



Ethical Challenges When Caring for Orthodox Jewish Patients at the End of Life

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Dying is a deeply personal process. The personal values, goals, and experiences of a lifetime come to the forefront during the end of life and may be shaped to some degree by the religious and cultural identity of the patient and family. When patients are part of a faith-based, religious, or cultural minority group, it can be particularly challenging for the clinical care team to gain the understanding and insights needed to reconcile disparities between majority and minority values. This article uses a case study to illustrate and review ethical issues, which frequently occur and can be anticipated in the end-of-life care of patients who identify themselves as Orthodox Jews. Although the specifics are unique to this faith-based minority group, the process of identifying, educating, and developing a means to incorporate faith-based and cultural minority beliefs and values in the provision of care can be applied to other such minority groups that the clinical team may encounter in their work.

The personal values, goals, and experiences of a lifetime, which come to the forefront during the end of life, may be shaped to some degree by the religious and cultural identity of the patient and family. The provision of high-quality end-of-life care necessitates that the care is truly patient and family centered. When the patients are part of a faith-based, religious, or cultural minority group, it can be particularly challenging for clinical team members to gain the understanding and insights needed to achieve this goal and to reconcile disparities between majority and minority values.² This article uses a case study to illustrate and review ethical issues, which can be anticipated in the end-of-life care of patients who identify themselves as Orthodox Jews. Although the specifics will be unique to this faith-based minority group, the process of identifying, educating, and developing a means to incorporate faith-based and cultural minority beliefs and values in the provision of care can be applied to other such minority groups that the clinical team may encounter in their work.

KEY WORDS

cultural awareness and sensitivity, culture, end of life, ethics, faith-based minorities, Orthodox Jews, palliative care, patient and family centered care

The most recent Institute of Medicine report on end-of-life care, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, emphasized in its title the critical importance and highly individual nature of this time.¹ Dying is a deeply personal process. Those working in hospice and palliative care recognized this long ago and continue to acknowledge it in their daily work. It is part of the rationale behind the interprofessional team essential to high-quality end-of-life care, whether in hospital- or community-based palliative care or hospice programs.

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JUDAISM AND ORTHODOX JEWISH PRACTICE

Jews have traditionally been identified as a religious, cultural, or ethnic minority group.³ There are three main branches of Judaism, Orthodox and Conservative and Reform, with many commonalities but also important distinctions. Although the long history of Jewish culture and historical background is beyond the scope of this article, it may be helpful to understand Orthodox Jewish perspectives. The plural *perspectives* is used because there are variations within and among those who identify themselves and would be identified by others as “Orthodox Jews.” Commonalities will be focused upon, whereas occasional areas of variation or differentiation will be highlighted. The Orthodox Jew endeavors to follow and observe Jewish laws and customs as dictated by the *Torah* (the first 5 books of the Bible) and interpreted by rabbinical scholars for contemporary application throughout history. Jewish religious law is known as *halacha*. It is composed of the first 5 books of the Bible or *Torah*, the oral tradition of the postbiblical period, which is found in the *Mishna* and *Talmud*, and the subsequent rabbinical responsa, which continue to elucidate Jewish law today. *Halacha* is a term that is derived from the Hebrew root word “to walk” and guides all aspects of Jewish daily life, religious practices,



rituals, and customs, including health care–related decisions. It is the role of a rabbi to guide the interpretation of *balacha* and its related texts. Orthodox Jews often consult a rabbi or *posek* before making major life decisions, including matters of health care, to ensure adherence to Jewish law.²

The experiences of Orthodox Jews as members of a cultural and ethnic group also influence their views, values, and perspectives related to end-of-life care. The history of Jewish persecution may make it difficult for them to take their safety for granted.⁴ The recent experience of Jews during the Holocaust may contribute significantly to the way a Jewish patient experiences life events. Whether they personally experienced anti-Jewish pogroms (organized massacres of an ethnic group, which occurred in Russia and Eastern Europe in the late 1880s) or concentrations camps during World War II, they may view the end-of-life experience through a lens of their culture, history of religious persecution, and faith.⁵ It may be important to consider this context when caring for Holocaust survivors and their families. Jewish identity is complex and multifaceted because it is composed of religious tradition, ethnicity, and cultural practice.³ When caring for a patient and family living with a life-limiting illness, consideration of all these elements in addition to the medical, emotional, and psychosocial elements can add to the complexity of care.

THE ROLE OF FAITH-BASED VALUES, PRACTICES, AND BELIEFS

Pikuach Nefesh, saving or preserving life, is a fundamental principal for Orthodox Jews when considering decisions about health care. Understanding the perspective that faith-based values may shape life and the preservation of life can allow clinicians to engage in crucial perspective taking when engaging in advance care planning with patients and their families. Life is viewed as a divine gift, which is to be treasured and protected. This principal creates an imperative, such that most other religious obligations are permitted or required to be set aside if doing so will result in saving or prolonging someone's life.⁶ At times, *pikuach nefesh* can be oversimplified, resulting in a notion that life must be prolonged for any period at all cost, irrespective of the degree of suffering the patient experiences. *Pikuach nefesh* is in fact much more complex. A nuanced, case-by-case analysis of the patient's condition, treatment options, and symptoms will allow prolongation of life to be considered, together with other essential principals informing end-of-life care for the Orthodox Jewish patient.

Every person is seen as being created in the divine image in the Judeo-Christian belief system, including Orthodox Judaism. As such, every person has inherent

dignity simply by virtue of their existence. The development of debility or need for assistance from others for activities of daily living does not change this inherent dignity. Provision of such assistance to those in need, whether young or old, is viewed as meritorious. Orthodox Judaism does contain a concept that earthly suffering can have a spiritual or redemptive value, but it does not encourage or mandate that physical or psychological suffering be experienced when it can be alleviated.

Pain, nausea, dyspnea, and other physical symptoms can negatively impact patients' quality of life. When symptoms are inadequately controlled, patients may come to view life as a burden rather than a gift. Depression, anxiety, delirium, and other psychological symptoms may also have this effect. The degree of suffering experienced by the patient with impaired consciousness is less clear. These symptoms may be accorded variable importance when making decisions about medical care, especially at the end of life.⁷

Given that all people are mortal, every person is closer to the end of their lives each day than they were the day before, but when exactly their life will end remains unknown and unknowable. When a person enters the phase of being at the “end of life,” it is often an arbitrary distinction. Hospice and palliative care endeavor to help patients live as best as they can without denying the fact of a life-limiting illness and mortality as part of the human condition. In health care settings, often because of regulatory considerations, “end of life” may be viewed as the time when there is a 6-month prognosis, conferring hospice eligibility, or the time when a patient meets the “surprise question” test. This means the clinician would affirmatively answer the question, “Would you be surprised if this patient died in the next year?,” which has been shown to reliably predict survival.^{8,9} The end of life may also be conceptualized based on when the patient has no additional disease-specific treatment options or has an increasingly limited functional status. Orthodox Judaism does have considerations of expected prognosis, with expected short-term survival (*chaye sha'ab*), relatively short survival (*tereifab*), long-term survival (*chaye olam*, living a full life span), and imminent death (*gesisab*, survival expected for <3 days). The patient and family may have a different understanding than health care providers about the term *end of life* because it can be used with so many different connotations.

Much has been written about faith, a system of strong spiritual beliefs that is often used when describing the doctrines of a religion. Although it is not the emphasis of this case study and review, it is important to acknowledge that faith impacts the actions, behaviors, and perspectives of the faithful. A component of this belief system for the Orthodox Jew, as for many people of faith, is that God's influence is felt in all that occurs in their lives. They



espouse trust that God's influence on events is unequivocally for the good. Lacking the omniscience that God possesses, patients and families (and even health care professionals) have a limited perspective and may perceive events as tragic, distressing, or terrible, rather than good, in the moment they experience them. At times, faith and trust in a divine being can contribute to the belief in miracles. The Orthodox Jewish perspective is that God usually influences events through the natural order. It also acknowledges that He created the world and His omnipotence allows for miracles, events that occur in a supernatural manner.

Hope is an important construct for patients from almost any religious or cultural background.¹⁰ There is an explicit acknowledgement in rabbinic literature of the role of hope in coping with serious illnesses. This can be oversimplified to understand that negative information cannot be given to a patient, out of concern that the patient will "lose hope." At times, a hospice or palliative care referral can be resisted by family for fear that the patient will understand from this that they are approaching the end of their life. Together with hope, safeguarding one's life and living life to the fullest are important values. Another important value is recognizing and appropriately preparing for death, which is modeled after the behavior of biblical and rabbinic figures. They recited confessional prayers, organized their affairs, and provided their descendants with ethical and financial bequests. Essential to balancing these competing priorities is skillful and compassionate communication. Acknowledging the importance of hope and exploring what hope means to the patient and family can be very helpful in navigating these delicate waters.¹¹

As mentioned earlier, Orthodox Jews believe that life is a divine gift. Individuals have a responsibility to act to maintain health or restore it when they are ill. Although there is a strong belief that God influences all events, individuals are obligated to take action and exert an effort toward achieving these goals.¹² This balance between divine providence and personal responsibility can be heightened when dealing with a serious illness. At times, patients and families will fulfill their personal responsibility by activities such as researching expert care or investigating alternative treatment options.

The evidence suggests¹³ that to remain in a home setting when needing health care or coping with an illness is often desired by patients and families. Similarly, Orthodox Jews value being able to be in their homes, surrounded by familiar and caring people, when their needs can be met there. Support for patients, whether they are children with complex medical needs or frail older adults approaching the end of their lives, is valued in the Orthodox Jewish community. This care may be provided informally by individuals or through community organizations. When pa-

tients require facility-based care, whether in an acute care hospital or a chronic care facility or hospice, there will often be a concerted effort to ensure that the care is *heimishe* or homelike. This can include personal or ritual items at the bedside, pictures of children and grandchildren, and family members taking turns being at the bedside so someone familiar to the patient is always present. Orthodox Jewish families are larger than the average family in the United States, so this can result in a large extended family being present and expressing interest in the patient's care. Family members accompanying the patient will need personal items, including kosher food and drink to sustain them, and may need changes of clothes depending on the duration of their stay with the patient. It is not uncommon for a family member to request to stay overnight in the hospital with the patient.

There is a potential for communication challenges when a patient has a large and involved family. Different strategies can be effective for day-to-day communication and major treatment decisions. Health care team members need to recognize that needs for information are likely to be higher as patients approach the end of life and need to be prepared to devote additional time to family communication.¹⁴ At the same time, health care team members can gently recalibrate family expectations if their communication needs are perceived as excessive and the team finds it challenging to meet these needs along with the needs of their other patients.

Appointing a family member as the primary contact between the family and the health care team can be a very effective strategy for day-to-day communication and is often recommended. Another effective strategy is to speak to the family member who is present, although that may be a different person in each interaction. That person would be responsible for bidirectional communication between the family and the health care team at that encounter. Members of the clinical team can encourage the family to develop effective communication among themselves, such as use of a calling tree, group text messages, or conference calls. When significant issues need to be discussed, it can be helpful to offer to include as many interested family members as possible in the discussions, so they have direct and simultaneous contact with the health care team rather than expecting them to disseminate the information within their family. Dissemination of critical information within the family can result in waves of questions to the health care team because successive groups of family members receive and process the information.

Another aspect of disclosure where sensitivity and awareness are of utmost importance relates to the tightly interwoven nature of social interactions in the Orthodox Jewish community. A desire for privacy or to control the flow of information about one's illness is not unique to members of the Orthodox Jewish community. There is



enormous variability in preferences for privacy versus information sharing, which depends more on the individual than the cultural reference group. The delicate balance between patient and family's privacy and the need for disclosure to access community support can be challenging, adding to an already complex and emotionally laden situation.

It is important to understand that Orthodox Judaism does not have a single central authority. Many decisions related to modern medical treatment and Jewish law require interpretation and extrapolation from ancient sources. As a result, rabbis with different approaches to interpreting rabbinic texts may come to different, but equally valid, rulings about a course of action. This is part of the reason there is variability in some aspects of religious practice within the Orthodox community. Orthodox Jews are accustomed to this degree of variability. Those less familiar with the Orthodox Jewish community and the process of developing *Responsa*, or those accustomed to religious systems with a central authority, may not be accustomed to this. Health care professionals should not be surprised if two Orthodox Jewish patients with similar medical situations each receive different guidance from their respective rabbis.

The specific details of the patient's medical situation, sometimes also including biopsychosocial considerations, will be the information used by the rabbi to determine the application of *halacha* to a situation. For this reason, the details of the case are critical. Health care professionals should be aware that patients or families will consult their rabbi or request that a knowledgeable member of the health care team speak with their rabbinical council about their case.

To create a treatment plan that is consistent with the patient's religious views and values, the health care professionals should understand the rabbi's role. The rabbi holds a significant place in the personal lives of the family. As described earlier, individuals have a close relationship with their rabbi and consult him regarding important life decisions of many types, related to all stages of life. To advise appropriately, the rabbi will want information about the medical situation and may want to speak to the health care professionals treating the patient to obtain relevant and accurate clinical information. With the patient's permission, this is not a violation of patient confidentiality. Health care professionals who are familiar with this normative behavior may ask Orthodox Jewish patients and families whether they would like a member of the treatment team to contact the rabbi to provide information. This may be performed with the family present, often by phone, or separately. This opportunity for direct dialogue relieves the family of a burden to accurately provide all the relevant clinical information and allows the rabbi to ask any questions to clarify information that he may need.

This can be especially important for high-stakes, emotionally charged, end-of-life care decisions. Analogous to medicine, where there are generalists and specialists to whom complex cases are referred, some rabbis will refer a question to a colleague who is a rabbi with known expertise in Jewish law related to end-of-life care if they are not comfortable advising the patient.

THE CASE

Sarah is a widowed octogenarian admitted to the hospital from home for dehydration and shortness of breath. She has stage IV non-small-cell lung cancer, diagnosed 2 years ago, and was found to have a progressive disease on immunotherapy at the time of admission, with new metastases to her liver. She has profound loss of appetite, and when she tries to eat, she complains to her family of early satiety. If she pushes herself to eat anyway, she develops profound nausea and vomiting. She is progressively sleeping more during the day and is restless and often awake during the night. She is unsteady on her feet and dislikes having to use a walker. She and her family are concerned about her risk of falling. Her family, consisting of four sons and three daughters, and a large cadre of involved children-in-law, grandchildren, siblings, and extended family are increasingly distressed by her weight loss and declining performance status. Her middle daughter has cerebral palsy and lived at home until Sarah was in her 60s, at which time she reluctantly agreed to have her daughter move to a group home where she could continue to have kosher food and religious observance when such an option became available.

She describes herself as a devout Orthodox Jewish woman who attends synagogue services weekly on the Sabbath. She prays daily during the week and has always served as the central address for family holiday and life-cycle celebrations. Especially since her husband died, her community has been very supportive and is an important part of Sarah's life. If she is not in synagogue on a given week, her friends will stop by to make sure she is not ill. She appreciates that her friends report praying for her when she has tests or doctors' appointments where she may receive important updates on her condition. Sarah and her husband were part of the same synagogue community during the last 25 years of their married life, and she has remained close to the rabbi of the synagogue since she was widowed 15 years ago. She was born in Europe and was interred in a work camp in Poland during the Holocaust. When she was younger, she did not speak about her experiences, but more recently, she has spoken often about how she maintained her faith in God during the time she witnessed many atrocities. She and two siblings survived. Her father and 11 siblings perished. Her mother remarried in a displaced persons camp after the war, and



she has three half-siblings from that marriage. She regularly impresses on her grandchildren how she believes she survived to realize a purpose God had for her.

At the last few office visits, which several family members attended with Sarah, there were lengthy discussions at which efforts to discuss Sarah's decline were perceived as having been "blocked" and a strong focus espoused by the family members that continued chemotherapy or other cancer treatment was of paramount importance, including considerations of seeking additional opinions from consultants in other institutions. There was acknowledgement of Sarah's weight loss, lack of energy, and pain by everyone except Sarah. Now, Sarah is lethargic and obtunded from hepatic encephalopathy. She is on 5-L oxygen by nasal cannula or mask, depending on what she finds more comfortable at the time. She has profound peripheral edema and a 3-cm area of deep tissue injury on her sacrum and a smaller area of redness on her left heel. She has some abrasions of her cheeks and ears from the oxygen mask strap.

COMMONLY ENCOUNTERED ISSUES

Understanding the patient's life experiences, family dynamics, and disease trajectory is an important consideration when encountering a complex end-of-life care decision for any patient, including the Orthodox Jewish patient. A number of the most common decisions that Orthodox Jewish patients and families face related to care at the end of life will be described hereinafter. Although it is not the focus of this review and case study, there are a myriad of other scenarios and issues that can occur at the end of life.

Futility of treatment was often used as the rationale for limiting treatment at the end of life. The notion of futility has fallen out of favor in the bioethics literature.¹⁵ The efficacy of a treatment requires a clear delineation of the desired goal. At times, disputes over the futility of care can develop when the goal is not clear or shared. With rare exceptions, health care professionals lack the ability to know, with absolute certainty, that a treatment will or will not achieve a goal. Health care practitioners provide recommendations based on evidence, which is a summary and analysis of completed research. Debating with patients and families about the certainty of a particular treatment outcome may not be helpful. Framing treatment recommendations around the goals of care can facilitate collaborative relationships between the health care team and the patient and family and is consistent with the diminished emphasis on futility in the bioethics literature.

As described earlier, leading life according to *halacha*, Jewish Law, is central to Orthodox Jewish identity. Central to modern principle-based bioethics is the principle of autonomy. Orthodox Jews respect the principle of autonomy

but may choose to exercise their autonomy by making decisions within a halachic framework. To do so, the Orthodox Jewish patient, or their representative, presents a rabbinic advisor with information about the patient's medical situation and the decision at hand, so that the rabbi can inform the patient whether a course of action is discretionary, prohibited, or required, according to Jewish law. For discretionary decisions, which are neither prohibited nor required, the patient's preferences factor significantly into the treatment plan. One can see how the value of the information presented to the rabbi in this process can impact the outcome.

The patient will commonly instruct their health care agents, surrogate decision makers, or health care practitioners, orally or in writing, that care be provided to them in accordance with Jewish law. They may list a specific rabbi whose approach is aligned with theirs, including his contact information on their health care proxy document.

Patients and families are often concerned about the adverse effects of opioid analgesics, such as sedation, hypotension, and respiratory depression, and fear that they may hasten death. They may be unfamiliar with the wide range of safe and effective doses of opioids used for analgesia or relief of dyspnea. Health care professionals often need to educate patients and families regarding these concerns when patients are in pain. In Sarah's case, it was important to educate her family about disease-related effects contributing to her declining performance status and clarify that this was not an adverse effect of opioids. This education facilitated Sarah's family understanding that the medications used to treat her symptoms were not making her worse. Rather, her progressive disease was the cause of her encephalopathy, and the opioids were treating symptoms of pain and dyspnea.

Health care professionals may also need to educate rabbis about these concerns when engaging in the process of conferring with the patient's rabbi to develop a treatment plan consistent with the patient's religious views and values, as described earlier. Providing reassurance about efforts to minimize adverse effects, such as hypotension, by using the lowest effective dose and/or the enteral or subcutaneous parenteral routes, may also be a part of this education and counseling to alleviate concerns about symptom treatment.

The rule of double effect is probably the most common bioethical principle used to address the concerns about opioid toxicity when treating pain at the end of life. The rule of double effect is derived from Catholic bioethics. The rabbi may arrive at a similar conclusion and determine that there is no violation of *halacha* if the pain is treated and the adverse effect is allowed to ensue. As described, there are multiple valid approaches to many questions about Jewish law, and it is also possible that the rabbi will advise that the adverse effect



must be treated. This could result in a treatment plan that includes giving vasopressors to counteract opioid-induced hypotension. This may seem counterintuitive to health care professionals involved in the patient's care if they are only familiar with the rule of double effect and not alternative approaches.

One of the important distinctions in bioethics for the Orthodox Jewish patient is that withdrawing and withholding life-sustaining therapies are not considered equivalent acts because they are in secular bioethical systems. This has important implications for the recommendation of a trial of therapy, with the understanding that it can be withdrawn if the trial is unsuccessful or the treatment proves to be too burdensome.¹⁶ If a treatment is continuous, such as a ventilator, there may be a decision to withhold it and allow a Do not Intubate order with dyspnea treated medically, rather than with intubation and mechanical ventilation. Once a continuous treatment has started, it may not be permissible to withdraw it unless the patient improves and no longer has a medical indication for the treatment. For a treatment that is intermittent, such as dialysis or vasopressors, each dialysis session or bag of medication is considered a new treatment. At the point of initiating each new episode of these intermittent treatments, there can be a discussion regarding continuing or withholding the treatment. As a result, it is not uncommon to have a request to complete the current vasopressor infusion bag and not hang a new one when a patient or family comes to a decision to discontinue vasopressors, rather than stop immediately at the time the decision is made. If the patient is experiencing an ill effect during the treatment, it may be permitted to stop it immediately. An example of this would be a patient who becomes hypotensive an hour after starting a hemodialysis session, which was planned to be 3 hours long.¹⁷

The timing of discussions about whether to attempt resuscitation or forego is sensitive for all patients, including those of the Orthodox Jewish faith. At times, a rabbi may advise a patient not to agree to do-not-resuscitate orders until he/she is very close to the end of life. This is often related to concerns that treatments other than cardiopulmonary resuscitation (CPR) will be withheld at a point in the disease trajectory when doing so might be contrary to *halacha*.¹⁸ Acknowledging this concern and being clear about the rationale for the recommendation to forego CPR when broaching the subject can facilitate an open dialogue. Explicit assurances that CPR is the only treatment that will be withheld can also be helpful, with the understanding that such an assurance should only be made if the team is prepared to act on that assurance. Sarah's family was initially reluctant to engage in any discussion about withholding CPR but was willing to consider the issue once reassured that this decision would be independent of decisions related to all other treatments

while the patient had a pulse. They had Sarah's attending physician provide their rabbi with information about her condition during this hospital admission. The rabbi used this information to guide the family on halachic considerations regarding withholding CPR as part of their decision-making process.

The Physician Orders for Life Sustaining Treatment (POLST) paradigm programs in the United States in the states that have implemented them are increasingly used as a vehicle for advance care planning and developing an end-of-life treatment plan.¹⁹ They allow stipulation of a decision to receive or decline the component treatments. Because the outcome of a thoughtful discussion can result in either decision, rather than simply focusing on a decision to forego CPR in a "do-not-resuscitate discussion," Orthodox Jewish patients and families may be more receptive to advance care planning using POLST paradigm documents. As the patient's condition changes, the treatment plan and accompanying documents are designed to be reviewed and modified.^{20,21}

Decisions regarding the provision of artificial nutrition and hydration (ANH) can be among the most challenging for patients, families, and health care providers, regardless of the specific faith, ethnicity, or culture. These decisions require an especially clear understanding of the goals and values of the patient and their family. Decisions related to ANH are highly nuanced. At times, in many cultures, feeding serves as a proxy for caring or nurturing. For Holocaust survivors such as Sarah, issues of anorexia and cachexia may have an additional psychological valence. Sarah and her family associated her weight loss from cancer cachexia with her weight loss from starvation during the war. This resulted in Sarah's children requesting ANH related to these psychological considerations.

When caring for a patient of the Orthodox Jewish faith at the end of life, there are unique factors related to the patient's faith, religious practices, and beliefs in addition to the usual consideration, making ANH decisions even more nuanced and complex. Health care professionals often evaluate the decision to provide ANH based on its contribution to a desired treatment outcome; it is primarily viewed as a medical intervention. Orthodox Jewish patients, families, and rabbinic advisors often, but not universally, view ANH as equivalent to hand feeding. For those who endorse this view, ANH is considered among the basic care due to any human being across the life span, such as being kept clean and sheltered. This fundamental difference in the nature of ANH can be a source of conflict if it is not understood and acknowledged.

When the rationale for providing or foregoing ANH is well understood by the patient, family, and interdisciplinary team, the amount of conflict or distress resulting from the decision can be markedly decreased. This includes families understanding the lack of effect on outcomes



and sharing their emotional, cultural, or religious needs to provide food to a patient, even by artificial means.

UNIQUE CULTURAL AND RELIGIOUS ISSUES

As with many cultures, spirituality can be correlated with prayer. It is not uncommon to observe family members at the bedside involved in religious study or reciting psalms, in addition to the thrice-daily prayer service. Prayer and reflection in Orthodox Judaism, as in many cultures, mutually benefit the ill person, as well as the person praying. As a patient approaches the end of life, these activities may intensify. Similar to other cultures, it is desirable in the Jewish faith for a patient not to be alone at the time of death. Often, the family will desire the presence of a prayer quorum, or *minyan*, of at least 10 men so that specific prayers can be recited as the patient dies. In an acute care setting, this request can be challenging to meet. Recognizing the spiritual significance to the patient and family at this critical time can help clinicians be as flexible as possible in their efforts to accommodate.

There is a well-known passage in the Talmud that says, “*tov sbb'rofim l'gehinom*” (the best doctors are destined for purgatory).²² This phrase is used to describe doctors who believe that their skills and knowledge are the deciding factor in the patient's outcome. As in other cultural and faith-based groups, the Orthodox Jews subscribe to the belief that divine healing and presence are essential to the health and healing of the patient. In particular, Orthodox Jews subscribe to the belief that physicians serve as healers with divine influence and are emissaries for God's will. This passage is quoted to help health care professionals retain humility and to encourage patients to maintain their perspective and belief in God's role in their response treatment, whether the outcome is good or bad.

Orthodox Jews believe that God is Almighty and controls the world, so it would seem paradoxical to the common phenomenon of families expending intense efforts to seek out physicians with reputations for being “the best doctors.” Several factors converge to explain this paradox. Large families result in many people independently needing to come to terms with a serious illness, needing to understand and develop confidence in the treatment decisions and researching options. When the family is large, often, only a few members will have a personal relationship with the treatment team, and the lack of a relationship makes it more difficult to have confidence in the decisions made.

Families that have been strongly influenced by Holocaust survivors may have an even more intense appreciation for the sanctity of life than the general members of

the Orthodox Jewish community. When the patient is an elderly Holocaust survivor, as was Sarah, the patient in our case example, there is often a sense of increased obligation to provide him/her with optimal medical care. There may be a propensity to discount negative prognostic information because these patients survived horrific torture and may have had instances of surviving circumstances that seemed to portend only death, during the Holocaust and in its aftermath. Family members will often seek advisement from community medical referral services or health liaisons who assist with navigating the health care system. They may question whether “better care” might be available in another institution and even request transfers, without regard to whether the patient's condition would permit it. Sarah's family demonstrated this behavior, focusing on chemotherapy treatment options to the exclusion of symptom management, although this was not presented as an either-or choice by Sarah's care team. Families may be frustrated when finding restrictions on transfers imposed by payers or outside agencies. This may add some complexity to an already emotionally charged situation.

OUTCOME AND LESSONS LEARNED

This clinical vignette demonstrates important ethical issues when caring for Orthodox Jewish patients at the end of life. Although this case is focused on the nuances of an Orthodox Jewish family whose matriarch is dying, many of the principles can be applied to other cultural or faith-based minority groups. Cultural humility and awareness of the values, beliefs, customs, and norms that shape the patient and family perspective of the clinical experience are essential for a positive and collaborative relationship. The fundamental approach of bidirectional sensitive communication when the patient's family is large and involved is central to providing family-centered care. The patient's personal narrative contributes to the meaning they ascribe to their experience of illness and their approach to the end of life.²³ The clinical facts are necessary, but they are not the only information needed to understand and support the decisions the patient and family make. Finally, when working with patients and families from cultural or faith-based minority groups, it is crucial that caregivers acknowledge the differences in beliefs and values about what constitutes adaptive coping with serious illnesses and the ideals in end-of-life care. Respectful inquiry can inform the health care professionals about the fundamental beliefs and values of patients who come from different cultural or faith-based traditions than their own. This can allow the health care professionals to support choices that are consistent with the patient's own goals and values, although they may not necessarily be in alignment with their own views and values (see Table).



CONCLUSION

The Institute of Medicine and the Joint Commission, among other national organizations, have emphasized the importance of patient-centered and individualized end-of-life care.^{24,25} This includes sensitivity and incorporation of individuals' core values, which are often influenced by their culture and/or faith traditions. These underpin the meaning patients ascribe to their lives, their life-limiting illness, and their dying process. Nursing, physician, social work, and other allied health care professional organizations have position statements that support the provision of culturally sensitive end-of-life care.^{26,27} These statements are fully aligned with the core ethics of health care professions, such as the American Nurses Association Code of Ethics.²⁸ This discussion focuses on the specifics of end-of-life care for the Orthodox Jewish patient. The partnership of religious and/or spiritual advisors within the health care team is especially important for end-of-life care, given the intensely personal and individual nature of living with a serious illness. This type of collaborative approach enables health care professionals to provide care that is in alignment with patients' values and beliefs.

In our increasingly diverse society, respect for the specific values of each patient and family and the willingness to incorporate them to create patient- and family-centered care are core to our mission as health care

providers, especially in the specialty of palliative care. The strategies described in this review, which incorporate respect for families, inclusion of religious and/or spiritual advisors, and sensitive communication, can be applied to the care of every patient and contribute to excellent end-of-life care.

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TABLE General Principles for Practice

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|---|
| <ul style="list-style-type: none"> • Cultural humility and awareness of the values, beliefs, customs, and norms that shape the patient and family perspective of the clinical experience are essential for a positive and collaborative relationship. |
| <ul style="list-style-type: none"> • Bidirectional sensitive communication when the patient's family is large and involved is central to providing family-centered care. |
| <ul style="list-style-type: none"> • The patient's personal narrative contributes to the meaning they ascribe to their experience of illness and their approach to the end of life.¹⁸ |
| <ul style="list-style-type: none"> • Clinical facts are necessary, but they are not the only information needed to understand and support the decisions the patient and family make. |
| <ul style="list-style-type: none"> • When working with patients and families from cultural or faith-based minority groups, it is crucial that caregivers acknowledge the differences in beliefs and values about what constitutes adaptive coping with serious illnesses and the ideals in end-of-life care. |
| <ul style="list-style-type: none"> • Respectful inquiry can inform the health care professionals about the fundamental beliefs and values of patients who come from different cultural or faith-based traditions than their own. |



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