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The Limits of Advance Directives in Maintaining Autonomy in Patients with Advanced Dementia

Donald O. Kollisch, MD,[a,b] **Robert B. Santulli, MD,**[c,d] **James L. Bernat, MD**[e]

[a]Departments of Medicine and Community and Family Medicine, Geisel School of Medicine at Dartmouth, Hanover, NH; [b]VA Medical Center, White River Junction, Vt; [c]Department of Psychiatry, Geisel School of Medicine at Dartmouth, Hanover, NH; [d]Department of Psychological and Brain Sciences at Dartmouth College, Hanover, NH; [e]Department of Neurology, Geisel School of Medicine at Dartmouth, Hanover, NH.

ABSTRACT

As dementia becomes more prevalent in the aging population, clinicians increasingly face the challenge of caring for patients who had told family members that they preferred death to life with advanced dementia. Advance directives can guide management, but usually are inadequate in caring for patients with advanced dementia. The "now" patient has very different sensibilities than the "then" patient who had expressed preferences for terminal care before dementia severely impaired cognition and executive function. Clinicians lack clear means of following a patient's directive to die rather than to live with advanced dementia. Withholding life-sustaining oral feeding or fluids is ethically problematic. Controversies remain over precedent autonomy as the justification for advance dementia directives, and the consequent legal, ethical, and practical issues clinicians face, particularly involving feeding.

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The tragedy of advanced dementia is increasingly common and always heartbreaking. Most everyone knows a family member or friend with advanced dementia and wishes to avoid suffering a similar fate. We all have heard the remark, "If I ever get like that, shoot me!," by which the speaker states a preference for death over a progressive, undignified, hopeless, and meaningless state of dependency without agency. Some patients with early-stage dementia draft advance directives refusing feeding, but later lack the ability to execute their plan.[1] The current limitations of advance directives consign most patients with dementia to enduring their feared fate.

Our society cherishes respect for autonomy and incorporates it into law and medical practice. But the problem remains how to respect the autonomy of patients with progressive dementia given the limits of advance directives, the ethical and legal barriers to various actions, and the practical problems of implementation. We analyze the limits of advance directives in dementia and how other societies have expanded them to allow patients to die prior to reaching advanced dementia. We identify areas of consensus and of no consensus.

MEDICAL CONTEXT AND ADVANCE DIRECTIVES

Dementia is a broad syndrome encompassing different pathologic diagnoses. While some signs and symptoms of dementia differ by diagnosis, most dementias show classic cognitive, functional, and behavioral features and vary more as a function of severity than of specific pathology.

Clinicians determine decisional capacity, but competency is a legal determination made in court, informed by a medical evaluation of decisional capacity. Decisional capacity requires the ability to understand the choices offered, the risks and benefits of each, the ability to appreciate one's present condition, the ability to clearly and consistently state one's choice for care, and to communicate the reasons for the choice.[2] Patients with dementia often retain decisional capacity in the mild stage, including the ability

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Requests for reprints should be addressed to Donald O. Kollisch, MD, Geisel School of Medicine at Dartmouth, 93 E. Wheelock St., Hanover, NH 03755.

E-mail address: donald.o.kollisch@dartmouth.edu

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to issue advance directives. As decision-making becomes increasingly impaired, surrogate decision-makers become necessary.

Advance directives for medical care are of 2 general types: written instructional directives (such as "living wills") and appointment of a durable power of attorney for health care (DPOA), authorized to make medical decisions on behalf of incapacitated patients. Advance directives have been shown to be useful in planning for future medical care, specifically in decisions to withhold or withdraw medications, life-sustaining treatment, medical nutrition and hydration, and hospitalization decisions.

Specialized advance directives have been designed for patients with dementia that govern treatment in later stages.[3-5] For example, the Dartmouth Dementia Directive permits patients to express preferences for medical care, feeding, and location of care, depending on the stage of dementia.[5] The patient may indicate whether the directive should be followed despite contemporaneous expressions to the contrary or if the DPOA should consider past wishes but make decisions based on current circumstances.

CLINICAL SIGNIFICANCE

- Clinicians increasingly face the challenge of caring for patients who say that they would prefer death to life with advanced dementia.
- The "now" patient with dementia has very different sensibilities than the "then" patient who had asked to not lose autonomy.
- The controversy of precedent autonomy as the justification for advanced dementia directives provides a framework for working through the inevitable conflicts.

Some scholars reject the validity of precedent autonomy and oppose dementia-specific directives. They propose that the patient discuss general treatment preferences and goals of treatment with the lawful surrogate, who later can adapt those general preferences to specific situations.[6] Written instructions are reduced to those legally necessary in their jurisdiction.

PRECEDENT AUTONOMY

The conceptual foundation for all advance directives is respect for precedent autonomy, meaning that a person with decision-making capacity can provide instructions to guide treatment decisions in future states of cognitive incapacity, and that those instructions should be followed to respect the autonomy of the earlier self. Philosophers have pointed out that the concept of precedent autonomy contains an ambiguity. Can it be valid to attribute a preference to an incapacitated patient who no longer can understand it and no longer may have that preference? Moreover, does an earlier capacitated patient possess the moral authority to exercise control over one's incapacitated future self?[7,8]

In his book *Life's Dominion*,[9] Dworkin strongly endorsed the concept of precedent autonomy and urged caregivers not to feed patients who had validly executed such a directive. Dworkin's analysis contained the insight that the conflict arose because everyone had 2 sets of usually compatible personal interests—critical and experiential. When they conflict, which interest should prevail? Critical interests are a person's longstanding convictions about what is important in life, which define that person's identity and personhood. In contrast, experiential interests are transient desires resulting from experiences of hunger, pain, pleasure, fear, or other sensations or emotions. Dworkin argued that critical interests demand greater respect than experiential interests because they venerate the autonomy of the longstanding self. He maintained that enforcing advance directives upholds precedent autonomy by permitting our critical interests to prevail over our experiential interests.[9]

Other scholars took the opposite view, arguing that it is the "now-self" who no longer knows or cares about his prior directive, and that desire should be respected.[6] Dresser[10] pointed out that an objective balance of benefits and burdens favored feeding the patient. Further, early life preferences about treatment can change with aging, such that older people often are content with a quality of life that they previously regarded as intolerable. We permit people to update their directives, respecting these changes with aging and infirmity.[10] The majority of palliative care physicians support respecting experiential interests of the patient at each stage of life.[11] In fact, "comfort feeding" of severely demented patients, without a goal of enhancing nutrition, is an accepted hospice principle.[12] Some states may require institutionalized dementia patients to be spoon-fed no matter what their advance directive stipulates.[13]

All forms of autonomy, including precedent autonomy, have limits. A libertarian interpretation of autonomy exaggerates the importance of independence and unfettered personal preferences, as if people lived their lives in isolation and cared only about themselves. A more realistic view of autonomy is that, because our lives are embedded within our families, friends, and cultures, we make decisions by considering how they will impact others for whom we care. For example, an older, chronically ill person may seek a do-not-resuscitate order and refuse all life-sustaining therapy, primarily to leave assets to his children and prevent them from being consumed by a long terminal hospitalization. Respecting autonomy to refuse life-sustaining treatment recognizes patients' motivation to altruistically enhance the welfare of others.

Does a formerly intellectually intact patient remain the same person as before or have they changed in a way so fundamental that it absolves the duty to respect an earlier directive? Obviously, the person with advanced dementia has changed, often dramatically. From both philosophical and legal perspectives on personal identity, however, the patient with advanced dementia remains the same person as before.[14] It would be arbitrary to demarcate a threshold within this continuum for loss of personal identity.[15]

ETHICAL AND LEGAL ISSUES

How much force should advance directives in dementia patients exert on caregivers to faithfully execute them? Ordinarily, specific directives should be followed. But what if caregivers believe that an advanced directive to forgo feeding the patient is unethical? This is not a purely theoretical concern. In some cases, the decision over honoring it has divided family members into opposing groups that quarreled over whether to respect the directive or to feed the hungry family member.

This conflict is an ethical dilemma because both respecting and ignoring the directive can be defended or attacked on ethical grounds. Some family members vigorously advocate upholding the terms of the directive as respecting the dignity and honoring the deeply held wishes of the patient. Others advocate ignoring the directive and addressing the current comfort and happiness of the patient by arguing that it is simply inhumane and cruel not to feed the family member who is asking for food. A parallel conflict also arises among institutional staff members, some of whom may make conscientious objections to following the directive.[16]

Legal questions in dementia care often parallel ethical ones. Are advance directives that prohibit oral feeding lawful and enforceable? Does following or ignoring such directives incur personal or institutional liability? The answers vary among states and usually require local expert legal advice to ensure compliance with state laws and regulations. Nevertheless, a few general points can be made.[17]

In 1991, the US Supreme Court in *Cruzan*, established that citizens have the constitutionally protected right to refuse all forms of therapy, including life-sustaining therapy without which they will die, which encompasses medically provided hydration and nutrition. American jurisprudence over 40 years has established the authority of capacitated people to issue directives to govern their care in future states of incapacity, including the naming of a surrogate decision-maker empowered to make medical decisions on behalf of a cognitively incapacitated person. The exact authority of the surrogate to refuse medically provided hydration and nutrition varies among states.[18] Nonetheless, surrogates and family members are expected to honor wishes of lawful advance directives.

Some advance directives test the limits of the duty of caregivers to comply. Currently, no regulatory, statutory, or case laws require caregivers to withhold oral feedings from patients who had stipulated in an advance directive that they did not want to be fed, but many states do have regulations requiring adequate nutrition of dependent elderly patients.[19] The liability of a caregiver who follows a directive not to feed remains theoretical, although it is plausible that not feeding a demented patient under these circumstances could be construed as elder neglect. Because of state laws requiring the provision of nutrition to their residents, institutions may face liability for following a directive not to feed. As a result, lawyers representing nursing residences routinely advise their staff not to comply with patients' non-feeding advance directives. Nevertheless, at least one law professor wondered if the act of feeding a demented person whose advance directive forbade it might be construed as battery,[20] and others insist that an advance directive forbidding eating and drinking in advanced dementia is already lawful.[21]

The Ulysses contract is a specific type of advance directive in which a patient with fluctuating decision-making capacity provides advance consent for treatment during predictable periods of incapacity. Ulysses contracts are most frequently used by psychiatrists caring for patients with bipolar affective disease. Patients, while healthy, authorize treatment during periods of acute mania, which they would frequently refuse because they are euphoric or deny illness.[22] The name derives from the Siren episode of Homer's *The Odyssey*. Odysseus (Ulysses) orders his men to bind him to the mast and to plug their ears with beeswax as they pass the Sirens whose songs would irresistibly attract them and wreck the ship on the rocks. Odysseus instructs his men not to release him even if he orders or begs them, which he does on hearing the Sirens' songs. The theoretical basis of a Ulysses contract is precedent autonomy, which empowers the healthy self to overrule irrational decisions made later by the sick self. An advance directive prohibiting oral feeding is a type of Ulysses contract but its medical and legal status, while established for psychiatric indications, remains untested in dementia.[23]

PRACTICAL ISSUES

The roles of clinicians, family members, and caregivers in managing patients with advanced dementia vary, depending on the setting of care. When a patient resides at home, important decisions are made by the patient and primary caregiver. These range from simple to profound, such as when to seek medical care, and when to stop eating and drinking. Other family members and home health aides can play an important role. Clinicians can help guide decisions with changes in clinical status. As the patient loses decision-making capacity, patients and families can consult elder lawyers.

Roles shift when patients are admitted to long-term care facilities.[24] Staff nurses and care aides make daily decisions, based on facility protocols, with family decision-makers assuming an advisory role.[25] Attending physicians, medical directors, and administrators influence decisions about nutrition and end-of-life care. During episodes of acute illness or injury, family and facility staff choose the intensity of medical care and decide whether to transfer to the hospital.

Hospitalized patients and families lose even more agency as decisions are made by unfamiliar staff. DPOAs provide guidance, but the role of families may be diminished. Palliative care teams can help staff respect the preferences of patients and families. Care management programs can help balance family preferences with knowledge of resources in the community. Chaplaincy services can provide emotional and spiritual support. Nursing and medical staff may seek the assistance of the hospital ethics committee to resolve disputes.

Decisions about nutrition and feeding present common challenges. If the patient expressed a desire not to be offered food or drink in a dementia-specific advance directive, home living offers few interferences with honoring that intent. These dynamics change with admission to a hospital or long-term care facility. The former role of a primary care physician, who knew the patient and his wishes, now shifts to the facility's medical staff. Nursing staff are now responsible for determining if a patient is hungry, and reflexive rooting and swallowing can be misinterpreted. Medical or nursing staff may disagree with an advance directive, and family members may find it difficult to advocate for the patient.[26]

"OPTIONS OF LAST RESORT"

Advance directives usually are insufficient to prevent the feared outcome of loss of personhood and dignity in advanced dementia. To allow people to fully exercise their autonomy and ensure that their life ends under control, a few societies permit interventions that accelerate the moment of death for terminally ill capacitated patients. Quill[27] termed these interventions "options of last resort" to emphasize that, while aggressive palliative treatment remains the medically indicated first approach in terminal illness, one of these options may be requested by a dying patient if palliative measures fail to adequately relieve suffering. Some of these options currently are unlawful in the United States but are lawful in a few countries.

Voluntarily stopping eating and drinking (VSED) to hasten death is lawful in all jurisdictions and increasingly common for patients with terminal illness and some severe chronic illnesses.[28] Patients must be highly motivated, and it is essential to enlist cooperation from family members and assistance from hospice nurses. But VSED is not a suitable option for patients with moderate or advanced dementia because such patients no longer can understand the reason, or voluntarily forgo food and water, as they may in early-stage dementia.[29] Nevertheless, some legal scholars have cited the societal acceptance of VSED in the capacitated patient as the precedent for refusing food and water by advance directive,[19] despite the fact that in the patient with advanced dementia it is no longer voluntary.[30]

In the United States, 9 states and the District of Columbia have legalized physician-assisted death (physician-assisted suicide), though none have legalized voluntary active euthanasia.[31] All states that have legalized physician-assisted death require the patient who requests it to possess decision-making capacity, for the request to be voluntary and consistent, and for the patient to be certified as terminally ill, usually meaning that death is anticipated within 6 months. Patients with severe dementia are categorically excluded from eligibility on all of the above grounds.[32] Nevertheless, some scholars have advocated that patients with advanced dementia should be permitted to request physician-assisted death by advance directive.[33] This option is lawful in Belgium and the Netherlands, and some scholars have predicted that it will become lawful in the United States in the future.[34] Voluntary active euthanasia in dementia by advance directive is practiced in the Netherlands, where 60% of surveyed Dutch citizens agree it should be available, but fewer than a quarter of physicians are willing to perform it.[35] The adequacy of oversight of this program has been questioned.[36]

Palliative sedation refers to a form of aggressive palliative therapy in which the only way comfort can be achieved is by sedating the patient to unconsciousness. It becomes necessary in some terminal illnesses complicated by intractable pain, nausea, dyspnea, or agitation. Palliative sedation remains controversial because it accelerates the moment of death and, although it has been called "slow euthanasia" by some critics, it is regarded as acceptable palliative care if no alternative can provide adequate comfort.[37] Severe dementia is not an accepted indication for palliative sedation, although some dementia patients with extreme agitation have been treated with it.[38]

FUTURE DIRECTIONS

Substantial challenges remain to maintaining patients' autonomy as dementia progresses. There is consensus that the goals of care shift from active management to palliation and comfort. Most advance directives—such as those covering do not resuscitate, do not hospitalize, and withholding antibiotics—can by followed without conflict.

Consensus is less developed over how to manage a patient with a do-not-feed advance directive who does not request food. Some experts believe that such patients should be offered food and water, and the staff of long-term care facilities may interpret state law to require it. Future research should explore the boundaries of precedent autonomy in managing oral feeding in patients with "do-not-feed" advance directives who appear to want to eat.

The extension of physician-assisted death options to patients with dementia would require major changes to laws and seems unlikely in the foreseeable future. Consensus is even more unlikely on the appropriateness of active euthanasia for patients with advanced dementia, which remains illegal in all jurisdictions for any indication.

Patients who seek to avoid the loss of dignity, agency, and autonomy of advanced dementia should explore the use of dementia-specific advance directives and express their desires and hopes as completely as possible with family caregivers and clinicians. Families of patients in long-term care facilities should discuss the patient's wishes with the facility's staff and leadership on admission.

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