Moral awareness and different orders of relevance in participatory research with older people and professionals

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Abstract: Limitations are described in the literature in relation to the actual involvement of older people in action research activities. Empirical social research involving any form of data collection has an impact on the people and the setting studied. Researchers should strive to be morally aware of such an impact. The article describes case studies of participatory research in Sweden, Italy and Portugal. It highlights moral issues confronted by researchers. Moreover actual examples of different order of priorities among researchers and participants are provided. The study shows possible spaces for collaboration, while recognizing the difference of interests and priorities among researchers and participants.

Keywords: older people, participatory research, action research, moral issues, data collection, social dimension of research activities

Conciencia moral y diferentes órdenes de relevancia en la investigación participative con personas mayores y profesionales

Resumen: En la literatura se describen las limitaciones en relación con la participación real de las personas mayores en las actividades de investigación-acción. La investigación social empírica que involucra cualquier forma de recopilación de datos tiene un impacto en las personas y el entorno estudiado. Las personas investigadoras deben esforzarse por ser moralmente conscientes de tal impacto. El artículo describe estudios de casos de investigación participativa en Suecia, Italia y Portugal. Destaca los problemas morales que enfrentan las personas investigadoras. Además, se proporcionan ejemplos reales de diferente orden de prioridades entre personas investigadoras y participantes. El estudio muestra posibles espacios de colaboración, al tiempo que reconoce la diferencia de intereses y prioridades entre personas investigadoras y participantes.

Palabras clave: personas mayores, investigación participativa, investigación acción, cuestiones morales, recopilación de datos, dimensión social de las actividades de investigación.

1.   Introduction

At present, there is a general move toward participatory approaches involving service users and in particular older people, in evaluating and improving service delivery, for example „patient and public involvement in research" (Baldwin et al., 2018) or „participatory design in gerotechnology" (Grigorovich et al., 2021, p. 6), „addressing the needs and preferences of older adults in the development of technologies for their use". Participatory video design (Von Faber et al., 2020) is involving older people in defining the age-friendliness of their neig-

hborhood. Visual participatory research (Quinton et al., 2022) involves older people in research using visual materials: videos, Internet-based images etc. The term „participatory research" refers to a broad research area including: action research (Baur & Abma, 2012; Buffel, 2018; Dick & Greenwood, 2015; Glassman et al., 2013); participatory research (Martins Corrêa da Silva et al., 2018); participatory action research (Bendien et al., 2020; Blair & Minkler, 2009; Corrado et al., 2020); community-based participatory research (Cargo and Mercer, 2008; Dabelko-Schoeny et al., 2020; Hall & Tandon, 2017); „co-production" approaches in community-based research (Buffel, 2018). These are research approaches engaging older people and other community members as co-researchers and involving them in personal, social and institutional changes. The research explores problems that matter to them and their communities. In this research approach, older people are generally conceived as involved in all phases of the research, from selecting the research topic and conducting data collection, to data analysis and dissemination of results; but this is not always possible to implement in all parts.

1.1. Limitations in the involvement of older people in research

Many researchers (Baldwin et al., 2018; Cargo & Mercer, 2008; Corrado et al., 2020; Grigorovich et al., 2021) describe, in fact, limitations in older people's involvement in research. Buffel (2018) points out: „The most common forms of involvement are skewed toward a 'tokenistic approach' in which older people have little influence over the research process." For example, Corrado et al. (2020) point out in their review of literature of participatory action research (PAR) that older people are often not involved in shaping the research questions. Moreover, learning opportunities to familiarize with research skills are seldom offered to older people, according to the research projects examined by Corrado et al. (2020). They also acknowledge that researchers' priorities, such as the pressure to publish, could pose limits on older people's involvement. They highlight the need to critically consider older people's involvement: „It is important to critically reflect on how assumptions about older adults' capabilities, interests, and motivation may set boundaries on if and how academic researchers involve them in PAR research" (Corrado et al., 2020, p. 423). They encourage researchers to challenge ageist beliefs and consider how older people can meaningfully contribute to all phases of research.

Buffel's (2018) very useful article describes in detail procedures for the effective involvement of older people in research, in particular recruiting, training and data collection. The co-researchers selected are all older educated people, mostly with university degrees. Forster et al. (2021, 6) point out a similar limitation for their study: „Volunteers over-represent white, English-speaking retired professionals: none of our team were from ethnic minorities or spoke English as a second language." In fact, Buffel (2018, p. 59) expresses caution in this respect: „Seeking to democratize knowledge production and fostering opportunities for those involved, projects such as the one described nevertheless run the risk of creating a further divide between an already more „privileged" group of older people and their more disadvantaged peers". In relation to the analytical phase of the research, older people participated actively in the coding process. There were codes predetermined on the basis of the theoretical framework, but emerging codes were collectively discussed and decided. Older people also participated in