

Can we change our minds?

Dementia, feeding, and advance directives in long-term care

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You have been caring for a 77-year-old man with severe dementia at one of the nursing homes in your community. The patient is nonverbal, incontinent of bowels and bladder, and completely dependent for all activities of daily living. There is no evidence that he recognizes family members or staff. When prompted with a spoon to the lips, he will open his mouth and accept food, chew, and then swallow. Before the onset of dementia, the patient was relatively healthy, and he currently takes only vitamin D, levothyroxine, and acetaminophen; a do-not-resuscitate order is in effect. When reviewing the patient's status with his daughter, she comments that her father would have been horrified to see himself in this condition; she is certain that he would rather be dead than continue with his current quality of life. She asks about his prognosis; given the lack of an acute medical issue, you explain that while severe dementia is a terminal condition, it is possible that he could survive in his current state for months or even years. This information is clearly painful to her, and she ends the conversation by commenting, trusting you will not misunderstand her, that she believes he would not want to be fed by hand, and she wishes that he could just pass away.

Dementia is very prevalent among Canadian long-term care residents. According to data collected by the Canadian Institute for Health Information in 2015 to 2016, 69% of those living in long-term care had a diagnosis of dementia; of those, 82% required extensive assistance or were dependent for activities of daily living.¹ With respect to degree of disability, 40% of residents with dementia were classified as having severe cognitive impairment (defined as a score of 4 to 6 on the Cognitive Performance Scale [CPS], a 0-to-6 scale extracted from standardized long-term care data). If we examine the most severe end of the spectrum (CPS score of 6, which indicates that the patient is either comatose or severely challenged with decision making and totally dependent for eating), data from 2016 to 2021 indicate that patients in this category make up more than 10% of the nursing home population across the country.²⁻⁶ While severe cognitive impairment is associated with mortality, death is not necessarily imminent: a 2010 study noted a 40.6% mortality rate over 12 months in a population of nursing home patients with CPS scores of 5 to 6,⁷ and in another group of similarly impaired patients, just over half (54.8%) died during the 18-month study.⁸

Ethical concerns

The survival of long-term care residents in a state of severe disability may raise serious ethical concerns for family members. Margot Bentley's story came to attention a decade ago when her daughter and husband asked the British Columbia nursing home where she resided to honour the patient's written request to stop providing food and water if she entered a state of extreme physical or mental disability. Bentley was trained as a nurse and had written down her end-of-life wishes in 1991; among her requests she pointedly directed that, "If at such a time the situation should arise that there is no reasonable expectation of my recovery from extreme physical or mental disability, I direct that I be allowed to die and not be kept alive by artificial means or heroic measures" and also that she be given "no nourishment or liquids."⁹ She was diagnosed with Alzheimer disease in 1999, and while her family was able to provide care for about 5 years, her ongoing deterioration eventually required her admission to long-term care. In 2011, with Bentley characterized as having "advanced dementia" but still accepting food when a spoon was brought to her mouth, her family approached the staff of the home and requested that assisted feeding be stopped in line with her written wishes. Administrators with Fraser Health Authority, the operator of the nursing home, refused this request, insisting that they had a responsibility to provide basic care to their residents.¹⁰

Eventually the case was taken to court. In 2014, Justice Bruce Greyell of the Supreme Court of British Columbia decided that "Mrs. Bentley is capable of making the decision to accept oral nutrition and hydration and is providing her consent through her behavior when she accepts nourishment and liquids."¹¹ Bentley's long-time family physician had argued that the fact that she opened her mouth when presented with a spoon was "a reflex and is not indicative of any conscious decision about whether to eat or not."¹¹ However, opinions from a palliative care physician and an incapacity assessor affiliated with the Public Guardian and Trustee held that Bentley was able to show some degree of consent to being fed; although on occasion she had to be prompted multiple times with a spoon before her mouth would open, she demonstrated a pattern of accepting several bites of a particular food before refusing to open her mouth, and then subsequently opening her mouth when presented with a different food. On the basis of this evidence, the judge ruled that hand feeding should continue.

Capacity and consent

This case, and the ensuing decision, raises a number of important questions pertaining to the care of individuals with advanced dementia in long-term care. First, is a patient's mouth-opening response to stimulation with a spoon a reflex or evidence of conscious behaviour? In the Bentley case, clinical assessments by physicians were conflicting. The association of consciousness with swallowing continues to be a topic of empirical investigation: a recent study recruited patients after recovery from coma caused by a severe acquired brain injury and noted that "effective" oral processing of food was found only in those rated as having some degree of consciousness (based on multiple clinical assessments and positron emission tomography).¹² While it is unclear whether these findings can be extrapolated to a population with chronically (rather than acutely) disordered consciousness from advanced dementia, the authors' conclusion that "the presence of an effective oral phase of swallowing seems highly dependent on cortical recruitment"¹² undermines the argument that eating behaviour can be construed as brainstem reflexes.

This observation raises a second question: If chewing and swallowing are conscious behaviour (to some degree), is this adequate to infer capacity to consent to hand feeding, particularly if this runs contrary to a previously expressed wish? Issues of capacity and consent are governed by laws that vary among the provinces and territories; in Ontario (the province where I work), the Health Care Consent Act guides decision making. The Act defines feeding as a "personal assistance service"¹³ and notes that a person

is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision ... and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.¹³

Consider the patient with severe dementia described at the outset and suppose that he previously (while competent) indicated that he did not want to receive nutrition if he were to develop marked dementia. In this case the patient has expressed wishes reflecting specific values about quality of life; if he now still opens his mouth to accept food, and we presume some degree of consciousness, does he appreciate the "reasonably foreseeable consequences" of continuing to eat, even if this perpetuates his existence in a state that he previously indicated was unacceptable to him? While his impaired cognitive status might initially lead us to doubt his capacity, it is an accepted principle that a patient may lack capacity to consent to certain kinds of treatments, but still maintain capacity for others; it is not an all-or-nothing determination. In addition, capable patients are allowed to change

their minds, and while a reversal in this scenario may be *improbable*, it is not *impossible*. If we accept the act of eating as consent, we guard against causing irreversible harm to a patient whose mind has changed. Given the difficulty of assessing the nature of limited consciousness in a patient with dementia, it seems probable that the presumption of a patient's capacity, encoded in the Health Care Consent Act and other pieces of legislation, would support the notion that an eating patient is consenting. An Australian assessment of "preplanned starvation" in the context of severe dementia concluded that the judicial outcome there would likely be the same as in British Columbia, and noted that there likely would be *no* form of advance directive that could legitimately implement this wish.¹⁴

Alternatives for action

As a clinician, then, how do you approach the dissonance between the family's (and possibly your own) understanding of how to act in the best interest of the patient, and the moral and legal concerns about interpreting a patient's wishes in the context of severe dementia? It may be appropriate to engage the family in a reevaluation of the patient's management using a palliative care lens; this could include prohibiting treatment of intercurrent illness, with a narrow focus on symptom management, as a means of respecting his daughter's misgivings about her father's current quality of life. Admittedly, the timeline of an approach such as this is uncertain; however, based as it is on the right of a patient (or substitute decision maker) to refuse treatment, it is well grounded in a clinical and ethical consensus.

However, in a health care environment that promotes patient centredness as a key value, it is not obvious that wishes declared while competent can simply be set aside. The debate around the validity of advance directives in the context of dementia continues, most recently in ongoing discussions of Canadian legislation regarding medical assistance in dying (MAID). Patients with severe dementia lack the ability to consent to the procedure, and it is doubtful that a patient in the early stages of dementia (and capable enough to initiate a waiver of final consent) could be considered to have death "reasonably foreseeable" (in the absence of serious comorbidities) as is currently required. Consequently, MAID would become an option only if an advance request were permitted; it is worth noting that the initial report commissioned by the federal government *recommended* recognizing advance directives in specific circumstances, but this was not ultimately adopted by politicians.¹⁵ The most recent amendment to MAID legislation (March 2021) requires that a government committee reconsider the role of advance requests; as a result, we now have an opportunity to discuss the societal risks and benefits of such a change, using the work that has already been done to frame the key issues at stake.¹⁶

Conclusion

As we anticipate increases both in the long-term care population and in the number of residents with dementia, health care providers will increasingly face questions from family members for whom the survival of their loved one runs contrary to that person's stated wishes. For patients who continue to eat (an action that is not obviously "reflexive"), it may appear that ongoing feeding violates one's right to self-determination, but there is a strong argument to be made that the principle of autonomy requires presumption of consent and continued care. At the same time, while the situation described here is not equivalent to considering MAID, many of the same principles and concerns apply when considering the impact of advance requests, and the current reappraisal of this subject provides a chance for citizens, caregivers, and clinicians to engage in conversation about where this fits in our framework of end of life. 

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Competing interests

None declared

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