

HONORING THY PARENT(S): APPLYING THE SPIRITUAL DOMAIN IN PALLIATIVE CARE DECISION MAKING

EDITH M. MEYERSON, DIANE E. MEIER, AND ALLISON KESTENBAUM

Rabbi, Associate Director, Pastoral Counseling and Bereavement Services, The Hertzberg Palliative Care Institute, Clinical Instructor, Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai
Co-Director, Patty and Jay Baker National Palliative Care Center; Director, Center to Advance Palliative Care; Professor, Department of Geriatrics and Palliative Medicine; Gaisman Professor of Medical Ethics, Icahn School of Medicine at Mount Sinai

Association for Clinical Pastoral Education Supervisor, Director of Programs, Center for Pastoral Education, Jewish Theological Seminary

ABSTRACT

Palliative care is an interdisciplinary approach to caring for individuals and families who are suffering with serious illness. Medical and psycho-social-spiritual symptoms and needs are assessed and addressed. Much of palliative care is about working with patients and families to bring their context to light, that is, to understand not only their medical situation but also their wishes, values, cultural background, previous experiences, and quality of life. As palliative care clinicians, we have seen how popular understanding and misunderstanding about what it means to “honor thy mother and father” can influence medical decision making. Whether or not adult children of patients have familiarity with the honor commandment, the biblical text “honor thy father and mother,” or whether they identify with a particular religious tradition, this theme plays a central—and often unaddressed—role as adult children strive to make decisions with and for a seriously ill parent. In this article we examine the commandment to honor one’s father and mother by exploring its religious, spiritual, textual, and cultural origins, as well as subsequent Jewish commentary. We also contextualize the honor commandment in the palliative care setting through clinical case studies that illustrate the concerns of adult children who wish to honor their parents but are perplexed or conflicted about what this mandate means in the face of difficult medical and psycho-social-spiritual circumstances.

KEYWORDS: spirituality, palliative care, honor commandment, family decision making, goals of care

INTRODUCTION

Palliative care is a relatively new interdisciplinary approach to caring for individuals and families who are suffering with serious illness.¹ Delivered by a team of providers from a range of disciplines, palliative care assesses and addresses medical and psycho-social-spiritual symptoms

¹ World Health Organization, “WHO Definition of Palliative Care,” accessed January 31, 2016, <http://www.who.int/cancer/palliative/definition/en/>.

and needs.² Unlike hospice, which is limited to care of the dying, palliative care is appropriate at any stage of a serious illness, and can be provided at the same time as other medical treatments. Although most palliative care programs in the United States are hospital based, it is available in many different health care settings, including the home, long-term-care facilities, and hospice.

While modern medical care typically focuses on the treatment of specific illnesses, palliative care providers work to understand the patient as a whole person in the context of factors that also have an impact on decision making, such as their moral and spiritual beliefs, family situation, and cultural background.³ Palliative care teams support medical decision making for patients in ways that honor as closely as possible their goals for care, values, and beliefs.⁴ Palliative care providers also help patients and their families navigate the fragmented and confusing terrain of medical interventions in an effort to clarify the benefits, risks, and side effects of treatment options, along with the impact on function, independence, and quality of life.⁵

Looking beyond the patient's illness, palliative care teams view the patient *plus* his or her family members and loved ones as part of a single "unit of care" that receives care and engages in decision making.⁶ The patient's spiritual, psychological, and social needs are key elements of whole-person care, and these needs are in turn grounded in a family and social system that influences his or her wishes and expectations for quality of life.⁷ For clinicians and health care providers, decision making in the context of the hopes and fears of the whole family presents both opportunities and challenges at the bedside. The presence of family members helps to fill in the story of who a patient is and what is most important to him or her. On the other hand, because there are many family members and loved ones involved, there may be a range of views about the best course of care and what exactly quality of life means for the patient. Family members may have opinions about the best way to care for the patient that conflict with those of other family members, including the patient, or the medical team.⁸ In some cases estranged family members may be reunited at the bedside and feel either entitled to and in charge of or at a complete loss about making decisions for sick family members who can no longer express their wishes and lack decision-making capacity.⁹ A further complication is that surveys have shown that an estimated 70 percent of Americans do not discuss these issues before a serious illness occurs or the end of life approaches.¹⁰ In the 2009 and 2010

2 "National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for Quality Palliative Care, Executive Summary," *Journal of Palliative Medicine* 7, no. 5 (2004).

3 Patrice Richardson, "Spirituality, Religion and Palliative Care," *Annals of Palliative Medicine* 3, no. 3 (2014): 150–59.

4 Sukanya Mitra and Nalini Vadivelu, "Multidisciplinary Approach and Coordination of Care," in *Essentials of Palliative Care*, ed. Nalini Vadivelu, Alan David Kaye, and Jack M. Berger (New York: Springer, 2013), 7–21.

5 Sukanya Mitra and Nalini Vadivelu, "Guidance with Complex Treatment Choices," in Vadivelu, Kaye, and Berger, *Essentials of Palliative Care*, 89–105.

6 Mitra and Vadivelu, "Multidisciplinary Approach and Coordination of Care."

7 Colleen M. Mulkerin, "Palliative Care Consultation," in *Oxford Textbook of Palliative Social Work*, ed. Terry Atilio and Shirley Otis-Green (New York: Oxford University Press, 2011): 43–51.

8 Anthony L. Back and Robert M. Arnold, "Dealing with Conflict in Caring for the Seriously Ill: 'It Was Just Out of the Question,'" *Journal of the American Medical Association* 293, no. 11 (2005): 1374–81.

9 Susan Dorr Goold, Brent Williams, and Robert M. Arnold, "Conflicts Regarding Decisions to Limit Treatment: A Differential Diagnosis," *Journal of the American Medical Association* 283, no. 7 (2000): 909–14.

10 See "National Consensus Project for Quality Palliative Care"; "New Survey Reveals 'Conversation Disconnect,'" press release, The Conversation Project, September 18, 2013, http://theconversationproject.org/wp-content/uploads/2013/09/TCP-Survey-Release_FINAL-9-18-13.pdf.

HealthStyles Survey, a mail survey designed to be representative of the US population, only 26.3 percent of respondents said they had a health care proxy or written advance directive.¹¹

Patient and family wishes and goals of care are informed by a variety of personal morals, values, and beliefs. Preferences are sometimes influenced by previous experiences of witnessing the serious illness or demise of a loved one.¹² Individuals are also deeply affected by messages they have internalized from their cultural backgrounds, including images and ideas from television and media.¹³ In addition, many Americans actively draw on the religious and spiritual beliefs of their faith leaders and consult the sacred texts of their own traditions to make decisions about care for their parent. One of the most powerful cultural and religious messages is the biblical commandment “honor thy father and mother.”¹⁴ Whether or not they have familiarity with the biblical text or identify with a religious tradition, this theme may play a central and often unaddressed role when adult children make decisions with and for an ailing parent. As palliative care clinicians, we believe it is important for health care providers to understand how popular understanding or misunderstanding about what it means to “honor thy mother and father” can influence medical decision making.

In this article we explore the commandment to honor one’s father and mother through its religious, spiritual, textual, and cultural origins, as well as some subsequent relevant commentaries found in the rabbinic ethical and legal tradition. We also present clinical case studies to illustrate concerns often expressed by adult children who wish to honor their parents but who are frequently perplexed or conflicted about what this mandate means, especially as they wrestle with the realities and limitations posed by difficult medical and psycho-social-spiritual circumstances.¹⁵

11 Jaya K. Rao et al., “Completion of Advance Directives among U.S. Consumers,” *American Journal of Preventive Medicine* 46, no. 1 (2014): 65–70.

12 Goold, Williams, and Arnold, “Conflicts Regarding Decisions,” 910.

13 See Susan J. Diem, John D. Lantos, and James A. Tulsky, “Cardiopulmonary Resuscitation on Television. Miracles and Misinformation,” *New England Journal of Medicine* 334, no. 24 (1996): 1578–82; Goold, Williams, and Arnold, “Conflicts Regarding Decisions,” 911.

14 Amy Zietlow and Naomi Cahn, “The Honor Commandment: Law, Religion, and the Challenge of Elder Care,” *Journal of Law and Religion* 30, no. 2 (2015): 229–59.

15 The authors were invited to contribute to this symposium issue of the journal exploring the biblical commandment to honor one’s father and mother and its influence on contemporary elder care. The authors, two board-certified chaplains and a palliative medicine physician, all with extensive palliative care clinical experience, analyzed the biblical commandment as it appears in scripture and in subsequent commentary.

We explored the linguistic and textual context of the honor commandment and selected prominent interpretations that we then analyzed through the lens of palliative care practice. We draw on personal observations of how uncertainty about what it means to honor one’s parent in medical decision making plays out in the palliative care clinical setting. The authors wrote case studies (altered to protect confidentiality) that illustrate these perspectives about the honor commandment. The case studies are drawn from experience as palliative care providers in acute care medical centers/teaching hospitals in urban areas. Each case study concludes with an explicit discussion of the spiritual dimensions of the vignette, with special reference to the role played by the “honor” commandment.

We acknowledge that of the four cases, one is about a Jewish family. The other three cases portray a variety of cultural, spiritual, and religious backgrounds and traditions. The two board-certified chaplain authors are molded by their Jewish professional training and clinical experiences. However, as professional interfaith chaplains, they are trained to allow Jewish ethics, texts, and thought that may have universal relevance to inform their clinical understanding of matters such as those explored in this article. Certainly other cultures or faith traditions might apply varying interpretations to these cases.

CONTEXT AND INTERPRETATIONS OF THE BIBLICAL “HONOR” COMMANDMENT

“Honor thy father and thy mother” is a well-known and often-quoted guiding ethical principle in many faith traditions. It is a concept that is pervasive, even in secularized Western cultures. However, while the phrase is familiar to many, the context and deeper interpretations of the honor commandment are often not well understood. In this article, we examine how this blurred misunderstanding leads to conflicting assumptions about children’s obligations when a parent is seriously ill.

Methods in exegesis (critical explanation or interpretation of a scriptural text) offer several options for analyzing the honor commandment. One strategy is to focus on the linguistic root and translation of the word “honor.” The Hebrew word used in the text is “kibbud,” which by most accounts is best translated to “giving weight” or importance to another person. Many commentators translate and interpret the word honor as referring to an obligation to give “weight” or “seriousness” to one’s parents. Being responsible for one’s parents and their medical decision making, especially in the event of serious illness, is indeed a heavy burden. Not only is there a wide range of opinion about what it really means to respect and honor a seriously ill parent, but also end-of-life care is complex and highly context dependent: there is rarely a straightforward answer or a handy “magic pill.” The palliative care model offers an explicit approach to the obligation to honor parents by highlighting the importance of preferences and drawing on multiple medical and psycho-social-spiritual disciplines to help identify those preferences. In our experience, palliative care provides a powerful exemplar of the ways that skilled interdisciplinary clinicians can help family members “give weight” to a seriously ill parent’s goals and preferences.

Another approach to understanding the honor commandment is to examine its context within the Torah. It is *part* of a biblical verse in the book of Exodus that appears in the context of the giving and receiving of the Decalogue (also called the Ten Commandments).¹⁶ The words of the first part of the verse are brief, yet centuries of biblical and ethical commentaries have yielded many meanings and interpretations for the word that has been translated as “honor.” It is worthwhile to also examine the second and much less familiar part of the verse. The complete verse is written as “Honor thy father and thy mother, that thy days may be long upon the land which the Lord thy God has given you.”¹⁷ Beyond this, the text goes on to provide instructions about how the receivers of the law should interact with it and that they will be “blessed” if they do so.

This verse raises the question of what “living long upon the land” and being blessed means for those living in a modern (that is, non-agrarian) and more secularized society. How is this ancient text relevant to caring for parents in the modern health care environment? Family members often state that although they know that their seriously ill mother or father would not want to be kept alive with artificial means, they are afraid of the weight and responsibility of deciding to cease such interventions. Health care proxies and surrogate decision makers find it difficult to separate their own feelings and beliefs from the role they must assume, which is to make a decision on behalf of the parent based on what they believe the parent would choose. We frequently hear statements to the effect that “I will not be able to live with myself” or “I can’t have that on my head.”¹⁸

16 Exodus 20. Biblical translations and references are taken from *Tanakh: The Holy Scriptures* (Philadelphia: The Jewish Publication Society, 1985).

17 Exodus 20:12. See also Deuteronomy 5:16.

18 See Bernard Lo, *Resolving Ethical Dilemmas: A Guide for Clinicians*, 4th ed. (Baltimore: Lippincott Williams & Wilkins, 2012); Goold, Williams, and Arnold, “Conflicts Regarding Decisions,” 911.

We believe that the second part of the biblical verse provides important context for children who are making difficult decisions with and for their seriously ill parents. In palliative care, part of treating the whole family unit is facilitating a process through which the adult children can bring the voice—the weight—of their mother or father into the room. A space is created where the parent’s hopes and wishes can be clearly stated and witnessed by the medical team. Adult children are thus empowered as the “experts,” or representatives of who they know their parents to be. Helping the child to honor his or her parent as a person with opinions and desires about what medical treatments the patient might receive can help assuage feelings of guilt, shame, stress, and burden felt by many decision makers. Once at peace with their decisions, they can subsequently live with themselves and “endure on the land,” that is, feel a sense of integrity and pride in their choices for the rest of the time that they will live on this plane of existence without their parents. “Enduring on the land” and “being blessed” are apt metaphors for helping to assure the emotional and spiritual well-being of adult children in the aftermath of the death of their parents.

A third method of revealing the meaning of the honor commandment is to examine the literature of interpretation about this biblical text. Medieval rabbinic commentators, for example, provide us with perspectives about whether or not “honor” includes blind obedience to one’s parents.¹⁹ While obedience is part of the parent-child relationship, especially during childhood, some argue that it also applies to adult children wrestling with complicated obligations to their parents. The idea of strict obedience can, however, lead to a common misinterpretation of the “honor” commandment.²⁰ Strict obedience is a limiting paradigm in the palliative care setting because it precludes the process of honoring parents by making decisions in their best interests when they can no longer make their own wishes known. Another example that highlights the limitations of defining honor as merely obedience is the situation in which the child was abused or neglected by the parent in childhood. This raises questions about the responsibility of a child to a parent who did not keep him or her safe during the most vulnerable stages of development.

Other commentators have explored the reasons why the honor commandment is included in the Decalogue at all. The inclusion of this principle in the Ten Commandments implies that it is of special importance. It is also one of the few precepts in the Decalogue that are framed in the positive, that is, prescribing what a person ought to do rather than what he or she “shall not” do. This proactive “commandment” exhorts us to not cast aside our parents, especially as they are sick or dying, and when the physical, financial, and emotional burdens of caring for them may be particularly extreme.²¹ The honor commandment reflects an aspect of social fabric and human relations that endures to this day and is manifested, for example, in laws guiding health care surrogacy that indicate that adult children of seriously ill patients should be consulted in decision making.²²

19 In fact there is a biblical and rabbinic teaching that the obligation to honor one’s parents does not allow one to transgress a commandment in a manner that might lead to a violation of Jewish law. Biblically, this is reflected in Leviticus 19:3. The rabbinic teachings are reflected through the eleventh-century French rabbinic commentary of Rashi, who comments specifically on the biblical verse Leviticus 19:3, as well as the rabbinic teachings found in Bava Metzi’a 32a in the Talmud.

20 Shai Held, “Honoring Parents: (Sometimes) the Hardest Mitzvah of All—Parshat Yitro,” *Mechon Hadar*, accessed March 30, 2016, <http://www.mechonhadar.org/torah-resource/honoring-parents>.

21 See J. N. Thai et al., “‘It Just Consumes Your Life’: Quality of Life for Informal Caregivers of Diverse Older Adults with Late-Life Disability,” *American Journal of Hospice & Palliative Medicine* (May 2015): 1–6; Merryn Gott et al., “No Matter What the Cost”: A Qualitative Study of the Financial Costs Faced by Family and Whānau Caregivers within a Palliative Care Context,” *Palliative Medicine* 29, no. 6 (2015): 518–28; Karin Oechsle et al., “Anxiety and Depression in Caregivers of Terminally Ill Cancer Patients: Impact on Their Perspective of the Patients’ Symptom Burden,” *Journal of Palliative Medicine* 16, no. 9 (2013): 1–6.

22 N.Y. Pub. Health Law § 29 (2010).

Many commentators, Maimonides²³ among them, have also focused on how the language for honoring one's mother and father, and the consequences for doing or not doing so, mirrors scriptural commandments to honor God. Most patients and families describe themselves as "spiritual" and have some belief in a higher force they refer to as "God."²⁴ Patients and their loved ones articulate a wide range of relationships with and beliefs in a higher power that connect them with something greater outside themselves, whether it be "God" as understood in religion and scripture, or a relationship with nature, a philosophy, a spiritual practice, an appreciation of the beauty of creation, or love of other human beings. Understanding the range and depth of these beliefs may provide insight into the relationship between seriously ill parents and their adult children.

The analogy between the relationship to a higher power and the honor commandment is supported by various theories positing that the experience of human relationship is a catalyst for spiritual development.²⁵ For example, some adult children express that making a medical decision on behalf of their sick parent carries so much weight because doing so is closely linked to the responsibility they feel for their parents and also to their understanding of morality and what is expected of them by a higher power. They fear making the wrong decision (imagining that there is an objectively correct decision) and then living with crushing guilt that they have wronged their creators—God and their parent.

Furthermore, when adult children are involved in medical decision making for their seriously ill parents, it raises existential issues and awareness of their own mortality. As they realize their parents' vulnerability to illness and death, their own future is thrown into sharper relief. In expressing their grief after the death of their parents many adult children have commented about their bewilderment at now being the "oldest generation," now "first in line," and what that means.

CASE STUDIES

The following four case studies illustrate concerns expressed by adult children who wish to honor their parents but who are confused about what this mandate means in the face of difficult medical and psycho-social-spiritual circumstances. Each of these cases highlights a paradigm that allows for consideration of some of the dynamics that clinicians can face.²⁶ We analyze each case study from the perspective of culture, religious and theological background, as well as clinical practice with the understanding and recognition of various limitations.²⁷

23 Maimonides (1138–1204; also Moses ben Maimon, or his Hebrew acronym Rambam) was one of Judaism's foremost scholars and philosophers. His writings about Jewish ethics and law, including the canonical fourteen-volume *Mishneh Torah*, continue to influence Jewish thinking and practice today.

24 See "Gallup Poll on Religion," accessed February 12, 2016, <http://www.gallup.com/poll/1690/Religion.aspx>; "Spirituality in Cancer Care—Health Professional Version (PDQ®)," National Cancer Institute, <http://www.cancer.gov/about-cancer/coping/day-to-day/faith-and-spirituality/spirituality-hp-pdq>.

25 Michele Shields, Allison Kestenbaum, and Laura B. Dunn, "Spiritual Aim and the Work of the Chaplain: A Model for Assessing Spiritual Needs and Outcomes in Relationship," *Palliative and Supportive Care* 13, no. 1 (2015): 75–89.

26 These paradigms are not intended to offer a comprehensive taxonomy, but rather highlight various details that we have found provide deeper understanding in the care provided to patients and their families when uncovered by clinicians and professional aiding in their care.

27 The authors acknowledge limitations in our methods and case studies and further work that could be done to expand the discourse on this topic. First, the analysis of the honor commandment was done primarily from a Jewish perspective. It would be worthwhile for spiritual caregivers from other faith traditions to offer their unique exegesis and present corresponding case studies. It would also be worthwhile for spiritual caregivers from

Our analysis is also informed by the framework used by palliative care teams when discussing clinical cases.²⁸

Case 1—The Unconditionally Loving or Beloved Parent

We can't honor Dad if he is dead.

The Case

Mr. R was a Caucasian Christian man in his seventies with heart failure who was not a candidate for a heart transplant. To assist his heart function, he received a ventricular assist device, or VAD, a surgically implanted artificial heart pump. In addition to heart failure, Mr. R had multiple medical problems, including continued infections. He also had a non-displaced hip fracture prior to hospitalization for which he was receiving rehabilitation therapy. He came to the emergency room with dark urine and a clot at the site of his VAD placement. He was admitted to the hospital's coronary care unit and required mechanical ventilation for altered mental status and respiratory failure. He also required vasopressor infusions because of low blood pressure, a result of septic shock.

The palliative care team was called to assist in discussions with his family because of the patient's critical condition in the intensive care unit.²⁹ In this initial meeting with Mr. R's daughter, she acknowledged that "things were looking worse." After seeking and receiving permission to talk about her father's condition, the team explained that the patient was dying, and that despite every possible intervention (intubation, vasopressors, antibiotics, and blood transfusions), he had developed multiple organ failure and was getting worse. She expressed understanding but said that she would not want any of these interventions stopped and wanted reassurance of that. She informed

non-Abrahamic faith traditions who do not have a personal religious or spiritual connection to the Bible to comment on the values and teachings of their tradition that relate to the parent-child relationship in palliative care. In general, more case studies are needed that explore other prominent spiritual themes to help the medical community at large to better understand the role and purpose of the spiritual domain.

Another limitation is that the clinical scenarios of this article were inspired by experiences in academic medical centers in large metropolitan areas. It may be worthwhile for caregivers in other settings, such as community hospice or hospitals, to reflect on these issues. Further study about how gender, ethnicity, culture, and national origin influences the spiritual domain may also be instructive. In addition, all of the cases were written about consultations with a palliative care service. We acknowledge that there are many clinical situations where the primary or front-line medical team also faces these issues.

Finally, we acknowledge that these cases were written from the perspective of clinicians, although we have tried to present some of the perspective of the patients and their loved ones. More can be done in this area. Perspectives from other members of the care team, such as social workers, psychologists, psychiatrists, and nurses could deepen these accounts. We would also welcome insights from legal professionals working in health care, such as those working in risk management or elder law.

- 28 Using the framework of palliative care, caring for the whole person, each discipline represented speaks to the various dimensions of a person that has an impact on his or her medical care. Typically a palliative care team will have a roundtable discussion about demographic information, medical history, current medical condition, and reason for hospital admission; reason for palliative care consultation and psycho-social-spiritual assessment; and plan. These teams revisit each patient and make a daily assessment and plan until the reason for consultation is resolved. As mentioned above, palliative care is consulted for patients with serious illness who need pain and symptom management or counsel in complex medical decision making.
- 29 The team consisted of a palliative care board-certified physician, a nurse practitioner, a social worker, and a chaplain.

the team that her plan was to discuss things further with her family, one of whom was traveling outside the country.

The palliative care team subsequently met with other family members, including other children living locally, a child who flew in from abroad, and the patient's spouse, along with the intensive care unit attending physician and resident. The family was updated regarding Mr. R's continued decline. The team conveyed that the primary and unfixable problem was a clot in the VAD: he would not survive the major surgical procedure required to remove it.

The family members uniformly expressed that they were depending on their religion to guide them, and described their belief that they felt obligated to continue "all measures," all "technology" that is available, or they would be left with guilt that they had "given up" on their father. They also wanted to ensure that medication would be continued to treat any pain he was experiencing. The family said that the patient believed that his children "could do no wrong." Mr. R was described as a generous spirit who would do anything and everything for his kids, would "give the shirt off his back for them or for anybody." The needs of others always came before his own.

Discussion of Honor/Spiritual Domain

The medical team in the intensive care unit felt limited in what they could medically offer the patient in terms of recovery because of his severe illness and prognosis. They needed assistance to communicate with the family about this reality.³⁰ The children did not explicitly mention the religious law to honor their parents as a factor in their decision making. However, they did speak about wanting to act from a place of "love" and "respect" toward their father in return for the unconditional love they felt they received from him, despite the fact that even with the application of all life-prolonging measures Mr. R was actively dying. The family also reported that their "do everything" position was informed by their religious beliefs. When the palliative care team asked the family about these religious beliefs, they articulated their fear that if they allowed anything other than "do everything" measures, they believed this meant that they would fail to honor—that is, reciprocate—the "do everything and unconditional love" they had always received. The family perceived their obligation to honor him in the same manner as he had loved them. Thus, for the family informed by their religious belief and family values, this meant prolonging life. To the clinicians, the family seemed to ignore the reality of his condition based on the family's values of what "honor" meant, a concept that was unmoored from the patient's medical reality. The family could not allow the natural progression of his illness to take effect because the spiritual and emotional pain of Mr. R's abandonment of them in death was too great for the family to digest.

Regarding legal considerations, the family's consent was required in order for the father to be removed from artificial life sustaining interventions. The patient had not assigned a health care proxy, so the laws of the state determined that his wife would be the surrogate decision maker. She delegated the choices to her children, who were therefore collectively and by consensus making health care decisions for their father.

Case 2—The Broken Parent-Child Relationship

Even though mom has an advance directive, we don't want to be responsible for deciding to end her life.

³⁰ This case represents a common reason for palliative care consultation. There can always be medical interventions offered but the question is whether or not this is in line with patient's goals and the hoped-for outcomes.

The Case

Ms. P was an Eastern Orthodox woman in her sixties who had been on a ventilator for several months after a witnessed cardiac arrest in a public park. She suffered severe brain damage from lack of oxygen and was permanently comatose and ventilator-dependent despite three months in the intensive care unit and two months on the medical floor. She had written an advance directive that indicated her wishes to be allowed a natural death if a situation like this one were to occur. Despite acknowledging her wishes, her three adult children struggled with accepting them and advocated for maintaining artificial nutrition and ventilator support. The patient's two sons had come to blows in the intensive care unit and had been escorted out by security. They had stopped visiting the hospital and failed to respond to repeated messages for weeks. Only the patient's youngest child, her daughter, remained. She maintained a near 24/7 vigil at the bedside.

The palliative care team was asked to meet with Ms. P's daughter. As specialists in the care of seriously ill patients and their families, they also offered consultation and support to Ms. P's primary medical team of the patient.³¹ In particular, bedside nurses and house staff were struggling with the children's insistence to continue ventilator support, especially because the patient had advance directives that stated otherwise. The team felt the patient was suffering as she had "the worst pressure ulcer [the team] had ever seen," and they asked, "Why are they making her suffer like this?" The nurses reported that the patient winced and moaned when they provided routine care, such as turning her and dressing her wound. The palliative care team began the meeting with the daughter with an invitation: "Tell us about your family." In her response, she recounted that she and her brothers had been physically and emotionally abused throughout their childhood by their now frail and comatose mother. Ever since they were small children, each had entertained fantasies of wanting their mother to suffer in return for the abuse they had experienced. The daughter expressed concern, although she knew it was not logical, that she had caused her mother's illness through these fantasies, and that allowing her to die would be a manifestation of acting on her childhood revenge fantasies. The fact that their mother was suffering was only a repetition, a mirroring, of their family experience.

Discussion of Honor/Spiritual Domain

While the family identified as Eastern Orthodox, it was the cultural perspectives and family history that influenced their decision-making process, more so than explicit religious or theological views. The children reported that they were raised to honor their parents regardless of their parents' actions or their physical or mental states. The palliative care team counseled the daughter through these cultural factors and barriers, as well as some of the challenging family dynamics. A significant milestone in this case occurred five months into the hospital stay³² when, for the first time, the daughter was invited by the palliative care team to tell her family's story. This open-ended question allowed her to divulge the abuse she and her brothers had experienced from their parent. Part of their struggle was that they were not able to reconcile their individual experience of being abused by their mother. They were unable to step out of their own experience and anger at their mother so that they could honor her wishes. Part of what the palliative consult service offered in this case was

31 The palliative care consultation service is often called on in such cases, where there is family discord and complex decisions that need to be made.

32 Part of the moral distress expressed by the staff related to this very long hospitalization. The palliative care consultation service provided support to staff on this issue.

an opportunity to identify and honor both the children's experience of being abused and the mother's clearly previously stated wishes. While her written advance directive technically provided legal guidance, as is often the case, best clinical practice entails that the surrogate decision makers or health care proxy must agree to honor the wishes. As she was able to speak openly about what happened in the past with clinicians trained and credentialed to solicit and hear this information, the memory of her mother's abusive behavior and her own fantasies of revenge dissipated. Talking with nonjudgmental listeners helped this daughter to accept the reality of her mother's condition and to see that her death was not her fault but rather the natural progression of the mother's illness. The ventilator and feeding tube were removed and the patient died peacefully several days later.

This revelation also helped the medical team. The medical team had become increasingly angry and morally distressed and frustrated as Ms. P's children insisted on continuing artificial interventions despite the suffering it was causing. Once the team became aware of the family history, their increased understanding of the root causes of this behavior led to a marked improvement in the team's ability to feel compassion and respect for the children's struggle.

Case 3—The Parent and Child in Loving Disagreement: Honoring as Giving Weight

Why won't you listen to me?

The Case

Ms. J was an African American woman in her sixties of no faith affiliation,³³ with a past medical history of diabetes, end-stage renal disease on hemodialysis, hepatitis C virus, and cirrhosis, who came from home with altered mental status, hematemesis (vomiting blood), and respiratory failure requiring emergent intubation. The patient's hospital course was complicated by infection, persistent confusion, and bleeding. The family decided on a do-not-resuscitate order, or DNR, to avoid a future intubation. Palliative care was consulted for goals of care discussion.

The palliative care team met with the family, including Ms. J's daughter, granddaughter, son-in-law, brother, and her best friend. The focus of the meeting was to establish the goals of Ms. J's care. Family members were asked about their perception of the patient's current medical state and asked to express how she might feel about her current situation. Her granddaughter, a hospice nursing aide, was able to tell her other family members about her experiences at work with similar situations. The intensive care unit team spent time explaining the patient's deteriorating condition. Some family members had strong views that if Ms. J knew that she was not going to recover to her previous state, then she would not want to live that way. The family said that "she's been on dialysis for a while and it was like pulling teeth to get her to go." The daughter said that she would tell her mother, "If you don't go to dialysis, you will die." And the patient always responded, "That's okay with me!"

Her daughter described several occurrences when her mother did not want dialysis or her medication but noted that she was always able to convince her mother to continue getting treatment. She expressed feelings of guilt that she had not made her mother go to the emergency room sooner when she started to show confusion. She was tearful as she talked about this. The patient had said

33 While patients may not have a faith affiliation or religious beliefs, palliative care philosophy recognizes that there are spiritual needs that deserve to be assessed, addressed, and honored because these inform patients' decisions and coping.

that she did not want to go to the hospital, and the daughter had said, “I’ll give you twenty-four hours, and if you’re not feeling better, I’m taking you.” The palliative care team provided support and counsel to the patient’s daughter surrounding the challenge of forcing someone to go to a hospital if she does not want to go. The team also expressed respect and appreciation for the daughter’s meticulous long-term caregiving provided to her mother. The team then asked, “If your mother knew what was going on with her medically now, what do you think she would she say?” The family described her as a feisty lady who cursed a lot. The son-in-law responded, “She would say ‘get this [expletive] tube out of me.’” The granddaughter turned to her mother and said, “You know what you have to do—we have to take the tube out because that’s what she would want. She wouldn’t want this. If she could speak you know she would be cursing us.” Hearing this, the daughter agreed that the patient would not want to live on machines and “she would want to be freed” from the machine.

Discussion of Honor/Spiritual Domain

This case illustrates the concept of “giving weight” and honoring who a person is at her core. Although the family did not express their understanding in terms of the honor commandment as a guiding religious principle, it was clearly a closely held value for them. This family described their loved one as a “feisty” person who would not want to live connected indefinitely to machines. Bringing her voice into the room honored her unique spirit and values. The patient did not have a designated health care proxy; therefore her daughter was the designated decision maker under the surrogacy guidelines of the state. Because Ms. J was not able to participate in the discussions, the palliative care team helped the family give voice to Ms. J’s voiceless self, asking, “If she were sitting here and could hear what was going on with her, what would she say?” Encouraging the family to voice and then agree upon Ms. J’s wishes took the weight of the decision off the caregiving daughter, who felt guilty and conflicted in her decision-making role. The family expressed a greater sense of peace as a result of receiving permission from the team to listen to the patient’s “voice.” Also, hearing other family members voice who Ms. J was as a person offered a gift of clarity to the daughter, as it created a space for her to separate her role as long-term caregiver from her role as decision maker. This differentiation allowed the daughter not only to hear her mother’s voice, but also to give weight to it and honor her wishes.

Case 4—*The Ambivalent Parent*

Mom, I just want to hear your voice so you can make your wishes known.

The Case

Mrs. S is a Jewish woman in her seventies with a new diagnosis of amyotrophic lateral sclerosis, a serious, progressive, neurodegenerative disease. During her diagnostic work-up she developed an infection, confusion, and difficulty breathing. Due to her altered mental status, she lacked capacity to participate in emergent decision making about treatment for her life-threatening symptoms. She had no written advance directive or a health care proxy to whom she had expressed her wishes. As her surrogate, her husband gave consent for a tracheostomy (making a hole in the trachea for ventilator access and airway protection). While she did regain alertness and could communicate through mouthing brief sentences and single words, she was unable to make decisions about the ventilator. When asked about her wishes by the palliative care team and the family, she frequently

mouthed the words “I don’t know.” When asked by the chaplain what she meant by this, the patient was able to say only, “This is all so new.” Whereas the family had digested and begun to adjust to the diagnosis and implications over the period of weeks while the patient was not alert, she was confronting and understanding her situation for the first time and was emotionally and spiritually overwhelmed.

After she regained capacity, all conversations about her care were conducted in her presence and with her permission. When the neurologist, her primary attending physician at the hospital, informed her of her diagnosis the patient asked, “Does that mean I’m dying?” The neurologist explained that she was dying but emphasized that it was unlikely that she would die suddenly; she would more likely experience a long decline. The neurologist told her that she would not recover from her illness and would remain dependent on the ventilator to breathe, but that her symptoms and pain would be well managed. Once the patient was medically stable, she and her family were faced with a decision: remove the ventilator and allow a natural death or move to an adult long-term care facility where she could be kept alive on ventilator support. The palliative care team facilitated a family meeting to revisit the patient and family’s goals of care. At the meeting and faced with this decision, her son began to cry and said “Mommy, these tears are important for me to shed because it makes me feel better. I’m suffering because I don’t know what you want, and I want to be able to honor you and your wishes. Please don’t be mad at me for crying.” Ultimately the patient mouthed to her family, “I just want more time with you all.” This significant expression of her wishes led to a decision to continue ventilator support and arrange for discharge to a ventilator facility. She was informed by the palliative team that if and when her situation were to become unbearable for her, and if her suffering outweighed any benefit from more life as she defined it, she retained the option of receiving palliative extubation and allowing natural death.

Discussion of Honor/Spiritual Domain

Mrs. S, her husband, and son all identify as Jewish. This family did not feel obligated to follow all aspects of Jewish law but were informed by ethical principles and values of the faith. Although the husband was the surrogate decision maker, he relied heavily on the son’s opinions and perspectives to make this and all subsequent decisions. They made decisions jointly because that is how this family operated. The son frequently stated, “I want to make sure my mother’s voice is heard and that her wishes are known. I know that the Torah tells me that I am obligated to honor my mother.” The son was speaking both literally and metaphorically—the patient would never be able to speak aloud again because she was now completely dependent on a ventilator support for breathing. The family meeting opened the lines of communication for the family and brought to light the son’s desire to honor his mother’s wishes and his distress that what she wanted was not clear. It was in response to the son’s anguish and direct request that his mother was able to make a significant decision: her desire for more time with her family outweighed any other quality-of-life considerations at this point. The involvement of the palliative care team and their ability to elicit and respect the patient’s decision for more time and affirm this as a legitimate choice for the husband and son to hear was critical. After this decision had been made and affirmed, the patient mouthed that “It is getting dark now and Shabbat is coming” and began to cry. The chaplain saw an opportunity to use the patient’s reference to a meaningful ritual of the family’s faith tradition to further affirm and honor the difficult decision they had made. The family discussed that while this was a dark time, their clarity about spending more quality time together was bringing them light, just as lighting Sabbath candles offer light in the darkness.

DISCUSSION

There are few published case discussions that focus on exploration of the spiritual domain in patient care.³⁴ Case studies depicting the spiritual aspects of decision making for palliative care patients are even more scant. This article lays out several clinical scenarios that highlight a prominent and complex spiritual issue: honoring parents in decision making.

Where the child-parent relationship is central to the patient's care, clinical caregivers must bring to bear the principles of social science, psychology, and human development. They must also be aware of the impact of their personal experience, including their own projections and counter-transference.³⁵ The parent-child relationship is complex in the best of circumstances, and the extreme stress and strain of hospitalization and life-and-death decision making compounds the complexity. In our work, we witness a great deal of conflict regarding decision making—experienced either internally by the child who is the responsible decision maker or externally among family members with different points of view. Our belief is that it is important and useful to explicitly identify and name when the child-parent dynamic and assumptions about what it means to honor a parent are at play in clinical situations. Rather than seeing such situations as pathological or unnecessarily difficult, normalization can be helpful. This naming and normalizing may occur during interdisciplinary team meetings, at family meetings, or in one-on-one conversations. Clinicians may consider using the concepts and themes of the scenarios described in this article as a guide to engage in discussions with patients and their loved ones. An approach to having these conversations might include carving out some time, beginning, for example, with 30 minutes, and inviting the patient or the family to tell their story of the events that led up to the patients' coming to the hospital. Giving a space to share their story and experience can not only be healing for them, but it can also help the clinician to understand the journey that the patient or loved ones have been on. Also asking about who the patient is as a person by inquiring "What matters most to you?" or "What gives your life meaning?" are other ways to begin these conversations.³⁶ If health care providers do not feel equipped or comfortable to initiate these conversations, they may call upon a trained and credentialed spiritual caregiver, such as a board certified chaplain, who is an experienced member of the health care team.

Understanding the issues raised in the common scenarios presented here may provide a helpful resource in a health care system that asks patients and families to make serious decisions very quickly. Decision making in palliative care can be emotionally and spiritually fraught even when patients have thoroughly discussed their wishes with a surrogate decision maker or health care proxy. Adult children are being asked to process the physical and medical realities, which are complicated for non-clinicians to easily understand in a brief time frame. When adult children do make decisions, they are not only attempting to make informed decisions about their parents' medical care, but they are making these decisions as children obliged to honor their father and their mother. For example, if a parent's medical condition is life threatening, an adult child's fear that his or her decision will be viewed by others and experienced by them as insufficiently devoted may be relevant and reflected in the choices he or she makes. Our hope is that these case studies will help medical providers

34 For one of the few examples of published cases, see George Fitchett and Steve Nolan, eds. *Spiritual Care in Practice: Case Studies in Healthcare Chaplaincy* (Philadelphia: Jessica Kingsley Publishers, 2015).

35 Diane E. Meier, Anthony L. Back, and R. Sean Morrison, "The Inner Life of Physicians and Care of the Seriously Ill," *Journal of the American Medical Association* 286, no. 23 (2001): 3007–14.

36 Anthony Back, Robert Arnold, and James Tulsky, *Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope* (New York: Cambridge University Press, 2009), chapters 9 and 10.

understand the complexity—what is going on in decision makers’ minds and hearts—in the midst of hospitalization for a loved one’s serious illness.

Remarkably, the basic human need to love and be loved is not explicitly mentioned either in the biblical honor commandment and subsequent commentaries or in the palliative care communication training literature. Yet “love” is exactly what countless adult children refer to when they have talked with us about making medical decisions with and for their parents. Although love cannot be empirically described or formulated into a conceptual model, we believe it is important to acknowledge how the need to love and be loved interacts with decision making. The parent-child relationship, as demonstrated by these cases, is by no means static, and it continues to evolve during illness and through and even after death. An adult child’s relationship to his or her parent may change even after the parent has lost his or her ability to communicate or has died. Clinicians, especially trained spiritual caregivers working in palliative care, have a unique responsibility and opportunity to draw upon the spiritual domain to help negotiate this complexity.

We hope that this article may serve as a springboard for conversations about the central role of the spiritual domain in supporting families making decisions about life-sustaining treatments. If spirituality is in fact embedded in the health care experience, as we would argue, how do we honor that reality at the bedside?

CONCLUSION

The commandment to honor thy father and mother is found in virtually all faith traditions.³⁷ When a parent becomes seriously ill, however, family decision makers may need help to identify and articulate aloud what it means to honor their parent for who he or she is as a person, especially if the parent is unable to make his or her wishes known. The powerful effect of the honor commandment is to encourage adult children to bring the parent’s voice into the decision-making process. This ancient text reminds us that modern medical treatments offered to a parent in the midst of serious illness must always acknowledge the parent as a human being—a person with opinions, priorities, and preferences that must be heard and honored.

ACKNOWLEDGMENTS

We are grateful to Rabbi Mordecai Schwartz for several helpful discussions regarding Jewish methods and study of textual sources. We appreciate Suzy Goldhirsch for her comments and edits on multiple drafts of this manuscript. We would also like to thank Carolyn Slutsky and Brian Garrick for their love and support and Nate Béla Garrick for being a teacher and inspiration. We thank Amy Zietlow and Naomi Cahn for their invitation and to the reviewers for their thoughtful comments on a draft of this manuscript. And finally, we dedicate this paper to our parents, who we strive to honor with our work in the field of palliative care.

37 Andrew Wilson, “The Purpose of Life in the Family and in Society,” chapter 4 in *World Scripture: A Comparative Anthology of Sacred Texts*, ed. Andrew Wilson (New York: International Religious Foundation, 1991), 169.