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“Nothing About Us Without Us”: Involving People with Dementia in Qualitative Research

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Abstract

People with dementia are increasingly asserting their rights as people with disabilities. Yet instead of inviting them into studies as participants, researchers often use surrogates—family members or healthcare professionals. I address this problem by bringing together qualitative methodologies that involve people with dementia directly in research.

Keywords: dementia, disability, research participation

A new disability rights movement of people living with dementia has emerged. Members of this movement are tackling social dis-ablement and structural discrimination against those with dementia (Crowther, 2016), rather than viewing it only as a medical diagnosis (Shakespeare, Zeilig, & Mittler, 2017). This shift is similar to the process by which chronic illnesses and mental health conditions, once viewed only through the medical model, are now considered disabilities. There are many similarities in the ways in which younger adults with developmental disabilities and older adults with dementia are devalued and infantilized. They are often considered burdens on their caregivers and frequently left out of decisions about their own lives. Yet these two groups of people with cognitive impairments exhibit agency by resisting the exercises of power over them. For example, Oldfield & Hansen (2020) show how “Susan,” who had a cognitive impairment her entire life, resisted being given orders by loudly exclaiming “I won’t!” “Helen,” who aged into cognitive impairment, resisted ableist devaluation by reframing her life changes positively. She explained, “I used to have a photographic memory, but it’s gone. But I have lots to be thankful for. I’m in good health” (Hansen, 134). Helen spoke positively of her changing body, saying “There’s a reason for my body changing as I get older. It wants my attention. I listen and take care of it ... I veer to the left, so now I use a cane to keep walking straight” (Hansen, 134).

Dementia activists Steele, Swaffer, Carr, Phillipson, and Fleming (2020) state that “people living with dementia are full humans, equal to everyone else,” and thus have human rights. Indeed, people with dementia are covered by the definition of the UN Convention on the Rights of Persons with Disabilities (CRDP): “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Crowther, 2016, p. 2).

“Nothing about us without us” has long been a slogan among disability rights activists to proclaim that all research, policymaking, and public activities concerning disability, should include participants with impairments (Williams, 2011), who

Yet qualitative research on dementia

often excludes people with lived experience (Novek & Wilkinson, 2017; Steele, et al., 2020). Instead, researchers still ask formal caregivers, health professionals, or family members to speak on behalf of people with dementia, even when they are verbally articulate.

Problematically, others' accounts may ignore the perspectives of people living with the condition or be filtered through dominant discourses about dementia. These discourses frame it is a tragedy to be feared (Van Gorp & Vercruysse, 2012) and thereby something to be detected early so that it can be mitigated. Additionally, representations of people with dementia focus on deficits (Zeilig, 2015), not assets, such as "Disability is creativity at a moment's notice" (N. Hansen, personal communication, March 20, 2021). Although family members and care workers may be able to observe the actions of people with dementia and reflect on them, they do not directly experience the phenomenon. Instead, they may filter it through the lens of negative representations of dementia. For example, media stories often describe people with dementia as patients "suffering" from it. They tend to take the viewpoint of adult children who feel that they have lost the parents they knew and that those parents have already died.

Media stories from the viewpoint of people living well with dementia are rare. However, Reimagining Dementia: A Creative Coalition for Justice, an international group of dementia activists and allies, challenges negative representations of dementia through play and the arts (changingaging.org/dementia/reimagining-dementia-a-creative-coalition-for-justice-join-us/). Because dementia is often seen through the eyes of nondisabled people, to accurately understand dementia it is crucial to directly involve people with dementia in research on the topic (Nygård, 2006).

This essay is informed by scholarly literature and nonacademic reports and websites, as well as research in which I explored how three types of time intersect in a North American nursing home. (These institutions are also called "long-term care facilities," "care homes," and "residential aged care.") (Oldfield, in progress). The first type is institutional time, the dominant force structuring daily life for both staff and residents. The second type is residents' time, which is how residents prefer to structure their daily lives. The third type is dementia time, the unquantifiable, fluctuating timescape of people with dementia (Yoshizaki-Gibbons, 2020), who comprise the majority of nursing-home residents. The research is part of an ongoing informal critical ethnography that centers on Helen, one of my family members, and her fellow residents. Critical ethnography, a methodology that incorporates observation, interviews, and reflection, exposes power differentials to promote social change (Ross, Rogers, & Duff, 2016). My ethnography is guided by critical disability studies, which looks at power relations from the perspective of people with impairments. The discipline counters the mainstream view of disability as tragedy by pointing out its advantages. For example, memory loss in dementia can be a benefit. As Helen explained, "I'm getting more and more content ... And I'm not looking a way ahead, wondering about things; I'm living *now* and *today* ... I'm not restless ... I'm actually quite peaceful, which is surprising" (Oldfield & Hansen, 2020, p. 134).

In this essay, I bring together four challenges with qualitative research in a nursing home involving residents with dementia: (a) gaining access to the research setting, (b) informed consent from participants with dementia, (c) working with participants who have dementia, and (d) mitigating emotional distress among researchers. For each challenge, I discuss how it may be addressed. At the end of the essay, I focus on one methodology, ethnography, which is particularly appropriate for exploring dementia with nursing home residents.

Gaining Access to the Research Setting

As a member of Helen's family, my access to the institution is unquestioned, although I must sign in and out at the security desk as every other visitor and staff member does. For researchers who do not have a family member living in a nursing home, gaining access can be more difficult. They will need to first build trusting relationships with administrators to gain permission to access not only the institution's spaces, but to recruit participants. Where permission is attainable, it is more likely to come from institutions who want to showcase their culture change, rather than from more traditional institutions. In the landscape of North American nursing homes, where many facilities are owned by for-profit corporations, competition for business may prevent corporate owners from risking scandals and damaged reputations by allowing researchers in.

Informed Consent from Participants with Dementia

One reason for excluding people with dementia from research is the assumption that they cannot give informed consent. Moore and Hollett (2003) challenge conventional measures for determining competence to consent. They argue that research participants are not required to be competent in making decisions about all areas of life but only a specific decision in a specific context. The CRDP recommends that shared decision-making replace substitute decision-making for people with disabilities. Nonetheless, even in some countries that have ratified the treaty (e.g., Canada), substitute decision-making is still the legal default (Walker, 2013). Seniors are advised to designate proxy decision-makers as part of advanced care planning, and these proxies hold sway in decisions about the lives of nursing-home residents. Therefore, research ethics boards may require proxies to give informed consent for participation in research. However, researchers can model techniques for sharing decision-making to ensure that participants with dementia take part in the consent process. These include using pictures to explain abstract concepts and involving trusted people (e.g., peers) who have listened to residents' wishes (Williams & Porter, 2015). Ensuring that their proxies are willing to share decision-making can be a criterion for selecting participants.

Nygård (2006) recommends that researchers build relationships with participants who have dementia well before requesting informed consent. During the research, researchers should remind participants who the researchers are, the purpose of the research, and that they are temporary visitors. Steele et al. (2020) note that the importance of obtaining ongoing consent during data co-construction by reminding participants of their freedom to participate, take a break, ask for support, or withdraw from the study. Moore and Hollett (2003) add that ensuring that participants understand the researcher's role is essential to continuing consent. Looking for verbal and nonverbal signs of anxiety can help researchers assess participants' willingness to continue (Pesonen et al., 2011).

Working with Participants who have Dementia

Involving people with dementia in research may require adapting research methods to take into account the needs of participants with cognitive impairments. The Scottish Dementia Working Group (2014), an advocacy organization of people with dementia, advises that researchers should:

- be empathetic, unpatronizing, and tolerant;
- communicate in inoffensive language that participants will understand;
- find out the best time for participants to meet, how they each keep track of time and want to be reminded of meetings;
- ask participants if they would like to have someone with them;
- ask about participants' emotional and physical safety needs at each meeting;
- offer access to counseling or emotional support;
- recap previous conversations at each meeting;
- give participants time to reflect and respond to questions;
- offer regular breaks;
- be cautious about asking participants to recall unhappy times, as they may trigger pain; and
- not stay longer than agreed, unless invited.

Dementia researchers suggest ways to adapt interview techniques for participants with dementia. These include scheduling interviews for when participants are mostly likely to experience the study phenomenon (Moore & Hollett, 2003). An unstructured interview format may be most adaptable (Nygård, 2006), in addition to fostering co-construction of knowledge. It also allows participants to direct the conversation to issues that matter to them (Moore & Hollett, 2003). Photo-elicitation, in which researchers ask participants to bring photographs to interviews that have meaning for them and then use the photographs to elicit stories, can be used to make interviews more concrete. Photographs and other objects in residents' rooms can also elicit stories. In asking about participants' daily lives, researchers should formulate questions that do not require recalling events or feelings (Nygård, 2006) and focus instead on participants' strengths (Moore & Hollett, 2003). Photovoice (Dassah, Aldersey, & Norman, 2017), which entails giving cameras to participants and asking them to photograph aspects of their lives that are important to them, can provide material for participants to discuss during interviews.

Williams (2011), in her book about conversations with people who have intellectual disabilities, asserts the need to avoid replicating day-to-day oppression. She advises presuming competence, ensuring conversation partners that you believe what they say, waiting for them to respond, following up on responses, and using friendly body language (smiling, sustaining eye contact, and showing interest through facial expressions). Pesonen et al. (2011) also advise researchers to use communication strategies “such as active listening, using concrete words, repeating questions differently if necessary, [and] tolerating silence” (p. 656).

‘Go-along’ interviews (Carpiano, 2009) facilitate the co-construction of data between interviewer and participant. Informally interviewing someone while accompanying them for discrete periods of time in their daily lives enables more concrete questions, prompted by things that both researcher and participant observe in the same moment (Nygård, 2006). Participants can also demonstrate what they mean (Nygård, 2006), adding to the richness of data. Photography can be used to document the locations visited and what was observed. The photographs can then be used to remind participants about the shared experiences in later interviews, where they can be explored.

Although interviews can be adapted for people with dementia, they usually rely on verbal communication. People with dementia or other cognitive impairments (e.g., stroke, neurodiversity, intellectual, or acquired brain injury) or Deaf people may communicate without using words. Interviewing participants who communicate differently requires a nonconventional approach. Teachman, Mistry, and Gibson (2014) developed such an approach to interviewing youth who communicate nonverbally using eye gaze, gestures, facial expressions, and technology. Their methods include observation, photo-elicitation, face-to-face and electronic interviews. The researchers are assisted by family members in becoming familiar with participants’ communication modes. Bourbonnais and Ducharme (2010) used a triad methodology to explore communication without words among people with dementia in a nursing home. Each triad comprised a resident with dementia, a family member, and a healthcare professional or a paid caregiver who knew the resident well.

Analyzing and interpreting data co-constructed with someone who has dementia may require novel approaches. It may help to create an advisory committee of people with dementia from outside the study setting, perhaps recruiting committee members through advocacy organizations of people with dementia, such as national chapters of Dementia Alliance International. Committee members can participate in the development of research questions, data analysis and interpretation. Data would, of course need to be de-identified (e.g., names and any other identifying details removed from transcripts and observations) before sharing it with advisory committee members. In addition, researchers can share the findings with participants, in ways adapted to their abilities, to check whether the findings resonate with their experiences. Visual methods (e.g., putting themes or concepts on cards, illustrating them with pictures, and asking participants to comment on the themes' or concepts' resonance with their lived experience) may work for member checking and can also involve participants in data analysis. Similarly, researchers can, in collaboration with participants, draw conceptual diagrams to interpret data. Advisory committee members can help translate knowledge from the study findings and share it with nonacademic audiences.

Ethical Issues in Working with Participants who have Dementia

Because relationships are so important in dementia, researchers should plan if and how they will withdraw from the setting (Moore & Hollett, 2003). Heggestad et al. (2012) point out that participants with dementia may perceive researchers as having power over them. Therefore, it is important to avoid increasing their vulnerability. As nursing-home residents, they are already objects of institutional power (Oldfield, 2019). Heggestad et al. advise researchers to keep a log about what ethical challenges they encounter and how they resolve them, possibly in consultation with health professionals and family members who know participants with dementia well. These methodical memos become data on which researchers can reflect during analysis and interpretation. The memos can also comprise an audit trail, in case researchers need to defend their decisions to research ethics boards or others.

People with dementia may not have been told their diagnosis, because the word confers stigma and invites stereotypes (Pesonen et al., 2011). Therefore, the authors advise against using this label (as it might be regarded through a critical-disability-studies lens) unless participants describe themselves this way. Instead, the authors used the term "memory problems" to prevent participant distress. When I interviewed clients of employment agencies serving people with disabilities (Gewurtz et al., 2019), I used whatever identity the participants adopted at the beginning of the interview when they described themselves and their job search. Similarly, when I talk to Helen, I avoid the term 'dementia,' an identity she has not adopted. Instead, I refer to memory loss because she brought the issue up herself. As a group member with dementia emphasized during a meeting of Reimagining Dementia in 2020, "If you've met a person with dementia, you've met just one person with dementia. We are all different."

In alignment with the disability-rights-movement slogan "Nothing about us without us," Heggestad et al. (2012) argue that "Not including vulnerable people in research may even increase their vulnerability. More knowledge [from the perspective of people with dementia] may also reduce the stigma associated with the disease and lead to more openness around it. Excluding persons with dementia from important research may be unethical and also a threat to their dignity" (Heggestad et al., 2012, p. 37).

Mitigating Researchers' Emotional Distress

Doing research in nursing homes with people who have dementia may put researchers at risk of emotional distress. The Scottish Dementia Working Group (2014) recommends that researchers "become aware of their own 'safe zones' and know where to go/not go" (p. 683). Individual researchers will, of course, interpret emotional safety differently according to their personal history and circumstances. Ethical and methodological uncertainties, along with ending relationships with participants can evoke distress (Pesonen et al., 2011). These authors recommend that researchers keep reflexive diaries and share their emotions with supervisors.

Next, I offer suggestions for emotional safeguards from my own experience. In a seminar I attended, a nursing-home researcher talked about feeling upset when she observed low-quality care (J. Choinere, Centre for Critical Qualitative Health Research seminar, January 16, 2019). I have certainly felt distress when witnessing how institutional power impinges on quality of life for Helen and her fellow residents; for example, when staff members demean residents or give them orders (Oldfield & Hansen, 2020). Over the years of my ethnography, I have developed relationships with some residents, and some have died. Their deaths have not been acknowledged by the nursing home. To let go of the anger I feel while observing these situations, I find it helpful to audio-record my feelings and reflect on them as soon as possible. As a family member, I am very careful not to criticize the home or its staff members. I strive to maintain pleasant relationships with them, not only to avoid defensive reactions but to protect Helen.

Discussing my observations with a family member of one of Helen's fellow residents who has become a friend and fellow advocate somewhat alleviates my distress. She is very familiar with the nursing home, coming daily to help her family member eat dinner. Both of us attend meetings of the home's Family Council, where we receive additional peer support. This informal support is one of the strategies recommended by Dickson-Swift, James, Kippen, and Liamputtong (2008). They also advise researchers investigating emotionally sensitive topics to look beyond peer support by taking the following actions: leaving time between data-collection episodes to process emotions, developing guidelines for ending research relationships and strategies for dealing with participant death, and having someone else transcribe interviews to avoid reliving traumatic experiences. If an advisory committee is involved in the research, they should be given access to the above strategies for mitigating emotional distress. They can also provide support to the researchers to mitigate emotional distress. By discussing their emotional reactions to the data and findings, advisory committee members and researchers can co-create reflective data.

I now look at how qualitative research, and one qualitative methodology in particular, ethnography, suits research involving nursing-home residents with dementia.

Ethnography as a Methodology for Exploring Dementia in Nursing Homes

Although quantitative research approaches are well suited to investigating countable institutional phenomena, qualitative approaches, such as ethnography, are better suited to investigating residents' perspectives because they are not easily quantified. Ethnography also involves researchers building relationships with participants over time. This time can increase researchers' understanding of the study context and enable them to get to know participants as individuals (Heggestad et al., 2012).

Ethnography enables researchers to draw on multiple data sources; for example, observation (participant and non-), document analysis, formal interviews, informal conversations, field notes, and memos. These multiple sources create a richer dataset than single methods may. Except for interviews, these methods do not require participants to recall past events or feelings. By focusing on the here and now, the other methods may be work better for people with dementia.

Researchers can compare data from different sources to identify similarities and differences and use one method to flesh out findings from another (Nygård, 2006). For example, during interviews, researchers can follow up on themes from their analysis of observational data, or vice versa (Heggestad, Kari, Nortvedt, & Slettebø, 2013). Ethnography also puts participants' situations in context, which can be investigated using other methods, such as document analysis. Because one way to adapt research for participants with dementia is to schedule multiple, short interviews, working with the same participants over time may enrich the data and facilitate data interpretation (Nygård, 2006). Ethnography allows for such longitudinal research, involving multiple interactions with participants at different times and perhaps in different contexts. Multiple interactions allow time to build trusting relationships between participants and researchers (Pesonen et al., 2011). Finally, triangulating data from multiple sources increases rigor.

Conclusion

Although all qualitative research about disability should include participants with lived experience, researchers rarely invite people with dementia to participate. Instead, they seek input from proxies, family members, care providers, and healthcare professionals. These indirect accounts may be filtered through dominant discourses about dementia and inaccurately reflect the perspectives of people living with the condition. In this essay, I offered suggestions for involving people with dementia directly as research participants.

Critical disability studies, through its insistence on including people with disabilities in disability research, has much to contribute to qualitative research that includes people with dementia, and to social change. The approaches, methods, and ethical issues covered in this article can contribute to research that includes people with other cognitive impairments (e.g., from stroke, neurodiversity, intellectual disability, or acquired brain injury).

Researching dementia through the lens of critical disability studies will help move dementia out of the medical model of disability into the social and human-rights models. This will shift thinking to the view that people with dementia are dis-abled by society and are protected against disability discrimination under the UN Convention on the Rights of Persons with Disabilities and the human rights laws of countries that ratified this treaty. Returning to the disability-rights slogan, "Nothing about us without us," research that more accurately reflects the views and experiences of people with dementia will provide a better foundation for planning dementia services and supports, policy making, and dementia-friendly social and physical environments. With time, research that includes people with dementia will help change how people with dementia are viewed by their families and friends, healthcare providers, and society as a whole—not as victims of fearful tragedy but as people with impairments who have meaningful lives.

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