



Research Article

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People with Dementia as Co-Researchers

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Abstract

Dementia is a global epidemic and is the leading cause of disability among older people. A priority in dementia research is engagement of people with dementia. Stigma affects their participation in research but there are approaches to ameliorate the effect of stigma to enable engagement of people with dementia. People with dementia should also be engaged in health research, where instead of being research participants, they act as collaborators in planning, executing and disseminating research findings. Barriers to co-participation are described to consider how to include people with dementia in co-research. This requires flexible attitudes and approaches, with acknowledgement that for people with dementia, circumstances can change over time and impact participation. Examples and outcomes of involving co-researchers with dementia illustrate the mutual benefits received by researchers and participants. Frameworks for participation and engagement of people with dementia in research are provided to encourage positive collaboration, particularly in action research.

Keywords

Dementia, Patient engagement, Patient participation, Research

Introduction

Dementia is the leading chronic disease causing disability and dependence among older people [1]. It has wide spread implications, including psychological and economic costs, affecting the individual, family and caregivers. To manage this crisis, the Global action plan on the public health response to dementia 2017-2025 was launched [2], which includes research as a priority to ensure evidence-based action. Based on a global research prioritisation exercise [3], among the research themes that are in demand currently are the delivery and quality of care for people with dementia, and an understanding of their experiences with the disease. This requires participation and engagement of people with dementia in research.

Stigma as a barrier in research participation for people with dementia

Stigma is defined as 'an attribute, behaviour, or reputation which is socially discrediting in a particular way. It causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one' [4]. It promotes social exclusion, causing reluctance to participate in community activities or seek help. Identifying research participants will be difficult if people are unwilling to seek evaluation of stigmatising symptoms or learn about opportunities to participate in clinical studies. It also causes unwillingness to enrol in clinical trials or persevere after assignment to treatment groups, affecting participant retention [5].

Stigma may affect research participation, and considerations are required to approach and minimise its impact. Public education to improve knowledge and attitudes related to dementia will help recruitment. Information given in study brochures or participant information sheets should avoid use of medical jargon and use non-threatening, label-free and value-neutral words and images. As participants may need to come to terms with diagnosis, psychological support may be required. Peer recruiters and study champions may help foster positive and therapeutic relationships between participants and researchers. It is also useful to offer choices, such as requests regarding disclosure of study participation and preferred contact times [5]. People with dementia should also be given opportunities to participate and collaborate with appropriate disability support if required, in all community aspects, including research.

When older people from the longitudinal study on Aging and Dementia in Stockholm were surveyed regarding their participation in the study, majority (80%) had a positive attitude [6]. However, those with cognitive impairment

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had the least positive attitude, reporting the first contact and cognitive testing as the most stressful situations. They also often refused parts of the clinical examination. The authors recommended more attention is necessary to the initial contact; reducing stressful or tiring examinations; and providing complete information about the research protocol, including the right to refuse individual parts of the study. Further work remains to be done to improve recruitment of people with dementia into research.

Engagement of people with dementia as co-researchers

Engagement in health research refers to inclusion of people with lived experiences, such as people with dementia, their family, friends and caregivers in the research process. Instead of being research participants, they act as collaborators in planning, executing and disseminating research findings. In a scoping review, Bethell, et al. described the extent and nature of patient engagement approaches used to involve people with dementia and their care partners [7]. This was possible in a wide range of research related to clinical, health services, social, cultural, environmental and population health aspects. People with dementia were engaged in research through focus groups, interviews, surveys and serving on study committees or advisory groups.

There may be difficulties experienced by researchers and people with dementia with this process. For researchers, co-participation required extra time and costs associated with engagement activities. There were also issues regarding protecting anonymity of study participants and adapting to sharing control over decision-making. It was difficult to identify 'representative' individuals and groups as co-researchers in terms of demographics and stage of dementia. For people with dementia and care partners, the perceived complexity of the research process and lack of research training and experience may be intimidating. There was also potential for distress when addressing certain dementia topics, which they may relate to personally. It was essential for researchers to carry out early planning and have appropriate and adequate resources and time for co-research.

Lorito, et al. recommends the following steps to limit the restrictions caused by dementia in co-researchers [8]. Simple and jargon-free language should be used, while minimising abstract language or concepts. Visual prompts, such as laminated cards, may aid peer researchers administer interview questions. Research roles should be flexible and discussed throughout the duration of research according to presenting circumstances. Counselling and emotional support should also be made available to peer researchers, who are at risk of emotional overburden or distress when hearing peers' stories during interviews. Support workers may also be considered to accompany peer researchers on research activities to ease travel burden.

Another important consideration is selection of peer researchers to reflect the diversity of people with dementia. While it seems practical to only include those with early dementia, this excludes the voices of people at later stages

of the disease. Academics who are reluctant to cede control or delegate tasks should commit to fully involve peer researchers and avoid the impression of just wanting to tick the user-involvement box. Practical research training is also necessary to enable people with dementia to take on more research responsibilities and familiarise themselves with the project. As dementia affects people differently, training sessions should also be tailored to the peer researcher's needs. It is necessary to define each researcher's role at the initial stage of collaboration to clarify responsibilities and expectations, in order to develop a relationship of trust and mutual respect. Co-researchers should also be realistic about their extent of involvement and be aware of their limitations when negotiating research roles.

There are several strategies to engage people with dementia as co-researchers. It is important to clearly define each researcher's involvement and roles, taking into account individual strengths, skills, preferences and needs. Co-research is facilitated by a 'good fit' with research tasks, which may involve adapting tasks to the person or finding the person for the task. Peer researchers should ideally possess social skills, such as being able to empathise, listen actively and communicate effectively (including non-verbally), as these qualities help gather enriched narratives from participant interviews. Key attributes for academic researchers are willingness to take time to engage and connect with co-researchers and extend motivations of people with dementia to engage with co-research opportunities. Practical considerations for dementia-friendly meetings, such as utilising familiar surroundings and having regular breaks also support participation of people with dementia. It is also crucial to provide training and support, with regular updates on study progress, results and outcomes. Overall, researchers should maintain flexible attitudes and approaches, acknowledging that with dementia, circumstances can change over time and impact participation [7,9].

Examples of co-research with people with dementia

Examples of co-research with people with dementia illustrate how the process can be mutually beneficial. Chenoweth and Kilstoff carried out participatory action research in a multi-cultural dementia day-care centre in Sydney after carers expressed dissatisfaction with some aspects of the day-care programme [10]. In this study, day-care staff and family carers consulted with clients to design, implement and evaluate a new therapy programme, with researchers acting as facilitators. In the initial stage, it was difficult to move from general concerns to specific issues by the skeptical participants. However, the mutual support from each other to effect change empowered participants to focus on developing the new programme. At each stage of the research cycle, the freedom to share feelings in a safe environment, receive and provide feedback, reflect on shared experiences and clarify personal goals were ensured. From this process, clients identified a renewal of close personal relationships with their family carers and experienced increased alertness with reduction in distress. Family carers

and daycare staff experienced an awareness of their purpose in the caring role and the dementia care programme. Subsequently, staff also increasingly consulted with clients and family carers in managing day-care participation.

Tanner investigated older people's experiences of transitions between care services as part of a national study across four sites in England [11]. Preparation sessions with co-researchers helped ascertain the extent that they can engage meaningfully in the interviews, utilising the skills they brought to the programme. Aspects co-researchers found difficult were identified early so these could be managed to minimise effects to the interview process. In this study, the shared identity of being someone with dementia facilitated relationships between researchers and participants. This enhanced the experience of the interview process for both parties and enriched data obtained from interviews. An unexpected benefit was that co-researchers talked positively about services they used, encouraging participants to 'give things a try', which appeared to ease the transition of people accessing dementia services. This highlights the value that access to peer mentors who are comfortable with their dementia identity can have for people more recently diagnosed with dementia. While co-researchers with dementia may not have skills and capacities to undertake effective qualitative interviewing, this experience suggests the need for a wider and more inclusive interpretation of 'communication skills'. Involvement of co-researchers also provided a sense of purpose and value, with identified capacity to connect socially and emotionally with participants. There is a need to explore potential benefits of peer support and opportunities for facilitating and supporting relationships between people with dementia by co-researchers.

Stevenson and Taylor involved individuals with dementia as co-researchers in data analysis of a qualitative study [12]. Co-researchers were recruited from an Alzheimer's Society Service User Review Panel in Northern Ireland. In this study, co-researchers were involved in analysing interview extracts from people with mild to moderate dementia who made decisions about care that involved risks and how risks were communicated by family carers and healthcare professionals. The main benefit gained through involvement of people with dementia as co-researchers was a richer understanding of the data from a user perspective. For example, individuals offered their own personal reflections on risk, including that risk is individual and depends on the stage the person is at. Risks were also often more of a concern to family members than the person with dementia. They also highlighted the importance of distinguishing between making someone aware of risks and making them worry about risks. These interpretations allowed researchers to identify the conceptualisations of risk that were most meaningful to people with dementia and to understand the significance and authenticity of interview responses from the perspective of a person with dementia.

Mann and Hung carried out a project on 'Co-creating Person-Centred Care in Acute Care' [13]. This started because hospital staff felt ill-prepared in terms of knowledge and skills to care for people with dementia admitted to hospital. It involved seven people with dementia as experts of lived

experiences to co-develop knowledge for change, working with 50 interdisciplinary staff to identify practical solutions in the physical and social environments. Their goal was to innovate and improve dementia care in a medical unit of Vancouver General Hospital. Co-researchers provided education workshops, including producing videos about their experience of the hospital environment for staff learning. Participants also shared stories regarding what mattered to them during their care experiences, what worked and what did not in the hospital environment. Outcomes include proposed design solutions that were submitted to hospital administration to request change; educational workshops on gentle persuasive approaches, peer teaching videos, 'This is Me' and 'My Daily Care Needs' communication tools to enable staff to know patients' preferences and abilities. A toolkit on the 'Art and Science of Person-Centred Care' was also developed.

These applied examples demonstrate how co-participation of people with dementia can be mutually beneficial for researchers and participants. When this approach is explored internationally, it is anticipated that salient learning points will improve engagement, reduce stigma and promote citizenship of people with dementia.

Useful frameworks for engaging people with dementia in research

There are a few useful frameworks to engage people with dementia in research. The CORTE guideline developed by Murphy, et al. aims to improve inclusion of people with dementia in qualitative research studies [14]. This consists of four main areas: Gaining Consent, maximizing Responses, Telling the story, and Ending on a high (CORTE). Basically, decision-making competence should not be considered an absolute issue but dependent on the domain assessed. Process consent is important, where the ongoing willingness of the person with dementia to participate is assessed at the start of the interview and continually throughout the interview; paying attention to body language and behaviours such as restlessness and agitation that may indicate disengagement. Strategies to maximise responses from people with dementia include managing the context, time and questioning, building relationships, interview questions and technique. Researchers can also help people with dementia tell their story by using different sources, such as photos, written accounts or recorded interviews. Finally, it is crucial to ensure the person with dementia feels they contributed positively to the research through formal acknowledgement, ensuring there is sufficient time for this at the end of the interview.

Mann and Hung offer a useful mnemonic 'ASK ME' as an approach to encourage positive collaboration in action research; Avoid assumption, Support the person to do the best, Knowledge needed to be put into action and acknowledged, Meeting regularly and early, and remember Ethical sensitivity and responsibility [13].

Finally, the Scottish Dementia Working Group Research Sub-group shares six principles for involving people with dementia in research [15]. These emphasise how people

with dementia are valued and involved in research; applying their lived experiences as valid knowledge; facilitate physical and emotional safety; enable accessibility of all aspects of research; provide training for co-researchers and awareness of the impact of time on research processes.

Conclusion

As dementia has widespread implications on a person's life and those of caregivers and family, co-research is required to examine these aspects using the lens of a person with experience of the disease. Stigma remains an issue, and approaches are required for limiting its insidious effects in research participation. It is hoped that the principles considered here will be applied to dementia research to improve involvement of people with dementia in planning and execution of research.

Conflict of Interest

The author has no conflict of interest to declare.

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References

1. World Health Organisation (2015) The epidemiology and impact of dementia: current state and future trends.
2. World Health Organisation (2017) Global action plan on the public health response to dementia 2017-2025.
3. Shah H, Albanese E, Duggan C, et al. (2016) Research priorities to reduce the global burden of dementia by 2025. *Lancet Neurol* 15: 1285-1294.
4. Goffman E (1963) *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, New Jersey: Prentice Hall.
5. Garand L, Lingler JH, Conner KO, et al. (2009) Diagnostic labels, stigma, and participation in research related to dementia and mild cognitive impairment. *Res Gerontol Nurs* 2: 112-121.
6. Von Strauss E, Fratiglioni L, Jorm AF, et al. (1998) Attitudes and participation of the elderly in population surveys: data from a longitudinal study on Aging and Dementia in Stockholm. *J Clin Epidemiol* 51: 181-187.
7. Bethell J, Comisso E, Rostad HM, et al. (2018) Patient engagement in research related to dementia: A scoping review. *Dement* 17: 944-975.
8. Lorito CD, Birt L, Poland F, et al. (2017) A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia. *Int J Geriatr Psychiatry* 32: 58-67.
9. Waite J, Poland F, Charlesworth G (2019) Facilitators and barriers to co-research by people with dementia and academic researchers: Findings from a qualitative study. *Health Expect* 22: 761-771.
10. Chenoweth L, Kilstoff K (1998) Facilitating positive changes in community dementia management through participatory action research. *Int J Nurs Pract* 4: 175-188.
11. Tanner D (2012) Co-research with older people with dementia: Experience and reflections. *J Ment Health* 21: 296-306.
12. Stevenson M, Taylor BJ (2019) Involving individuals with dementia as co-researchers in analysis of findings from a qualitative study. *Dement* 18: 701-712.
13. Mann J, Hung L (2019) Co-research with people living with dementia for change. *Action Res* 17: 573-590.
14. Murphy K, Jordan F, Hunter A, et al. (2014) Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dement* 14: 800-824.
15. Scottish Dementia Working Group Research Sub-group (2014) Core principles for involving people with dementia in research: Innovative practice. *Dement* 13: 680-685.

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