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Special Issue on participatory research with older people with a mental health condition and/or dementia: tensions and challenges.

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This special edition is a snapshot of current methodological and theoretical debates in our thinking and ‘doing’ of participatory research and their pivotal influence on research that involves older people with lived experience of a mental health condition, and/or dementia. Given that the International Journal of Geriatric Psychiatry has a broad audience, including health and social care professionals - psychiatrists, psychologists, social scientists, nurses, and other therapists - and neurobiological researchers, we want to present these debates through the examples of international practices and findings. Our aim in compiling this special issue is to guide and inspire the use of participatory research within applied health and social science research with older people, giving voice to what is meaningful to those with lived experience of mental health problems in later life, and challenging dominant power structures that exist within psychogeriatric research and practice. Reflecting on the edition we hope that we illustrate a breadth of topics and findings in relation to participatory work, and some of the current tensions in undertaking this kind of research.

The articles gathered in this edition reflect a range of up-to-date debates about our use of participatory research and, we consider, capture a key point in an ongoing paradigm shift, and an opportunity to reflect on how we can continue to work effectively within this shift to produce innovative and useful research.

Historically, people with lived experience of a mental health condition, and/or dementia have been marginalised and excluded from research and debates about their lives. However, in the last few decades, this has begun to change in many parts of the world, partly due to an increasing emphasis in policy on public involvement in research, but also, and perhaps more critically, due to the activism and self-advocacy of people with lived experience. In the UK, Heather and Ruth have both been involved in this socio-political shift in relatively instrumental ways - Heather met James McKillop in 1999, and together they established the Scottish Dementia Working Group (Weaks et al., 2012; Hare, 2020), and Ruth first investigated and documented the rise of dementia activism (Bartlett, 2014). This work and the actions of people with dementia have been embedded in a critical disability studies perspective, at the heart of which is the mantra - ‘nothing about us without us’. It has paved the way for the participatory research we see today.

Most researchers working in applied dementia research are on a quest to enable people with dementia to participate in their research. Researchers are keen to use research techniques and adopt approaches that are enabling (rather than disabling). This quest is fuelling the exploration of methods, challenging our ethics, pushing boundaries around the research process including analysis and impact, and more recently, amplifying the position of the person with lived experience into the coresearcher role. All this has been concurrent with a development and repositioning of participatory research methods that sit within the wider methodological debates around lived experience research in mental health and other fields (Gupta et al., 2023).
This has ridden the wave of change in research funding – so while dementia research funding is still comparatively low in some countries, there has been a shift in the understanding of research funders as to the research agenda, the refocusing on social research and with this, the willingness to fund work that focuses on experience. Indeed, the latest ‘blueprint’ for dementia researchers across the world, includes a call for the empowerment and engagement of people with lived experience in research (World Health, 2022). The framework is a welcome one for individual scholars, who inevitably draw on their disciplinary background and methodological preferences when it comes to designing and carrying out research studies.

Ruth’s first piece of funded research on the rise of dementia activism, drew on her knowledge of, and academic background in cultural politics. These are the power plays that happen in society, away from the traditional seats of power like Westminster or Holyrood. In the early 2000s, when Ruth was a lecturer at Bradford Dementia Group, she could see the cultural politics of dementia in the UK and other parts of the world. Individuals like James McKillop in Scotland, and Christine Bryden in Australia, were speaking out about the injustices they faced, and joining forces with other people with dementia to form action groups like the SDWG and Dementia Alliance International (McKillop, 2001). Ruth adopted a participatory approach, involving a modified diary method to enable the inclusion of people with dementia (who were campaigning for social change) in her project (Bartlett, 2012). Similarly, others are choosing to use methods more enabling than a traditional sit-down interview to elicit the voice and perspectives of people with dementia, like we see in this special issue.

Vanessa’s journey in older adult’s research began with a grounded theory study of the lived experience of people with dementia and carers from minority ethnic groups (Lawrence et al., 2008; Lawrence et al., 2011). This work took an inductive approach that sought to prioritise the perspective of the individual and family affected, yet, looking back, one wonders how this work would have been enriched by the closer involvement of those living with the condition in the design and conduct of this work. Vanessa’s research has since extended into other areas of mental health where participatory research has deeper roots. Grounded in the survivor /user activism of the 1970’s, survivor research has fought for equal rights, dignity and self-determination of those with mental health problems, and against a reductive reading of their experiences and distress (Faulkner, 2017). The power of participatory values and practices for reducing the power imbalance between the researcher and the researched, and for challenging existing mental health knowledge, is evident across adult and older adult research. Within this special issue we also see the huge practical advantages of using experiential knowledge as an instrument to direct research, ask meaningful questions, make sense of what is said and generate impactful outcomes.

We are now almost 25-years since the momentum for this work was started so it seems timely to highlight work that illustrates the development of participatory methods in the field of mental health and dementia, and the tensions that these ways of working raise as challenges in our field.

The call and outcomes

This current special edition builds specifically on a recent Editorial in the IJGP, on the role of qualitative research for understanding and improving mental health in later life (Lawrence et al., 2022). In that editorial, Lawrence, Samsi and Keady (2022) outlined their hope ‘to see more research with older co-researchers from these marginalised groups, and to see wider engagement with the ethical and practical challenges that this work poses’ (p2). Taking this to the next step, we invited a specific focus on high-quality participatory research that has engaged older people and/or their supporters in the research process, incorporating their voices as important partners in the
generation of knowledge. In response to the call, we received several manuscripts that offered qualitative methods but not participatory; this is indicative of the conflation of qualitative approaches with the specific intentions of participatory work. Additionally, even though the call for submissions included mental health, the majority of manuscript we received related to people with dementia. As such, there is one article from Nigeria that focuses on people with depression (which similarly gives voice to a marginalised group) among seven articles that focus on people living with dementia. While purely speculative, we felt this highlighted the positive move to greater inclusion of people with lived experience of dementia and a genuine exploration of methods to increase their participation. There is a notable dominance of work from Scotland, England and Canada reflecting the advances of this approach and the activism of people with lived experience in these countries. Despite these advances, participation in research still tends to be with people who are willing and able to engage verbally with speech – we remain hopeful that the power balance towards participation will continue to swing towards finding methods that allow people with varying degrees of impairment to take part.

In summary, this special edition offers a range of articles that capture the value of these, often challenging, participatory methods for generating new ideas and insights that can report on and inform innovative practice and care. In a move away from the randomised controlled trial (RCT), this kind of methodology and method offer different ways of thinking within the field of gerontology and geriatric psychiatry. More broadly, the research seeks to enable personal empowerment and contribute to social or organisational change. In curating the content for this edition, we noticed a theme throughout the articles and our discussions – that within this approach we have reached a ‘point of tension’ that requires critical discussion. This involves having the confidence to be critical of an approach that aims to challenge the dominant voices. Here, it is important to acknowledge the difficulty of conducting this work in the context of evidence-base medicine that continues to idealise the RCT, placing it at the top of the hierarchy of evidence with qualitative research, and experiential knowledge, at the bottom, despite growing acknowledgement that different research questions necessitate different methodologies. This has created a situation in which dominant research practices can perpetuate the power imbalances that exist in the clinical setting and reinforce the type of knowledge that is given the most status, authority, and funding (Russo, 2012). Like others, we believe that starting the process of enquiry from the explicit perspective of those who have traditionally been excluded from knowledge production promises to help challenge existing paradigms and create alternative knowledge (Faulkner, 2017). We also believe that it is vital for a full range of sources of knowledge to inform policy decisions. Reflecting on how qualitative research can promote its place in discussions around evidence and impact, Lester & Reilly (2015) highlight the importance of creating a space for constructive and diverse dialogue within applied qualitative research, which we hope to foster here (Lester & O’Reilly, 2015).

Overview of special edition:

We are excited to introduce a collection of insightful, eclectic, and thought-provoking contributions from authors located in six countries (Belgium, Canada, England, Netherlands, Nigeria, and Scotland) at multiple career stages and from within and outside of academia. These contributions introduce new contexts, ideas and possibilities for collaboration between academic researchers, practitioner and people with lived experience within the broad field of dementia.

This special issue is organised into three primary, albeit intersecting, themes: (1) the socio political context of dementia; (2) methods that challenge; (3) tensions in giving voice - a critical analysis of where we are currently. We begin by contextualising these themes, then describing the articles within these themes:
(1) Values - The socio-political context of participation

Our opening article by O’Connor et al provides a useful overview of the imperative to involve people with lived experience in research, and the role that Participatory Action Research (PAR) can play in making this happen. In providing this context, O’Connor et al also outline the need for our work to include theoretical sensitivity in applying the ideas behind this approach to more effectively actualize the ‘purpose, power, voice and agency’ of meaningfully involving people living with dementia in research. By placing this article first in the edition we set the tone of allowing us to engage critically with the ideas and methods in order to explore and reflect on ‘what it actually means to involve people with dementia in research’.

Also under the theme of socio-political context, and linking with our earlier challenging of moving beyond purely verbal means of participation, the work described by Collins et al, focuses on the ‘value of capturing and understanding movement as a vital means of communication for older people with dementia in a general hospital.’ By taking a mobilities lens, their narrative enquiry challenges our reliance on researcher led questioning and privileges the ‘voice’ of people with lived experience. This article also forefronts some of the ethical challenges in undertaking participatory work, specifically work that enables participation of people who do not fit into the traditional biomedically constructed ethical boundaries.

(2) Practice - Methods that challenge

Within this theme we include five articles that offer detailed examples of different kinds of methods and attempts to engage in participatory research. The first article (Campbell et al) uses home tour interviews, video and photographs to allow people to share their everyday lives in a way that creates insights into their home and community connections against a wider discourse of ageing in place. There is evidence that more creative approaches offer a more diverse level of participation and engagement.

The linked work described by Huizenga et al illustrates the importance of co-researchers moving beyond merely contributing to data but actually taking part in the analysis and interpretation of data.

The third article, by Ojagbemi et al, describes the how the involvement of older people using a participatory Theory of Change process in an area of Nigeria aimed to identify a pathway to impact for emhGAP-Age, an intervention to meet the specific needs of older people with depression.

In the fourth article, by Sokamoto et al, we see the challenges of a co-design approach to developing support technology, when most of the activities take place online. The authors offer practical recommendations on how to foster engagement in participatory activities for future health related design work.

Finally, an article focusing on asset-building community development by Phinney et al working across two regions in Canada, explores both the value and practice of participatory approaches. This work used interviews and focus groups to explore the practices within the community developments, highlighting relational patterns and the importance of participation in ‘Making Space at the Table.’

Central within the articles under the theme of ‘methods that challenge’ are the tensions around the nature of participation raising questions around who is participating at the moment? There is evidence of some diversity around method, yet challenges in the breadth of who we include. Much of the work is still language based, though with some examples of innovative practices focussing on movement and context that have facilitated inclusion (e.g., Collins). Furthermore, strategies for involvement remain more developed and focused on certain stages in the research process,
particularly indicating the need for further thinking on how best to include people with lived experience in the process of analysis. These tensions lead us into the third theme that frames our editorial:

(3) Tensions - A critical analysis of where we are

We included this theme partly based on our experience of reviewing of contributions for this edition that reinforced some of our wider practice experience. One contribution really made us think about the place of peer reviewed publishing in the process of considering participatory research. Given the context of the three themes above, we were keen to include work that wasn’t by a traditional research team. The contribution was submitted by a group that was primarily people with lived experience. However, the quality of the work and the account of the work was rejected at the peer review stage. This was a very live example of the tensions inherent in the values and practice of participatory research. It highlighted that the power imbalance inherent in the academic-lived experience research relationship can become confused. While it is important to amplify the voice of the persons with lived experience, there are also skills and expertise that form part of the research and publication process that remain within the remit and experience of the academic researcher. We spent a long time unpicking our position on this article – our values indicated that we wanted to push the boundaries of participatory research, including through the publication process; however, our research training and practices presupposed a certain quality/rigour/expectation around how knowledge is shared – so this is not about the knowledge production per se (which was collaborative and in this case held firmly by the people with lived experience) – it was more about knowledge presentation and dissemination. The article was not included and our concerns in relation to this tension remain unresolved.

The article included under this theme, by Warran et al, illustrates these tensions through a refocusing of the lens away from the people with lived experience and back onto the academic researchers in talking openly and critically about their experience of participatory methods. In an article co-written with people with lived experience, they pose critical questions and reflect on these checks and balances in an attempt to improve our ways of understanding and ‘doing’ participatory work that makes space for all expertise and experience.

We hope that this is a challenge that we have been able to address throughout this special edition.

CONCLUSION

There are questions to consider as participatory research develops in social and clinical research.

- How do we resolve these tensions?
- Does the nature of participation need to extend to include other forms of expression and communication?
- Does the nature of participation need to extend to include older people with depression, anxiety, and other mental health conditions?
- How do we avoid leaving no one behind? Some countries have policies in place to support public involvement in research, but not many. International context/International journal of geriatric psychiatry.
References


