



ETHICAL ISSUES IN THE MANAGEMENT OF THE DEMENTED PATIENT

The American Academy of Neurology Ethics and Humanities Subcommittee

The prevalence of dementia in the United States is increasing largely as a result of three factors: the number of elderly Americans is rising, the longevity of these elderly Americans is increasing, and the incidence of dementia increases with advancing age.¹ Because the prevalence of dementia is increasing, the medical and ethical problems of our demented elderly will rank among the most common issues faced in the future by American neurologists.

Ethical questions arising in the management of the demented patient vary as a function of the stage of dementia. In the early stages, issues of decision-making capacity and the execution of advance directives are paramount. In the middle and later stages, issues involving the appropriate level of medical treatment, decisions to restrain patients, and caregiver issues are most relevant. End-of-life treatment issues become the major ethical issues in the final stages of dementia. Problems resulting from impairments in the professional relationship between the neurologist and the demented patient can occur in all stages.²

The following statement summarizes the ethical issues arising in the management of the patient with dementia. It is intended to address how ethical considerations influence ideal patient management but is not intended to represent clinical practice guidelines.

Patient-physician relationship. The neurologist's relationship with the demented patient can become impaired and thereby jeopardize its therapeutic potential for three reasons. Neurologists may unintentionally depersonalize demented patients because subconsciously they may equate the loss of intellect with the loss of personhood. Neurologists further may fear the loss of their own intellect and, in an attempt to maintain denial, avoid the patient and neglect the patient's medical problems. Finally, neurologists may feel an overwhelming sense of failure and therapeutic nihilism because of their belief that no therapy possibly can benefit a demented patient. If unchecked, these impairments may create a self-fulfilling prophesy: nothing can help the demented patient and therefore nothing need be tried.³

Neurologists should optimize the therapeutic benefit of the patient-physician relationship by striving to maintain respect for the patient and recognizing and avoiding depersonalization behavior. They should practice the principles of chronic and palliative medical care that emphasize the priority of care over cure by (1) paying careful attention to the seemingly minor but personally important details of patient's daily life and attempting to maximize the patient's quality of life by such measures as optimizing nutrition, bowel function, and restful sleep, and improving safety, controlling agitation, and correcting urinary incontinence; (2) identifying and treating depression in the elderly, which may present as "pseudodementia" or may aggravate dementia; (3) carefully limiting the number and closely monitoring the dosages of medications to reduce the incidence of toxic encephalopathies that further can impair cognition; (4) carefully ensuring that coexisting medical illnesses are treated adequately, such as diabetes, hypertension, and chronic lung disease, because optimal treatment of these conditions may lead to improved cognition; (5) correcting sensory deficits by seeing to it that appropriate eyeglasses and hearing aids are prescribed because improved vision and hearing enhance the patient's ability to communicate; (6) encouraging patients to stop smoking tobacco and drinking alcohol, which could further impair their function and safety; (7) encouraging proper nutrition, with vitamin supplementation as necessary; and (8) providing continuity of care and availability in emergency situations.⁴

Advance directives for medical care. Neurologists should urge all patients, including those with early stages of dementia, to complete advance directives for medical care and educate them about the potential adverse consequences of not doing so. These directives can provide information about the level of medical treatment that the patient wishes to receive in various stages of illness. Patients can complete written instructional directives ("living wills") and can execute directives appointing health care decision-makers whose decision-making

authority is activated if the patient becomes incompetent later in the illness. Mildly demented patients should be encouraged to execute advance directives early in their course before they become incompetent.⁵

Patients should supplement their advance directives with detailed discussions with their physician and family about their preferences for medical care of varying intensities in different medical situations that are predictable because of their dementia and advanced age.⁶ These discussions are part of the ongoing process of informed consent and should be repeated periodically while the patient remains competent. As demented patients gradually lose decision-making capacity, proxy decision-makers must become involved to a greater extent. Completing and following advance directives is desirable ethically because it permits a type of patient self-determination even in states of incompetence.

The state of the demented patient's cognitive capacity should be reassessed whenever tests or treatment are ordered. Demented patients should be included in the consent process to the fullest extent consistent with their remaining cognitive capacity.⁷ In states of patient incompetence, the consent of an appropriate proxy decision-maker is necessary for all nonemergency tests and treatments.

Proxy decision-making. If the patient, when competent previously, had executed a written or proxy advance directive providing guidance for medical care, it should be followed as faithfully as possible and reasonable.

In the absence of clear advanced directives, an appropriate proxy decision-maker should be identified to make health care decisions for the patient. The neurologist has the duty to explain the patient's prognosis with and without treatment to permit the proxy to make an informed decision. The neurologist should make a treatment recommendation based on the neurologist's assessment of the benefits and risks of treatment, but the authority to consent to or refuse treatment rests with the proxy. The neurologist should follow the proxy's rational treatment refusal or consent.

Proxy decision-makers generally should try to use the standard of substituted judgment, to the extent permitted by law, and attempt to reproduce the decision that the patient would have made if he or she were competent. Accurate substituted judgment is difficult and requires both a knowledge of the patient's preferences and the courage to uphold them. In the absence of knowledge of the patient's treatment preferences, the proxy should use the standard of best interests. Using a best interests standard requires balancing the benefits against the burdens of medical treatment. If, in the judgment of the proxy, the perceived benefits of the proposed treatment exceed the burdens, usually the proxy should provide consent for the treatment. If the perceived burdens exceed the benefits, however, usually the proxy should refuse to provide consent.

Family of the demented patient. It is desirable for neurologists to maximize the success of the home caregiver of the demented patient, thereby permitting the demented patient more time to live at home before considering institutionalization, by (1) educating the caregiver about the ideal management of common outpatient problems of the demented patient through discussions, encouraging the caregiver to read available educational books, and arranging formal caregiver training; (2) identifying and attempting to minimize sources of caregiver stress, such as patient violence, accusatory behavior, incontinence, nighttime awakenings, and wandering; and (3) preventing caregiver "burnout" by arranging for assistance that might include caregiver training sessions, home-health aide visits, periodic respite admissions, adult day care, and caregiver participation in peer groups.⁸

Neurologists should be careful to keep separate the legitimate interests of the caregiver from those of the patient. The neurologist should attempt to support the caregiver in his or her difficult task, but the interests of the caregiver should not be permitted unjustifiably to supersede those of the patient when the two conflict. Neurologists should try to support caregivers and encourage them to be strong and independent, thereby preventing them from assuming a dependency role that could diminish their confidence and effectiveness. The caregiver and the neurologist should work in a joint partnership to provide the patient with optimal medical and home care.⁸ Encountering caregivers who appear preoccupied with their own welfare over that of the demented patient should alert neurologists to the potential of patient abuse.

When the caregiver wishes the neurologist to arrange nursing home placement, the neurologist should initiate a discussion with the caregiver. The neurologist should attempt to determine that the nursing home placement decision is appropriate for the patient and family and that reasonable alternatives have been excluded, such as periodic visits from home health aides, adult day care, caretaker training, and respite admissions.⁹ When appropriate to the circumstances, neurologists should try to place patients in specialized Alzheimer's disease care

units where they are available and to encourage the development of specialized units in nursing homes because they contribute to the betterment of care of the demented patient.¹⁰

Restraining demented patients. Mechanical and pharmacologic restraints commonly are ordered for and applied to demented patients to keep them from harming themselves and others. Institutional surveys of the prevalence of both types of restraints show that they are ordered with increasing frequency in increasingly severe states of dementia.^{11,12} Despite the putative benefits of improved patient safety and reduced institutional liability, restraints also pose potential risks to the patient, including injury from improper application or prescription and impairment of physiologic functioning from bodily restriction and sedation.

The following ethical guidelines should be observed in the ordering of mechanical or pharmacologic restraints for demented patients: (1) restraints should be ordered when they contribute to the safety of the patient or others and are not simply a convenience for the staff; (2) restraints should not be routinely ordered or ordered as a substitute for careful evaluation and surveillance of the patient, as appropriate for good medical practice; (3) the perceived need for restraints should trigger a medical investigation of the precise reason for them intended to correct the underlying medical or psychological problem; (4) restraints should be ordered with informed consent by the patient or appropriate proxy decision-maker with full disclosure of risks and benefits; (5) when indicated, mechanical restraints should be applied carefully with the least restrictive device possible; (6) when indicated, pharmacologic restraints should be prescribed with the proper agent in the lowest dose possible; and (7) all orders for restraints should be reassessed frequently so that they may be in effect for the shortest duration necessary to achieve their goals.^{13,14}

Palliative care and withholding and withdrawing life-sustaining treatment. The most difficult ethical problem surrounds the decision to withhold or withdraw life-sustaining treatment and apply only palliative care measures. This decision often arises in the setting of an institutionalized patient with advanced dementia who develops an intercurrent illness or requires a feeding tube. The neurologist may believe that in the setting of advanced dementia it is most appropriate to write orders to maintain comfort care but not to provide life-sustaining medical treatment. Such orders may shorten the life of the demented patient.

There is a growing consensus among physicians and the public that the most appropriate form of medical treatment for many patients with advanced dementias is palliative care.¹⁵ Palliative care refers to a class of orders of medical and nursing treatment that is intended to maximize patient comfort but not necessarily to extend life. In general, palliative care provides symptomatic treatment for disorders that produce patient discomfort but omits curative treatment for those disorders that do not result in patient discomfort, even if the patient may die sooner as a result of the lack of curative treatment. The goal of palliative care is not to cause death but rather to permit it, in as gentle, as comfortable, and as pain-free a fashion as possible. Palliative care should be provided in advanced states of dementia based on the duties to respect persons and to prevent their suffering.¹⁶

Palliative care plans often include supplemental oxygen; cleared airways; or morphine for dyspnea, atropine, or other therapies to reduce uncomfortable excess secretions; morphine for pain; antipyretics for fever; mouth care; hygienic measures such as bathing, grooming, skin care, bowel and bladder care; positioning; and passive range of motion exercises. Cardiopulmonary resuscitation attempts are not performed, and hospital admissions and surgeries are avoided unless it is likely that they will improve patient comfort. Oral hydration and nutrition are offered, assisted, and encouraged, but hydration and nutrition are not provided by artificial enteral or parenteral means unless they contribute to patient comfort or are chosen by the patient or proxy.¹⁷

Palliative care plans have been administered successfully in dementia hospital and nursing home treatment units.^{18,19} Orders for palliative care should be written explicitly, clarifying which therapies will and which therapies will not be administered in various circumstances.²⁰ Discussions with and explanations to the nursing staff are essential so they understand the ethical basis for the palliative care plan and concur that it is the correct course of treatment for the patient. In this way, demented patients can receive a treatment plan that is most appropriate for their degree of illness, follows their prior treatment wishes as expressed by their proxy, and remains consistent with the highest ethical standards of medical practice.

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