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## CRITICAL REFLECTION ON PRACTICE DEVELOPMENT

### The value of knowledge and persons living with dementia: a healthcare professional's reflection

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#### Abstract

*Background:* I am a social worker with experience in working with persons with dementia in long-term care. This is a critical reflection of my practical experience of my assumptions regarding the knowledge held by persons with dementia in long-term care. I will suggest my initial assumptions were influenced by positivist epistemology and outline how they change when I changed to a constructivist epistemological stance.

*Aim:* The aim of this article is to break down assumptions arising from a positivist epistemological stance so that I, and other healthcare professionals who might share similar assumptions, will better value the knowledge of persons with dementia and incorporate it into their care and our overall practice.

*Findings:* I identified my two inadvertent assumptions. First, I assumed cognition was the only way of knowing. However, persons with severe dementia can still know their needs and wants from their bodies (embodied knowledge). Second, I assumed that knowledge only had value if it was real to me, yet there could be multiple subjective realities.

*Conclusion:* A change from a positivist to constructivist epistemological stance can lead to a better appreciation of the knowledge held by persons living with dementia, and thereby allow them to have input into their own care.

*Implications for practice:*

Professionals could better value the knowledge held by persons with dementia by:

- Practising reflexivity
- Acknowledging the views of persons with dementia
- Thinking about the interrelation among various areas of care

**Keywords:** Dementia, epistemology, critical reflection, practice, long-term care, knowledge

## Background

I am a registered social worker in British Columbia, Canada, with a masters degree in social work. I have been practising social work with persons with dementia in different settings, including long-term care, for the past 10 years. When reflecting on my practice journal and notes I had taken about my practice and observations during practice, I noticed that I unintentionally undervalued the knowledge held by persons with dementia. There is limited international literature from the perspective of persons with dementia (Hoel et al., 2021; Ibsen and Eriksen, 2021); most literature on dementia is written from the perspective of healthcare professionals (Dombestein et al., 2022) or of families of persons with dementia (Culph et al., 2021; Holden et al., 2021). This indicated that a failure to value the perspective of persons with dementia is not just my problem but one reflected in the wider literature. I critically reflected on the reason for this and realised my assumptions about the knowledge held by persons with dementia arose from a positivist epistemological stance.

The population group of focus in this reflection is persons aged 65 and older living with dementia in long-term care. According to the Office of Seniors Advocate of British Columbia, Canada (2018), the average age of persons in long-term care is 85, and 63% of this population live with dementia.

In this article I will apply Rolfe and colleagues' model of reflection (2001), which invites healthcare professionals to ask themselves three questions:

- What? (What is the situation?)
- So what? (What have I learned?)
- Now what? (What will I do?)

Additionally, I will refer to the Person-centred Practice Framework (McCormack and McCance, 2017). It was initially developed from a study on nursing care with older adults in a tertiary care hospital. However, it is now widely researched and applied in different settings, such as long-term care (Mayer et al., 2020) and palliative care (Haraldsdottir et al., 2020), as well as disciplines such as physiotherapy (Dukhu et al., 2018). The framework places the person receiving care at the centre, considers people around the person (their family and others who are important to them), and explains how to do this in practice. It encourages healthcare professionals to consider five domains (McCormack and McCance, 2017):

- Prerequisites, such as the attributes, skills, and values of the healthcare professional
- The care environment, including the physical care environment, interdisciplinary team relationships and organisational systems
- Person-centred processes, including the needs, beliefs and values of the person, the engagement of the person, relationships, and shared decision making between the person and the healthcare professional
- Expected outcomes, such as the person's satisfaction with the care received, the person's wellbeing and positive changes to the care environment
- The macro context, including policy and strategic frameworks, workforce development and strategic leadership

In this article, I will identify and critically reflect on my assumptions, arising from a positivist epistemological stance, about the knowledge held by persons with dementia in long-term care in relation to my clinical practice experience. The goal is to break down these assumptions so that I, and other healthcare professionals who might have similar assumptions, can better value the knowledge of persons with dementia.

## The positivist epistemological stance

It is important to discuss positivist epistemology because according to my practical observation and the literature (Krishnan, 2018), it can be deeply rooted in healthcare professionals. Epistemology refers to the study of knowing (McNeill and Nicholas, 2019); it is about how we know, who counts as a knower, and what counts as knowledge (McNeill and Nicholas, 2019; Couper, 2020).

Positivist epistemology involves certain assumptions, key among which is that there is an objective reality (Tshabangu et al., 2021). We may not be able to get to this objective reality, but we can get close to it; by regulating variables, and systematic observation, we can uncover this reality, anticipate what will happen in the future, and generalise the findings to different populations and settings (Stepnisky, 2019). Positivist epistemology sees things in a linear way and categorises them (Stepnisky, 2019). Knowledge is value-neutral (Tshabangu et al., 2021). If we follow procedure, our values will not influence our knowledge. In our society, Staller (2013) suggests we have epistemological unconsciousness – that is, among different epistemologies, the positivist epistemology is privileged and institutionalised. It is taken for granted across different aspects of our lives (Krishnan, 2018). Historically, it has been privileged in science, health and social care. This influenced my initial perspective when working with persons with dementia.

### **What?**

In long-term care in British Columbia, there is an annual care conference for each resident. This is a meeting for each resident, their family and the interdisciplinary team to review and discuss the person's care plan. As a social worker, I am responsible for coordinating and facilitating the care conferences. I can invite the resident to attend or check with them whether they would like me to bring up any issue on their behalf. I have a lot of power over the residents because I can control who to invite based on my assumptions about their knowledge. Previously, I would not invite or check in with persons with a moderate to severe level of dementia, because I had the unintentional assumption that they did not know what they needed or wanted for their care, and anything they said was less valid because of their level of cognition. The danger of this power is that the person is allowed no space to express themselves and I will not have the understanding of their needs and wants that would help me provide person-centred care.

### **So what?**

Later, I learned about different epistemological stances through academic and professional development courses in social work. I realised that my assumptions came from a positivist epistemology. I also learned about constructivist epistemology. A constructivist epistemological stance considers that how we understand the world is socially constructed and different people have their subjective realities. My stance has gradually evolved from positivist to constructivist – an important change because it makes me better able to value the knowledge held by persons with moderate to severe levels of dementia.

The earlier positivist epistemological stance led me to assume that persons with moderate to severe dementia would not be able to communicate knowledge about themselves to contribute to their care. From a constructivist epistemological stance, I now see that experience of cognitive impairment is an individual process; it is different for different people. The notion of cognitive impairment is not fixed but a continuum (Kitwood and Brooker, 2019). I related my reflection to the Person-centred Practice Framework, which proposes that every person, including a person with dementia, can engage in shared decision making with healthcare professionals about their care (McCormack and McCance, 2017). This implies that a person always has knowledge about themselves to contribute to their care. Alongside cognition, all people, including those with dementia, can hold knowledge about the world and ourselves within our bodies – embodied knowing (Hyden, 2018; Isene et al., 2022). We can use our bodies to experience, interact with, interpret, and make meaning of the world and ourselves through our senses. I now consider that persons can still know from their bodies despite their cognitive impairment; this knowledge can contribute to planning their care.

Also, when I came from a positivist epistemological stance, I assumed inadvertently that there was an objective reality, which I knew while the person with dementia did not. Now, from a constructivist epistemological stance, I ask myself: 'What is reality? Is there only one reality? Can we have multiple realities?' When human beings try to understand the world, the concept is elusive (Millett, 2011). Instead, our interpretation of the world is subjective, that is, our subjective reality (Garrow and

Hasenfeld, 2017). This understanding is tentative and partial (McNeill and Nicholas, 2019); since there could be more than one interpretation of the world, there could be multiple subjective realities (McClean, 2020). I now no longer align with the perspective that there is only one objective reality but accept the possibility of multiple subjective realities.

This viewpoint relates to the Person-centred Practice Framework, which highlights the importance of understanding that each person is unique and of respecting their perspective (van der Cingel et al., 2016; Mayer et al., 2020). From observation, I began to learn what reality might look like or feel like from the perspective of the person with dementia. Dementia causes interruptions to the brain, leading to misperceptions, misidentifications, hallucinations, delusions and time shifting, and thus influences how the person makes sense of the world (Alzheimer's Society, 2021). From my practical observation, how the person with dementia makes sense of the world may not make sense to a person without dementia. This can cause frustration to the persons with dementia as people around them cannot understand them, even more so for those who cannot communicate verbally or even non-verbally. Previously I did not value the subjective reality of a person with dementia but this reality had meaning to that person, meaning that was independent of what I thought. It was real to them and, as a healthcare professional providing care to them, I should have respected and valued that.

### **Now what?**

I now align with a constructivist epistemological stance and have changed my practice. I now always invite or check in with all persons with dementia about their care conferences. For those who can attend, the approaches I use so that they can meaningfully engage include asking simple questions, breaking a long question down into shorter questions, and checking regularly to see if they can understand what I and other people are saying, and if we understand them correctly. I observe that they appreciate the opportunity to communicate what they know and being heard, which has positive impacts on their psychosocial wellbeing (Kitwood and Brooker, 2019). For persons with dementia, having this opportunity means being respected. If the person cannot communicate or is non-verbal, I still check with them by asking simple questions like, 'how satisfied are you with our care?' and using communication tools, such as a smiley face rating scale, asking them to point the face that represents their view. I and other healthcare professionals can provide better care by understanding more what the person knows about their needs and wants, how they see the world, and how they may communicate these things.

### **Practice implications**

I will now suggest how I translated what I learned from my critical reflection to my everyday practice. I found the following approaches helpful and I believe that they can promote a greater valuing of the knowledge held by persons with dementia:

- *Practising reflexivity (Garrow and Hasenfeld, 2017)*. I have underlying assumptions influenced by my values, and which are shaped by my social locations. Reflexivity means that I reflect on my social locations, acknowledge my values, and reflect on my relationship with people I care for who are living with dementia (Lumsden et al., 2019; Whitaker and Atkinson, 2020; Bast et al., 2021). Through these processes, I will be more critical, see the power and privilege between myself and the person with dementia, see my assumptions and how I may have missed the value of the knowledge they hold
- *Trying to understand the perspectives of persons with dementia (Garrow and Hasenfeld, 2017)*. I regularly check with them whether they feel I value their input. If the person is non-verbal or has difficulty communicating, I use simple questions and communication tools
- *Using the five interconnected domains of the Person-centred Practice Framework – prerequisites, care environment, person-centred processes, expected outcomes and macro-context – (McCormack and McCance, 2017)*. Reminding myself about the interrelations of these domains is helpful so I keep them all in mind when I work with a person with dementia. For example, when I thought of my social positions as a person without dementia and a social worker (prerequisites),

I realised how powerful I was in a long-term care context compared with a person with dementia (care environment). Therefore, I bear this in mind during my care provision (person-centred processes) as this could influence the person's wellbeing (expected outcomes). Also, I will think about how I can influence policy, such as inviting persons with dementia to attend care conferences, and writing this in the organisational policy (macro context).

## Conclusions

In this paper, supported by Rolfe's (2001) model of reflection and the Person-centred Practice Framework, I critically reflected that I had two assumptions when I worked with persons with dementia in long-term care, based on a positivist epistemological stance. Through revisiting the assumptions from a constructivist epistemological stance, I was able to achieve the goal of breaking down those assumptions so that I can better value the knowledge held by persons with dementia. I now align with a constructivist rather than a positivist epistemological stance. I hope my reflection can be helpful to other professionals working in long-term care who might share my earlier inadvertent assumptions.

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