

Editorial

Journal of Clinical Nursing

Published: 20th June 2019

<https://onlinelibrary.wiley.com/doi/full/10.1111/jocn.14957>

Equity of people with dementia in research, why does this issue remain?

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Research in dementia has moved beyond the question of how, why and should people with dementia be participants, to the question of how to collaborate with people with dementia in the development, design, implementation and dissemination of research in dementia. So, why are we still discussing the exclusion of people with dementia in research, and the need to develop human rights based frameworks to address issues of consent, capacity and inclusion?

Historically, people with dementia have been subjects rather than participants in research, often with the consent of a family member or a legal representative, due to the restrictive nature of informed consent applied by ethics committees. Restrictive practices were formed from a lack of understanding of dementia, such as the belief that people with dementia could not provide consent to participate. These misunderstandings excluded and prevented people with dementia from having their voices heard through participating in research, even research that directly affected them.

However, in the early 21st Century researchers and advocates began to challenge these practices and beliefs (Beattie et al. 2004; Whitfield and Wismer, 2006; Hellstrom et al. 2007), and explore alternative methods to obtain the consent necessary to allow participation in research (Dewing, 2007).

People with dementia have themselves challenged restrictive practices and a lack of understanding of dementia and have become their own advocates for equity in research. In 2014, a collaboration of people with dementia formed the Dementia Alliance International (DAI), with the aim to provide one unified voice of advocacy to fight for the autonomy of each individual with dementia, and the vision of 'nothing about us without us' (DAI 2019). Simultaneously in 2014, the Scottish Dementia Working Group Research Sub-Group, also a group with people with dementia, developed core principles for involving people with dementia in research, and challenged all researchers to re-consider how people with dementia are involved in research.

Models have also been produced to ensure meaningful inclusion of people with dementia in research, such as the CORTE guidelines, which include four main strategies for gaining consent (CO), maximizing responses (R), telling a story (T) and ending on a high (E) (Murphy et al. 2015). CORTE guidelines are based on the earlier work of developing strategies to support the inclusion, involvement and meaningful contribution of people with dementia in research, including that of: Bartlett and Martin (2002), Clarke and Keady (2002), Hubbard et al. (2003), McKillop and Wilkinson (2004), and includes the concept of process consent as suggested by Dewing (2007).

More recently, a contemporary review of the literature has explored the concept of safe participation and inclusion of people with dementia in research (Novek and Wilkinson, 2019). This work emphasises the movement away from exploring ethical issues, such as gaining consent to explore safe participation of people with dementia in research. Issues of safety identified involved the need to work with gatekeepers, the development and dissolution of the researcher and participant relationship, and the necessary and essential skills researchers require to work effectively in this context.

Another element that has supported the involvement of people with dementia in research is the emphasis of Patient and Public Involvement (PPI) by many grant holders. PPI has supported people with dementia not only to have their voice heard in research, but also to influence the focus and

development of research in dementia. PPI has occurred particularly in the UK, as the National Institute for Health Research (NIHR) funded the development of INVOLVE, a public body that promotes and supports public involvement in all elements of health research. The NIHR also recognise the need for PPI through collaboration with patient experts, including those diagnosed with dementia (Swarbrick et al. 2016).

An important consideration is the impact of people with dementia participating in research, especially qualitative research where they may be expressing negative experiences of living with dementia. However, people with dementia involved in research as participants found the experience supported their lifelong values, and they were proud to participate in such a meaningful activity. An important element was the positive relationships with researchers, which empowered people with dementia to both understand the risks of the research and to decline to participate if they wished (Hedmen et al. 2018).

Recent initiatives to work with people with dementia in research has supported their involvement beyond participation to guide the development, direction and focus of research in dementia, as collaborators, co-researchers and through co-production (Gregory et al. 2018; Shilling and Gerhardus, 2017; Phillipson et al. 2018). A contemporary review of the literature identified 54 studies where people with dementia influenced an element of the design of the research (Bethell et al. 2018). General guidance on engagement of patients as equitable partners in research were identified as being relevant to engage people with dementia, such as the guidance from the Patient-Centred Outcomes Research Institute (PCORI, 2014).

The development of models to support people with dementia as collaborators in research have been implemented, such as the CO-researcher INvolvement and in Dementia (COINED) Model (Swarbrick et al. 2016). COINED was co-developed with researchers and three groups of people with dementia, Open Doors, Scottish Dementia Working Group and EDUCATE (Early Dementia Users Co-operative

Aiming To Educate). An important and central element of COINED is the ongoing training, support and education of staff and co-researchers across the duration of the research (Swarbrick et al. 2016).

The impact on people with dementia collaborating in research is overwhelmingly positive, empowering and supported the direction of future studies (Gregory et al. 2018). An example is the PREVENT Dementia study (Ritchie and Ritchie, 2012), which found people with dementia successfully supported study design, implementation and recruitment through accessible and user-friendly recruitment materials, and recruitment avenues that would not otherwise have been implemented (Gregory et al. 2018). The benefits of people with dementia in research appear compelling although there remains a lack of research on the impact on people with dementia, the research process and outcomes, researchers and the wider society (Bethell et al. 2018).

Guidelines and models to support safe and meaningful engagement of people with dementia in research address barriers previously identified, such as the need to address issues of communication, consent and capacity, and acknowledging the strengths, needs, preferences and skills of people with dementia (Schilling and Gerhardus, 2017). There is wide acknowledgement of these essential elements of engaging people with dementia in research.

Therefore, why on the one hand are people with dementia involved in research exploring dementia as participants, collaborators, co-researchers and through co-production, and on the other hand are being excluded from the opportunity to participate in wider health research (Taylor et al. 2012). One reason may be the complex nature of dementia and the specific requirements needed to support people with dementia in research; however, these potential obstacles have been widely discussed, and addressed in research relating to dementia. However, there still remains inequity in the inclusion of people with dementia in health research, which urgently needs to be addressed.

Researchers can support this by both disseminating and implementing guidelines and models to include people with dementia in all health research.

Authentic and meaningful engagement and participation of people with dementia is essential to ensure all health research is fit for purpose and meets the needs of people directly affected by dementia.

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