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Person-Centred Care and Persons with Alzheimer's Disease

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At the heart of Catholic Bioethics is an interest in preserving and protecting the wellbeing and dignity of all human life at all of its stages. To this end, the focus is often on the edges of life, on issues like abortion and euthanasia as well as the techniques of assisted human reproduction and stem cell research. But the protection and preservation of human life is not restricted to these life and death topics; just as important and sometimes even more complex are the issues concerning vulnerable patient populations in long-term care settings, particularly persons suffering from Alzheimer's disease and other forms of dementia. Even here we may be tempted to jump immediately to issues such as the use of feeding tubes and terminal sedation; however, the day-to-day care of persons with irreversible dementia provides a very important opportunity to witness once again to the need to protect and preserve the dignity of all persons at all stages of life.

WHAT IS DEMENTIA?

The neurological impairment that is dementia comprises a number of symptoms: "a reduced ability to perform familiar tasks, impairment of memory, judgment and reasoning, and changes in mood and behavior."¹ While some forms of dementia may be temporary and/or treatable, others are irreversible and incurable. Alzheimer's disease is one of the latter. There are more than half a million people in Canada who have

dementia; of these, "more than 60% have Alzheimer's disease."²

CARING FOR PERSONS WITH ALZHEIMER'S

Although the risk of developing Alzheimer's increases with age, and neurological impairment may be profound, many persons with Alzheimer's disease are nevertheless physically very capable. This has care implications. For spouses or adult children committed to keeping the person with Alzheimer's "at home" the constant vigilance needed to keep the person with Alzheimer's and other family member safe can be daunting. The person with Alzheimer's may leave home without proper clothing and become lost. She might inadvertently turn on the stove; she might leave bathwater running. As her disease progresses, family members may have to take on additional tasks of bathing and toileting the person with Alzheimer's, tasks that can become difficult if the person with Alzheimer's becomes agitated and anxious. As well, some persons with Alzheimer's may develop behaviours that caregivers find very difficult. These "need-driven dementia-compromised behaviours" may include "sleep-wake cycle disturbances, screaming, crying, repeated calling out, and pacing."³

Because the likelihood of developing Alzheimer's and the severity of the disease increase with age, the care of the person with Alzheimer's often falls to a spouse who may be frail and in need of care himself. Eventually the decision may be made to place the person with Alzheimer's disease into a long-term care facility.

Many families try to put this decision off for as long as possible because they are afraid of what may be awaiting the person with Alzheimer's in an institution: staff too busy to toilet the residents; incontinence products left unchanged for hours; the smell of urine permeating the hallways; residents labeled “uncooperative” or “noncompliant” when they resist being fed or bathed; staff being unfamiliar with residents’ customs and language of origin; residents being treated like infants and talked down to; residents simply being left on their own for hours. In some institutions, chemical and physical restraints may be used for safety or to ensure compliance. And with increased agitation on both the part of residents and staff, there may also be the risks of verbal and physical abuse.

ROOTS OF CARE CHALLENGES

Why might persons with Alzheimer’s be at risk of receiving poor care in long-term care facilities? There are two main reasons.

The first is the tendency to reduce Alzheimer’s disease to a biomedical condition that concentrates on neurological degeneration of the person who has Alzheimer’s.⁴ This not only fails to capture the complexity of the phenomenon that is Alzheimer’s, but it has care implications as well. With the focus on disease, pathology and loss, care becomes directed to symptom management and physical care of the person with Alzheimer’s. This so-called “task-centred care” is custodial with the resident a passive recipient of care that is directed towards accomplishing activities associated with daily living—feeding, bathing, toileting and so on—all according to a schedule set out by the caregivers. As one caregiver in a task-centred care setting put it, “You do the bare necessities. You get them washed and you get them dressed. You don’t have time to treat them like a person. They are just somebody to get done and then you go to the next one.”⁵

With tasks taking precedence, residents can be regarded as obstacles when they do not cooperate and make accomplishing tasks harder.

Adversarial relationships between staff and residents can develop and, with the emphasis on accomplishment and efficiency, staff can experience high levels of stress when faced with “difficult” residents.

For the person with Alzheimer’s, the consequences of task-centred care can be devastating: “focusing on the patient’s losses or deterioration may reinforce negative perceptions and treatment of the individual with dementia and may also have a significant impact on the progression of dementia.”⁶ Furthermore, “the resulting neglect of psychosocial needs means that many people with dementia spend long hours alone and emotionally distressed in residential care.”⁷

The second risk factor is the tendency to equate loss of neurological functions with loss of personhood. It isn’t uncommon to hear of persons with Alzheimer’s being described as “gone” or “no longer there.” When this happens, it may be easy to objectify people with Alzheimer’s and to believe that their neurological impairment prevents them from having any awareness of how they are being treated. And because of their neurological impairments, persons with Alzheimer’s may not have the resources to fend off the objectification being imposed on them by others.⁸ As non-persons, they become regarded as burdens to others—to caregivers especially—and as “things that need to be managed and controlled”⁹ rather than as very vulnerable individuals in need of very personal and personalized care.

PERSON-CENTRED CARE

In the 1980s, Tom Kitwood, a British psychologist with a background in natural sciences and theology, became interested in the care of people with dementia. Influenced by the

work of Carl Rogers, he became convinced that good care required attending to the psychosocial dimensions of Alzheimer's disease and that the wellbeing of persons with Alzheimer's could not be achieved unless they were regarded and treated as persons.¹⁰ With his colleague Kathleen Bredin, Kitwood determined that the needs of persons with Alzheimer's "began with love at the centre surrounded by ... comfort, attachment, inclusion, occupation, and identity."¹¹ Essential to all of this was the relationship that existed between persons with Alzheimer's and their caregivers and caregivers' constant affirmation of the personhood of people with Alzheimer's, communicated through care and regard.¹²

In a long-term care facility, for instance, person-centred care means that caregivers know residents' names, and *who they are*—their preferences, their histories, their friends and family members. Time is spent engaging persons with Alzheimer's in their own care, and providing choices, meaningful activities and contact. Among the "personhood enhancing interactions" identified by Kitwood are "*Recognition*: Acknowledging the person through words and gestures"; "*Collaboration*: Working together or 'doing with' the person with dementia"; "*Play*: Having fun and being spontaneous and expressive"; "*Celebration*: Allowing for joy in the moment".¹³

In person-centred care, staff avoid the use of language that would demean or objectify persons with Alzheimer's. People who have Alzheimer's disease are not "cases", for instance, nor are those persons who require help with eating or drinking to be called "feeders, anymore than someone who experiences distress or agitation at the end of the day a "sundowner."¹⁴ Staff also understand so-called "undesirable" behaviours as forms of communication and work to address the underlying causes of anxiety and aggression. In person-centred care, it is the person who has Alzheimer's who has priority, with the heart of

caring located in the relationship that exists between residents and caregivers.

BENEFITS OF PERSON-CENTRED CARE

There is a tendency to equate "skilled" care with the medical and technological approaches of the acute care setting and to think of less technological or hands-on care of long-term care settings as "unskilled." This is a false dichotomy. In fact person-centred care requires education, mentoring, and commitment on the part of staff and management.

Is this kind of investment worthwhile from a utilitarian point of view? This remains under investigation but studies so far show that, with person-entered care, persons with Alzheimer's exhibit less agitation and anxiety when being showered and bathed,¹⁵ that sleep patterns were better for residents in institutions that took an individualized approach to scheduling activities, including providing a choice in bedtimes¹⁶ and that agitation generally was reduced for persons with dementia in institutions practising person-centred care.¹⁷ It should be noted that residents' agitation is expensive because of "costs in increased staff time and potential for falls and use of restraints."¹⁸

Person-centred care does not only affect persons with Alzheimer's—staff benefit as well. For instance, person-centred care leads to *staff* empowerment by encouraging "all staff to initiate, become involved in, and take ownership of changes in practice"¹⁹ In task-centred long-term care institutions there are very high rates of absenteeism and job turnover for front-line staff caring for persons with Alzheimer's because of the stress that accompanies the job.²⁰ However, it has been found that when they feel empowered, staff "experience positive employment outcomes, such as increased job satisfaction and reduced stress" which in turn leads to "improved quality of care."²¹

However, for staff members to practise person-centred care, they must first “be treated in a person-centred way” by management.²² They must be respected by managers and administrators as the unique and valuable persons that they are; they must receive the ongoing education and training they require to prepare them for their very important role in the lives of persons with Alzheimer’s; and management must provide staff members with “emotional support as they deal with their own emotional reaction to the decline of residents over time and their eventual death.”²³

In person-centred care, what begins as care of persons with Alzheimer’s permeates and informs the entire long-term care facility.

CONCLUSION

Person-centred care for persons with Alzheimer’s is part of a general trend in changing the culture of nursing homes, from places that are task-oriented to communities that are person-centred. By cultivating meaningful relationships between persons who have Alzheimer’s and the persons caring for them, residents thrive, and so do staff and residents’ family members. While the focus of Catholic Bioethics is often on the life-and-death issues of acute care settings, this very important development in long-term care provides an essential component in the protection of and respect for persons, which is central to the Culture of Life. ■

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¹ Alzheimer Society of Canada, “Guidelines for Care: Person-centred care of people with dementia living in care homes framework,” January 2011, p. 8. http://www.alzheimer.ca/en/About-dementia/For-health-care-professionals/person-centred-care-in-long-term-care-homes/~media/Files/national/Culture-change/culture_change_framework_e.ashx (accessed August 2012)

² Ibid.

³ Lynn Chenworth, et al., “Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia

—care mapping, and usual care in dementia: a cluster-randomized trial,” *The Lancet Neurology* 8 (April 2009), p. 317. <http://journals1.scholarsportal.info.myaccess.library.utoronto.ca/tmp/10485854628711901670.pdf> (accessed August 2012).

⁴ Trevor Adams, “Kitwood’s approach to dementia and dementia care: a critical but appreciative review,” *Journal of Advanced Nursing* 23 (1996), pp. 948, 950.

<http://onlinelibrary.wiley.com.myaccess.library.utoronto.ca/doi/10.1046/j.1365-2648.996.10613.x/pdf> (accessed August 2012); Timothy D. Epp, “Person-centred Dementia Care: A Vision to be Refined,” *The Canadian Alzheimer Disease Review* (April 2003), p. 14.

http://www.livingdementia.com/downloads/newsletters/2010/sept_oct/person-centred_dementia_care.pdf (accessed August 2012).

⁵ Valerie Griss, et al., “Job Stress Among Nursing Home Certified Nursing Assistants: Comparison of Empowered and Nonempowered Work Environments,” *Alzheimer’s Care Quarterly* 5 (2004), p. 211.

http://ovidsp.tx.ovid.com.myaccess.library.utoronto.ca/sp-3.6.06/ovidweb.cgi?Job+Stress+Among+Nursing+Home+Certified+Nursing+Assistants%3a+Comparison+of+Empowered+and+Nonempowered+Work+Environments&link_from=S.sh.18.19.22.25%7c7&pdf (accessed August 2012).

⁶ Epp, p. 15.

⁷ Chenoweth, et al., p. 317.

⁸ Sam Fazio, “Person-Centered Care in Residential Settings: Taking a Look Back While Continuing to Move Forward,” *Alzheimer’s Care Today* 9 (2008), p. 157.

http://ovidsp.tx.ovid.com.myaccess.library.utoronto.ca/sp-3.6.0.6/Person-Centered+Care+in+Residential+Settings%3+Taking+a+Look+Back+While+Continuing+to+Move+Forward.&link_from=S.sh.56.57.60.63%7c12&pdf (accessed August 2012).

⁹ Sherry L. Dupuis, Elaine Wiersma and Lisa Loiselle, “Pathologizing behavior: Meanings of behavior in dementia care,” *Journal of Aging Studies* 26 (2012), p. 163.

<http://journals2.scholarsportal.info.myaccess.library.utoronto.ca/tmp8582742567723476250.pdf> (accessed August 2012); see also: Adams, p. 951.

¹⁰ Adams, p. 948; Fazio, p. 156.

¹¹ Fazio, p. 156.

¹² Fazio, pp. 156-7; Epp, p. 15.

¹³ Fazio, p. 157; italics in original.

¹⁴ See: Alzheimer Society of Canada, “Person-Centred Language,” January 2012.

http://www.alzheimer.ca/en/on/Living-with-dementia/~media/Files/national/Culture-change/culture_person_centred_language_2012_e.ashx (accessed August 2012).

¹⁵ Alzheimer Society of Canada, “Guidelines for Care,” p. 11.

¹⁶ Epp, p. 16.

¹⁷ Chenoweth, p. 318.

¹⁸ Ibid., p. 324.

¹⁹ Chenoweth, et al., p. 324.

²⁰ Griss, et al., p.208.

²¹ Ibid. p. 209.

²² Alzheimer Society of Canada, “Guidelines for Care,” p. 17.

²³ Ibid.