ETHICS, PUBLIC POLICY, AND MEDICAL ECONOMICS

The Care of Patients with Dementia: A Modern Jewish Ethical Perspective

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Patients with dementia and their families can face many difficult and agonizing ethical dilemmas over the course of the illness. An awareness of the Jewish ethical response to some of these issues can help clinicians in treating patients of the Jewish faith and also serve as an example of how one ethical system addresses these questions. The Jewish response is grounded in a profound respect and value for human life in all its forms and man's responsibility to preserve it, but Judaism rejects unproven therapies and recognizes the limitations of modern medicine. Jewish law also codifies normative obligations that children have toward their elderly parents. With these principles in the forefront, this article analyzes a Jewish ethical response to various problems in the care of the demented patient such as truth telling, transfer to a nursing home, artificial nutrition, and end-of-life care, taking into account modern concepts of the doctor-patient relationship and ancient Jewish tradition. **J Am Geriatr Soc 53:881–884, 2005.**

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Patients with dementia, and especially their families, face many difficult and often agonizing ethical dilemmas. Jewish medical ethics can provide a philosophical framework for these issues and offer some practical guidance. This is true of course for people of the Jewish faith, but the approach may interest others as well, as an example of a carefully thought-out ethical system. In addition, an understanding of these issues may help clinicians in their interactions with Jewish patients and their families by providing a moral and ethical context for discussion of these difficult issues.

A statement from the Talmud (a compilation of Jewish law, thought, and lore)[1] that explains that the broken Decalogue tablets were kept guarded in the Holy Ark along with the new ones to teach that an elderly person who has lost her wisdom should nevertheless be honored and respected as much as one who still has all of her faculties can best illustrate the basic Jewish approach to treating patients with dementia. This Talmudic aphorism has implications for patients and their caregivers. Patients with dementia retain their intrinsic human dignity and are as worthy of protection as those who are healthy. The message for caregivers is that, no matter how difficult caring for such a person may be, there is still a responsibility and a duty to serve and respect patients with dementia. The statement also highlights some important Jewish bioethical principles, which will be discussed below.

Perhaps the two most fundamental principles in Jewish medical ethics are the concept of the sanctity of life[2] and viewing man as a "called" being with duties and obligations in addition to rights.[3] In the struggle for survival and in the fight for life itself, Judaism assigns to individual human life an intrinsic value, probably higher than any of its cognate faiths.[2] This is perhaps best expressed by the passage in the Talmud describing the creation of Adam: "Therefore man was created as a single human being, to teach that if any person causes a single life to perish, Scripture regards him as if he had caused an entire world to perish; and if any person saves a single life, he is regarded as one who has saved an entire world."[4] This statement demonstrates the extraordinary value placed on even a single human life, irrespective of its quality, in a totally nonutilitarian way. According to Judaism, life possesses an intrinsic value as a divine gift of creation. This absolute value has enormous implications for how Judaism views the patient, especially one with dementia.

Judaism is much more concerned with man's responsibilities and duties than with his rights. In Jewish tradition, man does not possess title to his life or his body. Man is but the temporary steward of the divine possession that he has been privileged to receive. The terms of this stewardship are not of one's choice but are determined by God's commands. As such, this formulation often limits autonomy, and this system expects an observant Jew to look to formal aspects of Jewish law for answers to ethical dilemmas.

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One important ramification of this construct is that Jewish law mandates that man do everything in his power to heal himself when ill and is also obligated to save the lives of others. As expressed by one of the leading Jewish religious philosophers of the last century, this duty goes even further. "Scientific medicine . . . has always been considered by the Halacha [Jewish law] as a great and noble occupation. Unlike other faith communities, the Halachic community has never been troubled by the problem of human interference on the part of the physician and patient with God's will. On the contrary, argues the Halacha, God wants man to fight evil [and illness is a form of evil] bravely and to mobilize all his intellectual and technological ingenuity to defeat it. The conquest of disease is the sacred duty of the man of majesty and he must not shirk it."[5] Mankind also has an obligation to fight and cure disease on a communal level. The quotation refers to "scientific medicine." This was one of the terms initially suggested for evidence-based medicine and has important implications for this discussion. Judaism has mandated only the use of what is called "refuah bedoka": medicine that has been proven to work[6] and thus is fully consonant with the paradigm of evidence-based medicine. The obligation to heal oneself only applies to therapies that have a reasonable chance of success.

With this brief introduction to Jewish medical ethics, specific dilemmas in the care of patients with dementia can now be addressed, with the caveats that Judaism is not monochromic in its outlook and that reasonable differences of opinions have been a hallmark of Jewish legalism since its inception. The approach that will be taken in this article is an Orthodox one, relying heavily on rabbinic precedent; Reform or Conservative Jewish thinkers might have a different perspective on these sensitive issues.

TRUTH TELLING

Recent ethical guidelines have been almost uniform in calling for full disclosure on the part of the physician. For example, the Physician Charter on Medical Professionalism states that, based on the principle of patient autonomy, "Physicians must be honest with their patients and empower them to make informed decisions about their treatment."[7] This call for truth telling has also been applied to informing patients with Alzheimer's disease of their diagnosis and prognosis.[8]

That being said, various reasons for not telling patients their diagnosis have been offered. They include fears that such disclosure could precipitate symptoms of anxiety and depression, a desire to protect patients from the realities of the disease, and a reluctance to face the patient's knowledge and reaction.[9] These arguments have been countered by arguing in favor of patient autonomy and the need for informed consent.[10] According to the latter approach, only the patients have the right to decide what they should or should not be told. In addition, in a current search of the literature, no convincing evidence was found that informing patients will lead to worse outcomes than not telling them.

Recent research has shown that, for the most part, patients would like to know the diagnosis and prognosis of dementia[11,12] but that family members are often much more reluctant to have them learn the truth.[9] As opposed to what has evolved with respect to the diagnosis of cancer, many physicians still routinely do not inform patients of a dementia diagnosis.[13,14]

Traditional Jewish ethicists have taken the general position that one should avoid informing patients of a grim diagnosis for fear of harming them or causing psychic anguish. For example, Jakobovits wrote in 1959, "The rabbis insisted on maintaining the patient's hopefulness not merely by withholding information of his imminent death, but by positive means to encourage his confidence in recovery."[15] Although this approach may well have had some justification in the past, modern developments in the nature of the doctor-patient relationship and lack of evidence that truth telling can be harmful are convincing reasons for a change in approach. Although there are instances in Jewish medical ethics, as opposed to secular ethics, in which the principle of beneficence may override autonomy, there has to be convincing evidence that withholding the truth is truly beneficial to the patient. An example of this priority of beneficence would be the decision to force feed a hunger striker who would surely die if not fed.[16] That exception notwithstanding, in the absence of otherwise compelling evidence, the patient should continue to be viewed as the primary decision-maker. From the Jewish point of view, one author has argued eloquently that, because God gave man the obligation and responsibility to preserve his own life, he should be the ultimate decision maker regarding his body.[17] But more important than simply telling the truth is how one does this. Judaism has always maintained that, in addition to the physical health of the patient, the physician is also responsible for the patient's general well-being,[18] in a sense anticipating the biopsychosocial model of health care. Truth telling should be approached in this context. Patients have the right to decide how much they want to know, and physicians need to be trained in the art of truth telling in an empathic and compassionate manner.

TRANSFER TO A NURSING HOME

The decision to transfer a demented patient to a nursing home is one of the most difficult and agonizing decisions that family members must make. Patients are usually reluctant to leave their familiar surroundings and understandably have a great fear of the unknown. For many, it represents the beginning of the dying process. Children sometimes view it as abandonment of their parents, and many are guilt-ridden over the decision. Much has been written concerning the difficulties encountered by family members in caring for a patient with dementia,[19] but often not enough is done to help these families, especially if they lack financial resources.

The formal Jewish approach to this question begins with an understanding of children's formal responsibilities toward their parents. As evidenced by the Ten Commandments, one of the cardinal injunctions of Judaism is the obligation to honor ones' parents. This obligation is basically one of personal service, expressed concretely in the requirement to feed and clothe them, but there are also limits to this obligation. For example, one does not have to use, to spend ones' own money to perform this service. (According to the letter of the law, one is not required to buy the food or clothes.) Additionally, more than 800 years ago, Maimonides, the famous physician and preeminent medieval Jewish legal authority, codified the normative Jewish approach to this issue as follows.

> One whose father or mother has become deranged tries to behave with them according to their mental state until they should receive mercy [die]. But if it is impossible for [the child] to bear this because of their excessive derangement, he should leave them and go his own way, and command others to treat them in that manner that is appropriate to them.[20]

The majority of subsequent religious authorities have accepted this ruling, which forms the legal basis for the permission granted to a child to transfer his or her parent to a nursing home, but a close reading of this citation adds two important caveats. First, the children must make a sincere effort to care for the parent to the best of their abilities, and only after they have reached the breaking point, may they hand care over to another. Second, the children must ensure that the parent is cared for in a "manner that is appropriate to them." The child's obligation does not end once the patient is transferred but continues as an ongoing responsibility to oversee the care of the parent. Despite its normative nature, Jewish law shows great sympathy to the plight of both the parent and the child. It recognizes that sometimes it is impossible for a child to care for a parent despite the best intentions and allows for the child to delegate this responsibility. The fact that the children are required to have made a maximal effort to avoid this outcome and the nature of their ongoing responsibilities might help to alleviate any subsequent guilt. The requirement that the child supervise the care and that the parent receive appropriate care ensures protection of the parent. Transfer to an institution that is not able to provide this standard of care is not permissible. This obligation may help explain the sometimes-difficult relations that can develop between Jewish children and formal caregivers, especially in an institutional setting. An understanding of these ethical concerns might help in communicating with the patients' families and developing collaborative therapeutic relationships.

ARTIFICIAL FEEDING

Many patients with severe dementia become unable to maintain an adequate intake of food and water through normal feeding, and the question arises in these patients whether to feed them artificially through a nasogastric or gastrostomy tube. Recently, many voices have called for a halt to such "artificial feeding"[21,22] for two main reasons. First, there is serious debate as to whether tube feeding improves any important clinical outcome. This technology has not been shown to prevent aspiration, reduce the risk of infection, or provide palliation in patients with advanced dementia and can cause significant morbidity[21] and discomfort, including the necessity of restraining an artificially fed patient to prevent interference with the tubes. Second, others have argued on ethical grounds that tube feeding in these patients is equivalent to other medical treatments, especially those judged as futile, which can be withdrawn or withheld in certain circumstances.[23]

Jewish tradition strongly disagrees with the second assertion. According to the majority of Jewish religious authorities, nutrition in any form is a basic human need and should be provided to all patients.[24,25] It makes no difference how cognitively impaired the patient is, because human life at all stages and of any quality is of supreme value to Judaism. However, there is an important caveat to this approach; the nutrition must be of benefit to the patient. As discussed above, Jewish tradition relies heavily on the most up-to-date and rigorous scientific evidence when making its ethical judgments. In light of this, the question of artificially feeding a patient with severe dementia is no longer primarily an ethical one but has become primarily a medical judgment. If the feeding can be shown to prolong the life of the patient or decrease discomfort, Jewish tradition would support it, but if there is no evidence that it is beneficial and in fact might be harmful, there would be no reason to artificially feed a dying patient.

From a Jewish perspective, there is another important point to be made. Some authorities have argued that, for these patients, the most appropriate way for them to be fed is by slow and careful hand feeding and that the reason this is not done more often is because of the time and cost involved.[21] According to Jewish law, this is an unacceptable excuse. As discussed previously, a child has an obligation to honor his parents; an integral component of this is the responsibility to make sure they are properly fed. If the parent is in a nursing home receiving inadequate nutrition, it is the responsibility of the child and not only of the nursing home to rectify the situation. Ideally, the children should do the feeding personally, but they may also designate a surrogate. However, Jewish law goes even further. It is not enough to just feed your parents; it must be done in a kind and considerate manner. One of the authors (AJ) has argued previously that the techniques suggested (e.g., the use of finger foods, altering the size and frequency of meals, modifying noise levels) to increase the likelihood of successful hand feeding would fall under the legal rubric of providing nutrition to your parents in a thoughtful and congenial manner.[26] Tube feeding, in all of its artificiality, cannot be considered as such.

END-OF-LIFE CARE

Even though Judaism values infinitely every second of life, the tradition certainly recognizes that, at times, even modern medicine has nothing further to offer the patient and that treatment is just delaying the inevitable. The source for this opinion is the famous ruling of the RAMA (a preeminent medieval rabbinical figure) in the authoritative Code of Jewish Law who not only permits but even requires the cessation of treatment that is prolonging the dying process, even if this act will cause the patient to die more quickly. In other words, one may remove impediments to death in a terminal patient.

How to apply this ruling in practice is one of the most difficult questions in Jewish medical ethics. Factors that are relevant in deciding to stop treatment are the amount of pain from which the patient is suffering, the prognosis of the patient, the stated preference of the patient, whether the treatment is considered extraordinary, and how to precisely define a terminal condition. How to define these variables and the relative importance of each is subject to much debate. Nevertheless, even if at times Judaism may sanction and even mandate a palliative care approach, it never condones an active act of euthanasia.

At present, how the patient with advanced dementia fits in to this Jewish paradigm of end-of-life care is difficult to interpret. Even when end-stage dementia is recognized as a terminal disease, it is still difficult to accurately predict prognosis. In addition, it is difficult to gauge the amount of pain and suffering if any that the patient is experiencing, and the patient is in no position to inform the medical team of their preferences. Until answers to these difficult questions can be clarified, it will be difficult to apply these principles to patients with dementia, leaving one to judge each situation on a case-by-case basis. Difficult as it may seem, this approach is highly consistent with the Jewish legal tradition, in which decision-making on an individual basis is more highly valued than broad generalizations.

Another factor may also influence clinical decision-making in this context; Judaism does recognize the concept of triage and the effect of limited resources in decision-making, medical and otherwise. The community is considered to have a responsibility to provide adequate health-care to all its citizens but not in an unlimited manner. For example, in every institution, there is a limited number of intensive care beds, and preference may be given to patients with a better prognosis, thus decreasing the priority of certain patients, such as those with end-stage dementia.

CONCLUSION

This article has touched briefly on some of the ethical dilemmas facing clinicians, patients, and their families in the context of dementia. Jewish law continues to value the life of these patients and mandates a high level of responsibility toward them, particularly by their children. At the same time, it recognizes the limitations of human behavior, the fact of finite resources, and the potential contribution of new evidence to the discourse. This outlook has and should be compared with the perspectives of other cultures and religions on these seminal issues in the care of older people.[27] The Jewish response is not always an easy or simple one, but its outlook is consistent in its approach to preserving the sanctity and dignity of human life.

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