

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 identity 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 McKeivitt, 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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