



## Exploring the Experience of Living with Dementia: Gaps in Qualitative Nursing Research

By: Alexandra Ansell<sup>1</sup> (BScN, RN, EN(C), MN Student – Nurse Practitioner Stream), University of Alberta, Edmonton, Alberta, Canada

<sup>1</sup> The first author, Alexandra Ansell ([aloeffel@ualberta.ca](mailto:aloeffel@ualberta.ca)) living in Edmonton, submitted the original draft of this paper for an assignment in a graduate research course in the Faculty of Graduate Studies and Research, University of Alberta, NURS 513, Qualitative Research in 2020.

### Abstract

The focus of this paper is the importance of including persons living with dementia (PLWD) in qualitative research. Both the barriers and ethical considerations that researchers face in this context are discussed. By highlighting the value of personhood, selected research methods and dementia research design are explored to advocate for and support the inclusion of PLWD in research. When ethical obstacles cause researchers to overlook vulnerable groups, such as PLWD, they are deprived of the autonomy and inclusive consideration they deserve. While existing literature has captured the beneficial and therapeutic effects of including PLWD in research, there is a marked absence in documenting people with dementia as a source of insight. Inclusive models for research are more ethically appropriate and offer a more functionally congruent framework for the research process. While methodological and ethical obstacles endure, considerations for adapting both methods and methodologies more suitable to dementia research should be considered. Qualitative nursing research of PLWD remains an undeservedly neglected source of insight into the experience of dementia and subsequent research that will influence and shape dementia care and policy.

*Keywords:* autonomy; dementia; dignity; ethics; inclusive research; nursing research

---

Dementia can be defined as a collection of conditions wherein cortical function is reduced, impeding cognitive skills like judgement, thinking and learning, and motor coordination (Dlugasch & Story, 2019). Often times, the cognitive decline of dementia is demonstrated by

people experiencing forgetfulness, memory impairment or changes in personhood. One of the largest existing barriers to researching PLWD has been the ethical and methodological challenges presented (Bond & Corner, 2001; Hellström et al., 2007; Hubbard et al., 2003; Novek & Wilkinson, 2019). These barriers are largely related to the belief that PLWD are highly vulnerable and are stigmatized as such. Inclusion has been obstructed by the understanding that PLWD are inherently unreliable because of their cognitive condition (Murphy et al., 2015). Many of the existing obstacles to research of PLWD are a consequence of the biomedical and positivist paradigms that much of health sciences research has been rooted in (Bond & Corner, 2001; Hubbard et al., 2003). Many traditional methods of research are generally unsuitable for people with dementia (Dewing, 2002) and other covert stigmas of this vulnerable population contribute to much of their absence in qualitative research (Hellström et al., 2007; McKeown et al., 2010). This exclusionary stance contributes deindividuation to PLWD (Murphy et al., 2015). PLWD remain unjustly excluded from research which continues to extinguish their voice and usurp their dignity. The realms of health science research have an ethical obligation to propagate the understanding of people with dementia through research and maintaining their dignity (Heggestad et al., 2013). Although they can provide valuable insight, it has been recognized that people without dementia cannot accurately narrate the experience of PLWD (Cahill et al., 2012). In order for research to ethically elucidate the experience of PLWD, research must continue to be designed and carried out in a respectful, inclusive manner. As it is commonly nurses who work most closely with PLWD, there is promising opportunity for nursing research to illuminate PLWD as an indispensable source of insight.

## **Background**

In the research setting, it is often falsely presumed that a person with limited cognitive capacity lacks the ability to partake in meaningful discussion that is reliable (Cahill & Diaz-Ponce, 2011; Heggestad et al., 2013; Hellström et al., 2007). Researchers frequently utilize the Mini-Mental State Exam (MMSE) to test cognitive function, but incorrectly interpret a low score to suggest the person lacks potential to engage purposefully (Heggestad et al., 2013; Hellström et al., 2007; Warner et al., 2008). Although people with severe cognitive impairment often feel socially isolated (Cahill & Diaz-Ponce, 2011), in most cases they are capable and interested in expressing their thoughts and emotions (Cahill & Diaz-Ponce, 2011; Heggestad et al., 2013). A growing body of evidence demonstrates that including persons with dementia in research can have beneficial and therapeutic effects (Hellström et al., 2007). However, obtaining the consent of people with dementia has remained a contentious issue over time. It is important to note the difference between consent and assent, particularly in the context of research of those with cognitive impairment. For a person to grant consent they must be fully informed, where assent requires an ongoing demonstration of a will to participate from someone which consent cannot be granted (Murphy et al., 2015). Qualitative research of PLWD warrants a less traditional approach to consent. There is a need to transition from a “one size fits all” (Dewing, 2002)

*Gaps in Qualitative Nursing Research of PLWD*

exclusion focused model towards a more inclusive model that evaluates capacity within the specific context. Owing to the fact the PLWD have reduced cognitive capacity, they are subsequently increasingly dependent those around them. This vulnerability necessitates the need to assess capacity for consent situationally and acknowledge the specifics of what is being asked of that person in that particular context. Decisional capacity, the ability to make decisions, can be deconstructed into four main groups which include capacity to: understand, appreciate, reason and choose (Cacchione, 2011). In the context of dementia, the literature is divided regarding capacity. Research demonstrates some PLWD lose most capacity with progression of the disease, while some individuals preserve their ability to reason and choose (Cacchione, 2011). Interestingly, in the context of qualitative research, people with dementia retain more capacity to understand and express their feelings and emotions, compared to their power of recall with numbers, dates or facts (Hubbard et al., 2003). Consent is also more widely accepted as a condition that requires continuous revisiting and verification, rather than a one-time event (Batchelor-Aselage et al., 2014). Process consent requires authentic efforts to confirm and monitor consent throughout the research process, which is more appropriate for PLWD (Dewing, 2008). Through ethical prioritization of process consent, both parties can co-design a space and structure of research that allows for the formation of a meaningful relationship and strong rapport. By understanding the person with dementia, the researcher can more accurately interpret their words and actions and assess their willingness to continue their participation (Murphy et al., 2015). This conceptualization of ‘process consent’ or ‘ethics as process’ provides a more ethical and functionally congruent framework for dementia research (Heggstad et al., 2013; Hellström et al., 2007; McKeown et al., 2010). Ultimately, consent remains the responsibility of the researcher, and in this setting, a closer and more cohesive partnership with the participant is needed to better establish process consent models in qualitative research (McKeown et al., 2010). A lack of adequate methodologies for inclusionary consent and person-centred research denotes a gap in the literature (McKeown et al., 2010). Contemporary literature might capture different perspectives surrounding the research of PLWD, and it is important that this research continue. However, when discussing the gaps of qualitative nursing research of PLWD, a significant number of classical references, though dated, remain extremely relevant and include Le Navenec & Vonhof, 1996 and Dewing, 2002.

**Gatekeepers and Proxies: Is there any autonomy out there?**

When a person with dementia is deemed incapable of providing consent, conventional standards turn to proxy consent. Dewing (2002) argued that obtaining informed consent by proxy was insufficient on a moral basis and deprived the research of person-centred values. She also emphasized how proxies can devastate the “moral-space” that should be used to include research participants in a meaningful way, by subverting the focus and value of the participant. Gaining more critical review in recent years, proxy consent is highlighted for its attention being placed on the wrong person (Hellström et al., 2007). Furthermore, a proxy may also play the role of a gatekeeper and may impede the research process by operating as a barrier to recruitment, consent or data collection. Although the intended function of a proxy is protection of the research participant, gatekeeping of persons with dementia has been shown to further degrade their

*Gaps in Qualitative Nursing Research of PLWD*

dignity by incorrectly representing their wishes (Novek & Wilkinson, 2019). Although intended for safety, when research of PLWD incorporates a trusted, “non-affected” person as a gatekeeper with the ability to veto certain research questions, this additional ethical layer that was ultimately found to be exclusionary of PLWD (Hellström et al., 2007). The practice of obtaining proxy judgement, whereby the proxy chooses what they believe the participant would have, is often challenging for decision makers, if making conclusions about their loved ones (Cacchione, 2011). With gatekeepers and proxies continually influencing the direction of research outcomes by having the power to overrule decisions, PLWD have much of their autonomy compromised (Holm, 2001). In addition to traditional models of consent, the principles of autonomy and beneficence, doing good, warrant custom application to research of persons with dementia (Dewing, 2002).

**Morals and Methods: The person-centred approach**

Qualitative research of PLWD calls for a considerate approach to language. While the absence of an explicit diagnosis may hinder some dementia research (Cubit, 2010), the formal discussion of the diagnosis during interviews may do more harm than good (Heggstad et al., 2013; Novek & Wilkinson, 2019). Discussing the diagnosis of dementia has been “morally problematic” as traditional frameworks would deem it necessary for consent, even though this may cause distress for the participant if they are unaware of their diagnosis (Heggstad et al., 2013). Qualitative research of PLWD, vulnerable as they are, necessitates a person-first or person-centred research approach (Dewing, 2002; Heggstad et al., 2013; Hellström et al., 2007; Novek & Wilkinson, 2019). The philosophical construction of dementia research must support personhood (Dewing, 2002) so that research can occur within a safe space, intentionally designed by the researcher to foster trust, comfort and kindness (Hellström et al., 2007). A significant consideration in understanding the personhood of PLWD is gaining insight into their subjective experience through research (O’ Connor et al., 2007). Gaining understanding into the experience of PLWD is valuable in both early stages of dementia, and the advanced stages. Gaps in the literature exist requiring more longitudinal investigations into the experience of PLWD as their disease progresses (O’ Connor et al., 2007). Person-centred research also calls to focus the relationship between researcher and participant, which can hold significant influence on the trajectory of the research, and the participants themselves (Hellström et al., 2007). In interviews that may not have firmly established relationship as priority, participants with dementia felt pressure, as if the interview was a test (McKeown et al., 2010). Cultivating this safe space then gives PLWD the power that they may inherently lack because of their vulnerability. When they explored ethnographic accounts of persons with dementia using two different methods, Hubbard et al. (2003) found that interviews provided valuable information on how persons with dementia understood and made sense of their lives, while observation exhibited the complexities of their surroundings and how they related to the rest of society. Decisions about the research process, including the contextual details of when and where the interview occurs, can be consequential, thus, these decisions should be greatly influenced by the participant (Hubbard et al., 2003; McKeown et al., 2010; Novek & Wilkinson, 2019). In order to maintain the dignity of PLWD,

## *Gaps in Qualitative Nursing Research of PLWD*

the focus on personhood must encompass the whole person; past and present (Dewing, 2002). Furthermore, the life-course trajectory of PLWD is not exclusively coordinated by their neuropathology, but rather their personhood is strongly influenced by opportunities to remain socially integrated over the course of their life (O' Connor et al., 2007). Researchers have an ethical obligation in order to preserve personhood, broaden our understanding of PLWD, and inform future dementia-care and policy (O' Connor et al., 2007).

### **Dementia and Design**

While ethical and methodological limitations exist, strategies for improvement have been identified in the literature. Utilizing methods outside of the MMSE that are more appropriate for estimating capacity can allow for a more accurate reflection of a person's potential and avoid judgement from researchers (Murphy et al., 2015). In order for research to reliably reflect the voices of PLWD, the process of obtaining consent should be described in detail, and more inclusion of persons living with advanced dementia is essential (Murphy et al., 2015). More consistent processes could be achieved by implementing researcher training on verbal and non-verbal communication and language of persons with dementia (Hubbard et al., 2003). Additionally, researcher training should include education on the complexities of consent, and the need to prioritize building rapport and relationship with PLWD (Murphy et al., 2015). Researchers should ensure they are spending time with PLWD prior to the interviewing stage, to ensure they can recognize the person's comfort level, and if they are ready or reluctant to participate (Hellström et al., 2007). Research findings from individuals or combined accounts must be explicitly communicated, to ensure that results are not obscured with accounts from the proxies of PLWD (Murphy et al., 2015). While these accounts are beneficial and contribute to uncovering rich narratives of PLWD, findings should be categorized appropriately (Cahill et al., 2012). Research committees should also pursue and endorse methods that aid in recognizing and reacting to distress in this population (Dewing, 2002; Miller & Boulton, 2007). A need remains to explore and document the ethical challenges encountered when researching PLWD, in order to produce more knowledge, minimize stigma and create space for more transparency (Heggstad et al., 2013). To help address this gap, research should continue to discover the views of persons with dementia, but also those of other minority groups (Novek & Wilkinson, 2019).

### **An Ethical Imperative**

In the context of qualitative research in dementia, the projected shift from should we to how can we remains an evolving goal. While methodological and ethical obstacles endure, considerations for adapting both methods and methodologies more suitable to research of PLWD should be considered. A transition away from the biomedical lens on dementia towards a more holistic view will allow research to capture the historically diminished perceptions of PLWD (Murphy et al., 2015). Yet, research and the subsequent policies it shapes can only be truly holistic if it accurately reflects the needs and experience of this population (Murphy et al., 2015). In order to improve clinical outcomes of PLWD, researchers must pursue the stories of these

*Gaps in Qualitative Nursing Research of PLWD*

individuals directly (Cacchione, 2011). PLWD constitutes a minority group with a uniquely significant view and understanding of the world around them. They must be treated with compassion and respect for their personhood, especially in the realms of research (O' Connor et al., 2007). Qualitative research of PLWD can help produce a deeper understanding that reduces stigma and ultimately helps transcend prejudice (Murphy et al., 2015).

**Funding**

As an Alberta Registered Nurses Educational Trust (ARNET) Scholar, the author has received academic scholarship funds that help financially support her publication endeavours.



## References

- Batchelor-Aselage, M., Amella, E., Zapka, J., Mueller, M., & Beck, C. (2014). Research with dementia patients in the nursing home setting: A protocol for informed consent and assent. *Ethics & Human Research, 36*(2), 14–19.
- Bond, J., & Corner, L. (2001). Researching dementia: Are there unique methodological challenges for health services research? *Ageing & Society, 21*(1), 95.  
<https://doi.org/10.1017/S0144686X01008091>
- Cacchione, P. Z. (2011). People with dementia: Capacity to consent to research participation. *Clinical Nursing Research, 20*(3), 223–227. <https://doi.org/10.1177/1054773811415810>
- Cahill, S., & Diaz-Ponce, A. (2011). I hate having nobody here. I'd like to know where they all are: Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? *Aging & Mental Health, 15*(5), 562–572. <https://doi.org/10.1080/13607863.2010.551342>
- Cahill, S., O'Shea, E., & Pierce, P. (2012). *Creating excellence in dementia care: A research review for Ireland's national dementia strategy*. Dublin, Ireland: The School of Social Work and Social Policy, Trinity College, Dublin and The Irish Centre for Social Gerontology, NUIG. Available at: <https://www.atlanticphilanthropies.org/research-reports/report-creating-excellence-dementia-care-research-review>
- Cubit, K. (2010). Informed consent for research involving people with dementia: A grey area. *Contemporary Nurse, 34*(2), 230–236. <https://doi.org/10.5172/conu.2010.34.2.230>

- Dewing J. (2002). From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia, 1*(2), 157–171.
- Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research Ethics, 4*(2), 59–64. <https://doi.org/10.1177/174701610800400205>
- Dlugasch, L. & Story, L. (2019). *Applied pathophysiology for the advanced practice nurse*. Jones & Bartlett Learning,
- Hall, D., Cridland, E., Fleming, R., Brennan-Horley, C., Guggisberg, N., Frost, D., Hasan, H., & Phillipson, L. (2019). Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. *Dementia (14713012), 18*(7/8), 2679–2694. <https://doi.org/10.1177/1471301218754455>
- Heggestad, A. K. T., Nortvedt, P., & Slettebø, Å. (2013). The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics, 20*(1), 30–40. <https://doi.org/10.1177/0969733012455564>
- Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics, 14*(5), 608–619.
- Holm, S. (2001). Autonomy, authenticity, or best interest: Everyday decision-making and persons with dementia. *Medicine, Health Care, and Philosophy, 4*(2), 153–159.
- Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging & Mental Health, 7*(5), 351-362. <https://doi.org/10.1080/1360786031000150685>



- Miller, T., & Boulton, M. (2007). Changing constructions of informed consent: Qualitative research and complex social worlds. *Social Science & Medicine*, 65(11), 2199–2211. <https://doi.org/10.1016/j.socscimed.2007.08.009>
- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13–14), 1935–1943. <https://doi.org/10.1111/j.1365-2702.2009.03136.x>
- Murphy, K., Jordan, F., Hunter, A., Cooney, A., & Casey, D. (2015). Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia (14713012)*, 14(6), 800–824. <https://doi.org/10.1177/1471301213512489>
- Novek, S., & Wilkinson, H. (2019). Safe and inclusive research practices for qualitative research involving people with dementia: A review of key issues and strategies. *Dementia*, 18(3), 1042–1059. <https://doi.org/10.1177/1471301217701274>
- O'Connor D, Phinney A, Smith A, Small J, Purves B, Perry J, Drance E, Donnelly M, Chaudhury H, & Beattie L. (2007). Personhood in dementia care: Developing a research agenda for broadening the vision. *Dementia (14713012)*, 6(1), 121–142. <https://doi.org/10.1177/1471301207075648>
- Warner, J., McCarney, R., Griffin, M., Hill, K., & Fisher, P. (2008). Participation in dementia research: Rates and correlates of capacity to give informed consent. *Journal of Medical Ethics*, 34(3), 167–170. <https://doi.org/10.1136/jme.2006.019786>