arthritis? Or, more specifically, how do disorders affecting verbal expression differentially impact daily life as opposed to disorders with comprehension, or reading, or articulation, or word finding, or even decreased voice volume? An older individual who must speak in public may need greater voice volume than one who does not. Living with a condition such as Parkinson's disease, the consequence of which might be lowered voice volume, can be more devastating to one person than to someone else (Miller et al., 2006). Understanding the true impact of health conditions which affect communication is essential.

More knowledge from research will inform policymakers to reduce the number of obstacles in accessing public services or navigating urban and rural spaces. Easing communication barriers might also help older individuals connect with loved ones and help reduce social isolation. Unfortunately, much of the data that might inform public policies is lacking because of the inherent difficulties in conducting research with participants who struggle to take part in these studies. It may not be surprising that this group is often excluded. Research protocols involve being able to respond to questions given orally or in writing or being able to exchange information through conversation or through groups. The purpose of this chapter is to highlight the importance of including older individuals with communication disorders in research protocols, to explore the ethico-legal and practical challenges faced by researchers and to offer some solutions and stimulation for debate to help address these challenges.

Background

Some of the most common health conditions in older adults cause disorders of communication. A stroke might cause a problem with speech or language, Parkinson's disease might affect one's voice and cognitive problems like dementia might affect one's ability to maintain conversations (Brookshire and McNeil, 2015). Individuals with communication problems may have concomitant cognitive problems affecting judgment and decision-making such as in moderate to advanced dementia. However, this is not the case for all individuals with communication problems. A great many others, whose communication problem is caused by a single stroke, such as in aphasia, may be fully capable of giving consent and making decisions, provided some effort or adaptation is made to bypass the communication difficulty (Brady, Fredrick and Williams, 2013). Unfortunately, many researchers, policymakers and members of civil society fail to acknowledge this difference. As early as 1995, Kagan made reference to aphasia as a mask of an individual's true competence (1995). Unless the interlocutor attempts to lift the mask by facilitating communication and revealing the underlying competence, judgments researchers make about their capacities may remain erroneous. The older adult may thus be falsely judged as being incompetent and incapable of making decisions and reliance on an authorized third party might be inappropriate for these participants. Such perceptions may result in exclusion from research studies. Misperceptions can result in significant social isolation, impingement on life-long learning, inability to participate in community life or in maintaining interpersonal relationships without this needing to be the case (Chapey et al., 2000). Clearly it is important for clinicians and the community at large to understand these distinctions. But, as well, the research community on ageing must seriously consider including these individuals in their studies.

The need for society to adapt to those with functional limitations is not new. In 2001, the World Health Organization launched its International Classification of Functioning, Disability and Health (ICF) (WHO, 2018). The ICF was developed as a classification system serving as a common language worldwide to document the impact of various health conditions on body systems, functional limitations and social participation. Part of the classification also identified environmental factors such as physical design features (e.g., wheelchair ramps), assistive technological aids and other factors such as natural environmental changes like climate, changes in social support, government policies and programs. Through research and conceptual frameworks clarifying the relationship between level of impairment, environmental factors and the resulting situation of handicap, it is possible to arrive at policies that modify environmental factors and make life better for those with functional limitations. This reasoning, for instance, has led employers to understand how wheelchair users can contribute significantly to their workplace if only they were provided with elevator access or ramps. Likewise, researchers wishing to include wheelchair users in their protocols must make sure that their testing labs are accessible. Impairment with communication, however, presents special challenges to being included in research protocols since much of the methods used to enquire about lived experiences requires language. As a consequence, the recognition of the potential of individuals with communication disorders is less understood and their value less recognized for lack of providing "communication ramps" (Kagan, 1995). Surely the lived experiences of those who survive a stroke and retain their ability to communicate are different from those who become non-communicative. Measures of quality of life after stroke, based on data taken from participants who could talk cannot be generalized to participants who cannot speak. Our understanding of experiences based on data gathered from non-aphasic stroke survivors will necessarily bias how policymakers and the general public view the post-stroke experience (Mazaux et al., 2013; Ellis and Peach, 2017). Policies might focus primarily on the physical adaptations needed by those with hemiplegia or other physical limitations, in part because people with aphasia were not included in early studies. In addition, it is hard to have a voice and make your challenges known when communication is difficult. Individuals with aphasia have exceptional challenges advocating for themselves in public fora. Research can go a long way in making their needs and experiences known to others.

It is important for researchers to understand the consequences of exclusion. Lessons can be learned from other populations where a subgroup was once excluded or not singled out from research results. One such example comes from studies on the presenting symptoms of cardiovascular disease (Bucholz and Krumholz, 2015). Women were dying of cardiovascular disease in greater numbers than men. As the results from studies on men were generalized to women, it remained unrecognized that women presented symptoms that were different from men. Many early public awareness campaigns of warning signs were therefore based on initial studies where there occurred a gender imbalance in study participants (Dougherty, 2011). Following careful examination of the subpopulation of women, it became clear that a new awareness campaign was necessary and one could not rely on the earlier studies to educate the public (Brown, 2015). Likewise, in Canada, where the French-speaking population finds itself in a minority situation in most of the country, it has become important to understand how services, which are mandated by law, are not necessarily designed to respond to the needs of the francophone population. Even though they seem to respond to the general need of the majority English speaking population, this is not always the case for the French speaking population (Schofield and Gauthier, 2007). The recognition of this difference has led some institutional review boards to require that researchers indicate the reasons for excluding any linguistic population group. In a country such as Canada, which prides itself on its respect of diversity, questions about inclusion are important for individuals of various faiths, genders, socio-economic status, ethnic origins or languages. Some research ethics boards now ask researchers to justify if they have included participants who identify with different genders and whether these groups will be analyzed differently. This is also the case for some important marginalized groups in Canada such as members of the aboriginal population (SSHRC, 2018). Not including them may lead policymakers and clinicians to design policies and interventions that are ill adapted or simply unhelpful to the target population. Exclusion, whether intentional or not, can have grave consequences and the same can be said about excluding older participants who have difficulty communicating.

Prioritizing policies and programs based on the skills and adaptations needed to make the world a more communication-friendly place for older adults with communication problems should be an important social objective. Even in age-friendly and dementia-friendly community recommendations, there is reference to communication as one of the key parameters (WHO, 2015). Yet, there is very little that speaks to how one might adapt differently to someone who has challenges understanding versus someone who has challenges expressing themselves. The research community would benefit from a more detailed consideration of these subgroups in research on ageing.

Being convinced of the importance of including participants with communication disorders is only the first step. Understandably, researchers might find accommodating their protocols to this population difficult. If the research community is ready to adapt how it does research with this section of our population, then there should be some level of understanding of what communication is and how it can be impaired.

What is communication?

It is difficult to obtain statistics on the incidence and prevalence of communication disorders. The National Institute on Deafness and Other Communication Disorders in the United States estimates that between six and eight million Americans have some form of language impairment and approximately 7.5 million have trouble using their voices (NIDCD, 2016). Generally, it is agreed that about one-third of stroke survivors have aphasia but the rates are hard to obtain and can vary from 18–38 percent, precisely because of the consistency in reporting this disorder (Ellis et al., 2018). There is no clear or reliable way to know what the prevalence of disorders of communication is with the older population. The Australian Bureau of Statistics concluded that of its 1.8 million older Australians living with a disability in 2015, 42 percent had a functional limitation with communication (Australian Bureau of Statistics, n.d.). It is also estimated that 70–90 percent of individuals with Parkinson's disease have problems with their speech and voice (Lirani-Silva et al., 2015). These statistics are not negligible and when we add the diagnosis of dementia to the mix, the number of individuals with difficulties in communication skyrockets. With the ageing of the population worldwide, the need to understand the impact of these disorders from a communication standpoint and for comparison to those who can communicate is undeniable.

Communication is a complex process that involves much more than speaking and understanding. It involves an intricate process of encoding and decoding through verbal and non-verbal means, analysis and interpretation of content, adjustment of interpretation of rapidly incoming information and thoughts, and elaborate methods of expression as sounds, words, sentences and conversations are created through a physiological web of coordinated muscles and timing, or translated to written forms or signs.

Researchers' need to adapt

How researchers adapt to individuals who struggle with any of these processes can have profound impact on the relationship they have with these participants and the results they obtain. This means that any challenges in communication in individual A can impact how the researcher will interpret and interact with that individual. Not only can the message be affected by the communication disorder itself, but the researcher may be distracted by these difficulties and forget to seek the underlying message. As different communication disorders should be differentially considered for research, so too must they be studied separately as we consider the impact on people's lives. In addition to factors related to the speaker, the hearer and the message, extraneous factors can cloud the communication process (DeVito, 2016). For instance, there is the "method" through which the message is transmitted (i.e., phone, etc.), the interference as the message is being transmitted (e.g., sudden noise), the encoding and decoding processes and abilities (e.g., reading non-verbal cues), the context (e.g., a job versus participation in a research study) as well as the feedback that is given and perceived throughout the exchange. All these factors can influence the outcome of the exchange even in people without communication disorders, but their impact might be amplified when communication is difficult. Adapting to these participants can go a long way in obtaining relevant and useful data and obtaining informed consent.

One classic example is the difference between aphasia, a language difficulty resulting from stroke, and cognitive language abilities resulting from dementia (Worrall and Frattali, 2000). A large number of individuals with aphasia from a single stroke typically do not have judgment impaired because of their stroke and they are fully capable of giving consent and participating given that a protocol is adapted to their needs (Brady et al., 2011). Dementia typically affects other cognitive parameters such as memory and judgment and can hinder someone's ability to maintain a conversation or to conceptually understand what is required. Adaptation to this type of disorder is different from aphasia. People in the early stages of dementia might be able to give consent but because of the additional cognitive impairments, attention needs to be given to the contribution of the communication difficulties to the overall cognitive picture. Similarly, someone with dysarthria or speech and voice disorders will have other communication challenges that people with dementia or aphasia may not have (Brady, et al., 2011). They might be able to circumvent the verbal expression of the message by using written channels or communication aids and may have absolutely no difficulty understanding what is said to them. Hence, lumping all communication disorders into one category is unfair and unethical. Some individuals who could fully give consent and participate in research might be denied access to research as participants simply because they have a communication disorder, without any consideration on the part of the researcher to adapt to their condition.

In considering the role of researchers, a crucial point is that the ability to consent to research cannot be based on diagnosis alone. Of course, in some cases, the stroke or dementia will affect competence. In others, less so and individuals will be able to give informed consent. This is not an all or none phenomenon. Therefore, determining capacity is key to engaging individuals who have difficulty communicating into research protocols.

Consequently, in this chapter, we have chosen to be somewhat fluid about the distinction between dementia and aphasia, in order to focus on the notion of capacity. The following section addresses the need to clarify the legal and ethical responsibilities arising within this context.

Inclusion in research – human rights and ethico-legal perspectives

Several international instruments are relevant to a discussion on the ethical and legal dimensions of including older adults with communication challenges in research protocols. For instance, the *United Nations Principles for Older Persons* (UNPOP; United Nations, General Assembly, 1991) promotes the independence, participation, care, self-fulfillment and dignity of older citizens. More specifically, in terms of participation, UNPOP provides that older persons "should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations" (UNPOP, article 7). By highlighting social integration and active participation, UNPOP emphasizes the importance of incorporating the input of older persons in all facets of life. This includes the possibility of involvement in research, especially if the focus is on older individuals' health and well-being. A second relevant international instrument is the *Declaration of Helsinki* (DoH), adopted in 1964 by the World Medical Association (World Medical Association, 2013). The DoH provides, as one of its general principles, that "[g]roups that are underrepresented in medical research should be provided appropriate access to participation in research" (General Principle 13). As well, the American National Institutes of Health (NIH), has adopted the *Inclusion Across the Lifespan* policy, taking effect as of 25 January 2019. The age-related inclusion policy applies to all NIH conducted or supported research involving human subjects and requires that "individuals of all ages, including children … and older adults, must be included in all human subjects research, conducted or supported by the NIH, unless there are scientific or ethical reasons not to include them" (National Institutes of Health, 2017). In Canada, the *Tri-Council Policy Statement* (TCPS2), the guideline for the ethical conduct of research involving humans in that country, provides at Article 4.1 that researchers shall not exclude individuals from the opportunity to participate in research on the basis of age unless there is a valid reason for the exclusion (TCPS2, 2018). As can be seen, these international and national instruments clearly support inclusion of older persons in research, especially when they come from populations that are not adequately represented such as persons with communication challenges.

Despite the principles outlined in these international instruments, in the context of clinical and non-clinical research participation, the traditional approach has been to lean toward great caution as far as older adults and people with functional limitations are concerned. Several studies have shown that both researchers and research ethics committees will routinely exclude participants who are perceived as "vulnerable" (Finnigan and O'Donoghue, 2019). This includes older adults in general (Jensen et al., 2019), but also children, people with dementia and adults lacking capacity. However, in recent years, there have been many calls for fuller participation of these so-called vulnerable populations (Cascio and Racine, 2019), and this has led to intense debates about how best to protect these participants and, at the same time, respond to the moral demand to conduct research related to the underrepresented groups to which they belong (Shepherd, 2016; Helmchen et al., 2014).

Research involving humans may expose participants to physical, emotional, privacy or other risks. Therefore, both legally and ethically, participants must provide voluntary and informed consent. Based on autonomy and self-determination, informed consent insures that participants make their own decisions grounded on their own values and goals. Informed consent is both an ethical and legal requirement to participation in research. Several elements are involved, namely disclosure, comprehension, voluntary choice and authorization (TCPS2, 2018, art. 3.2). Of great importance is the fact that informed consent goes beyond simply obtaining a person's agreement to participate. Rather, it is a process where, through the dialog with the researcher, potential participants assess risks, benefits, alternatives and other relevant information such as withdrawal, dissemination of findings, protection of confidential data etc. in order to make their decision (TCPS2, 2018, art. 3.3)

Crucially, in order to participate in the informed consent process, the participant must have the required capacity. Therein lies one of the main challenges when considering research with older adults coping with disorders affecting communication. Indeed, their difficulty in communicating in a conventional manner does not necessarily mean they lack the required capacity to provide informed consent to a research project.

In both the legal and ethical context, capacity is defined through a functional approach. In the legal realm, capacity is defined in relation to care and treatment and involves the ability to (a) understand relevant information and (b) appreciate the potential consequences of the treatment (e.g., Health Care Consent Act, 1996 (HCCA), section 4(1)). In many jurisdictions, this two-prong test has been adapted and applied to the research context (Vaishnav and Chiong, 2018, p. 540). A good example is the Canadian TCPS2 where decision-making capacity is defined in terms of understanding information presented about a research project and appreciating the consequences of the decision to participate or not (TCPS2, 2018, art. 3.9).

From a legal standpoint, adults are presumed to have the capacity to consent to treatment (e.g., HCCA, section 4(2); Mental Capacity Act, 2005, section 1(2)) and by extension to research participation. This being said, recognizing that, for some individuals, difficulties in communicating will be linked to health conditions impacting the capacity to make informed decisions is essential. If researchers suspect that an adult potential participant does not have the required capacity, they must carry out a capacity assessment. If capacity is lacking, specific protection mechanisms (recourse to a third party for instance) will become essential. This is where the role of substitute decision-makers or surrogates becomes very important. Nonetheless, the argument made here is that researchers and Institutional Review Boards (IRBs) should not assume that, because a person has communication challenges, they necessarily lack capacity to provide informed consent.

Capacity is challenging to assess and requires the researcher's professional judgment. The fact that capacity may vary depending on the context, or on the moment at which it is assessed, is one complicating factor. While disorders common in older adults such as stroke or dementia affect individuals' abilities, communication skills and possibly judgment differently, the impact of these disorders may change drastically over the course of the trajectory of the illness or condition. In some cases, the communication disorder may lessen or even subside while, in others, it will get worse.

But, perhaps more importantly, protocols, policies and laws often provide little guidance about when and how to assess capacity (Dalpé et al., 2019, p. 7). Indeed, Vaishnav and Chiong (2018, p. 540) emphasize that "there is no clear legal standard specifically tailored to determining capacity to consent to research". In such a context, it is perhaps unsurprising that researchers and ethics committees will err on the side of caution when they perceive that a participant may belong to a population seen as "vulnerable".

This being said, there are validated instruments, such as the MacArthur Competence Assessment Tool for Clinical Research, on which researchers have relied to assess research decisional capacity. This tool is based on structured interviews that purport to measure understanding, appreciation, reasoning and expression of choice (Vaishnav and Chiong, 2018, p. 541). However, when dealing with older adults with communication disorders these instruments are not necessarily ideal (Jeste et al., 2007). Indeed, the researcher's task is to insure that the information conveyed is received and understood and that the person has the tools to convey their willingness to participate. Evidently, having difficulties expressing oneself poses real challenges. As mentioned previously, participants with communication disorders may inherently have their competence "masked" by their disorder and may struggle in making it known to others that they understand the information being given to them and that they appreciate the consequences of the decision to participate. In these cases, the researchers grapple with the decision as to whether they need to go to a substitute decision-maker or not. For example, in a study on randomized clinical trials for neurovascular emergencies, Rose and Kasner note that researchers "subjectively estimate" the capacity to provide informed consent and decide, on their own, if surrogate consent is called for (2011, p. 4). Therefore, there is a need for further development of capacity assessment tools for non-communicative potential participants. Some studies have started to explore better adapted tools, often condition specific (e.g., Seaman et al., 2015).

In some cases, participants with communication disorders may be seen as "vulnerable" in the research context. Vulnerability is not easy to define. In fact, there is disagreement over its meaning and application in research ethics. In their survey of major international and national research ethics policies, Bracken-Roche et al. (2017) found only a few definitions in their sample. One of them comes from Canada's TCPS2 2018 where the following definition is suggested:

> A diminished ability to fully safeguard one's own interests in the context of a specific research project. This may be caused by limited decision-making capacity or limited access to social goods, such as rights, opportunities and power. Individuals or groups may experience vulnerability to different degrees and at different times, depending on their circumstances.
>
> (Glossary "vulnerability")

The TCPS2 2018 addresses directly participant's vulnerability and research in Article 4.7 and states that participants should not be inappropriately included or automatically excluded from participation in research on the basis of their circumstances. This chapter is based on the core principles at the heart of the TCPS2 2018, namely Respect for Persons, Concern for Welfare and Justice as well as on the notion of Equitable Distribution of Research Benefits. This last element entails that participants in research projects may draw "direct benefits" (better health for instance), or "indirect benefits" (advancement of knowledge improving conditions for the group to which the participant belongs) from their participation (TCPS2, 2018, art. 47). The crucial point is that vulnerable groups are entitled to these benefits. The challenge is to attain this objective without compromising a potential participant's safety. Finally, Bracken-Roche et al. (2017) point out the growing literature arguing that vulnerability is relative in nature and flows from power imbalances between potential participants and researchers and IRBs. They suggest that recognizing this phenomenon could stimulate a closer examination of the notion of vulnerability by IRBs and researchers who may consequently be more attentive to the importance of empowerment and the promotion of agency when dealing with “so-called” vulnerable adults (Bracken-Roche et al., 2017, p. 16).

One of the common safeguards when seeking the participation of a potential participant whose capacity to decide may be compromised is to rely on an authorized third party who has the legal authority to make decisions on the participant’s behalf. Reliance on such third parties is not without challenges, however. First, while a number of national and international instruments provide for the use of a legally authorized substitute when necessary (e.g., DoH), others such as Ontario, Canada’s largest province, expressly provide that such representatives cannot be relied on in the context of consent to research (HCCA, section 6(1)) (see Thorogood et al., 2018, p. 87). Second, some concern is expressed in the literature about the authorized third party’s ability to properly identify the participant’s preferences or safeguard his or her interests (e.g., Finnegan and O’Donoghue, 2019, p. 67). In the case of an older adult struggling with communication, the surrogate may face additional challenges in ascertaining the wishes, intentions and preferences of the participant – even if capacity is present. Exploring fully this question is not possible within this chapter but the importance of further reflection and research on the matter is undeniable if one is to promote more active participation in research by older adults with communication challenges.

As can be seen in the discussion above, international human rights instruments provide a strong basis for the inclusion of older adults in research protocols. However, researchers and ethics committees are hesitant to include participants who they perceive as lacking the capacity to provide informed consent because of age or of functional limitations, including communication challenges. While improvement of capacity assessment tools may assist researchers, a number of other measures may be envisaged as well. Researchers must provide a “safe space” for participants to fully take part in research projects. Importantly, researchers who rely mainly on a diagnosis to determine if a person will be included in a research project will not be in a position to recognize if the potential participant’s ability to understand the information provided, or to appreciate the consequences of participating and the choices offered. The next section of this chapter highlights some of the suggested strategies that might be adopted to conform to the principles of good research when including older individuals who have communication disorders.

Best practices for inclusion of older individuals with communication disorders in research

There are yet no universally accepted guidelines regarding the inclusion of people with communication disorders in research on ageing. What follows are strategies to consider for improving how researchers interact with participants whose communication is a challenge. As mentioned previously, one of the fundamental concerns is that judgment not be based solely on diagnosis but rather assume some sensitivity to the nature of the communication issues, regardless of diagnosis. Two of the most common primary sources of literature guiding researchers on how to interact with older adults who have difficulties making their needs known are studies on aphasia and on dementia. The case of dementia is interesting because it is now recognized that individuals with this condition can and should be active participants in research and efforts should be made to obtain informed consent as often as possible (Brady et al., 2013). While these individuals may also have some difficulties with decision-making and appreciating the choices in front of them, some attempt should be made to reduce the communication barriers. What follows are suggestions for researchers, institutional review boards, publishers and granting agencies and for communities of older adults who live with communication challenges. It is beyond the scope of this chapter to offer an exhaustive summary of techniques for involving older adults with communication challenges in research. The reader is encouraged to consult the very rich literature on the lived experiences of aphasia for examples. Our purpose is to stimulate dialog amongst researchers who would normally exclude such participants and to the organizations that support fair and ethical research on this issue.

For researchers

1 *Be open. Assume capacity but be sensitive to possible vulnerabilities.* Regardless of diagnosis, the researcher should assume capacity and be cognizant that the communication difficulties exhibited by the participant may indeed be masking an underlying competence to participate in the research protocol (Dalemans et al., 2009). In other words, researchers should be open to this possibility and be ready to adapt their protocols to give potential participants a fair chance of being included. Recognizing that including these individuals in research will help shed light on the nature of the disorders as well as the impact it might have on those who live with these challenges is crucial. By including them in larger studies that are not focused on the communication aspect itself, researchers will be contributing to knowledge of the differential impact of communication vis-à-vis other functional limitations.

2 *Adapt your recruitment strategies.* As part of a report on a research summit on dementia care, organized by the Office of the Assistant Secretary for Planning and Evaluation in the US Department of Health and Human Services, Lepore and colleagues (2017) have outlined some cautionary advice and some useful suggestions for recruiting people with dementia into research. There is a sensitivity to person centeredness that is also relevant to older adults with communication disorders in general. One advice is to be aware of the danger of relying on gatekeepers based on the common belief and bias that individuals with communication challenges cannot participate in research. In many studies, recruitment will rely on healthcare staff and sometimes family members to identify potential participants. In fact, Bartlett, Milne and Croucher (2018) specifically suggest that nurses be part of recruitment strategies. While this is indeed a useful approach, the participation bias noted above is also common in these gatekeepers. Some health professionals may not have the time to assess the potential participants in some depth and may have forgotten or not known that abilities are context dependent. This means that while some potential participants might appear to be non-functional in their milieu, in the right context and with the right support, they could very well participate in a research project. As a result, some gatekeepers may underestimate the participant's competence and consequently omit to refer them to the researcher for inclusion. Lepore and colleagues (2017) suggest that one way of diversifying recruitment strategies is to use modalities that do not rely on gatekeepers but, rather, connect directly with the potential participants themselves. These might include online recruitment through support groups or by engaging advocacy groups and health charities such as aphasia associations or dementia societies. Another strategy is to make sure that recruitment documents are accessible from a communication standpoint, such as aphasia-friendly documentation (Howe et al., 2004). In some cases, it is important to recognize that information may be easier to understand through written language for some, and through non-verbal means (e.g., pictographic) for others. Recruitment

strategies, therefore, need to use multiple modalities if they are to reach the persons with communication disorders themselves.

3 *View obtaining informed consent as a complex process.* Obtaining informed consent for research is far from straightforward and, as mentioned above, the desire to respect choice and decision-making is challenged by a researcher's ability to determine capacity. Penn and colleagues (2009) rightly point out that obtaining informed consent is a process, involving more than the simple signature on a legal document. Every effort should be made to provide a research context where people with communication challenges can have the time to understand what is involved and have the support to communicate their choices. Penn and colleagues provide an excellent breakdown of all the components that are often part of informed consent, from understanding the rationale of the project to knowing whom to contact. In their study they videotaped, transcribed and analyzed in detail the interactions between participants with aphasia and researchers while informed consent was being sought for a clinical trial. Participants were later interviewed and asked, amongst other things, whether the study had met their expectations. While the authors included just a small number of participants, the in-depth analysis highlights the need to make sure that information is well received and processed from the outset. How informed consent is obtained in this population is crucial to inclusion and adherence to principles of ethical research. Yet, in the same paper, Penn and colleagues reviewed and found that only 41 out of 458 existing studies that included people with aphasia had mentioned obtaining informed consent, and only a few actually described the process. The quality and ability of researchers to obtain consent with this population is partly dependent on the researcher's ability to communicate with participants and some useful suggestions are summarized below. Minimally, obtaining informed consent should be done in a face-to-face encounter in a quiet environment, and consideration should be given to the use of pictogram-based consent forms made available by entities such as the Aphasia Institute. Finally, because it is difficult to know what the person has understood, some authors (Jensen et al., 2019, p. 329) suggest a re-evaluation of informed consent a few hours after the initial decision to include has been made.

4 *Rely on a legally authorized third party as a last resort.* All efforts must be made to include the participant before seeking consent from a legally authorized third party (Lepore et al., 2017). As is often noted, the surrogate's perceptions of lived experiences are not always synchronized with the participant's perceptions and care should be taken not to rush to the conclusion that the potential participant lacks capacity or is unable to take part in the research (Mendyk et al., 2015). As discussed above, however, there is a need for further development of tools to assess capacity of older adults with communication challenges.

5 *Adjust data collection.* The communication strategies mentioned above are not only useful for obtaining informed consent but also for all aspects of a research protocol that involves understanding or transmitting information. Because much of what we do as researchers involves communication, it is also appropriate to adjust our style to insure that we obtain the best data possible from participants who have difficulties understanding or expressing themselves. Contrary to individuals who may just need time to say what they want, as may be the case with someone who has problems with articulation, individuals with more advanced dementia might need frequent reminders and facilitators, such as visual support material, to contribute to the interview (Smeets and Moser, 2012, p. 12). In the case of questionnaires, if not time constrained, the

participant can respond at his or her leisure. In the case of focus groups, others can help to provide context, but the researcher must be careful to give the participant who cannot express himself or herself easily, the time to respond. Sometimes the communication strategies outlined below can help the participant understand or get his or her point across, even in focus group or interview formats.

6 *Diversify communication strategies.* Whether the researcher is recruiting, obtaining consent, judging for assent or dissent, or engaging in communication-based protocols, some knowledge, training or adaptation is necessary if individuals with difficulties communicating are to be included in a protocol. What follows are some suggestions for researchers to consider. Readers are strongly urged to consult the literature on the training of communication partners and supportive conversation. A seminal article by Kagan and colleagues (2001) leads to a body of research on the topic.

   a Since the researcher will likely not have a detailed evaluation of the potential participant's communication challenges, access to multiple ways of making the information understood would be useful. Aids such as photos, written material, videos, objects and pictograms could facilitate communication. Similarly, the participant should have access to various ways of communicating with the researcher such as writing or drawing instruments and paper.
   b The key to successful communication is flexibility with the strategies that are used. If something is not working in terms of comprehension or if the researcher struggles to understand what the participant is saying, another strategy from the communication toolkit should be tried. Importantly, reliance solely on oral communication should be avoided as some participants will need one or more different modes of communication at different times in order to reveal what they know or want to say.
   c Researchers should insure that the environment is quiet so that the person who has the communication problem can focus on the task at hand.
   d Researchers should insure that there are no sensory barriers to communication. This means that hearing aids and reading glasses should be in place if necessary.
   e The atmosphere should foster a feeling of trust and patience. Periods of silence may mean a need for extra processing time. Research staff are encouraged to treat participants as competent adults, regardless of their status.
   f In order to make sure that messages have been correctly understood by the participant, research staff could ask alternate specific questions to verify apparent understanding. This will prevent the participant from simply repeating what the research staff has said and will increase the chances that the participant has processed the information.
   g As well, research staff can paraphrase and repeat back what they have understood. This gives participants a chance to correct or confirm the message they were trying to convey.
   h Researchers might consider hiring a trained language expert to facilitate with protocols and obtaining consent (McCormick et al., 2017).

7 *Develop materials for research.* Some of the reasons leading to the exclusion of individuals with communication disorders include the lack of standardized tools for inclusion and of modified consent forms, as well as the absence of research staff able to adapt to the needs of this population for any given protocol. Research protocols adapted for people with communication difficulties are therefore needed and must be

tested for validity and reliability. Researchers who include older adults with dementia or stroke in their studies will interact with individuals with communication difficulties on a regular basis. The need for sharing and evaluating the impact of strategies is pressing indeed.

For institutional review boards

Institutional review boards have strict guidelines regarding research protocols with "vulnerable" populations. In trying to protect these populations, these guidelines may in fact be doing a disservice to many groups and individuals alike. As discussed previously in this chapter, participants might be denied access to research when they can indeed participate provided there is some degree of adaptation. Indeed, some studies show that IRBs are at times "overly focussed on legal risk and not always hearing the voice of older adult research participants" (Pachana et al., 2015, p. 705). Researchers who would like to be granted more flexibility in their approaches are restricted by IRBs. More recently Jensen and collaborators (2019) have offered some interesting guidelines which may be considered by IRBs. Because diagnosis is not sufficient to determine capacity, these authors suggest that the assessment be based on the following four elements. We have added questions which IRBs might ask investigators to consider and answer prior to granting ethical approval.

1. Understanding. What measures has the researcher put in place in order to insure that the potential participant has understood the information essential to make an informed decision?
2. Appreciation. What measures has the researcher put in place to assess whether the participant is able to determine the effect and consequences of his or her choice?
3. Reasoning. What measures has the researcher put in place in order to ascertain the participant's comprehension of the rationality and reasonableness of the request, within the current context? Can the participant judge that the request is reasonable?
4. Choice. What measures has the researcher put in place to insure that the participant can communicate his/her choice?

Before a participant is excluded from a project, Jensen and colleagues propose strategies for determining capacity. These suggestions are made within the context of dementia but the strategy seems quite respectful of participants' inclusion in the decision process and should be considered for potential participants with communication challenges. For instance, because their population base is dementia, the decision to accept a person in a study first includes scores on a cognitive test. However, the decision to include or exclude is not limited to these scores and is further refined based on the level of risk associated with the study. Jensen and colleagues propose to include a level of flexibility in situations where the possibility of a participant wrongly agreeing to take part in a study creates a minimal risk of harm. There are further adjustments for all levels of cognitive scores where measures for evaluating assent or dissent must be included in the protocol, and these measures must include interpretation of non-verbal communication. Furthermore, Jensen and colleagues recommend the presence of individuals who are trusted by the participant to support the decision-making process. While these individuals are not there to act as proxies, they can provide support and help create a safe space for communication. The strategies proposed by these authors for individuals with dementia are respectful of participants' (in)ability to communicate and make their needs known. They also recognize that the needs may change over time. Regardless of whether IRBs decide to adopt such strategies, they could, at a minimum, encourage researchers to engage participants who might at first seem unable to participate.

For granting agencies and publishers

More and more, researchers are indeed asked to make an effort to include the voices of the population of interest into their studies. In the area of ageing, this will increasingly include individuals whose voices are difficult to accommodate. In order to do this, while adhering to the ethical principles of autonomy, beneficence and justice, granting agencies and publishers will need to accept that a certain level of flexibility is required when assessing research protocols in which communication challenged individuals are considered as participants. For instance, agencies could check if a protocol includes more time for recruitment and for execution of the research. Granting agencies may need to consider budgets that help researchers overcome the costs associated with increased use of materials or specialized research staff. They may need, as well, to consider the standardization of pictogram-based assessment tools that facilitate communication in research. Publications should incorporate some flexibility in accepting details about how informed consent was obtained and what efforts were made to be inclusive. This will allow readers the chance to properly evaluate the meaningfulness of the results. Adhering to principles of inclusion involves time and money. As researchers are urged to adopt programs that are properly adapted to populations who have communication challenges, they may need extra funds and a more prominent place in publications to insure that this population gets the place it deserves in scientific inquiry.

For older individuals with communication disorders

The individuals that have the most to lose from not being included in research are, of course, the older individuals with communication disorders. Advocates of older adults might promote efforts for inclusion of all individuals whose voices must be heard. Armed with the knowledge that some older individuals are actually excluded from research without scientific basis, advocates might urge the research community to adapt research protocols, to revisit assumptions about capacity and its link to communication, to avoid exclusive reliance on diagnosis to determine possible inclusion and to consider the use of less traditional tools to explore informed consent.

Conclusion

The number of older adults who live with communication challenges will likely increase in the foreseeable future given the anticipated growth of the older adult population worldwide. Older adults who face challenges with communication could contribute to the advancement of knowledge regarding the impact of their conditions whether they draw direct benefits from participation or not. However, currently, while there is some opening toward the inclusion of so-called "vulnerable populations" in research, there is still a tendency by IRBs and the research community to exclude individuals with communication challenges from protocols, all the more if they are older. This is perhaps understandable to a certain point given that informed consent, the key ethical and legal safeguard for research participants, is dependent on the communication of information and the researcher/participant interaction. As well, communication is essential for recruitment, written or oral participation, focus groups and interview. However, there is a need to revisit this state of affairs and to consider how best to respond to the need for increased participation while ensuring that participants are not exposed to harm or exploitation.

As discussed above, current key international instruments support the right to participate in research and outline quite clearly the need of non-discrimination and respect of individual autonomy – even as people grow older and/or deal with challenging health conditions. This is an excellent backdrop for the research community to embrace inclusion and to reflect on how best to proceed. In the chapter, we have identified the need to focus on capacity and the development of tools to assess more efficiently participants' ability to understand the information they are given and to appreciate the consequences of the choices they make. We have noted as well new trends in the understanding of vulnerability as a concept having the potential to empower people otherwise left behind. We have challenged researchers to be sensitive to the subtleties of communication in general, regardless of diagnosis, and to consider a number of measures to augment the cohort of older adults with communication issues in their research projects. A number of suggestions have been made to the research community to enhance the participation of these individuals.

Recently, interest for the inclusion of traditional "vulnerable populations" in protocols has intensified worldwide. While the literature on dementia has developed particularly quickly, studies on older adults with reduced communication abilities have been less common. This chapter has highlighted the need for research communities to increase their contribution to the understanding of the true impact of living with communication challenges. This quest for better knowledge will only be possible if participation in research is facilitated. This is, after all, what is expected of us all within our legal and ethical contexts.

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22 Exploring the life experiences of less-educated rural older adults

Challenges and the possible solution – life story interviews

Shirly HZ Chen and Vivian Wei Qun Lou

This chapter provides a life-story interview strategy to encourage research participation when interviewees are less educated and less articulate. Unlike the traditional life-story approach or oral history method which emphasize the "natural emergence" of participant's life experience, this strategy suggests a starting point, a triggering "linguistic frame" and a "acceptable interview field" to facilitate interview involvement.

This strategy could be used in circumstances when participants feel their story is "too normal to be told" or when the knowledge background between interviewer and participants is remarkably significant. Further research needs to be conducted to improve method rigor.

Introduction

It's almost been a research trend to use qualitative studies to encourage marginalized participants to "speak out" and share their stories (Lincoln and Lanford, 2018); however, it is challenging to encourage inarticulate, marginalized, less-educated or even illiterate older participants to articulate their experiences and stories (Lloyd, Gatherer and Kalsy, 2006; Wenger, 2001). On the one hand, participants with a lower educational level/illiteracy tend to employ an unstructured expression style and respond with more direct, concrete answers that are inadequate for explicit phonological analysis (Ardila et al., 2010). On the other hand, lower education levels and illiteracy are so closely related with being marginalized that these individuals have been positioned in a "listener's" point of view for life, hence they see their life story as "not much to tell" (Gheorghiu, 2011; Nagar-Ron and Motzafi-Haller, 2011). This issue was illustrated by sociologists and anthropologists who explored the experiences of marginalized groups (e.g., immigrant women or economically disadvantaged people). Those participants also manifested certain levels of anxiety during the interview – they were afraid to say "something wrong" or "something valueless" in front of a "authorized figure", that is, the researcher (Gheorghiu, 2011; Puvimanasinghe et al., 2014).

Very few studies have presented methodological solutions for interviewing less-educated/illiterate older participants, but there is, fortunately, a substantial amount of literature that has provided methodological guidance for interviewing inarticulate participants (e.g., those with intellectual disabilities and learning difficulties) (Hollomotz, 2017; Lloyd, Gatherer and Kalsy, 2006). It is notable that illiteracy cannot be equated to cognitive impairment or learning difficulties, yet they do share some similarities in terms of linguistic and cognitive performance, such as inarticulateness and unresponsiveness (Ardila et al., 2010; Booth and Booth, 1996), concrete expressive style (Julayanont and Ruthirago, 2018), deteriorated memories (Paddick et al., 2017) and problems with tracking time (Lloyd, Gatherer and Kalsy, 2006). All told, illiteracy and low levels of education might hinder interviewees' ability to engage with what mainstream qualitative interviews seek to establish as a "serious, effective and successful communication" process (Wenger, 2001).

This chapter is based on a dissertation project that aimed to examine the decision-making processes for Ageing-in-Place (AIP) among "three-nos" older persons population in rural China. Three-nos older persons are a special group of people that the government is responsible for, including all their health and social care till the end of their life. Eligibility to be deemed a "Three-no" older person requires: (1) aged over 60; (2) unable to work; (3) no source of income and (4) no children or other individual with a legal responsibility for support and care (Wu, Mao and Zhong, 2009). The three-nos older persons in rural contexts who participated in this study were impoverished, less-educated, marginalized and vulnerable. Demographically, they were more often male than female and were socially isolated and socio-economic (SES) disadvantaged. More importantly, they usually had dropped out of school at an extremely young age (at an average of eight years old) or even never attend school because of historical turbulence and poverty. Three challenges met with during the interview process will be discussed, followed by a discussion on the potential solution of a life-story interview strategy being used to tackle such challenges in order to achieve a more collaborative interview result.

Here the author illustrates three challenges hindering the "natural emergence" of stories among Chinese three-nos persons (Charmaz, 2017): (1) unresponsiveness, (2) difficulties with time and (3) "good policy" and self-repression.

Unresponsiveness and fragmented responses

Unresponsiveness is an umbrella concept that comprises a variety of situations such as interview silence and resistance (Booth and Booth, 1996; Lloyd, Gatherer and Kalsy, 2006). In this chapter, unresponsiveness accounts for participants' inability to answer certain types of questions, especially open-ended questions that employ abstract terms (Booth and Booth, 1996). In fact, it is true that open-ended questions (e.g., "could you please describe your daily life"; "could you describe your childhood") might receive little valid information from less-educated individuals.

RESEARCHER: Could you please tell me about your daily life?

DW: Nothing, just nothing. I don't have to do anything [related to farming in residential facility], even harvesting grass from the land.

DW (76-year-old) was a disabled, childless and illiterate woman who had been residing in a rural residential facility for three years. DW relocated into residential faculties because of a conflict: her nephew had offered her a room and "a place to eat", but then her nephew's mother deemed her as "unable to work" and "a waste of food". When asked about the scenario that caused her to relocate to the residential facilities, her answer is fragmented:

RESEARCHER: So, what happen? Why did you relocate here?

DW: Because the policy is good and supportive…. My husband died, I don't have children, the policy is good.

RESEARCHER: Who asked you here?

DW: [silence and confused for three seconds] My nephew didn't allow me to come here, but I arrived in last year.

RESEARCHER: Why?

DW: He thought moving was inconvenient. Then his mother blamed me. Then I came there from home, my nephew come, then he leads me, again, so that I'm here.

The dialog above is full of fragmentations and misinterpretations. Theoretically and understandably, "all human stories are told in a fragmented and unitary form" (Gheorghiu, 2011); however, for participants with expressive difficulties, they are prone to a more direct, concrete linguistic style when narrating their stories (Ardila et al., 2010; Hollomotz, 2017).

Unresponsiveness is not merely a linguistic constraint but is generally overlaid with other social factors such as low self-esteem or oppressed experience (Booth and Booth, 1996). For example:

RESEARCHER: Could you please describe your daily life?

SP: [confused and laughs]

TRANSLATOR: It's just your daily life; what do you do after you wake up? When do you eat your breakfast?

SP: I'm just … cook and eat. I could basically do things [support her independent living], so I just … chop woods, burn, cook. It's basically enough for me.

Understandably, for the majority of participants, "eating after farming, farming after eating" was too routine to be narrated. Their silence and confusion did not signify a misunderstanding the interviewer's question; rather, they question the merit of their own stories and struggled with the necessity and appropriateness of narrating. In other words, marginalized participants exhibit uncertainty about "what is worth telling" when placed in a story-teller's position (Nagar-Ron and Motzafi-Haller, 2011).

Ambiguous sense of time

Low-educated/illiterate participants might also have an ambiguous sense of time (Ardila et al., 2010; Lloyd, Gatherer and Kalsy, 2006). They usually refer to an abstract marker of personal significance (e.g., birthday, celebration day) rather than an actual, numerical point of time to organize their memories (Hershatter, 2011; Hollomotz, 2017). For instance:

RESEARCHER: You went to XX village [another village far from her home] when you were young. When? Could you elaborate more?

HM: I was tall enough to cook. [Stoves in rural area were approximately one meter in height.] Then the Liberation came. After the Liberation, I came back.

For HM, her own "biographical map" relies on her height relative to the stove and the coming of the Liberation. Scholars also suggested that the way the rural women remembered their past was deeply influenced by the collective narrative of the *Liberation* (*jiefang*) and collectivisms that are a significant "memorial millstone" and influence their future expectations for every aspect of their life (Hershatter, 2011). Hence the intertwined memory between someone's life event and historical events is obvious, embedded into one's matrix of experience and comprises one important part of one's self.

The "good policy" and oppressed self

All stories have their structural foundation, and all plots have their own political origins (Hyvärinen, 2016). Less-educated Chinese rural residents sometimes refer to "good" government and "good" policies to contextualize their individual choices and, more importantly, to avoid researcher's questions.

RESEARCHER: Could you please tell me about your daily life?
TS: Daily life? It's hard to tell, but the government policy treats us so well.
RESEARCHER: No, I mean, just your life.
TS: No matter what, it's a good policy. We were old and single men; it's satisfactory if we consolidate together [with his brothers] and contribute to the society. We feel grateful. It's not the government's responsibility on some issue, and it's unspeakable.

It is reasonable that this rural Chinese citizen was "trained" to answer inquiries from authorized figures such as government official with a formal, "socially proper" language form (e.g., individual responsibility, contribute to the society) (Hershatter, 2011). The research setting replicates such "trained" experiences wherein low-educated rural residents were used to being situated in the listeners' position rather than narrator's position. Therefore, like many other oppressed groups who had also long been invisible and silenced, the mainstream discourse failed to provide a legitimate narrative framework to establish a discursive model or accommodate the interviewee's individual identity (Nagar-Ron and Motzafi-Haller, 2011).

In general, it is not easy to encourage less-educated Chinese rural residents to present a holistic "life story" and/or "self" in front of a researcher. The traditional interview strategy could be challenging when stories are not "naturally emerging" because of participants' inarticulateness, which also contributes to their cognitive conditions, linguistic skills and subordinate social positions (Booth and Booth, 1996; Charmaz, 2002; Hershatter, 2011). Less-educated Chinese rural residents were full of stories and experiences, so the difficulties encountered during the interview cannot be simply encompassed as "inarticulateness". Feminist historian Gail Hershatter (2011) concluded that there should always be a humbling reminder for the qualitative researcher to consider "the missing voice" and the "story behind" the main narrative. More importantly, it is always significant to remember that even the most inarticulate people can disclose a great deal more than their conversation reveals (Booth and Booth, 1996).

A potential solution: a life-story interviewing style

Unresponsiveness, ambiguous sense of time and self-suppression could be tackled by certain interview techniques, specifically, life-story interviewing strategies. The life-story approach arranges events in a sequential and causal order, containing characters, plot and usually a certain "theme" (Hyvärinen, 2016). It allows for researchers to contextualize individual actions while either developing or refining a conceptual framework for further understanding (Lanford, Tierney, and Lincoln, 2019).

The life-story oriented interview strategy is used to encourage participants to be "involved;" it allows for the "natural emerge" of interviewee's stories and the co-authoring and co-production of participants' experience (Charmaz, 2002; Lanford, Tierney, and Lincoln, 2019). Ideally, the life-story approach allows for the researcher to minimize his/her influence during interview by following the participants' own narrating structure and style (Adriansen, 2012; Jessee, 2019); however, this approach could still present difficulties when innerving less-educated/illiterate Chinese people from rural backgrounds. Here we propose a pragmatic life-story interview strategy to interviewing low-educated and illiterate older participants, in order to encourage those marginalized group to collaborate and become involved with the interview process.

Starting point

The traditional method employed during a life history approach encourages the participant to start by responding to an open-ended question about a very early retrospective experience or significant life event (Adriansen, 2012; Lincoln and Lanford, 2018). In contrast, scholars also suggested that open-ended questions might receive little information from inarticulate participants (Hollomotz, 2017). Usually, the lack of responsiveness to open-ended questions requires the researcher to adopt a more direct interviewing style (Booth and Booth, 1996); the "active" style, by definition, means broaching a conversation topic that is more "attractive" and "answerable".

Narrating the experience of illness is a strategic and problem-solving approach to gain a sense of body-mastery (Seale and Charteris-Black, 2008). In China in particular, rural older people tend to relate their health status to acquaintances and receive advice from their peers in order to maintain and cultivate their social capital in "a society of the familiar" (Anson and Sun, 2005). Chinese rural older participants were more willing to describe their health status and history of illness rather than their routine life, perhaps because such physical experiences are situated in the middle of the spectrum of being "too normal" and "too complicated" so that its constitutes a "worth-telling story". Scholars also suggested a "milestone" technique when interviewing inarticulate participants; that is, to create a concrete frame of reference using artifacts such as photos in order to trigger participants' willingness to share (Hollomotz, 2017). For older, less-educated rural Chinese people in particular, the experience of illness – including pain management, hospital visits and the history of disease – constitutes an effective "frame of reference", which fostered a relationship of trust and a more considerate attitude on the one hand and smoothing the way into answering more difficulties questions and enabling them to organize a legitimate and "socially proper" story on the other. Other "frame of reference" approaches such as farming activities and farming lands could be also examined upon further study.

Historical events and significant life events

The past is durable and continuous. The narrative of the past is individually and collectively constructed and embedded in a framework of dominant political discourse that rules out "other versions of stories" that were inconsistent with its narrow representation of reality (Hyvärinen, 2016). Social historian scholars pay attention to the c*onstructive* characteristics of storytelling wherein individuals select merely one fragment of the past, present and future to narrate and present a story, which empowers them with a capacity for subjectivity so that their narrated versions of stories were, sometimes, diverse and even rebellious (Jessee, 2019).

A methodological concern about gaining data is using the historical timeline of events, which could be stimulated and vivid when compared to the direct, flattened interviewing style that regards participants as merely "information provider" (Adriansen, 2012; Kat

Kolar etal., 2015). However, for less-educated older participants from rural China, their narrated timeline might not be linear (Hershatter, 2011; Hollomotz, 2017). What follows are several life events and historical events that were commonly and intensely experienced by rural Chinese populations that may encourage less-educated participants to speak out.

Individual life events: (1) early childhood and parents; (2) education; (2) marriage and children; (4) house division; (5) history of illness.

Historical events: (1) the Liberation; (2) the Great-Leap Forward and Collectivism Period; (3) the Family Responsibility System; (4) the relocation of villages.

Significant historical events could stimulate participants' memories about their past and enable them to relate these stories so that the patterns of how the stories were constructed could be analyzed and reconstruction from various versions in order to achieve the inner consistency (Hershatter, 2011). Hence, it is effective to remind less-educated rural participants of the larger context their stories occurred within certain "answerable" topics and "historical milestones" that could also soothe their anxiety, bridging their individual experience with a broader, more structured perspective and facilitating the co-construction or even re-construction of their own stories (Adriansen, 2012).

Triangulation

Triangulation describes the process of the researcher referring to other sources of information to add contextual interpretation or cross verification of certain scenarios during or after the qualitative interview (Kat Kolar et al., 2015; Puvimanasinghe et al., 2014). Scholars also advocated for a collective analysis method which includes the presence of "local voice and meanings" through the final stages of study, particularly when dealing with the "hidden transcript" or "invisible figures" of research participants (Dodson, Piatelli and Schmalzbauer, 2007; Puvimanasinghe et al., 2014). Unfortunately, collective members who share similar social backgrounds with the participants were only involved during data analysis process (Almlund, 2013).

This chapter endorses such collaborative approaches of "involving the local, maybe non-academic third party" to fill the gaps of understanding and knowledge construction. It could be a person who worked as local drivers or forest rangers, who could even marginally understand the academic language and "disassemble" some of abstract, formal term which the researcher didn't realize its abstraction.

RESEARCHER: When did you come to the residential facility? What happened?
HM: My nephew died. I lived in the high mountain over there [a village 3 km from research site]. I was been *bounded* to there.
RESEARCHER [confused]: What is …?
TRANSLATOR [to researcher]: It was the Old Society (before Liberation) when she was kidnapped and adopted to that village. You know, after the Liberation, she came back.

Most of time it is not the content of the questions that should be translated, it is the expressive style and abstract terms that are taken for granted in mainstream and academic discourse, yet expressions outside the participants' routine language frameworks should be disassembled and re-narrated in a more direct, concrete and "answerable" way (Hollomotz, 2017; Kat Kolar et al., 2015). Besides, the additional informant or translator would not merely be functioning as a supplemental informative figure; instead, they could bring local meaning and reflexivity into interview settings by de-constructing what the researcher had assumed.

Summary

Low levels of education/illiteracy might hinder the interviewer gaining in-depth data; however, is it not reasonable to question participants' ability to elaborate their stories (Hollomotz, 2017; Lloyd, Gatherer and Kalsy, 2006). Low-education/illiterate rural participants have certain difficulties expressing their experience, and such expressive challenges were not merely the result of their linguistic skills but were embedded in a broader socio-economic context – a rural/urban distinctive discourse wherein rural residents' living experience were encompassed as "backward and primitive" (Lai, 2016).

The authors advocate a life-story interview strategy to encourage participants' willingness to reveal their stories. By using a concrete and "answerable" starting point, by intertwining life events and historical events and, by inviting a local translator, interviews could smooth participants' nervousness and encourage them to relate their stories. This methodological technique is inspired by the time mapping approach wherein participants' life events could be co-authorized by researchers and participants alike (Adriansen, 2012). It paves the way for individual reflexivity of one's stories as well (Kat Kolar et al., 2015).

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23 Senior-oriented empirical research in nursing homes for the elderly

Experiences from Austria

Renate Kränzl-Nagl and Daniela Wetzelhütter

Despite the increase in studies on the quality of life among senior citizens in nursing homes so far only a small number have shed further light on the practical aspects of carrying out empirical surveys in these institutions. Based on experience with empirical research in Austrian nursing homes and the theoretical approach developed by Ackermann (2005), the steps in the research process are presented and discussed in this chapter, looking into the factors which may influence the research findings. It has become clear that the results of such investigations are affected by many factors, which all have to be taken into account both when planning the research and when carrying it out. These include features specific to the organization of nursing homes and to the target group, i.e., elderly people in need of care. Methodologically, the problems caused by the target group's cognitive impairments are of particular significance. In general, experience shows that is possible to carry out empirical surveys with nursing home residents, although they do place relatively high demands on researchers. Another lesson learned is that studies should be carried out taking other perspectives into account – especially those of the relatives and nursing staff – to gain a full picture of nursing home residents' quality of life. Another point which has become very clear is that close cooperation between the researchers and the nursing home's management and nursing staff plays a key role in the success of such projects.

Introduction

For a long time, relatively little importance was attached to research on care home residents' quality of life (European Centre for Social Welfare Policy and Research, 2010, p. 19). This was not only true of German-speaking countries. This circumstance is explained by the strong focus on the traditional topics related to the quality of care and – associated with that – a certain hostility toward research and measurement among those committed to improving elderly people's quality of life (Kane, 2001, 2003). Since the 1990s, there has been a rise in the amount of research not only carrying out evidence-based examinations of the quality of care and nursing but also dealing with quality of life among elderly people in need of support and care (e.g., Albrecht, 1997; Lee, Woo and MacKenzie, 2002; Schnabel and Schönberg, 2003; Gelbmann, 2005; Schönberg, 2006; Wahl and Schneekloth, 2009; ZeSG, 2010; Herold-Majumdar and Behrens, 2012). Recent studies measuring the impact of social services have now also begun to address this topic (Kränzl-Nagl, Lehner and Prinz, 2019). Other factors which have led research to focus more sharply on elderly people's situation in life include the increasing customer focus found in social services for senior citizens and the need for evidence-based data when implementing quality management and quality assurance techniques in homes for the elderly. This is related to efforts to take elderly people seriously as subjects of research, and to include them in empirical surveys.

In methodological terms, this endeavor has shown that surveys on the situation of people in need of care pose specific challenges in the residential context. On one hand this relates to the particular characteristics of the target group, senior citizens; on the other hand, it is linked to the very specific conditions found in nursing homes, which are both the place where elderly people live and are cared for, and the nursing staff's workplace.

With this in mind, this contribution addresses the question of how empirical surveys can be fitted into the structures and processes of a nursing home and what factors influence such surveys (the next section of this chapter). This will involve taking a closer look at the characteristics specific to care home residents, as a target group, as these characteristics are methodologically relevant in many respects (the third section of the chapter). The chapter then sets out how the research process is structured in empirical studies in residential institutions, involving both residents and their relatives. This section draws upon experiences from Austrian research practice. At each stage of this process, a connection will be made to the influencing factors described at the start. The contribution is rounded off with a final summary.

Empirical surveys in nursing homes: overview of influencing factors

Empirical findings collected in different care and nursing settings are influenced by a variety of factors. This can be conceptualized using the model Ackermann (2005) designed for empirical studies with care home residents in field experiments. This is presented and reflected upon in greater detail below in the context of nursing homes in Austria.

Ackerman's model of factors influencing empirical studies in nursing homes (2005)

According to Ackermann (2005, p. 96f.), the factors influencing empirical research into the perspective of care home residents can be divided into four groups:

1 influences of the research setting (structural conditions);
2 influences of the residents as the "object of investigation";
3 influences of the researcher's presence;
4 influences of the research design and selected method.

As Figure 23.1 illustrates, these factors do not exist independently of each other, but instead influence one other – a circumstance that has to be taken into account both when planning and when implementing empirical surveys in the field of care for the elderly. The model thus shows parallels to the "total survey error" (TSE) concept, which places the emphasis on assessing the errors which can influence the survey findings. This concept (Biemer, 2010a; Biemer and Lyberg, 2003) convincingly demonstrates that, when assessing the quality of a survey, it should be remembered that there is already a likelihood of potential "errors" being committed when the research concept is being planned, and that this possibility does not fade away when the data is prepared, but in fact lasts at least until it is analyzed. In other words, although the total survey error is made up of sampling and non-sampling errors (Biemer and Lyberg, 2003; Weichbold, 2008, 2009), it is not measured

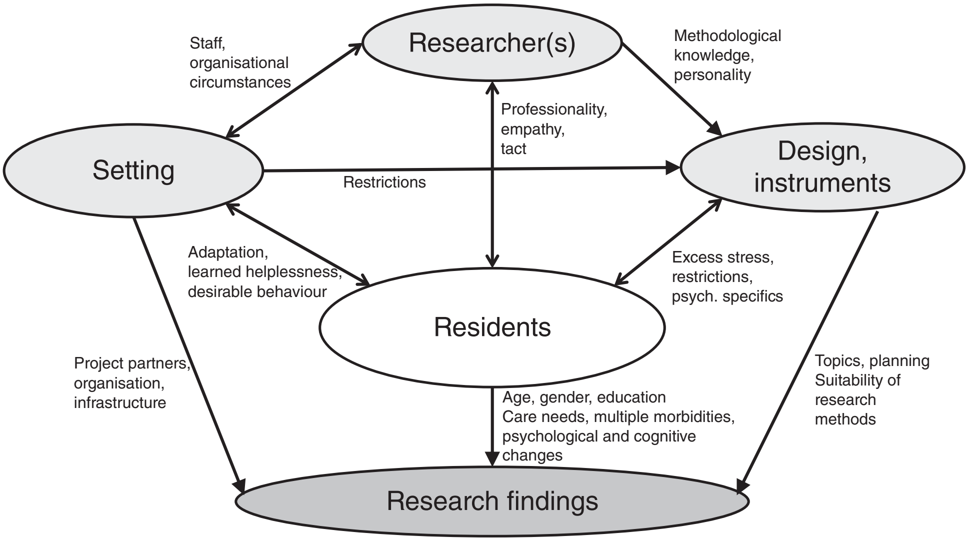

Figure 23.1 Model of factors influencing empirical research with nursing home residents in field experiments.

Source: taken from Ackermann, 2005, p. 96; the author's own translation.

as the sum of individual aspects or criteria (Biemer 2010b). Rather, the concept of total survey error is an attempt to describe the errors occurring within a logical sequence of individual steps of a "whole" process (Groves et al., 2004).

The influencing factors which fall into the category of the *survey setting* comprise the *basic structural conditions* in which a survey is taking place, and which may affect the findings (Ackermann, 2005, p. 96). These include a home's human and material resources, architectural structures, the staff's training level and the home's internal organizational structures and processes (mealtimes, rest periods, doctors doing their rounds, internal events, organized activities etc.). These factors are examined to ascertain the quality of these structures and processes; in combination with empirical investigations into the quality of the findings, this helps paint an overall picture. When carrying out surveys of nursing home residents, researchers from outside the home must necessarily familiarize themselves with these structural conditions, ideally even at the planning stage. The specific rooms in which the survey takes place can, for example, influence the findings.

The values and norms fostered by an institution or provider, e.g., those set out in mission statements, are also relevant to empirical surveys. An organizational culture driven by – and, what is more, practicing – appreciation and a sense of customer focus can create a climate in the home which also suits the needs of empirical research. One important factor contributing to the success of empirical surveys by external researchers is whether or not they become familiar with the particular care setting, enabling them to make decisions relevant to the survey. In this context, the support they receive from the management and nursing staff at the home plays an important role. Ackermann (2005, p. 96) also includes staff support for the survey in this set of factors; their support relies on timely internal information and motivation, especially on the part of management.

The second set of factors relates to the *influences exerted by the residents* as the "object of investigation", i.e., the particular characteristics displayed by the target group of old people in need of help and care. This is by no means a homogeneous group; instead, its members display specific characteristics including the state of their health, their cognitive and functional ability and mental factors such as their attitudes or values, which have to be taken into consideration throughout the research process (Ackermann, 2005, p. 96). On one hand, the characteristics of this target group influence the selection of the survey instruments and the interpretation of the data gathered. On the other hand, they affect the respondents' motivation or how open they are to empirical research (for further details, see next section). This can be encouraged by providing information at an early stage and arranging trust-building and motivating schemes.

The influences of the *researcher's presence* comprise the classical "experimenter effects" (Ackermann, 2005, p. 97) such as their professional background, qualifications, previous experience, methodological skills, internal psychological factors and personality traits. One especially important aspect influencing the success of studies in the field of care for the elderly is the methodological skills which play a key role not just in developing but also in applying the survey instruments. Experience has shown that this is especially true of oral interviews with elderly people, which require a high degree of sensibility, empathy and patience, and the creation of an atmosphere characterized by trust, respect and appreciation. This, in turn, demonstrates how important personal skills, especially social skills, are to the success of empirical surveys. Accordingly, the aim must be to select research staff specifically in line with these requirements and to offer them continuing education and training in these fields. Interviewer training is another means of reducing experimenter effects.

Finally, the *research design* and *selected method* affect the outcome of a study; they also have a decisive influence on the research process and thus the course of the investigation (Ackermann, 2005, p. 97). The decisions which have to be made when formulating the research design (choice of facilities, methodological approach, frequency of surveys, etc.) do not only serve to precisely define the project; they also take into account the above-mentioned structural framework of the care setting, and the target group.

In this context, one factor which is particularly significant is making a suitable choice of method based on the goals of the study, the special features of the clients in question and, ultimately, the available financial resources. Thus, a relatively small project budget speaks against the use of multiple methods or instruments, however desirable that may be in many cases. In this field of research, as elsewhere, project planning and design are caught in a tug of war between people's interests and the available resources. Apart from funding, the contribution made by organizations running nursing homes lies in internally defining and specifying the goals, and how the research is expected to benefit the organization, at an early stage in the process. The resulting findings and knowledge of the structural conditions allow scientific experts to formulate a suitable research design and select which methods to use.

As well as methodological aspects such as the above-mentioned "TSE", Ackermann's model (2005) also reveals theoretical connections that are relevant when studying the views held by nursing home residents. This relates, for example, to concepts for studying quality of life based on the two classical dimensions of subjective and objective indicators. Objective indicators relate to people's situation in life and thus to the underlying structural conditions of life in nursing homes for the elderly, whereas subjective indicators focus on assessing those situations in life, i.e., people's individual perception and assessment of quality of life (Noll, 2007; Wahl and Schneekloth, 2009; Koller et al., 2009).

From an empirical point of view, if those two perspectives match ("good" objective conditions and a high rating from a subjective, individual point of view), this can be seen as high quality of life, whereas quality of life is not as good if one of the two components is less positive. However, empirical surveys of elderly people indicate that there is often only a tenuous connection between objective and subjective quality of life. One explanation for this comes from the "paradox of ageing" (Mayring, 1987, quoted by the European Centre for Social Welfare Policy and Research, 2010, 18), according to which elderly people exhibit a particularly high level of subjective satisfaction with their lives as their objective resources wane. The question remains unanswered of the extent to which this will be true of subsequent generations. Nonetheless, the paradox of ageing indicates that the classical dimensions of research into quality of life research cannot simply be transposed unquestioningly to elderly people (see Noll and Schöb, 2002; von dem Knesebeck et al., 2006). These insights raise the question of whether people in care homes exhibit any other special features that are relevant for empirical research.

Features specific to nursing home residents as a target group in empirical surveys

The characteristics specific to the target group of elderly people which need to be taken into account when planning research and selecting a research method consist in the age-related sensory, functional and cognitive *impairments of varying levels*, the occurrence of which can be subject to change (e.g., fluctuations in their condition from one day to the next).

Rising life expectancies and the trend of preferring non-residential to residential care (for as long as possible) mean that Austrian nursing homes are tending to accommodate *increasingly aged residents, often with multiple morbidities*. In addition, an increase has been noted for many years in the number of people *suffering from forms of dementia*. Estimates by the Austrian Ministry of Health and Women's Affairs (Bundesministerium für Frauen und Gesundheit, 2017) suggest that 115,000 to 130,000 people living in Austria currently have some form of dementia. According to projections, by 2050 that number will have increased to 260,000 people with dementia (Höfler et al., 2015). These developments are also changing the resident structure in nursing homes, with the percentage of residents suffering from dementia increasing.

One key characteristic of elderly people in need of care and nursing is the fact that they are in the "fourth age" of life (Laslett, 1995, quoted in Kösler, 2004). That fourth age brings with it a drop in their strength, resources and abilities, and is thus usually characterized by increasing need for support.

Another feature specific to this target group is the *influence of their individual biography*, which is shaped by the respective historical background of their times, and thus also by "historical" *values and norms*, as well as by their subjective experience of biographically relevant events. This can, for example, affect how the target group behaves when they are being interviewed or observed. In particular, it may result in response bias effects such as social desirability or a tendency to yea-say.

Negative *images of elderly people* which are prevalent in contemporary society (e.g., see Wahle, 2009) can also lead to lower self-esteem, which can be reflected in a humble attitude among senior citizens and a lowering of their expectations. As experiences of qualitative interviews with elderly people show, in some cases this is reflected in extreme cautiousness about expressing wishes, concerns and criticism. In such cases, social desirability also has an effect in that the people interviewed express opinions which are in line with other people's expectations, e.g., those of the nursing staff (see also Janßen et al., 2003, cited in Kannonier-Finster and Ziegler, 2008).

The features specific to the target group of elderly people in need of care cannot be solely ascribed to individual, personal characteristics; instead, they correspond closely with the elderly people's living conditions. In the case of nursing home residents, this means the particular institutional *characteristics of their care setting*. One point which should be taken into account, for example, is that as well as impaired health, another reason for a move into a residential institution may be a lack of social networks, e.g., due to increasing social isolation in the fourth age (Hicks, 2000). This circumstance means that clients are more strongly attached to, or dependent on, the staff. When people reach the fourth age, this increases their dependency both on other people and on predetermined structures and processes.

This *dependent relationship* must accordingly be noted as a feature specific to nursing home residents, and taken into account during surveys. Although nursing homes are increasingly opening up to their surroundings, and efforts are being made to reduce to a minimum the formal rules which might have a negative effect on residents' quality of life, they can still be described as "moderate total institutions" (Gebert and Kneubühler, 2003), and some central characteristics of the total institutions described by Goffman (1973; see also Heinzelmann, 2004) remain valid. These include both the fact that the residents have to act out every aspect of their lives within the institution and that these institutions have the authority to determine the main norms and rules which specify how people live together in this non-voluntarily formed community. It is still typical for nursing homes to comprise two different social and cultural worlds: that of the residents and that of the staff. The point should thus not be forgotten that there is a relationship of mutual dependency between the two groups which can result in a fear of sanctions on the part of nursing staff, which in turn may influence the outcome of the research. People living in homes may also fear sanctions on the part of their fellow residents. The relationship of mutual dependency between the residents and staff can, for instance, have a negative effect on people's motivation to participate or how they respond to surveys. On the other hand, precisely this close personal relationship can be used to motivate elderly people to take part in surveys, meaning that there can also be positive effects.

Planning and carrying out empirical surveys in care homes for the elderly: experiences from practice

Despite the increase in studies on the quality of life among senior citizens in nursing homes, so far only a small number have shed further light on the practical aspects of carrying out empirical surveys in these institutions (e.g., Höwer, 2002; Schönberg, 2006; Roth, Rester and Seeberger, 2009; Kränzl-Nagl and Maun, 2013). On the basis of experience with empirical research in Austrian nursing homes, the individual steps in the research process (e.g., see Kromrey, 2006; Schnell, Hill and Esser, 2006; Atteslander, 2008; Diekmann, 2008) are presented below, looking into the factors which may influence the research findings, as described above. Particular attention is paid to how such projects are supported by management and nursing staff, as this has proven to be a key success factor. The level of support required varies over the different stages of the research process, from the planning stage to making use of the findings.

Planning and preparation stage

Whatever methodological approach is selected to assess quality of life and satisfaction among nursing home residents, a series of decisions are required even at the planning stage which are crucial to the success of an empirical survey in different care and nursing settings. These include establishing precise objectives, settling on the basic conditions and data protection issues, addressing how to use the findings, choosing a specific survey design, gathering important information and finally announcing the project to residents, their relatives and the nursing staff.

Establishing precise objectives

One of the first, important steps proves to be settling on and narrowing down the goals of the survey. This is carried out jointly by the principal investigators and the nursing home management (if possible also involving the organization running the home). At this stage, agreeing upon the survey's purpose from the point of view of the organization or institution (e.g., in terms of strategic processes or marketing) is just as important as how the content of the project relates to the organization's mission statement. Another point which needs to be agreed upon is the researchers' specific interests. These are connected to the project goals. Defining objectives thus means reconciling the researchers' academically oriented viewpoints with those of the practice-oriented executives; ideally, these potentially different viewpoints will complement one another. Establishing the objectives of the planned research at as early a stage as possible also encourages the client to identify with the aims of the study. This identification can then be passed on to other levels of the organization, especially the nursing staff. In addition, establishing the specifics at this early stage means that targeted information about the project can be provided early on.

Settling on the basic conditions

Another important step is to clarify the basic conditions in which the investigation is to be carried out. Generally, this includes the care concept and aspects related to the schedule, location, organization and financing, which differ from one nursing home to another. Sorting out the organizational aspects involves on one hand adapting the investigation to the home's structures and processes, and on the other hand the question of how the management and staff will support the project. Crucial prerequisites include selecting communication channels and contact people, drawing up a realistic timetable and agreeing upon responsibilities.

Settling data protection issues

Data protection issues also need to be settled in the lead-up to research. This comprises access to and handling of the personal data required to conduct the empirical research (e.g., a list of all residents as the basis for sampling). When carrying out surveys, appropriate steps must be taken with regard to current data protection law (in Austria the General Data Protection Regulation, GDPR). As well as complying with the data protection rules regarding available data, maintaining anonymity and treating newly gathered data (e.g., from surveys) as confidential is a basic principle of research ethics, as is making participation in surveys voluntary. In the case of elderly people who are no longer able to give consent due to impairments, consent must be sought from their relatives or other representatives. This must be informed consent, i.e., they must both be willing to take part and have been informed about the planned investigation (Bortz and Döring, 1995, p. 43).

Using the findings: explanation and information

It is very important for everyone involved to be told how the findings will be used, even at this very early stage. This is not only designed to increase their motivation and support, but is ultimately a question of research ethics. This does not just mean aspects of appreciation and respect (which are guiding principles when conducting surveys) but should also be expressed in the subjects being given feedback about the findings. On the part of the management, the decision must be made as to when and in what form the residents and their relatives will receive feedback on the empirical findings.

Experience shows that the decision on whether the findings are to be made accessible to the broader public (e.g., providing abstracts online) is made at a later date. As new findings are not only useful in practice but are also intended to drive academic discourse, it makes sense to establish whether the findings can be used for scientific purposes at an early stage.

Choosing a specific survey design – information required

Based on the objectives and basic conditions which have been established, the next step lies in choosing a research design. This task falls to the researchers due to their specific expertise, and involves selecting the method or methods (if several are used), the target group to be surveyed and the selection process to be applied, etc.

In this regard, it is important to cooperate with the home's management so as to gain internal information relevant to the project. If, for example, surveys are planned, the question must be resolved beforehand of which people, or how many, can take part in the survey. On one hand, this provides information about the population and is thus a prerequisite for sampling (if planned); on the other hand, the information about the elderly people can be used to develop the survey instruments, such as questionnaires or guidelines for qualitative surveys. If people suffering from dementia are to be included in the investigation, and observation methods are to be used, this also requires more detailed information about these people (e.g., the degree of dementia, biographical details). As a word of caution, the decision on who should be included in the investigation should not be left to the institution. This leads to an arbitrary selection which in turn can influence the study findings. This effect can be counteracted by developing criteria for staff to evaluate, e.g., whether people can take part in a survey, or other selection criteria. Under data protection law, anonymity must always be guaranteed.

Once the details of the research design are sufficiently specific, it should be presented to the management. Experience from practice shows that transparent planning and effective communication between the researchers and management are important factors affecting whether surveys can successfully be conducted in nursing homes.

Announcing the project: transparency thanks to information

The next step should be to announce the project in a timely manner within the organization, i.e., both to the nursing staff (including volunteers) and to the residents and their relatives. The more clearly and transparently the goals of an empirical survey and the support which is expected are expressed, the greater everyone's motivation to take part. At this point, it is important for the research team to make personal contact with the staff, the residents and their relatives at an early stage, mainly so as to avoid any of the possible adverse effects related to an external evaluation (e.g., reservations, uncertainty and fears) from the start.

When presenting the planned investigation to the residents, it is important to insure that the information is introduced in an age-appropriate manner, not only to the people in care but also to their relatives, who are often themselves also elderly (e.g., partners). Involving them at an early stage can be seen as one aspect of work with relatives, which has become increasingly important in the field of care for the elderly (e.g., see Engels and Pfeuffer, 2007).

Developing and using the survey instruments

In line with the research design, which sets out the research approach (quantitative or qualitative), methods (survey, observation, etc.) and instruments (questionnaires, interview guidelines etc.), the next step is for the research team to develop those instruments.

For the operationalization process, it is not only important to be familiar with relevant specialist literature; the use of explorative, qualitative methods is also recommended (Flick, 2006). To complement the information about the organization and residents, explorative preliminary studies provide information which is valuable when developing further instruments.

Although it is now generally agreed that elderly people are able to take part in surveys (Lage, 1999), the choice of method hinges on the level of any cognitive impairment. If the decision is made in favor of a survey then, when developing the instruments, the question must be asked what cognitive tasks the respondents can be expected to perform, as indicated by cognitive response theory (Groves et al., 2004). According to this, answering a question takes four steps: (i) comprehension of the question, (ii) recall and retrieval of relevant information, (iii) judgment and estimation based on the retrieved information and (iv) reporting an answer by linking it to the response category provided (see Groves, 2004, pp. 202ff.).

Studies in which surveys were carried out with elderly people show that it is especially important to design the instruments in a "senior-friendly" way (re the opportunities and limits of resident surveys, see e.g., Höwer, 2002; Schönberg, 2006). If questionnaires are used, it should be insured that they are not too long and are written in a large font, with a clear, attractive layout and precisely formulated, clear questions which are not too long or complex. They should also include instructions so that the elderly people can easily fill them in on their own, as is usually the expectation. If, on the other hand, the plan is for the questionnaire to be filled in with the help of an interviewer, appointments are to be made which fit in with the daily routine or schedule at the home. Generally, a pre-test should be carried out to check whether the instrument is "senior-friendly".

Qualitative surveys involving oral, loosely structured interviews are generally carried out by the researchers themselves. Such interviews typically take place in a familiar environment, i.e., the nursing home. Experience has shown that this requires plenty of time to be scheduled, and the respondents' daily routine needs to be taken into account. The limits of such interviews become apparent when respondents show signs of fatigue, or physical or psychological factors indicate that the interview should be discontinued and, if appropriate, resumed later. Cases of this kind should be taken into account beforehand, in terms both of organization and the amount of time planned. In addition to this, oral surveys with elderly people require the interviewers to be extremely empathic, sensitive, patient and flexible when conducting the interview. In this respect, it is productive to train the interviewers and test the interview guidelines in advance.

The interview situation itself is also an important factor which can influence findings. When conducting oral surveys in homes, for example, it should generally be insured that the atmosphere is peaceful and familiar. In the case of quantitative surveys, there is often no control over the interview situation, as the questionnaire is usually completed in the researchers' absence. This can prove problematic if nursing staff are asked to help complete the questionnaire and thus influence the way the respondents answer. To avoid effects of this kind, it is constructive to provide information about the survey and what staff should do if this happens. Methodologically, even with quantitative surveys it is advisable to use face-to-face interviews in nursing homes, although these usually incur considerable costs.

Whichever method is used, if researchers are not carrying out the interviews themselves, or if questionnaires need to be given to residents, researchers depend on the support of staff, who can offer significant help with organizing surveys thanks to being in permanent contact with elderly people. Getting the questionnaires back is slightly trickier. To maintain anonymity, one tactic which has proven successful is to hand out the questionnaires in sealed envelopes, which are collected by the staff. Another option is to set up boxes into which residents post the completed questionnaires, which are then collected by the researchers after the response period is over.

One method which is generally not recommended, by contrast, is for the nursing staff to survey the residents, due to the expected effects this would have on how the senior citizens respond. It would also not be reasonable due to the time required, especially as staff in residential care for the elderly have a high workload as it is (see Stadtler, 2009; Nienhaus, Westermann and Kuhnert, 2012; Dietrich, Kirch and Rößler, 2014).

In the case of people in need of care who are suffering from dementia, there are clear limits to any survey due to their cognitive impairment. As a result, a survey method is required which can measure quality of life among this group of people who are generally considered unable to respond to surveys. Here, observational techniques have proven their worth; above all, the Heidelberg instrument to measure quality of life with dementia, "H.I.L.D.E." (Becker et al., 2005) and the non-participant observation method of Dementia Care Mapping (DCM) (Innes, 2004; Müller-Hergl, 2008) are worth special mention. Observational methods can also be used with residents not suffering from dementia, e.g., in addition to surveys. As homes are more or less self-contained systems, non-participant observation methods would appear more difficult to apply than participant observation, during which researchers can interact with the residents.

Evaluating and preparing the data

The task of evaluating the data collected falls to the research team; for this reason, the management are not involved in this phase of the research process. It does, however, appear advisable to hold occasional meetings with executives, on one hand to discuss interim findings together and on the other hand so that the management can help settle unresolved interpretation issues, based on their internal knowledge. In addition, discussing the findings is an important step in developing corresponding recommendations. In this regard, it has proven worthwhile to carry out "findings workshops" involving the researchers and, ideally, representatives of different management levels.

Provision of the findings

The question of how the residents, their relatives and the institution staff will be given feedback on the findings made should be considered from the beginning. In practice, a step-by-step approach has proved successful in this respect: first, the findings are presented in a small, internal circle of executives, next the findings and conclusions are jointly presented to all the employees internally, and only after that are the findings presented to the residents and their relatives (e.g., at family evenings).

This consists not only in presenting the empirical results but also in setting out the subsequent steps and measures resulting from them. The implications of the investigation are not only of interest to the residents and their relatives, but also, especially, to the nursing staff. Accordingly, suitable structures are needed to engage with the findings and the measures to be derived from them. For example, plans for improvement and strategies to implement them could be developed in small working groups. Meanwhile, announcing the findings and the next steps to be taken is a means of raising internal acceptance of such measures.

Finally, the decision must be made as to whether, and how, the findings are to be announced to the public at large, leading to corresponding activities such as press conferences, articles in various journals, lectures, etc.

Conclusions

Empirical surveys of nursing home residents, which typically record the subjective views, needs and requirements of elderly people as clients, provide valuable, evidence-based data for quality management and quality assurance in residential institutions. Although a rising number of studies deal with quality of life among nursing home residents, only a small number examine the practical aspects of research in any detail.

This contribution focused on the planning and implementation of empirical surveys in nursing homes based on experience gathered from Austrian research projects. One point which has become clear is that the results of such investigations are affected by many factors, which all have to be taken into account both when planning the research and when carrying it out. These include features specific to the organization of nursing homes and to the target group, i.e., elderly people in need of care. Methodologically, the problems caused by the target group's cognitive impairments are of particular significance. In general, experience shows that is possible to carry out empirical surveys with nursing home residents, although they do place relatively high demands on researchers. One recommendation which can certainly be made is that studies should be carried out taking other perspectives into account – especially those of the relatives and nursing staff – to gain a full picture of nursing home residents' quality of life. Another point which has become very clear is that close cooperation between the researchers and the nursing home's management and nursing staff plays a key role in the success of such projects.

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24 A critical reflection on Photovoice applied in exploring the lived experience and needs of male caregivers

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Photovoice allows participants to speak freely about their life and roles by using the camera to capture their first-hand situations in photographs, and by later recalling the related stories. On the one hand, this methodology shifts the focus to involving participants in order to amplify their own voices and thus enhance their agency; but, on the other hand, for certain groups of people – in particular, the most deprived populations who have unequal power relations with scholars – this authorization still falls under the researcher's dominance in the details of the operation. Therefore this chapter argues Photovoice should focus on empowering participants to establish stronger social networks and to improve their local communities, and it should always be operated with innovative measures that consider contextual influence.

Introduction

Unlike traditional methodology, visual materials are no longer used exclusively by researchers. Photovoice is a participatory method that allows participants to speak freely about their life and roles, as they use the camera to capture their first-hand situations in photographs and later recall the related stories (Angelo and Egan, 2015). Voice involves "voicing our individual and collective experience" (Wang and Burris, 1997, p. 381). Participatory methods of gaining new information involve participants addressing issues that are important to them; in this context, researchers are able to create knowledge that is more closely centered on the experiences of individuals, rather than viewing people simply as data sources and typically subjects of research trials (Letts, 2003).

Rooted in the three theoretical assumptions of critical consciousness, feminist theory and documentary photography (Wang and Burris, 1997), Photovoice creates spaces and opportunities for marginalized voices to be heard. Grounded in lived experience, Photovoice can help communities identify, discuss and resolve significant structural problems as they seek to use social action to inform policy. Having participants create knowledge based on their lived experiences can lead to the development new ways of seeing and understanding the context of social problems; participant-created data has the potential to challenge stereotypes and offer alternative explanations of the causes of, and answers to, social problems. In terms of narrative analysis, Photovoice offers first-hand experiences and inspires researchers to explore from more perspectives (Angelo and Egan, 2015). It allows investigators to gain an intimate familiarity with the community in which participants live and make participants' voices heard by stakeholders and policymakers.

Photovoice has been gaining popularity as a participatory research methodology and has been applied widely in studying populations from various socio-cultural backgrounds, including gender minorities (Harcourt, 2013), youth (Ardiles et al., 2019), the elderly (Novek, Morris-Oswald and Menec, 2012), homeless people (Seitz and Strack, 2016) and people with intellectual disabilities (Povee, Bishop and Roberts, 2014). This qualitative method of inquiry is mainly used for three purposes: (1) to provide a forum to present participants' lived experiences through the images, language and contexts defined by participants themselves and, based on that, to identify the strengths and weaknesses of their community; (2) to promote critical dialog and knowledge about personal and community issues; and (3) to approach policymakers in the participants' area (Wang, 2006).

Contextualize Photovoice in male caregiver study

The project *Defining Sonhood: The Exploration of Lived Experience of Caregiving Sons in their Late Adulthood in Hong Kong* is an exploratory study in which researchers attempt to conceptualize a new framework on solid field studies into community and to conduct a deep investigation into caregiving sons' lived experiences. Photovoice was selected as the dominant methodology and was supplemented by interviews and focus groups. As a participatory method, Photovoice fits the criterion of allowing caregivers to speak freely about their role. To thoroughly understand the lives and needs of this group, the research project has three major aims. The first aim is to examine factors that predispose sons to take on a caregiving role and to see how sons manage this role in their later adult life. The second aim is to investigate the lived experiences of caregiving sons in Hong Kong, mainly from three aspects: how they define caregiving, pains and gains in caring for their parents, how the caregiving role impacts other aspects of their individual life and to explore the practical implications of conceptualizing sonhood for social issues.

Photovoice was used as a primary method to collect the data, whereas interviews were used to prompt participants to explain their stories, mainly including experiences associated with the photos, notes and photo-taking process. The photos encourage participants to reflect on their experiences through their own lens. In addition, interviews were used to investigate the factors of being caregiving sons, their pains and gains in caring for their parents and how their caregiving role impacts other aspects of their individual life.

Research on caregiver burden is predominantly quantitative in nature (Adelman et al., 2014). It associates lack of support for daily caregiving tasks with higher caregiver burden (Kaufman et al., 2010) and poor caregiver quality of life with physical and mental health issues (Chang, Chiou and Chen, 2010). Quantitative research concentrates on the categories of specific caregiving tasks, the level of the burden and the influence of the burden on caregivers. However, no official statistics focus on male family caregivers in Hong Kong, and, in academia, no solid and systematic studies have been conducted to understand how men perceive their roles and caregiving behaviors when age and family relationships intrude in different combinations.

As a result, Photovoice was chosen as an appropriate method to capture the reality of people's lives and to present these realities and moments to others. Photovoice thus provides an opportunity for male caregivers to present their lived experiences through images and language. Physical environments and narrations of the photos defined the contexts in which the strengths and weaknesses of the local community were examined by the participants themselves.

As reviewed in the above section, Photovoice is widely accepted in studying minorities and marginalized populations. Men, a group not traditionally recognized as caregivers, are rising to the occasion. Conventionally, women have been assumed as nurturers and the primary caregivers in the family, including in Hong Kong (Cheung and Halpern, 2010) while men have been established as breadwinners who focus on the external world. As a gendered concept, caregiving is often defined as feminine, and caregivers are treated as a subordinate class; caring practice engenders a feminine identity, while masculinity is seen as incompatible with caring skills (Hanlon, 2009). In that case, male caregivers were socially constructed as a marginalized group.

As described above, Photovoice was supplemented by message descriptions and interviews to examine this marginalized group. Caregiving was regarded as a practice-based framework defined by narration of the photos, which record the caregiving experiences of specific moments.

The targeted sample is caregiving sons in later adulthood (aged 45–65) in Hong Kong, and 60 participants are invited to participate. Due to the fact that Hong Kong does not have official statistics on caregiving sons, it is impossible to employ random sampling. Furthermore, scholars have pointed out that hegemonic masculinity makes men too anxious to accept the caregiver role (Hearn, 2004): the conflict between the social expectations of men and the emotional abilities required for caregiving leads to rejection of a caregiver identity. In addition, it is not common for men to seek help and emotional support from the community.

As such, besides purposive sampling through non-government organizations (NGOs) and the researchers' personal networks, peer research was also employed for recruitment. Purposeful sampling was adopted, in which specific socio-demographic characteristics of Hong Kong caregiving sons will be considered in setting up the inclusion and exclusion criteria for sample recruitment. Peer research is applied to studies involving hard-to-reach populations (O'Reilly-de Brún et al., 2015). By borrowing the praxis of peer research for recruitment, this study could reach greater numbers of a marginalized group, with the collected data more accurately representing community needs and increasing opportunities for recognition of self-identity and empowerment.

The modification of Photovoice

The whole process of Photovoice includes four major parts: (1) participants are required to take photos portraying their experience of the investigated phenomenon; (2) participants illustrate what they want to express through the photos; (3) researchers contextualize the photos by analyzing them and their narrations; (4) interviews and focus groups elicit the story behind the photos in order to further understand participants' caregiving experiences. These four parts are attained through a standardized procedure with four meeting sessions, including the orientation session, the photo collection with elicitation interview session, the reflection session and the group discussion session.

This project modified the above procedure. The data is collected more flexibly, with photo collection and interviews. The whole procedure includes four major steps: (1) proposed protocol based on literature review; (2) capacity building of researchers; (3) refined protocol; (4) coping with the challenges encountered during initial recruitment and adjusting protocol. During the initial recruitment in February and March 2019, ten successfully contacted male caregivers as well as partnered NGOs disclosed their difficulties in committing to attending four sessions of Photovoice, since they usually have full-time jobs and/or other engagements in their personal lives. It is very hard for them to spare time for four sessions in busy, fast-paced Hong Kong. Although they are interested in participating in this project, four session-designed activities are too demanding for them. Moreover, participants expressed their concern about disclosing about their personal lives in front of strangers.

Meanwhile, as mobile devices become advanced and popular among the general population, the technology literacy of using smart phone apps – such as mobile cameras – is increasing among older adults. Most participants have already acquired skills to use multi-function instant messaging apps for communication (e.g., WhatsApp), and most participants were familiar with taking photos by smart phone. As a result, the methodological operation was redesigned, emphasizing flexibility throughout the whole process. The sessions required by the traditional Photovoice flow can be conducted in an innovative way. For instance, interviews and discussions can be conducted via phone, email or instant messenger apps such as WhatsApp, while photos can be collected through tools such as Google Drive and email.

Discussion

This participatory approach aims to promote critical dialog and knowledge about personal and community issues. Unlike other methods that do not penetrate the community, Photovoice enables participants to work as partners and collaborators of the researchers. In a social process of critical consciousness (Carlson, Engebretson and Chamberlain, 2006), researchers help individuals express their own experiences by critically reflecting their assumptions and interpretations of reality. Participants are only able to conduct dialog with relevant policymakers based on their understanding of their identity as caregiver and the situation they were experiencing (Wang, 2006).

To realize this goal by research–participant collaboration, two critical issues should be faced throughout the process: (1) the balance between the role of researchers' decision-making in the process on the one hand, and participants' dominance in portraying their experiences by photography on the other hand; and (2) the barriers of and empowerment from using the Photovoice technique among participants. Meanwhile, methodological strengths and weaknesses were reflected on to improve the Photovoice application throughout the entire project.

The balance between the role of researchers' decision-making in the process on the one hand, and participants' dominance in portraying their experiences by photography on the other hand

The utilization of Photovoice was based on the balance between researchers' decision-making and participants' dominance in portraying their experiences. In Photovoice studies, the relationship of researchers and participants cannot simply be described in terms of the outsider–insider (Fletcher and Kerr, 2010) and dominance–obedience binaries. Data collection is completed by the participants, which engages and enables community members to participate as partners/collaborators in the research process (Porter, 2016). From three dimensions, researchers and participants worked as partners and collaborators throughout the process of this by balancing the dynamic between the researcher's decision-making and the participants' articulation.

First, researchers and participants co-defined the term “male caregiver” and co-conceptualized the framework of “caregiving”. As stated above, the conceptualization of “caregiving and caregiver” has been feminized; consequently, the description of the inclusion criteria was modified after interactions between researchers and participants. Before the recruitment, researchers defined “primary caregiver” as someone who provided no less than four hours of care per week to one or both parents, or who visited parents who live in nursing homes and providing assistance in care on a regular basis.

With the first round of recruitment, it was found that potential candidates had different understandings of “caregiving” and “primary caregiver”, which was not expected when recruiting female counterparts. A woman could definitely identify herself as a primary caregiver by counting caregiving hours and providing a straightforward framework of caregiving tasks; however, a man could hardly articulate his caregiving contribution to this framework. One participant’s response was representative of the sample:

> I am confused about the definition of “caregiver”. I think I would recognize myself as a primary caregiver if I stayed up all night to guide the domestic helper and I experienced pressure as both a caregiver and a son. But I did not physically assist in showering or toilet use by myself if you define those tasks as caregiving.

For this reason, the definition of the targeted population in the recruitment was modified by adding “self-identity as a primary caregiver” and excluding those who only provide financial assistance.

Second, researchers and participants co-create the methodological procedure. At the preparation stage, researchers designed the study to strictly follow the theoretical flow, as detailed above. However, in reality, not all the participants in the targeted age group (“later adulthood”) were retired, and, as such, some participants still had a full-time job besides their intensive caregiving workload. Even if professionals – including social workers – have taken the lead in the research, placing additional burdens on this group for research purposes cannot be justified.

As a result, the operating flow of Photovoice has been adjusted based on the convenience of the participants and the theoretical coherence of the methodology. All the photos were collected via WhatsApp as soon as they were taken; instead of conducting photo-elicitation interviews and focus groups in the final session, researchers conducted interviews and focus groups on a more flexible schedule. Participants were invited to take part in phone or face-to-face interviews if they were unable to attend the session. Furthermore, to guarantee minimal influence on outcomes, participants were asked to write short instant memos to describe the photos when sending them to the researchers.

Third, the researchers and the participants co-interpret the photos. Photovoice gives the participants voice and enhances their agency to express their stories, but, at the same time, it also requires researchers to make decisions in order to attain the research aims. In this project, participants took photos following by a set of guidelines:

- take photos to show what your current life is like;
- take photos to convey your concerns when caring for your parents;
- take photos to convey what you think relates to caregiving;
- take photos to show your greatest contribution to taking care of your parents;
- take photos to most accurately represent the relationship with the one you give care to;
- take photos to show your individual life outside taking care of your parents.

This process was carried out from an "insider" perspective; participants were encouraged to define and depict "caregiving" according to their own understanding. The SHOWeD approach (Gant et al., 2009) was applied to interpret the photos from an "outsider" perspective, in order to examine the related social issues and to facilitate policymaking. The question guideline is listed below.

SHOWeD Approach (Gant et al., 2009)

- What do we see in this picture?
- What are we seeing in this picture?
- What is this picture about?
- How does this picture relate to your life here?
- What should we/other people understand about your experience from this picture?
- What do you want others who see this picture to understand about your experience as shown in the picture?
- What are your thoughts/feelings about this picture?
- Why do these issues exist?
- How can we become empowered by our new social understandings?
- What can we do to address these issues?
- Given what we have learned so far, what should we explore next?

By probing into the questions above, participants and researchers collaborate to give thick descriptions of relevant social issues, which give rise to increased understandings of contextual influence.

The barriers of and empowerment from using Photovoice among participants

As stated above, Photovoice can empower participants; it authorizes their voice to articulate caregiving experience by taking photos and reflectively narrating those photos. Photographs capturing physical and social environments drew out a range of emotions and experiences in different settings. However, some participants were resistant to learning how to use smart phones and social media, a phenomenon that is more common among the targeted population of this study. Other challenges also repeatedly occurred during the study, such as participants preferring words and conversations over taking photos to present their sentimental issues, having concerns about sharing personal photos with others and finding Photovoice to be time consuming and just another burden to their workload.

At the same time, the method of Photovoice to some degree marginalized institutional ideologies/arrangements and facilitated more critical thinking of related social issues. Practically, in those caregivers' personal lives, they better understood their roles as caregivers and developed critical awareness of their community; this reflection made them feel more at ease in taking on the caregiving role. Participants developed close attachments and better relationships with their parents by recalling memories and collecting photos. Lastly, this study allowed participants to expand their social networks among peers and to build connections with professionals (research partners and policymakers).

Reflection on methodological strengths and weaknesses of practical Photovoice use

As seen in the above analysis, practical issues and challenges in methodological practice sometimes conflicted with the theoretical principle of Photovoice as “liberatory enactment” (Malherbe et al., 2017, p. 165). As a participatory, collaborative visual study, Photovoice is “a process by which people can identify, represent, and enhance their community through specific photographic technique” (Wang and Burris, 1997, p. 369). Scholars proposed that, unlike focusing on researchers’ dominance in traditional praxis, Photovoice shifts the focus to involving participants in order to amplify their own voices and thus enhance their agency.

However, for certain groups of people – in particular, the most deprived populations who have unequal power relations with scholars – this authorization still falls under the researcher’s dominance in the details of the operation. In this project, participants of older ages and with lower education levels tended to quit during the process. In other words, rather than emphasizing a diminishing of the imbalance between the participants and the researchers, Photovoice should focus on empowering participants to establish stronger social networks and to improve their local communities. To that end, Photovoice should always be operated with innovative measures that consider contextual influence.

Conclusion

To conclude, this chapter briefly explained how Photovoice has been conceptualized and how it is increasingly being used in social science research, particularly in studying marginalized populations in the areas of public health and social work. To be specific, this study used a research project on sons as caregivers in Hong Kong to illustrate how Photovoice was flexibly used, along with the theoretical assumptions of the modification.

The fundamental aim of Photovoice was to empower the participants’ voices by providing a forum for participants to present their lived experiences through images, language and contexts defined by participants themselves, thus enabling participants to promote dialog and knowledge about their own identities and the strengths and weaknesses of the local community. The innovative way to collect the data reminded the researchers to balance the role of their decision-making with participants’ dominance in portraying and interpreting their experiences throughout the process. In addition, the barriers of and the empowerment from using IT-supported techniques and social media were also reflected on. It was necessary to understand how the technique could shift the power dynamic between the researcher and the marginalized population, at the same time keeping in mind the potential barriers and possibilities of changing of power relations.

Finally, the ultimate goal of using Photovoice is to establish a stronger community by informing the broader, powerful society. Photos and the stories accompanying them are encouraged to be exhibited to the public with ethical permission, which would help create a space for conversation between participants and their local community.

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25 Recapitulation

Ageing research on highways and byways of methodology

Maria Łuszczyńska

This publication's authors set for themselves the task of introducing the reader to the multiplicity of research methods on old age, as well as presenting reflections on their applications and practical implications. The authors have shared their own experience of using two research paradigms – the quantitative and qualitative – with an inclination toward seeking ways of employing them simultaneously, rather than viewing them as being in conflict with each other.

As part of their thought centered around those two main paradigms, the authors have shared their experience and reflections on the following specific techniques, approaches and tools in research on the phenomenon of ageing:

- desk research;
- evidence-based practice;
- experimentation;
- life-story interviews;
- longitudinal studies, cross-sectional studies and within-person change studies (e.g., data sources, trend study, cohort study and panel study, separating the influence of cohort, age and period effects);
- material culture studies and science and technology studies (STS);
- National Transfer Accounts (NTA);
- observation;
- participatory action research (PAR);
- participatory peer research (PPR);
- population health intervention research (PHIR);
- qualitative cross-national comparisons;
- the qualitative narrative gerontological approach (QNGA);
- quantitative-qualitative interviews;
- self-reported scales;
- semi-structured interviews;
- social marketing tools;
- structured interviews.

The techniques noted above have been discussed in relation to the literature on the subject and with an indication of practical challenges that arise during their application within research.

There are several general conclusions regarding the methodology of research on old age that emerge from the considerations presented in this book. A researcher who wants to undertake studies of old age in a serious manner should take into account the following threads for reflection.

1. *Flexibility and an interdisciplinary and transdisciplinary approach to ageing research.* Study of the different phenomena associated with ageing requires engagement of the conceptual apparatuses of various disciplines; one should thus develop an awareness not only of the interdisciplinary approach to research on old age, but also of the transdisciplinary context of such research. Various approaches and analyses can be combined, which creates the possibility of studying a complex problem from different perspectives. Ageing and gerontology are complex and contested fields of study and practice, and therefore seem well-suited to interdisciplinary and transdisciplinary approaches. Such approaches recognize the value of disciplinary insights, even as they build on, integrate and transcend disciplinary perspectives and conventional assumptions about how research and research education should be framed and undertaken. The book has presented tools particular to sociology, economics, legal sciences and philosophy as examples of the transdisciplinary specificity of gerontological research.
2. *Embedding research in existing theoretical systems.* It is necessary to embed research assumptions in knowledge, theoretical concepts and existing theoretical systems. We definitely recommend that ageing research be conducted with sufficient theoretical background and with regard for current social, political, religious, ideological and economic circumstances, which aims at eliminating methodological pitfalls. In addition, using insights from the existing pool of knowledge can facilitate the development and enrichment of research, as well as verifying its currency. Ignorance and balancing the open doors of knowledge should be avoided.
3. *Ethical reflection in research.* Ethical thought must be incorporated into the design and implementation of research. The researcher should competently anticipate the effects of individual research steps in the context of their axiological references. The fundamental human rights of older adults should be always protected in every research procedure.
4. *The use of many different research methods and paradigms.* The greater the variety of research techniques used in research, the more fully the trends and realities of the studied persons will be captured. It is thus important to develop a range of valid and reliable tools to research and address ageing. Because every phenomenon associated with ageing is complex and multidimensional, it is advisable not to limit yourself to just a single research paradigm. In particular, we encourage you to carry out research in teams that include experts in qualitative and quantitative research, thereby facilitating the creation of mixed models for research. The catalog of possible methods is open, and combining them in innovative ways can yield surprising results that more effectively present the reality of older people.
5. *The researcher as an important factor in the research conducted.* It is important to realize that the researcher is involved as a human being in the relationship with the respondent. It is not possible to reduce the researcher to some pure, objective consciousness devoid of prejudices, worries, emotions, sympathy and antipathy – especially when sensitive issues are being studied. The so-called “human factor” should be taken into account on the side of both the researcher and the respondent. An important element that can complement the primary study may be knowledge gained by a researcher about the situation taken from sources other than the interview itself; we call this backstage knowledge.

6 *The specifics of the so-called "sensitive issue".* Whether a topic is "sensitive" is determined not only by the nature of the research problem or the people participating in the research but also by relevant authorities and their views. Sensitive research need not be associated solely with qualitative methods and (above all) narrative interviewing; the study of sensitive issues can also be undertaken using quantitative methods.

7 *The role of technology and objects.* Not only older people can serve as the subjects of one's research; material objects and technologies likewise add to our view of age(ing). As a result, it is no longer only interactions between human beings that are examined, and objects are no longer understood simply as parts of a purely physical environment. Awareness of such phenomena can aid in pinpointing the role that objects play in constituting old age; objects can co-constitute life in old age if they provide more than resources or functions for older adults. The same situation arises when using technical equipment, IT-supported techniques and social media, which can create many possibilities for changing power relations.

8 *Cross-national comparisons.* Thinking about research on old age in such a way that allows results to be compared between different populations in different countries is a huge challenge for those who design and execute studies, especially in international teams. Such circumstances reveal differences in approaches to methodology, in the understanding of theories and the correlation of data, and in addressing issues relating to validity, reliability and ethical considerations. Carrying out research involving rigorous cross-national comparison demands extensive language skills, cultural understanding, resources and time. To achieve the research aim, it is essential for a researcher to collect information about the relative effects of different actions on actual welfare outcomes in different countries. Building research projects whose results can be compared with those of other projects seems to be the greatest challenge facing researchers on ageing worldwide.

9 *Putting research solutions into practice.* Research should be designed with its application borne always in mind. Ageing interventions are complex; research in this field must help us both find new solutions to those challenges facing the ageing population and insure the viability of such solutions in different systems connected with older adults' lives. Thus, research methods must evolve to better integrate different aspects of complexity: how will an intervention work? How can the intervention be implemented to produce the same results as in experimental contexts? In which conditions could the intervention be adapted? All of these questions allow us to define the conditions in which ageing interventions can be implemented, evaluated and transferred. Answering them involves considering new research methods that are more comprehensive and integrative of the real conditions in which research professionals work. Research on ageing needs to be followed up with interventions for enacting change in clinical practice. While many initiatives are currently being promoted by public organizations and associations, complementing them with appropriate research and evaluation would increase efficiency in the long term by building up the necessary evidence base.

10 *Engaging seniors in the research process.* Participatory peer research has undoubtedly helped in creating inclusive, equitable and responsive research. In addition, it serves to enact empowerment at the individual and community levels. One can positively state that the involvement of older people in ageing research is a necessity, not a nuisance. In this context, one should also take into account the possibilities and perspective of seniors with various challenges – for example, problems caused by conditions like

> Alzheimer's disease, Parkinson's disease or aphasia. Similar challenges might exist when interviewing older rural participants who are less articulate or who consider their experience as "too normal to be narrated". It is always important to be aware of the fact that the flow of information in a qualitative interview might not be as mutual as is assumed; a participant's sharing of his or her life story might be minimally responsive, fragmented and structurally shaped. Adapting recruitment strategies, modifying consent forms, adjusting the data collection process, developing more accurate tools to assess capacity and diversifying communication strategies are part of the strategies for achieving better research outcomes.

The broad context for organizing ageing research is learning how to honor the life experience of our elders. Instead of calling them "the elderly", it is better to address them as "older adults" or even "elders", which indicates those with wisdom. The most important component of life experience is the "ingenuity of ageing", which means the ageing experience of the aged.

Moreover, it is important to build bidirectional trust, which means enhancing trust by offering elders ownership of research. Instead of framing elders as passive subjects for research, we advocate a co-creation methodology. While acknowledging both traditional models – the medical and social dimensions of ageing – we embrace the "Cultural Model of Ageing" as a means of capturing how older people tackle their own ageing issues.

The final and most important remark is about enhancing the role of older adults as active participants in the research process, which is essential for the future development of more participatory methods for our common issue: ageing. We must expand roles for those who are the co-creators of our super-ageing society, in which public and statutory authorities must work with older people in planning future services in order to insure that our communities will be fit for all ages.

In concluding, I would like to express the hope that this book will have provided true inspiration for readers to undertake further research on the phenomenon of ageing, and that the content of individual parts of this book will have been a source of new ideas regarding research on old age and of guidelines for developing increasingly reliable methodologies. Research on ageing is not only our passion, but also our future. Together with other researchers, we carry out such work not only as scientists, but also as persons who, like all human beings, will experience what it is to grow old.

Appendix 1

Chapter 18

Daniela Wetzelhütter, Katrin Hasengruber,
Renate Kränzl-Nagl and Tina Ortner

This contribution deals with work-based stressors perceived by nurses and caregivers. For this reason, care concepts are required which not only meet the needs of such residents in care homes, but also reduce the stress affecting caregivers and nurses. The extent to which this is achieved was investigated in a research project; the findings were gained using the survey instruments below. These have been translated for this publication; in practice, German versions were used. These instruments made it possible to assess the subjectively perceived work-based stress affecting nurses and caregivers working with residents suffering from dementia, taking into account the background conditions in each case and factors influencing the perceived extent of the stress.

A Guidelines: expert interview

Date: ....
Interviewer: ....
Interview number: ....
Interviewee: ....
Function: .... Since: ....
Start of interview: ....End of interview:..................Date:.................
Special circumstances: ....
....

Brief discussion of the interview framework

- Welcome, thanks for taking part, time frame
- Aims of the interview
- Confidentiality/anonymity

Lead-in (for interviews with nursing managers). As already briefly mentioned, I would first like to talk to you about your experience caring for dementia sufferers in nursing homes for the elderly, and also about the skills this requires.

- Thinking about work with people in need of care in homes for the elderly, which experience that you have gained so far is especially valuable for your everyday work?
- Now, thinking about your staff, what attributes should a member of staff ideally have in order to nurse and care for clients in your nursing home? (competences, soft skills, personality)

  - … with a focus on nursing home residents suffering from dementia?
  - What combination of staff do you have in your nursing home (training, professional experience, etc.)?

Lead-in (only for interview with psychologist). To begin with, I would like to talk to you about working with caregivers and nurses, and about the skills they require.

- Please briefly outline how you collaborate with the nurses in the nursing home.
- From your perspective, what attributes should a caregiver ideally have to work in a nursing home? (competences, soft skills, personality)
  - … with a focus on nursing home residents suffering from dementia

Now for the working conditions and/or work-based stressors. E.g., required working hours, residents' behavior, social interaction, etc.

- How would you describe the current working conditions/background conditions in your nursing home, e.g., in only two or three sentences?
  - … with a focus on care for residents suffering from dementia?
- What (what circumstances) would you consider to be stressful (or somewhat stressful) for nurses and caregivers in your nursing home?
  - Which of these circumstances or stressors particularly apply to care for dementia sufferers?

Perception of work-based stressors

- To what extent is it clear to you whether your nursing and care staff are exposed to work-based stressors?
  - … whether they are stressed when working with residents suffering from dementia?
  - How can you tell whether staff are stressed? How are work-based stressors expressed? (levels of sick leave, employee turnover, etc.)
- What are the primary stressors? What do you believe are the central stressors?
  - How often do these stressors occur? (everyday, rare)
- Perceptions of how stressful the work is may not always be the same. Are there fluctuations in work-based stress? (in the course of a day, a year)

Influences/working conditions

- In your view, what conditions/factors exacerbate or aggravate the stressors described earlier as arising during nursing and care for the residents in your nursing home?
  - Background conditions at the institution: office management, leadership culture, equipment, etc.
  - Personal characteristics
  - Professional skills
  - Staff members' personality/attitudes: coping strategies, attitude to work, social skills etc.
- Have steps already been taken in your nursing home which are designed to help reduce these stressors when nursing and caring for the residents of your home?
  - If so, what steps have already been implemented? (supervision, involvement in roster planning, team meetings, etc.)
  - Are there any records of that? – *Request records*
- In your opinion, what else could be done to reduce work-based stress?

Close

Now, we have talked about your perception of your staff's working conditions and work-based stressors. During the project, the caregivers and nurses will also be asked directly about their working situation using questionnaires.

- What topics do you think should definitely be brought up in this questionnaire?
- Is there anything else you would like to tell me?

B Guidelines: focus group

Topic	*Line of questioning or aspects*	*Method*	*Props*	*Time*	*Start*
Welcome and Introduction	• Welcome and thanks for taking part • Moderators introduced • Topic and goals → mention dementia sufferers • Project information • Record the conversation of the focus group • Sensitive handling of data (anonymity) • Time frame: 2 hours • Rules for discussion: interest in all opinions, no agreement necessary, wait for people to finish their point • Questions beforehand?	–	Welcome flipchart	5 mins	10:00–10:05
Introductions	• First name • Time spent working in care for the elderly	–	Adhesive labels	10 mins	10:05–10:15
Job satisfaction	If you think about your daily work, caring for and nursing people with dementia, where do you currently see yourself? *Near the sun – a positive feeling if you think about work – or near the storm cloud, as things might not be going so well at the moment.*	Prepared poster in the center of the table: continuum from "sun" to "storm cloud" (in the middle of the poster, leaving space in between, above and below): participants place themselves on it with a large sticky dot	Poster Sticky dots		
Lead-in to work-based stressors	*Comment on image (arrangement of "sticky dots")* You are probably all know how it is: there are some days when things don't go too well, or circumstances that are not very simple. Please now talk about your work in twos or threes. What are some *circumstances or situations* that are difficult when nursing and caring for residents *suffering from dementia*? Please note keywords about them on these cards. If possible, just one fact, situation, task etc. per card	Work in groups of up to 3 people Moderators help write things down	Cards, pens Flipchart with topic	10 mins	10:15–10:25

Topic	*Line of questioning or aspects*	*Method*	*Props*	*Time*	*Start*
Brainstorm stressors; clustering	Please tell us what you have written down. What (what else) do you experience as *stressful* in this situation? When all the cards are pinned up, and all stressors have been collected → *follow-up question*: Do any other *work-based stressors* come to mind?	Moderator notes further work-based stressors on cards Work-based stressors are pinned to two pinboards, in categories Moderator notes headings on moderation cards and pins them to pinboard	Pinboard Pins 2 pinboards with poster (distribute) Pins, moderation cards, pens	15 mins	10:25–10:40
Stressor weighting	What do you experience as stressful? Please stick dots on the work-based stressors which primarily affect you. You can distribute your three dots however you like. Put all three dots on one stressor you perceive as especially intense, or spread them out.	Visualization with sticky dots. Each participant receives three red sticky dots, which can be stuck to the stressor cards. (All on one card or spread across several.)	36 sticky dots	5 mins	10:45–10:50
Split up	–	Split the group, with 1 employee per home in each group Take one pinboard	Pinboard Pins	–	–
Conditions/ factors which exacerbate/ reduce work-based stressors	What influences the perceived work-based stressors? In your view, what increases, exacerbates or reduces these work-based stressors? Is there anything that makes these stressors worse? Or anything that reduces the stress – any steps that have already been taken? • *Background conditions at the institution: office management, leadership culture, equipment, etc.* • *Personal characteristics* • *Professional skills* • *Staff members' personality/ attitudes: coping strategies, attitude to work, social skills etc.*	Discussion in small groups Moderators or participants make notes on green/red cards and pin them straight to the stressors (pin separately for general factors/conditions)	Moderation cards Pens Flipchart with topic	25 mins	10:55–11:20
Each group adds to the influencing factors brought up by the other group	–	Groups swap places	Moderation cards, Pens	10 mins	11:20–11:30
Two groups join again Break	–	–	–	10 mins	11:30–11:40

continued

Topic	*Line of questioning or aspects*	*Method*	*Props*	*Time*	*Start*
Ideas about solutions	In your opinion, what is required to deal with stressful situations as well as possible?	Work in small groups of 3 Each group works on 1 of the sections (clusters) Write down keywords again Ideas are presented to the group and pinned up	Yellow cards Pens Possible separate poster, depending on space	15 mins	11:40–11:55
Final round	Instant feedback: each participant can make a comment	–	Hand out exit tickets	5 mins	11:55–12:00
Conclusion	Thanks to the participants	–			
CREATE PHOTO RECORD					

C Quantitative questionnaire

Page 1: cover sheet
Page 2: privacy information sheet

Occupational group and working hours

1 **I work as a …**
☐ healthcare professional and nurse (DGKP)
☐ social carer for the elderly (DSB “A”)
☐ social carer for disabled people (FSB “B”)
☐ home assistant
☐ (other occupational group, namely:)
____

2 **I work …**
☐ full-time
☐ part time, _______ hours a week

Working conditions

3 **In the institution where you work, is there a specific area explicitly set aside for nursing and care for dementia sufferers?** *e.g., residential group for residents with dementia*
☐ Yes ☐ No ☐ Don’t know
If there is, how often do you work in this area which is specifically designed to care for and nurse dementia sufferers?

always	**mostly**	**sometimes**	**rarely**	**never**
☐	☐	☐	☐	☐

4 **Thinking of all the residents you take care of, how high would you say is the proportion of dementia sufferers?**
Please circle the estimated proportion of residents suffering from dementia.

0% 5 10 15 20 25 30 35 40 45 50 55 60 65 70 75 80 85 90 95 **100%**

5 **The work I do when nursing and caring for dementia sufferers is:**
On each line there are two opposites. Please select one answer for every line.

	very	**quite**	**half/half**	**quite**	**very**	
Varied	☐	☐	☐	☐	☐	monotonous
Self-determined	☐	☐	☐	☐	☐	pre-set
Over-demanding	☐	☐	☐	☐	☐	under-demanding

6 **Thinking of your work with residents suffering from dementia as a whole, how much do the following statements apply?**
Please select one answer for every line.

	strongly agree	**somewhat agree**	**half/ half**	**somewhat disagree**	**strongly disagree**
I really enjoy work.	☐	☐	☐	☐	☐
I draw strength from my work.	☐	☐	☐	☐	☐
My work requires so much energy that it has a negative effect on me.	☐	☐	☐	☐	☐
I see my work as enriching.	☐	☐	☐	☐	☐

7 **When working with residents suffering from dementia, what situations do you see as enriching?** *Please name some examples.*

8 **How much do the following statements apply to the working conditions in your nursing home?** *Please select one answer for every line.*

	strongly agree	**somewhat agree**	**half/ half**	**somewhat disagree**	**strongly disagree**	**unable to say**
I feel at ease in the premises.	☐	☐	☐	☐	☐	☐
The premises' physical spaces (living areas, corridors, rooms, the garden, etc.) are well suited to work with dementia sufferers.	☐	☐	☐	☐	☐	☐
I am provided with all necessary materials and work equipment.	☐	☐	☐	☐	☐	☐
My wishes and needs are considered as far as possible when making up the duty roster.	☐	☐	☐	☐	☐	☐
My wishes and needs are considered as far as possible when planning holiday leave.	☐	☐	☐	☐	☐	☐
There is a sufficient selection of training and CPD schemes available.	☐	☐	☐	☐	☐	☐
My salary is appropriate	☐	☐	☐	☐	☐	☐
I cope well with daily nursing and care for residents during the day.	☐	☐	☐	☐	☐	☐
I cope well with nursing and care at night.	☐	☐	☐	☐	☐	☐

9 **Now think about your immediate superior(s).**
How much do the following statements apply?

	strongly agree	**somewhat agree**	**half/ half**	**somewhat disagree**	**strongly disagree**
I know exactly what she/he expects of me regarding my work.	☐	☐	☐	☐	☐
If necessary, I get help and support from him/her.	☐	☐	☐	☐	☐
He/she shows appreciation and recognition for my work.	☐	☐	☐	☐	☐
He/she takes my ideas and suggestions into account.	☐	☐	☐	☐	☐
I think her/his leadership style is good.	☐	☐	☐	☐	☐

10 **Please now think about your *colleagues* working in care and nursing.** *How much do the following statements apply?*

	strongly agree	somewhat agree	half/ half	somewhat disagree	strongly disagree
If necessary, I get help and support from my colleagues.	☐	☐	☐	☐	☐
I get on well with my colleagues.	☐	☐	☐	☐	☐
My colleagues and I work well together.	☐	☐	☐	☐	☐
My colleagues are always there for me if I have a problem at work.	☐	☐	☐	☐	☐

11 **Now think about collaboration with *external occupational groups*** (e.g., doctors, psychologists, therapists). *How often does the following happen?*

	very often	often	sometimes	rarely	never
I work with external occupational groups.	☐	☐	☐	☐	☐
Members of other occupational groups come to me for my specialist knowledge in nursing/care.	☐	☐	☐	☐	☐
External occupational groups are not brought in, although in my view it would be useful.	☐	☐	☐	☐	☐

12 **Looking back on the last three working weeks, how often …**

	very often	often	sometimes	rarely	never
Did you feel that tasks were unfairly distributed?	☐	☐	☐	☐	☐
Did you feel rushed in your daily work?	☐	☐	☐	☐	☐
Were you frequently interrupted while carrying out your duties?	☐	☐	☐	☐	☐
Did you not have enough time to respond to residents' wishes and needs which could otherwise be fulfilled?	☐	☐	☐	☐	☐

13 **Looking back on the last three working weeks, how often …**

	very often	often	sometimes	rarely	never
Were you given all the information you needed to do your job well?	☐	☐	☐	☐	☐
Did you feel you had been given too much responsibility?	☐	☐	☐	☐	☐
Did you have to do things that seemed unnecessary to you?	☐	☐	☐	☐	☐
Did you want to have more responsibility than you were given?	☐	☐	☐	☐	☐
Did you take on tasks for which you are not actually qualified?	☐	☐	☐	☐	☐

14 **For the next questions, think about caring for and nursing the residents you care for who suffer from dementia.**
How often do the following aspects occur *in residents suffering from dementia*?

	very often	often	sometimes	rarely	never
Mental disorders (depression, panic syndromes, paranoid ideas …)	☐	☐	☐	☐	☐
Challenging behaviors (constant demand for attention, aggressive behavior, uncooperative behavior …)	☐	☐	☐	☐	☐
Challenging activities (the urge to wander about, confusing day and night, lack of drive …)	☐	☐	☐	☐	☐
Challenging communication (constant repetition, disruptive sounds such as monotonous noises, sexually suggestive comments …)	☐	☐	☐	☐	☐

Stressful and supportive aspects

15 **Please now think about the following behaviors which occur when working with dementia sufferers. I find …**

	very stressful	somewhat stressful	half/ half	not very stressful	not at all stressful
Mental disorders (depression, panic attacks, paranoid ideas …)	☐	☐	☐	☐	☐
Challenging behaviors (constant demand for attention, challenging behavior, uncooperative behavior …)	☐	☐	☐	☐	☐
Challenging activities (the urge to wander about, confusing day and night, lack of drive …)	☐	☐	☐	☐	☐
Challenging communication (constant repetition, disruptive sounds such as monotonous noises, sexually suggestive comments …)	☐	☐	☐	☐	☐

16 **How often do you find the following types of interaction among residents stressful** (e.g., including among residents suffering and not suffering from dementia)?

	very often	**often**	**sometimes**	**rarely**	**never**
Conflict due to psychological impairments (depression, panic attacks, paranoid ideas …)	☐	☐	☐	☐	☐
Conflict due to challenging behaviors (constant demand for attention, challenging behavior, uncooperative behavior …)	☐	☐	☐	☐	☐
Conflict due to challenging activities (the urge to wander about, confusing day and night, entering rooms …)	☐	☐	☐	☐	☐
Conflict due to challenging communication (constant repetition, disruptive sounds such as monotonous noises, sexually suggestive comments …)	☐	☐	☐	☐	☐

17 **Please now think about the following aspects of working with relatives of dementia sufferers.**
I find …

	very stressful	**somewhat stressful**	**half/ half**	**not very stressful**	**not at all stressful**
Insufficient knowledge about the symptoms of dementia	☐	☐	☐	☐	☐
False or unfulfillable expectations	☐	☐	☐	☐	☐
Lack of appreciation	☐	☐	☐	☐	☐
Family conflicts among a resident’s relatives	☐	☐	☐	☐	☐

18 **How often do you find working with others to be stressful? In the case of …**

	very often	**often**	**sometimes**	**rarely**	**never**
Direct superiors	☐	☐	☐	☐	☐
Colleagues	☐	☐	☐	☐	☐
Members of external occupational groups (e.g. doctors, psychologists)	☐	☐	☐	☐	☐

19 **Looking back on the last three working weeks, how much of a toll do you feel your work took on your health?**

	none at all	**not a lot**	**medium**	**quite a lot**	**very high**
Physical stress	☐	☐	☐	☐	☐
Mental stress	☐	☐	☐	☐	☐
Social stress (social contacts, relationships, conflicts etc.)	☐	☐	☐	☐	☐

20 **Thinking about your daily work nursing and caring for residents suffering from dementia, how helpful are the following aspects for you?**

	very helpful	**quite helpful**	**half/ half**	**not very helpful**	**not at all helpful**	**don't know/not applicable**
Your training	☐	☐	☐	☐	☐	☐
Your professional experience	☐	☐	☐	☐	☐	☐
Your validation approach	☐	☐	☐	☐	☐	☐
Your institution's care concept	☐	☐	☐	☐	☐	☐
Internal and external CPD attended (e.g. lectures, workshops, seminars)	☐	☐	☐	☐	☐	☐
Supervision	☐	☐	☐	☐	☐	☐
Team discussions	☐	☐	☐	☐	☐	☐
Discussion among colleagues in the institution	☐	☐	☐	☐	☐	☐
Joint team activities (e.g. regular team meetups, company outing)	☐	☐	☐	☐	☐	☐
Recreation/relaxation in free time	☐	☐	☐	☐	☐	☐

21 **Now, thinking about the current care concept, how would you rate it?**

A) With regard to professionalism	**very good**	**good**	**average**	**not very good**	**not good**
In terms of professionalism, the concept is …	☐	☐	☐	☐	☐

because (please give reasons for your answer):________________________________

____

B) In terms of implementation	**very easy to implement**	**good can be implemented**	**can be implemented in part**	**not easy to implement**	**cannot be implemented**
The concept is …	☐	☐	☐	☐	☐

because (please give reasons for your answer):________________________________

____

22 **Thinking about your daily work nursing and caring for residents suffering from dementia, how helpful are the following schemes for you?**

	very helpful	**quite helpful**	**half/ half**	**not very helpful**	**not at all helpful**	**don't know/not applicable**
Consultant service with specialist diagnostics and in-house treatment	☐	☐	☐	☐	☐	☐
In-house psychological testing	☐	☐	☐	☐	☐	☐
Case-specific communication and discussion with psychology department and specialist	☐	☐	☐	☐	☐	☐
Group schemes offering individual support	☐	☐	☐	☐	☐	☐
Group schemes offering individual additional resources	☐	☐	☐	☐	☐	☐
Discussions to reflect on group schemes	☐	☐	☐	☐	☐	☐

23 **If you could go back in time, would you choose your current occupation again?**

yes, definitely	**probably**	**half/half**	**probably not**	**definitely not**
☐	☐	☐	☐	☐

24 **Can you imagine still being able do your job in five years' time?**

yes, definitely	**probably**	**half/half**	**probably not**	**definitely not**
☐	☐	☐	☐	☐

25 **In the last six months, how often have you considered a change of career?**

never	a few times a year	a few times a month	a few times a week	almost every day
☐	☐	☐	☐	☐

26 **Please give reasons for your answer to the last question.**

____

27 **Finally, we would like you to answer a few questions about yourself.**

a) I am … ☐ female ☐ male

b) I am … ____ years old.

c) I have … been working in nursing and care for elderly people for about __ years.

d) My mother tongue: ☐ German ☐ another language, namely: ________________________

If *German is not your mother tongue*, how would you rate your German language skills?

☐ very good ☐ quite good ☐average ☐ not very good ☐ not good at all

This space is for other comments on the topic of nursing and care for residents suffering from dementia.

Appendix 2

Chapter 17

Principal characteristics of French gerontopoles

Name of gerontopole	*Region*	*Founding members*	*Year of creation*	*Principal missions/focus*	*Size of center*
Gerontopole Toulouse	Toulouse region	Prof. Bruno Vellas, CHU Toulouse, INSERM	2007	Alzheimer's disease Frailty and maintaining autonomy Nursing home clinical research	67 employees
Gerontopole PGI Bourgogne Franche-Comté	Bourgogne Franche-Comté region	CARSAT BFC, CHU Besançon and Dijon, Bourgogne and Franche-Comté University	2010	Research and innovation Transfer of competences and training Prevention	9 employees 52 members
Gerontopole Pays de la Loire		Prof. Gilles Berrut; Conseil Régional; CHU Nantes, Angers; chamber de commerce et d'industrie (CCI) Pays de la Loire	2010	Research Economic development Training Supporting local community groups (public policy evolution in ageing)	8 employees
Gerontopole AURA	Rhône Alpes	St Etienne; CHU St Etienne; Mutualité française	2014	Living Lab call for projects Frailty detection Themed days	2 employees
Gerontopole Koz'ensemble	Brittany	Sciences Politiques Rennes, Harmonie Mutuelle Prof. Dominique Somme, CHU Rennes	2015	Organization by Labs/ Nutrition /Training /Living conditions /Social life /Mobility /Health	No employees
Gerontopole Champagne Ardenne	Champagne-Ardenne	Prof. Jean-Luc Novella, CHU Reims	2015	Silver economy Research in clinical and fundamental prevention Training and support for new professions	–
Gerontopole Gérond'if île de France	Ile de France	AP-HP, FHF, FEHAP, URIOPSS; Prof. Olivier Hanon, Fondation Hôpitaux de Paris-Hôpitaux de France	2016	Gerontotechnology Research Evaluation of innovative pathways Ethics and social issues	18.4 employees
Gerontopole Normandie	Normandy	Pôle métropolitain de l'estuaire de la seine, CARSAT Normandie Gr hospitalier du Havre Caen la mer Normandie communauté urbaine, Université le Havre, Fondation Filseine, Pôle TES.	2016	Living conditions and mobility Conferences Training ambition	1 employee
Gerontopole Sud	PACA	Prof. Olivier Guérin, CHU Nice	2019	Gerontopole under development	–

Appendix 3

Chapter 16

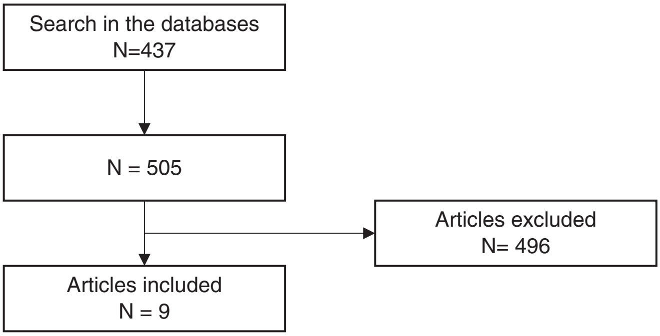

Figure A3.1 Flowchart pertaining to the literature review process.

Appendix 4

Chapter 16

Table A4.1 Assessing the use of the seven reference criteria of the social marketing and the observed impact on the increase in physical activity

Interventions	*Target*	*Behavioral change*	*Population study*	*Segmentation*	*Exchange*	*Marketing mix*	*Competition*	*Evaluation*	*Observed impact on the increase in physical activity*
(DiGuiseppi et al., 2014)	>60 years	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
(Verma et al., 2016)	>60 years	Yes	Yes	No	Yes	Yes	No	Yes	Yes
(Kamada et al., 2018)	40–79 years	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
(Newton et al., 2015)	18–79 years	Yes	Yes	No	Yes	Yes	No	No	No
(Wilson et al., 2015)	18–85 years	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
(Withall et al., 2012)	≥18 years	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes

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