**How is the pandemic affecting people with dementia? A case study**

Dena Shenk, PhD and Andrea Freidus, PhD, Department of Anthropology, University of North Carolina Charlotte

Our team is completing a rapid appraisal study of the perceptions of frontline long-term care (LTC) workers in a southern state about care during the COVID-19 pandemic. One specific area of heightened concern is caring for people with dementia in congregate facilities during this global health crisis. Person-centered care for people with ADRD (Alzheimer’s Disease and Related Dementias) is based on the knowledge that the care environment plays a large role in determining the nature of the experience and the course of the disease (Shenk 2009). In a person-centered approach, others in the environment must help people with ADRD preserve their sense of dignity and personhood (Agnelli 2015; Higgs and Gilleard 2016; Kitwood, 1997). Person-centered care recognizes people with dementia and, of course, all older adults, as intentional agents and their behavior as purposeful (Hennelly, Cooney, Houghton and O’Shea 2019; McLean 2007, p. 38).

In the current situation, LTC facilities are reportedly either keeping residents in their own rooms or allowing residents with dementia to wander, as we know they often do. The following case, presented in the words of an advocate for residents in LTC, illustrates key concerns about physical distancing and social isolation and alludes to the broader issues related to staffing in caring for people with dementia:

What we get is from family members. And family members are very frustrated. Part of what has happened is, pretty quickly facilities were shut down, as in access to facilities were shut off. So one, the regulators can't go in, the ombudsmen can't go in, family members can't go in. So part of it is like, we have no idea what's going on in some of these facilities. I've got a personal story, not of myself, but someone who I'm close to has a mother who is living in a continuing care retirement community and that facility has done a great job of working with her. Very open communication.

So her mother has dementia, had been in assisted living for not long, three, four months maybe. Was adjusting very well and was really pretty high functioning. The next thing you know, they have an outbreak, a staff member showed up with COVID. So the facility's response. Now, they were absolutely clear with the families, they didn't hide anything, they did everything the way they were supposed to do it. But now think about this. So all the group activities at the facility shut off.

DS (Dena Shenk): Locked in to your room.

People are now isolated in their own rooms and the staff are now all masked up. So the only interaction she has are with human beings that have masks on. As a person who has mild dementia, she does not have a clue what's going on. She becomes agitated. She becomes withdrawn. The facility is doing everything they can do to help this woman communicate with her family. They're using FaceTime, they're using these kinds of things. And my friend is saying that, "When I talk to mom," and she talks to her mom four times a day, "That when I talk to my mom, I'm the only face she sees all day. And she cries, does not have any idea what's going on, doesn't understand. So she stopped eating.” When I'm saying she's become agitated, she's become combative. She's now a, she had not been a wanderer before. She's trying to get out of the facility.

 After several weeks, they had to transfer this woman to nursing and they transferred her to nursing not because she was so sick, but because they didn't have the staffing to manage her behaviors. That woman has gone straight downhill, has now stopped, not completely, but she has stopped communicating. And that woman's gonna die, and she is not gonna die of COVID or anything related to COVID.

DS: But she is.

But she's gonna die.

DS: And it won't get counted as COVID.

No, no. It won't get counted. And that happened in three months. So this example I just talked about is a facility that is a terrific facility, is working with the family in every way they can, is trying to set up as many ways to get communication into this person as possible, has been trying to do programming with her to keep her active and all the rest of it, and it's still headed south.

In a long-term care facility that has focused on transparency and communication, the required physical distancing and social isolation instigated a rapid decline for this woman who was living with dementia. The fact that a staff person introduced the virus raises multiple issues related to staffing that we will discuss in future writings. These include scheduling, high turnover and low pay, equipment as well as staff shortages, working multiple jobs, stress and personal issues. This case highlights major issues around living with dementia in congregate LTC communities, and the impact of social isolation particularly staffing in caring for people with dementia. As we battle this global health emergency, what will we learn and how will we prepare for the future as we try to give care to people with ADRD? Based on our on-going study of the perceptions of frontline LTC workers during the COVID-19 pandemic, we have identified key issues and are developing an understanding of how care has pivoted, in order to inform policy recommendations for future responses to healthcare emergencies. What will we as a society make of this moment?

References

Agnelli, M. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard*, 30(7), 46-50.

Hennelly, N., Cooney, A., Houghton, C., and E. O’Shea. (2019). Personhood and dementia care: A qualitative evidence synthesis of the perspectives of people with dementia. *The Gerontologist*, December 19, 1-16. doi:10.1093/geront/gnz159

Higgs, P. and C. Gilleard. (2016). Interrogating personhood and dementia. *Aging and Mental Health,* 20(8), 773-780.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Berkshire, UK: Open University Press.

McLean, A. (2007). *The person in dementia: A study of nursing home care in the US.* Broadview Press.

Shenk, D. (2009). Moral agency of direct care workers and the people for whom they care. *Journal of aging, Humanities and the Arts* 3: 285-299.