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An Ethical Discussion on Voluntarily Stopping Eating and Drinking by Proxy Decision Maker or by Advance Directive

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The number of people living with Alzheimer disease and other dementias continues to grow because of the aging of the US population. Increasingly, the issue of patient- and/or surrogate-directed withholding of oral, hand-fed food and fluids in cases of late-stage dementia is confronting caregivers. Major media outlets have covered several cases wherein patients with explicit directives or clear surrogate decision making were not allowed to face the end of their lives according to their wishes. Ethical and legal scholars, as well as many end-of-life advocacy groups, are working to develop a framework and provide guidance in these cases. A local hospice organization was faced with these ethical deliberations when an activated proxy decision maker advocated for caregivers to stop hand feeding an incapacitated patient with end-stage dementia. In this article, this case is summarized, and this important ethical issue is presented in the setting of a literature review and nursing implications.

KEY WORDS

advance directive, dementia, proxy, surrogate, voluntarily stopping eating and drinking, VSED, withholding

It is estimated that more than 3.5 million Americans are living with Alzheimer disease today; of those, 1.5 million are in the late stages of the disease.[1] Those individuals diagnosed with this form of dementia, as well as those with other types of dementia diagnoses, are often encouraged to complete advance directives before a time comes when they may be unable to make their wishes known; approximately one-third of these patients do.[2]

Increasingly, the ethical issue of withholding hand-fed oral nutrition and hydration has confronted health care providers treating patients with late- and end-stage dementia. The individual patient's right to engage in voluntarily stopping eating and drinking (VSED) has long been recognized as an autonomous choice for patients with terminal illness. The ethics of VSED continue to encourage conversation, but the process has long been seen as not being analogous with suicide in the terminally ill. However, ethical considerations abound when caregivers are faced with stopping oral nutrition and hydration in the patient who no longer has capacity.

Recently, there have been cases wherein patients' end-of-life (EOL) wishes have not been honored to not be hand-fed oral nutrition and hydration,[3,4] including both patients with written directives and the decisions and directives of patients' activated health care proxies. Although both direct patient directives and proxy decision making are accepted to direct the withholding or stopping of artificial nutrition and hydration (eg, enteral tube feeding, total parenteral nutrition, intravenous fluids), both are considered questionable as direction for stopping oral nutrition and hydration in those with advanced dementia. Rarely will an argument be made that a patient dying from dementia should be forcefully hand fed, but what about when the patient still voluntarily opens his or her mouth and is able to swallow safely when fed? What happens if they appear to enjoy food or even spontaneously request it?

CASE PRESENTATION

H.P. was a 72-year-old patient in the final stages of Alzheimer disease. He had been diagnosed with the early onset of the disease 14 years earlier, at the age of 58 years. H.P. was admitted to the inpatient hospice facility under routine care status after a hospitalization for sepsis related to aspiration pneumonia and a urinary tract infection. He had been hospitalized 3 times in the year prior for pneumonia and falls. His prognosis was expected to be short, but he stabilized after his admission to hospice.

H.P.'s wife of 40 years was his activated power of attorney for health care. Since his admission, she had been agreeable that H.P. be hand-fed whatever types of foods he was able to enjoy, despite past dysphagia and aspiration. Most times, when hospice staff hand fed him, H.P.

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would open his mouth, chew, and swallow what was given to him. His wife later said she had agreed to this because of how short-term his prognosis was expected to be.

After being a routine patient of the unit for approximately 2 months, H.P. continued to open his mouth when fed, despite being nearly unresponsive to his surroundings otherwise. He had continued to lose weight and had become even more frail. H.P.'s wife requested a care conference with the hospice team where she requested that the hand feeding be discontinued. As his health care proxy decision maker, she felt this would most closely honor H.P.'s clearly stated wishes that no life-sustaining treatment be continued once he was in the final stages of his disease. She felt that he did not want to eat and was only opening his mouth reflexively when his lips were touched. In addition, she stated it was clear to her that he was no longer enjoying the act of eating. She said they had even once talked about the concepts of VSED and physician aid in-dying, which H.P. supported in use for patients with terminal illness. The request from H.P.'s wife was discussed by the hospice interdisciplinary team and leadership and was met with ethical concerns from some staff members, including some nurses and unlicensed assistive personnel (UAP) who cared for H.P., as well as the hospice's administration.

SUMMARY OF THE LITERATURE

Adults facing a new dementia diagnosis have important choices to make. They are frequently urged to complete an advance directive wherein they designate a proxy decision maker and document their wishes regarding measures they want or do not want to be taken at the end of their lives. These patients should be directed to have difficult discussions with their families and proxies regarding their wishes. When it comes to the concepts of "VSED by proxy," or "VSED by advance directive," there are a host of new complicated decisions and processes to be considered.

Despite enhanced advocacy, there are still patients who do not or are unable to complete a standard advance directive after a diagnosis of dementia. When no EOL wishes are documented, proxies (whether officially appointed as power of attorney or appointed by next-of-kin statutes) are generally designated as decision makers for incapacitated patients. Although it is generally agreed upon that including family and friends in surrogate decision making improves care, it can also be problematic.[5] There will always be a question of whether the proxy is making an accurate decision or a decision the patient would have made for himself or herself. Considerable stress can be put on the shoulders of the surrogate not only to make decisions that seem morally sound for the situation but also to honor the patient's wishes.[5]

When studied, family decision makers tend to use "patient's likely wishes" or "patient's tendencies in life" as key inputs in their thinking.[6] They also tend to take into account new medical information that was not previously available to the patient and recommendations from health care providers in their decision making. This can lead proxies to make decisions that may be different than even the documented wishes of a now incapacitated patient.[6] Many decision-making aides have been created to assist surrogates in making serious decisions for incapacitated patients. In addition, new, detailed advance directive for dementia (ADD) documents may facilitate patient self-advocacy.[2,7-9]

End of Life Choices New York has created an advance directive document to specifically address the issue of hand feeding in those with end-stage dementia. The document, entitled "Advance Directive for Receiving Oral Foods and Fluids in the Event of Dementia," gives individuals the ability to choose between 2 detailed options. These 2 options are only to be acted upon if patients are both unable to make informed decisions (incapacitated) and they are unable to feed themselves.[10] Patients are able to make an informed decision between "option A" (stating the desire for no hand feeding whatsoever, even if one opens his or her mouth in response to being fed) and "option B" (stating several provisions where hand feeding would be acceptable [one opens his or her mouth willingly or seems to enjoy the food]) until one stops opening his or her mouth when fed. The directive goes on to discuss wishes for hygiene and comfort and where care should be performed.[10]

Importantly, the End of Life Choices New York document[10] contains several pages of instructions for anyone considering its use. In addition to giving guidance on the completion of the directive, it encourages users to name an agent for health care decision making, consider completion of a medical order for life-sustaining treatment with a physician, and provide multiple copies of the document to anyone who may be involved in its execution.[10] One of the additional steps the organization urges is for the directive user to create a video statement wherein he or she explains why the directive was completed and what values guided his or her decision-making process.[10] In addition, the user should specify that the decisions made in the directive were made without coercion. End of Life Choices New York advocates the use of videos such as these as a way of potentially facilitating a legal defense of the directive if necessary.[10]

Another advocacy group, End of Life Washington, has created a document entitled "My Instructions for Oral Feeding and Drinking," intended to be used for the same purpose.[9] In this document, one is able to direct future caregivers to provide "comfort feeding" by hand until any of several conditions occur, including the patient appears indifferent to being fed, does not willingly open the mouth, spits out food, or turns the head away during feeding.[9] Both of these advance directive documents specifically state that the signer does not wish to be "cajoled, coerced, or forced to eat" at any time in their disease progression.

Both ADD documents also encourage the patient to ensure any long-term care facility they may enter will honor the wishes described in that document. This may be due, in part, to several high-profile cases where such facilities refused to honor patients' EOL wishes to not be hand fed. The New York Times,[4,11] The Hastings Center,[12] and Kaiser Health News[3] have all published articles addressing this issue. All discuss the difficult position that skilled nursing facilities are put in when faced with an advance directive instructing caregivers to withhold oral food and fluids.

One particularly high-profile case was litigated in British Columbia, Canada, between 2011 and 2014.[13] In this case, the patient, a retired nurse, had completed a statement of wishes directing that "all nourishment and liquids" be held once she was in the advanced stages of her dementia.[13] Later, when her family advocated for the following of these wishes at the patient's care facility, the facility denied compliance with the directive. There was a police order obtained to stop the removal of the patient from the facility by the family. In the end, the court issued a judgment that did not specifically speak to the legality of following an ADD. Instead, the court ruled that the directive was not specific enough to be legally followed. The patient had not specified that she would want "oral" nourishment and liquids held. She had also not detailed whether her named surrogates could make decisions for her beyond the scope of what is deemed "health care." The court said it was unclear whether the patient would have wanted them also to make decisions regarding her "personal care."[13] This patient's case has become a legislative touchstone for continued development of very specific directive documents.

ETHICAL CONSIDERATIONS

One of the most challenging ethical questions created by cases such as these considers whether the provision of oral hand feeding constitutes a health care procedure or whether it is basic care. Does the stopping or continuation of oral nourishment fall under the scope of decision making granted to a surrogate in a traditional advance directive? Often, the concern raised by the care facilities that have opposed withholding oral food and fluids from patients lies with this ethical question: Is providing spoon feeding to patients who cannot feed themselves considered health care? Or is it basic care akin to bathing and other personal or custodial cares?[4,11,12]

When either asked by an activated health care surrogate or legally directed by patients themselves to stop hand feeding, should highly regulated facilities have the right to decline honoring patients' wishes? Can patients and/or their loved ones ethically make such a request and expect nonfamily caregivers to carry it out? Does opening one's mouth and swallowing constitute consent for feeding? And if so, why is this the only thing to which an incapacitated person is allowed to consent? What if, when honoring the wishes of a patient to not be hand fed, he points to food or requests it specifically? These and other questions are the reasons this topic remains such an important ethical issue.

It has been established that medical providers are unable to forcefully feed or hydrate a competent, terminally ill patient who has chosen to engage in VSED,[14] but what then about "VSED by proxy" or "VSED by directive?" Can this version of patient decision making to engage in what has been deemed an ethically acceptable method of hastening death be ignored? The health care community has accepted both advance directive and proxy decision makers to ethically and legally stand in for patients deemed incapacitated to make their own decisions. Clinicians have decided to allow directives and proxies to speak for a patient, even if there are personal objections to these choices. The implementation of detailed advance directives, those specific to decision making in patients with dementia, will be necessary as this topic continues to provide ethical apprehension in those caring for such patients. In addition, consideration needs to be given to whether it is appropriate for caregivers or facilities to be able to conscientiously object to the carrying out of withholding food and fluids from patients with advanced dementia.

Significant moral objections to the withholding of oral food and fluids are raised and must be carefully considered in an ethical discussion on the topic. Heath[15] argues that requests to follow any of the new ADDs are actually requests for euthanasia. By starting with the assumption that a competent, terminally ill individual who engages in VSED is committing suicide, she crafts a logical argument that VSED by directive/proxy is a passive form of euthanasia.[15] In addition, Heath[15] contends that VSED by directive or proxy lacks a crucial consideration that exists when VSED is used by a competent person: the ability to change one's mind and reverse the decision at any point in the process by simply starting to eat and drink again. She feels that, because the individual no longer has the ability to stop the process at any time, as a competent decision maker would, this is no longer a choice and now something being forced upon a vulnerable, compromised person.[15]

Cantor[16] contends that both patient and surrogate directives for the rejection of hand feeding and hydration should be honored, citing a Thomas Cochrane argument[17] that patients' constitutional right to self-determination holds that patients should reasonably be able to forbid any and all unwanted touching of their person. Both Cantor[16] and

Cochrane[17] posit that, because VSED is an accepted and legally upheld means of hastening one's death, there is no reason for advance directive or surrogate decision making to be viewed as anything but the patient deciding to engage in such an act. Because it is accepted that advance directives and proxy decision making can be ethically adhered to in place of a patient being competent to make choices about all other health care matters, we must ask why would such a decision about what kind of nutrition/hydration a patient should receive be viewed any differently?

OUTCOME OF THE CASE

An extensive ethical review within both the hospice organization and the partner organization was conducted regarding the case of patient H.P. Considerations were many, including the partner organization being a religious entity, hospice staff being morally opposed to carrying out H.P.'s spouse's wishes, and the family advising that they would "take the patient home to stop the feeding" if the hospice was unwilling to do so. It was determined that the hospice would honor the wishes of H.P.'s spouse. Hand feeding and provision of fluids would be stopped, and the patient would be kept in the controlled environment of the facility to help ensure all possible comfort measures would be available to H.P. H.P. died comfortably several days later.

Although the outcome of this case may seem tidy, it is not without complications. At least 1 member of the hospice staff expressed ongoing feelings of guilt about this case, so much so that they were considering leaving hospice nursing altogether. In addition, during the ethics committee review of this case, differences between the hospice organization and its partner became clear. Because, in part, of the partner's religious affiliation, they felt the hospice's decision to honor the wishes of the proxy decision maker for H.P. constituted a moral failing of the organization. The partner remained unwilling, also, to provide alternative solutions or referrals for other providers. As the partner was not a directing authority for the hospice, the final decision was made by hospice staff and administration. The case of H.P., with all of its intricacies and emotional deliberations, has remained with those involved long after the case was resolved.

NURSING IMPLICATIONS

Nurses are frontline, beside caregivers for patients at all stages of illness, but particularly at EOL. Hospice nurses and UAP provide the hands-on cares for patients and provide support and education for the patients' caregivers and loved ones. As demonstrated in the case presented, nurses and UAP may have deeply held, moral objections to engaging in the withholding of oral nutrition and hydration from incapacitated patients. Some may have religious beliefs that prohibit participation in any activity that is seen as hastening a patient's death. Moral distress caused by either feeling forced to participate in the withholding of hand feeding or feeling that a patient's wishes are not being adhered to must be considered.

One of the guiding principles outlined in the American Nurses Association's *Code of Ethics for Nurses*[18] provision 1 is the nurse's responsibility to honor the right to self-determination. This provision provides a framework for the nurse to practice with respect for the inherent dignity of every person. Specifically, the nurse is guided to understand that patients have the right to accept or refuse care of any kind and to advocate for patients' decisions in that regard.[18] This Code of Ethics provision also states that "patients have the moral and legal right to determine what will be done with and to their own person."[18] Although nurses are unable to make these difficult decisions for patients, they are directed by this accepted Code of Ethics to both support and advocate for their wishes as long as they are within the legal rights of patients.

All health care organizations, especially palliative care and hospice agencies and long-term care facilities, should consider development and implementation of policies addressing the new ADD and surrogate decision making regarding oral provision of food and fluids to patients with advanced dementia. Organizations have already formally been encouraged to develop policies to guide clinicians' practice in the treatment for patients who have chosen to engage in VSED.[12,19] These policies should be expanded to help nurses understand the role they play as well as the organizations' directives on the issue of VSED by proxy or directive.

In addition to developing formal policies on the topic, employers may consider providing formal nursing education on VSED and the withholding of oral food and fluids. Discussion on nursing ethics, American Nurses Association and state organizations' guidance, and organizational ethics should be facilitated. Furthermore, especially in palliative care and hospice agencies, as well as assisted living and skilled nursing facilities, specific education should be tailored on topics including advance directives (standard and ADD) and the concept of VSED, either individually carried out by a terminally ill patient or by a proxy decision maker.

Formal support and debriefing sessions should be offered for all nurses and encouraged specifically for those most at risk of moral distress. In hospice, interdisciplinary support should be recognized as a helpful option as those teams tend to work so closely on plans of care for their patients. Finally, organizations and agencies should consider what their policy/course of action will be if a nurse morally objects to the care they are being asked to give to a patient.

Often, nurses are able to opt out of executing a plan of care that they object to on a spiritual or moral basis, as long as the care can reasonably be provided by another staff member or agency with minimal impact on the care of the patient.

CONCLUSION

Because of the growth of the aging population in the United States, it is anticipated that the incidence of Alzheimer disease and all dementias will continue to increase in the coming years. Whether it is legal, ethical, or acceptable for a patient's health care surrogate decision maker or a patient's advance directive to direct the withholding of hand feeding and hydration will continue to be a question faced by those providing care for those with advanced and end-stage dementia. It is expected that state legislatures and, potentially, state and federal high courts will have to rule on these cases and subsequently create laws to govern how these decisions are made. Advocacy groups on both sides of the issue are working to ensure the voices of those they represent are heard.

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