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

some publications: „The group also co-produced a brochure presenting key findings from the research." The academic articles were written by researchers.

Buffel's (2018) research project was a great experience for older people to be involved in. They learned a lot. But it also shows some limitations of participatory research, its patronizing side: Older people can participate, but only to a certain extent. Many authors point out the limited participation of older people in research, in particular in data collection and analysis (Baldwin et al., 2018; Blair & Minkler, 2009; Cargo & Mercer, 2008; Corrado et al., 2020; Grigorovich et al., 2021) How could it be different? Why should they be interested, unless older people are or become researchers themselves? Participatory research needs a different perspective from which to look at older people participating in research.

The aim of this article is to critically reflect on the risks, limits and opportunities of older people's involvement in participatory action research and to present a different perspective that can be relevant to social research in general. We start from considering the social dimension of research activities and their moral dimension. Then we elaborate on our perspective on participatory research, reflecting on the different orders of priority among older people and researchers. We will then discuss these issues on the basis of the relevant literature, providing various examples from our research practices.

1.2.   Moral awareness of the social dimension of research activities

Any kind of data collection in social sciences, such as interviewing, focus groups, observing ordinary activities and/or audio-video recording them, is achieved through actual social interaction among researchers and participants in social encounters, within the setting studied. Issues of face (Goffman, 1967), practical management of sense making (Heritage & Watson 1980), appropriateness (Nikander, 2000), politeness (Hutchby, 2008), to name but a few, are necessarily implied in such interactions, as well as identity construction issues (Antaki & Widdicombe, 1998; Paoletti, 1998) and moral issues (Jayyusi, 1984); above all, research relationship „demand[s] emotional engagement and ethical responsibility"(Sasser, 2014, p. 6), as with any other human encounter. The social dimension of research activities furthermore implies unavoidable effects on the settings and the people studied. An example is provided by the observer paradox described by Labov (1972, p. 209): „The aim of linguistic research in the community must be to find out how people talk when they are not being systematically observed; yet we can only obtain these data by systematic observation." The objective of the sociolinguistic research was describing daily vernacular, but Labov noticed that informants were likely to adopt a formal register when they were interviewed. If we consider the social dimension of interviews, they can usually be described as encounters between strangers (Gallagher, 2016), therefore a formal register may generally appear appropriate. Research interviews have also characteristics that are present in institutional talk. More recently in the ethnomethodological tradition, Speer and Hutchby (2003) conceptualize social research activities as part of the setting studied. Research activities have an influence on research participants, and they contribute to producing an image of the social setting studied.

Action research (Blair and Minkler, 2009) and in general, participatory research (Bendien et al., 2020) are approaches using the unavoidably transformative character of social research. The research process may become the instrument of participants' personal development and

empowerment, community transformation and enactment of changes. In fact, participatory research could be an approach helping researchers to manage the effects of research activities on research participants and the setting, making sure they are mainly positive effects. But a different perspective is needed to conceptualize the relationship among older people and researchers, that is, to acknowledge their different orders of priority and concern.

1.3.   Researchers' and older people's different orders of relevance

Researchers are pressured by their institutions to publish. In order to publish they need to do massive amounts of reading; moreover, they are generally interested in theoretical problems that are outside the scope and interest of the general public. Such problems are mostly relevant only to researchers, but theoretical aspects of research are also those that can at times produce the more useful outcomes in practical terms (McCain, 2016). Corrado et al. (2020, p. 423) mentioned the pressure of rapid publication of results most researchers are confronted with and the consequent lack of time that hinders the actual involvement of older people.

The pressure to publish makes it difficult for academic researchers to integrate the time and processes required to ensure that the research priorities chosen matter to the community, to involve older adults throughout the various research phases, and to involve older adults when implementing the findings in a way that encourages tangible change in the community.

Baldwin et al. (2018, p. 806) point out the lack of research skills of co-researchers, while Blair and Minkler (2009, p. 653) highlight the limited participation of older people in data collection and analysis. At times carers and not older people are involved in participatory research (Klaassens & Meijering, 2015).

Bendien et al. (2020) describe the difficulties in involving older people in the actual analysis of data: „data analysis, specifically content analysis, turned out to be too theoretical for the co-researchers, who preferred to concentrate on more practical matters." Could there be real involvement of older people in this aspect of research? Would older people be interested in theoretical aspects of research and massive reading? Why should they? Do researchers have to give up their theoretical interests? They certainly cannot give up publishing.

An illustration can outline a different perspective on participatory research and the relation among older people's and researchers' different orders of relevance:

Figure 1. Order of relevance perceived by older people and researchers: an overview of similarities and differences in relation to participatory research.

Older people's order of relevance.   Researchers' order of relevance
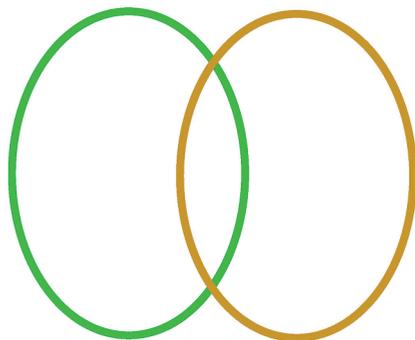
The intersection: Participatory research

Source: authors' own work

The intersection between older people's and researchers' orders of relevance is the space for participatory research. The position of the two ovals can vary; they could almost correspond, but they will not coincide, that is, the forms taken by participatory research are multifold, but should not have the claim of total identification, or role switching. Cooperation between older people and researchers should be between human beings that deserve the same respect for their life experiences and purpose and with the determination to find common ground. You can then do participatory research with the homeless, to name among the least privileged older people. It is a matter of finding the space for actual shared interests, and space in research for older people's orders of priority, maintaining our order of relevance as researchers. We can find ways to involve older people in actual research activities, but, as researchers, we can also use some of the research activities to make space for older people's aims and purposes; the social changes initiated in the process could continue after the end of the research, as reported, for example, by Blair and Minkler (2009, p. 658), that is, community initiatives which grew out of the initial research.

For example, Buffel's research actually involved older people in practically all phases of research. But she acknowledges that she could only have privileged older people as co-researchers and, in the analysis and publication their contribution was minimal. It is not a criticism of Buffel's work; it could not have been different. It is a criticism of a perspective on participatory research in which researchers are doomed to be wrong. In most cases, older people's participation can only be limited. As social researchers, if we acknowledge that we cannot avoid having influence on the people and the settings we decide to study, we can start to make space for participants' interests, aims, questions, preoccupations and so on, respecting older people as human beings who have the same values as any researcher. It thus becomes a matter of moral responsibility for researchers to embrace it. Participatory research becomes a form that this moral sensitivity can take, and participatory research could then take many forms. The focus would still be on participant involvement and empowering, and the pro-

motion of social and institutional change, but also acknowledging the different orders of priority and concern between older people and researchers.

The article is aimed at describing a theoretical approach to participatory research that can combine the different orders of relevance between participants and researchers, maintaining moral awareness of research participants' well-being, integrity and safety in relation to a research activity. What should a researcher do when confronted with the research participant's suffering triggered by research questions? Who decides the topic of research in participatory research? Can we make space in research activities for actual research on participants' needs and interests? These are some of the questions we will address in the article. In the following section, we will illustrate in detail various experiences of involvement of participants in research that takes into account the social dimension of research activities and their moral dimension, starting from ongoing research conducted in Sweden.

2.   Moral issues in action research with older people

2.1.   Example 1. Sweden: The Media project: soliciting sad memories

Working with interviews and readings of older people's media environment in their homes we[1] aimed at creating co-produced content based on remembering, oral histories and selected objects in the home to be able to use these as meaningful selections for people's own use, for their relatives and/or staff at the care home where the study was conducted (Economou & Cedersund, 2020). Its main (moral) issue would thus be to designate a role of storyteller, one of agency and value as the „owner" and „producer" of content for participants; and further-more, to make this content available to others, in their home but also, potentially for a larger audience at an exhibition.

In this project we aimed to talk about memories of media, both public media like the cinema, or family produced, like photo-albums. We wanted both to analyze older persons media and cultural environments but also to use their stories as examples of personal de-scriptions that could be important for relatives and care staff, as well as in the public exhibition we created from this content. This view is inspired by studies in communication and re-membering seen as situated memory work that takes place in the present, rather than as triggering cognitive storage (see Middleton & Brown, 2005). Thus we wanted to construct the participants as active co-creators alongside us: also from a theoretical perspective on the position of the storyteller as valuable agent for knowledge, rather than the passive recipient of media (or of care for that matter); investing in this notional theoretical point that the role of producer of knowledge, stories and remembering is a role that can return agency and recognition in later life where the common-sense notions are the opposite; of loss of capacity and importance.

In this project we have worked within a frame of wanting to formulate an „invitation" to create, to co-produce content of remembering for our participants. This can be seen as an invitation for older persons to „give", to tell us researchers something they themselves em-body, or own, but that we do not. Thus, an important storyteller position is created as one of a

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1   „We" in Example 1 refers to two of the authors of the present article (Economou and Cedersund) who conducted the study described in the first example (Economou & Cedersund, 2020).

knowledgeable person, possessing agency to tell and to select what is worthy of telling, as expert in their own story while the researchers take on the role of listeners. The interviews have been thought of as conversations facilitating the sharing of selected, relevant and viable content, rather than being centered on reports of people's living or medical conditions, feelings or current situation. Not only do we aspire to see participants as active, we also claim that our relationship develops into a co-productive relationship in that we not only aim at „extracting" facts or data, but jointly become involved in a social process of creating content that we want to share with a larger audience, in this case a collection of older persons' stories and an exhibition at the community leisure center which we were curating. Of course, the somewhat idealistic notion behind this is one of equality or taking the informant seriously as someone who could actually take the position of co-producer, or who would even actually want to do so at all. In this sense we adhere to an idea of creating an arena of participation in which older people are the providers of knowledge directed toward other listeners or spectators. This, we hope, gives older persons a turned around position of „owners" or experts of what is told *by* them, not *about* them. This perspective is in line with participatory research as presented by Buffel (2018, p 52), who discusses co-research that is „conducted *'with'* or *'by'* older adults rather than *'to'*, *'about'* or *'for'* them as research subjects".

In excerpt 1.1 below, our: the researchers' –,various concerns might be converging, or maybe the will to include more concerns might create a problem. Why would the participant (who is an informant, but also a giver of content, also a „host" to inquisitive researcher/ producers, and, as well, a co-producer) consent, adhere, or even recognize these different possible roles? Does co-production give rise to a more difficult problem of „simultaneity" despite the goodwill of equality and empowerment?

In the excerpt[2] that was taken from one of our interviews (or maybe we should call it a conversation) to investigate possible common content for research and public display, the conversation with Agnes, an informant/co-producer, a woman in her 90 s becomes divided into several topics. It starts with the focus on media as a storage medium and a family technology that could be reflected upon, to the actual remembering of the situation of watching photos and what this act can give rise to:

Excerpt 1
From a conversation between *researcher Q* and *Mrs. Agnes*, 92 years old, who is visiting a local meeting point for older persons which is taking part in our project.
Researcher Q: … did you have photos as well? Photographs?
Agnes (A): Yees.
Q: With Instamatic, or? Something other, like instant photos you get directly … in your hand?
A: No, I don't know if we have any …
Q: they are developed then
… had ordinary cameras, but you know, these old, old kind of photo albums!
A: Yes.
A: Yes!
Q: Do you ever look in them?

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2   The original transcripts are in Swedish; see Moerman (1988) and Nikander (2008) for the complex issues involved in using translated transcripts.

A: Yes sometimes … when the grandkids were smaller … it was their favorite, the best they knew … that we should look in them … but I have, we have them recorded, or put into the computer, but that's the more older ones … but I can't watch them.
Q: …they have taken pictures?
A: I can't, I can't.
Q: Ehh, why not?
A: I cry.
Q: Why is that?
A: Well, our cottage, our beautiful cottage, and we had all the beautiful flowers and all that … and I haven't been out to our cottage … it was sold immediately when my husband died, and I said; thank God he didn't have to see that …
Q: And you feel emotional?
A: Yes emotional, I can't make it … I can't take it.
Q: Yes and we have to respect that …
A: It's so difficult for me … we said we should drive out there (to the cottage) to see, what it looks like now, see if they've ruined much … but I don't know I can make it.

In the excerpt above, the conversation starts with the topic of media storage and what might be kept in her possession, and of general media knowledge and use, something we as researchers were interested in as both ethnographic data, and as possible content for our project′s production, and the researchers become more involved in asking about the media. The question about using the photo albums though: *Do you ever look in them?* becomes geared toward the social and situated interaction of showing photos to the grandchildren: centering more on the frame of „showing to" others something of importance to oneself, making her the owner and purveyor of content. However, instead of continuing a more technical issue of media use, or the family viewing situation, the topic then becomes embedded in the feeling of loss of the actual depicted phenomenon that the photos trigger. The loss of the summer cottage that old age forced her family to sell.

The researcher's notion of giving voice to: and „looking for meaningful stories" (showing the grandchildren, formulating Swedish history of the early holidays, the possibility of acquiring a small holiday cottage, a modernist dream for the ordinary working class that this story contained) becomes overtaken by the strong personal feeling the conversation has triggered.

Our point here would be to reflect on the awareness of the researchers purporting to work with the participant and offer inclusion and co-production: a moral awareness of how the older person shifts, in this short example, between three different concerns. First, how is remembering accessed in various media, where are they kept and „stored". Second, how do they become situated and given use, as in the interest of the grandchildren, but third, what emotions can the content of the medium actually evoke? In studies of the use of family photographs, Marianne Hirsch (1997) has extensively discussed the use of images as memory work, formulating the term of „post-memory" to delineate the dilemmas of remembering difficult and painful events and feelings; situating them in a present, of oneself as well as others, be they relatives of different generations, or in our case, working with old people′s stories to possibly create media and exhibition content with public address. A moral dilemma that can be deduced from this example then becomes that our „offer" of co-production, authorship and agency in our research and the media production process can result in remembering, leading

up to a feeling of loss and of the impossibility of making good: the cottage is not available anymore. Also, we have triggered this feeling in a situation we would want to be empowering, but have got a result of remembering that our co-producer/informant already had a strategy of avoidance: by having chosen to avoid watching the photos in the first place.

So, showing the importance of a sensitivity that extends beyond merely one concern: as in a more clear-cut relationship between researcher and informant, our project has made us realize that co-production is more complex than idealistic. We need to take into account more sensibility of what we „offer" when we set up collaborative situations with older persons, as well as what we want to get out of it. In the next instance a very dramatic example of the suffering that an interview may trigger will be presented in relation to a project on older workers conducted in Italy.

2.2.   Example 2. Italy: The older workers' project: Deciding to stop data collection because of the suffering of interviewees

The older workers assignment was an action research project (Paoletti, 2008) aimed at raising public awareness of the condition of unemployed people 40 plus. It was conducted in 2008 at the Social Research and Intervention Centre in Perugia, Italy, in collaboration with older workers' association ATDAL (a national grass-roots organization for the protection of older workers) and the Older Women Network Europe. The action project was aimed at rising public awareness on the condition of older unemployed people. Data collection initially comprised conducting audio recorded semi-structured in-depth interviews with unemployed 40 plus, unemployed grass roots organizations' leaders and union representatives.

Personal sufferance

When studying the issue of unemployment in middle age and age discrimination at work, the suffering that these conditions imply, becomes immediately evident (Harris et al., 2018). It is not just a matter of financial problems that in many cases are dramatic, but the personal suffering is stunning. Older unemployed people, who lost their jobs in delocalization and restructuring processes, are victims, but they are the ones feeling ashamed and guilty. Isolation (Rözer et al., 2020) is the direct consequence of this type of feeling, but also depression (Whooley et al., 2002), drugs (Azagba et al., 2021), alcohol abuse (Popovici and French, 2013) and suicide (Cunningham et al., 2021).

While carrying out the interviews, the perception of suffering was evident even in people who were very reactive and capable of dealing with the situation and who managed to find a job after a while. Dario is one of them; he had lost his job because the small firm in which he was working closed. Describing his situation he says[3]:

Excerpt 2

At a psychological level it is not easy, you always really feel a failure with all the people who are around you, a shit, at a certain point even rationalizing everything, you also start saying to yourself „it is impossible that I was unable to come out of this situation", then you doubt about yourself, even if you can give yourself all possible reassurances and rationalizations.

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3   The original transcripts are in Italian.

Dario appears able to reassure himself, to rationalize, but to a certain extent and at certain times he cannot avoid doubting himself. In all the data collected, the expression of suffering was very often present, in fact, in many cases the personal impact of unemployment was quite severe. Lucio, for example, arrived at a point where he had to find professional help to overcome depression because of being unemployed:

Excerpt 3

I felt guilty with myself, and I doubted my ability in everything. In my family I thought that my children and my wife believed I was a failure. I didn't speak about it with anybody, I would act in such a way that nobody knew of the situation apart from my family. My ex-colleagues did not exist.

Many times I thought about disappearing, running away from home, leaving no trace behind, at times about killing myself. To overcome these moments … I started psychoanalysis.

Secrecy, self-imposed isolation and depression are very frequent among older unemployed workers and have an effect also at a political level. The president of ATDAL declared that it was very difficult to organize a rally or political activities; not many in the association were prepared to make themselves visible as unemployed; he used the expression: „to show their face".

After a few interviews it was decided to stop interviewing older workers because of the acute suffering that questions about unemployment had been triggering in interviewees. The project was modified. Awareness of the social dimension of research activities and their impact on research participants goes beyond ethical procedures (Paoletti et al., 2013; Paoletti, 2013). It is a matter of moral responsibility and ethical sensitivity in carrying out one's own work, taking decisions accordingly. The need to protect participants during data collection cannot often be foreseen at the ethics review phase; ethical problems can arise unexpectedly during data collection or at any other research phase (Sabar & Naama Sabar Ben-Yehoshua, 2017). Ethical problems are „difficult to predict" as Swauger (2011) points out. Researchers cannot be spared from taking moral decisions: „The craft of field research rests, first, in keeping oneself open to these vital contingencies and, second, in responding to them skillfully with innovative methodological and ethical solutions" (Liberman, 1999, p. 62). Similar attention is necessary to detect and include participants' interests, priorities and concerns in participatory research. In the next section some examples of participatory research conducted in Sweden and in Portugal illustrate the issue of recognizing different orders of priority between service researchers and participants, but also between professionals and service users in participatory approaches to service delivery priorities.

3. Priority issues in participatory research with older people

3.1. Example 3. Sweden: The power imbalance and the different orders of priority between service users and professionals

Participatory approaches are not only widespread in research, but also in service provision (Cowdell et al., 2020). Service users are at times encouraged to become active participants in services provision. This third example is focused on participatory service provision carried out in Sweden (Kvarnström, Hedberg & Cedersund, 2012). This example draws a parallel among these two dimensions of participatory approach: research and service implementation. It illustrates the difficulties involved in participatory approaches to service provision. In particular it tries to explore the power imbalance between professionals and service users. A similar power imbalance may also exist between research participants and researchers.

The referenced study is focused on how professionals perceive the concept of user participation. In this case too, awareness of different orders of relevance among professionals and service users could be useful: users' needs and preferences in relation to the service; professional awareness of the institutional dimension of the service, that is, the limits in relation to cost, personnel availability, time frame, etc. of delivery of the service. Negotiation among professionals and service users could be effective, clearly acknowledging these different orders of priority.

This study has provided in-depth knowledge of how professionals approach and reflect on the phenomenon of user participation. These ways to think and act may also have an impact on how professionals understand and develop their view of users' participation in different care situations. Professionals develop a way of understanding users and their view of participation; it may imply that in their professional activities they can meet the wishes and expectations of users in a more developed way. But it can also include control of what users can request in the meeting with professionals.

Some quotes from the interviews are given below in order to illustrate variation in the descriptive categories, and the dimensions found in data. For example, some professionals perceive participation as self-determination and freedom of choice, highlighting the meaning perceived as a *right to self-determination:* „the rights of service users to decline the offered service (…) the right to turn down activities and interventions" (Kvarnström, Hedberg &Cedersund,. 2012, p. 296). Personal responsibility through insight was stressed by some professionals who put an emphasis on the service user's *insight and change:* „Through the relationship with professionals, service users reflect, learn, and develop insight and understanding" (Kvarnström, Hedberg & Cedersund,. 2012, p. 299). The interprofessional dimension of user participation was perceived by some professionals as the user's increased opportunities for involvement. It could also make it easier for the user to understand what was going on and to absorb guidance provided by a group of many different professionals.

Results from the study (Example 3) show that recipients' responses contain dimensions that also indicate that perceptions of participation among users are associated with different orders of relevance (Figure 1). Effective negotiation can be carried out if these different priorities among professionals and service users are perceived and acknowledged, in particular by the group that holds more power: professionals. At times they may decide that some service users' needs and preferences must come first, despite institutional limits.

In the following paragraph, a study from Portugal will illustrate further the concept of balancing different orders of priority. In this case the researcher makes space for research participants' order of relevance in organizing the final workshop of the research project.

3.2. Example 4. Portugal: The APSE Project: Making a space for participants' interests

The APSE project (2009–14) (Paoletti, 2014; 2017; Paoletti & Gomes, 2014; Paoletti & Gonzalves, 2017) involved an interdisciplinary team of researchers, professionals and older people in documenting innovative social services contributing to paths out of poverty and social exclusion for the aging population in Lisbon. The project was designed to identify effective intervention for older people, in particular, services promoting their active role in the community and full participation in social life. Many activities aimed at the social inclusion of older people in Lisbon were based on the consideration of poverty not only as lack of resources, but also as a lack of access[4] (Paoletti, 2014). With practically no financial support, incredible creativity and the ability to –mobilize a vast network of institutional agencies: not only health and social services, but museums, theaters, cinemas, libraries, universities and grass roots organizations, these professionals and activists managed very effectively to include older people, and particularly older women, as protagonists in a variety of cultural events (conferences, performances, tourist tours, etc.), gaining access to prestigious sites in Lisbon (Paoletti, 2014).

Friendship and gratitude toward these professionals were very natural, having included the research group for over three years. The desire to give them something back was sincere, something relevant to them as practitioners (see Gupta and Kelly, 2014; Sasser, 2014). producing an event that professionals could find useful in relation to their specific order of relevance. Toward the end of the project in 2013, a workshop was organized for professionals: „Inter-institutional intervention with older people: communication practices and intervention with older people living with dementia", with the same spirit: with no financial support, creativity and networking. The professionals had identified dementia as the topic, one of the most difficult areas of intervention.

A colleague from Scotland, an expert in dementia, accepted an invitation to come as speaker and discussant at her own organization's expense. Calouste Gulbenkian Foundation paid for the interpreting services and offered to host the workshop in their premises, one of the most prestigious cultural sites in Lisbon. At the workshop, various groups of professionals from different districts in Lisbon presented their experiences of intervention with older people living with dementia. Then the expert in dementia started her presentation and commented on their experiences. The workshop helped the professional and their organization to gain visibility, moreover it was a useful occasion for reflection and critical appraisal of their work. The seminar was a relevant part of the research outcomes of the APSE project. In this case the research order of priority, focusing the seminar on research results, had made space for participants' order of priority: presenting to the public their valuable working experiences and learning about dementia from a researcher working at close contact with professionals.

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4   „The meaning of inclusion for these professionals is accessibility, that is, granting access not only to basic means of subsistence, but to culture, leisure and political participation" (Paoletti, 2014).

The main point here is that during the research process we can make genuine space for participants' interests; and within the limits of our expertise and resources, we can produce actions that may be beneficial for our participants.

4. Discussion

4.1. Ethical dilemmas

As described in this article, ethical dilemmas might be more difficult to recognize, and more complexly reflected in the micro-interactions of interviews and encounters than in the preordained statements and agreements signed and established within our ethical guidelines in academia. The concerns of researchers when consent to participate is needed could be directed toward ascertaining that people are comfortable with their presence at the interview, establishing this more intimate relationship, and in the room where we meet. Rarely would we claim to see the informant as co-author though, at least in traditional research. What then with our intersecting in, and claims of transcending, these roles? We argue that a more subtle sensibility needs to be developed as we extend the role of informant to become a co-participant in ways we would ideally want. Sensibilities for ethical dilemmas enable us and force us to act as participants in the actual meeting of persons, regardless of our roles as designated „co-producers" or owners. In these meetings we have seen something emerge that makes us halt and pause; to be able to stop the interview, to reframe the conversation to better understand that a seemingly innocent question has triggered a deep feeling of loss, or of shame: sometimes openly expressed by people in spite of it not being a preferred topic in the conversation, sometimes not so openly expressed but felt as unease or maybe as having triggered an imbalance in the interaction which breaks up the (notion of) equality of the relationship. This sensibility on the part of the researcher is what we argue is an important key in being able to retain and develop a co-producing relationship: to be able to let go of our second concern of obtaining material for research and act on our first: to retain a relationship with participants, and be prepared to listen and understand their point of view.

4.2. Co-production and later life

Maybe the notion of co-production can be more important in the study of later life: the prevalent societal outside view of older persons as vulnerable can help us develop a counter position of them as knowledgeable actors with ability to take on the role of co-creators or producers just by establishing this as a viable joint concern. In the Swedish media project (Example 1) we cast the participants in the role of storytellers: i.e., the ones who are in the know, and have the ability to tell others, a role that counters the one of just being the recipient, and furthermore frames the individual as someone who is important as a giver, or „publisher" of content, but with what knowledge or willingness from them to take that role? But what we attempted in the media project (Example 1) is to see together the material we produce as content that would be of interest to others in order to produce an exhibition[5] for older people

5 The exhibition took place in March 2020 in Norrköping, Sweden.

themselves, their relatives, carers or even a general public. That arguably turns the position from repository of data to producer of noteworthy stories of more general importance. By combining research questions and analysis with older persons' own stories as „telling something about" the world, the times, the issues that they choose to remember, they become active owners of knowledge, perspective and formulation as well as addressors, or broadcasters of that content. The difference, simply put, is that they are telling us something important that they know of and we do not, rather than being told something about themselves produced by us. But, again, a co-producer's relationship that could achieve this role-shift must be based both on sensibility and sensitivity toward the participants, and be aware that the researchers' purpose or concerns might not coincide with those of older participants. As researchers we might be forward looking toward the contribution to new scientific knowledge (or the meritocracy of publishing) and participants might be looking back at their experiences and contributing to the larger story of life for their generation. Our method of co-production becomes sensitive to, and able to see data not only as signs from „experiences" or memories, but rather as possible communicative events of relevance not only to persons themselves and their immediate surroundings, but moreover as „signs" and statements of their generational common narratives, and as such important in a public discourse. Also, in this larger sense our fieldwork method invites participants to a more important „producer" role of representing their generation, time and place.

In the Italian unemployment project (Example 2) the role for interviewees becomes the role of embodying loss of a different kind: of self-value that has suffered and of self-doubt that has ensued, but the interview puts them in a position of representing not only their personal loss but also the larger issue of unemployment as a societal outcome, and so encompassing both the individual's story as well as the structural issue. The participants had not asked for it, and the prize of trying to elicit political change is for them to agree to be broadcast as victims. Thus, the decision to stop the interview becomes an action of mercy, necessary for preserving moral responsibility toward participants. As Hand et al. (2019, p. 518) point out: „There is a need to build flexibility into initial project objectives and design to enable the project to evolve and new questions to form beyond the bounded project." This move, even if it means stopping the data gathering, might be a relevant consideration in research. Importantly, we should develop a sensitivity in participatory research, which could include the possibility of stopping or shutting down the interaction when we discover that participants' reactions might be negative or damaging. This sensitivity needs to be part of the methodology, not only because negative feelings or experiences might be triggered in interactions with participants, but also because they might be part of the research issues themselves.

4.3.   Participants' interests and concerns

It is possible to make space in the actual conduct of the research and among the research activities for the participants' interests and concerns in relation to social and institutional transformation. This is probably the gist of participatory research. In the fourth example, the Portuguese project, a public event that could have been used by researchers for presenting the research outcomes, is transformed into both a training opportunity in relation to dementia for the professionals, and into a showroom for the professionals' presentation to the public of their excellent inclusive initiatives toward older people. This workshop was not just a public event,

it was included in the official research outcomes of the project. As in the Swedish project, research participants were offered an opportunity to tell their own story.

So, it is important to assess the order of relevance between participants and researchers (see Figure 1) which could foster a proper and better participatory interaction and relationship, including as a theoretical as well as methodological tool. It is important to realize the importance of having space between the circles that can contract or expand both in how the research projects, and the roles between the researcher and participant are defined in the research design. This is as well as in the actual micro interactions that take place, for example in the course of interviews. Furthermore, one could perhaps say that the lines of the circles themselves can sometimes be blurred in the center, or intersected by factors that were not considered beforehand: as in Example 1 with the photo album that triggered sadness and loss, or the unemployment theme that triggered feelings of low self-esteem and identity loss. These can be dealt with by developing precisely the sensitivity that we want to emphasize: to see the other in what s/he expresses with caution and consideration can be built into our methodologies: and could be employed by listening carefully to what people have to say – and adjusting accordingly.

5.   Conclusion

In this article we focus on some moral and methodological issues in relation to participatory research with older people. As practitioners of action research, we have been reflecting and theorizing about our specific field experiences, highlighting inconsistencies, incongruities, contingencies of our field work and proposing theoretical reflections for their understanding and management.

Focusing on the social dimension of data collection research activities, we pointed out the importance of researchers' moral alertness at all phases of the research. Negative emotional reaction may occur during data collection, as was illustrated in both the first Swedish example and in Example 2, the Italian project with older unemployed. In both cases research questioning was causing pain to the interviewees. As a researcher, listening to your own emotional reactions can be important, for example, when interviewing older unemployed persons, the noticeable pain expressed by interviewees caused pain and uneasiness also to the interviewer. When participants have these negative reactions, researchers too may be affected. In the first Swedish example, with the photo album and pictures of the lost summer cottage, we realized that we nearly missed the older person's reaction due to our focus on her media use rather than the memory and emotion it gave rise to. This not only gave us the feeling of having instigated an awkward moment in an otherwise friendly and informative conversation, risking re-framing the situation of the interview, but also of a feeling of shame that has partly remained. We could not assess the possible pain in remembering loss in an important life event, and we did not foresee it but of course, the lingering feeling of uneasiness made us rethink the situation and learn from it. These insights may signal relevant ethical issues that have to be dealt with, and at times research has to be revised and changed (Hand et al. 2019). Particular attention should be given to older people participating in research. In our experiences as researchers, we very often noticed a spontaneous willingness to contribute to research

among older people. You need to be especially observant, that is, close attention should be taken toward older people, verifying that they are really intending to participate, and that participation has no negative effects for them. In fact, in this article, we pointed out that participation is not always positive; it can also have some negative aspects and consequences.

Participatory action research for older people and participatory approaches to service delivery are more fairly managed when keeping in mind the differing orders of priority between researchers and participants. According to Example 3, the Swedish study on participatory approaches in service delivery, users' self-determination and freedom of choice is contrasted with the need to acknowledge the institutional limits in service provision. Participants' priorities and concerns should be identified and acknowledged. After this, fair negotiation could begin. In some cases, genuine space could be made to research participants' interests and concerns, as was exemplified in Example 4, the Portuguese project, in particular it illustrates how both researchers and professionals can be morally alert and fair in their respective activities.

Our intention is that through this article we can point to the richness and social potential of contemporary action research (Gunnarsson et al., 2016) in that this research approach may been shown to contain the possibility of renewal both of society's welfare institutions and in working life in general. Through our analyzes of the four examples that formed the basis of the empirical parts of this article, we have the intention to make use of the development that has taken place within action research during the past decade, as well as the development of a democratic society that is at the center of this research approach. Our article highlights not only the strength of participatory approaches in research and service delivery but also some of their negative aspects, and how these may be overcome. Above all this article aims to open up a debate on various aspects of action research that are often left in the background, in particular the relation between researchers and research participants. Keeping a reflective attitude towards our field research practices should become a constant preoccupation, a working style, a topic of theoretical reflection. This sensibility towards participants in the field, their needs, wishes, feelings can contribute not only to action research development, but to the improvement of field research in general.

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