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# Advance Directives for Dementia Meeting a Unique Challenge

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**I**n the coming years, an increasing number of people will experience dementia.

Worldwide, the number of people living with dementia is projected to increase from 47 million in 2015 to 132 million by 2050.<sup>1</sup> Family members and clinicians are often unsure whether the care they provide for such patients is the care that patients would have chosen. Across the care spectrum, including skilled nursing facilities, hospital wards, intensive care units, and outpatient clinics, family members and clinicians commonly encounter this dilemma.

National campaigns have increased awareness of advance care planning to guide care for patients who can no longer make decisions for themselves. The Conversation Project, for example, has developed partnerships with more than 400 community organizations across the United States to provide tools to promote end-of-life conversations.<sup>2</sup> Advance directives, when incorporated into comprehensive goals-of-care discussions, are an important part of this planning and help reduce family anxiety about surrogate decision-making.<sup>3</sup>

Standard advance directives are often not helpful for patients who develop dementia. Dementia is a unique disease from the standpoint of advance directives. It usually progresses slowly over many years and leaves people with a long time frame of diminishing cognitive function and loss of ability to guide their own care. Advance directives typically address scenarios such as an imminently terminal condition or a permanent coma, but they generally do not address the more common scenario of gradually progressive dementia.

Clinicians, perhaps unsure of the goals of care for such patients, often may continue to provide the same care they would have in the absence of dementia, without addressing whether plans should be adjusted. Clinicians and family members often find it easier to continue current treatment paths rather than having conversations about whether such care is what a person with dementia would have wanted.

Meanwhile, more people are witnessing first-hand the realities of advanced dementia. Many people may view living with advanced dementia as an unacceptable loss of

dignity and loss of meaning, feeling that if they entered such a state, they would not want medical interventions to prolong their life.<sup>4</sup>

Although progress has been made developing video aids and conversation kits to facilitate discussions about advance care planning in dementia,<sup>4-6</sup> many patients do not have access to a simple written document to express their wishes for care if they should develop dementia. Primary care clinicians frequently encounter patients who are concerned about what would happen if they developed dementia. Many such patients most likely would welcome having an opportunity to provide guidance about their care should dementia occur.

Medical decisions for patients with dementia are typically made by health proxies because patients with dementia, although it progresses slowly over many years, at some point quickly lose decision-making capacity. These proxies often experience enormous anxiety trying to guess their loved ones' wishes. A dementia-specific health directive could lessen this burden by providing some clarity about patients' values and goals that could then help support decision making.

Achieving concordance between patients' informed goals and their medical care is emerging as a valuable quality measure,<sup>7</sup> and governmental agencies, such as the US Department of Health and Human Services, are paying increasing attention to improving quality of care for patients with dementia. Implementing dementia-specific advance directives could improve care for patients with dementia by promoting more thoughtful, compassionate approaches to care in the later stages of the disease.

How might a dementia-specific advance directive be framed? For practical, widespread adoption, the directive would need to be brief and accessible but detailed enough to address 2 variables: (1) the changes in cognition that occur as dementia progresses and (2) the changes in goals of care that patients would want along the continuum of the disease.

To address changes in the disease, the directive could list cognitive milestones of dementia grouped into mild, moderate, and severe stages. A paragraph could describe each stage by listing several developments that typically occur at that stage. Examples of developments that could be listed at the various stages include difficulty remembering recent events for mild dementia, difficulty understanding simple conversations for moderate dementia, and losing the ability to recognize people and manage self-toileting for severe dementia. Patients could then be guided to choose goal-oriented values for each of these stages, choosing from a specific set of options at each stage.

Possible example of goal-directed options for a dementia-specific Advance Directive:

*If I had (mild, moderate, or severe) dementia, then I would want the goal for my care to be:*

- *To live for as long as I could. I would want full efforts to prolong my life including efforts to restart my heart if it stops beating.*
- *To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked and I would not want to be placed on a breathing machine. Instead, allow me to die peacefully. I choose this option, at this stage, because if I took such a sudden turn for the worse, my dementia likely would be worse if I survived, and I would not want the trauma of cardiopulmonary resuscitation or a breathing machine.*
- *To receive care only in the place where I am living. I would not want to go to the hospital even if I were very ill. If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to a hospital. Instead, I would want to be allowed to die peacefully. I choose this option, at this stage, because I would not want the possible risks and trauma that can come from being in the hospital.*
- *To receive comfort-oriented care only, focused only on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.*

The best time for patients to complete a dementia-specific advance directive would be before they develop signs of dementia. This is because even with early cognitive impairment, patients may lose the ability to complete complex planning about future medical decisions. As such, a directive like this ideally should be offered to patients before dementia occurs, as a supplement to a standard advance directive form.

One particular issue that causes difficulty for some families is whether to use feeding tubes in late-stage dementia. This raises the question of whether the use of feeding tubes should be included as an option in a dementia-specific advance directive. Their use in advanced dementia has been carefully studied, however, with wide consensus that they pose significant harm without measurable benefit.<sup>8</sup> For this reason, there is little rationale for offering artificial nutrition as an option in a dementia-specific health directive.

The question of whether people are able to give guidance about care they would want in a future state has been raised as a concern for all types of advance directives.<sup>9</sup> For dementia, given the long time frame and gradual loss of "self," such considerations are especially important. These ethical concerns, regarding advance directives in general, have been resolved by considering that enough of a person's identity remains that their previously expressed wishes can still provide useful guidance,<sup>9</sup> and society has widely embraced the general value of advance directives. The complexity of this issue in relation to dementia, however, clearly highlights the need for continued discussion and research in this area.

Fully developing a practical dementia-specific health directive will require input from many groups including patients, clinicians, families, and experts in the fields of dementia, geriatrics, and palliative care. Once this advance directive is developed and

completed, patients would have the assurance that their values and goals have been recorded, clinicians would have the guidance of using such a document with families as part of advance care planning, and families would have the comfort that the care plans they choose for their loved ones are guided by what their loved ones would have wanted.

The alternative, of allowing patients to reach late dementia without being given a simple, practical opportunity to indicate the care that they would want, will facilitate an epidemic of suffering and burdensome health care. An increasing number of people have views about the care they would want if dementia were to occur, and every effort should be made to honor those wishes.