CE Ethics Series

1.0 ANCC Contact Hour

Hope for a Miracle

Treatment Requests at the End of Life

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Living with a life-threatening illness is challenging. It is not uncommon for patients and caregivers facing medical uncertainties to utilize religious coping as a tool to foster adjustment to changes along an illness trajectory. Religious coping can promote a sense of meaning, emotional well-being, and hope. This article explores requests for aggressive treatment stemming from strongly held religious beliefs and overarching hope for a miracle. A case example highlights the complexities of religious coping, belief in miracles, and requests for life-prolonging treatment at the end of life. The article closes with a discussion of the ethical considerations and strategies for best communicating with and caring for patients who request life-prolonging medical care in advanced illness.

KEY WORDS

bioethics, decision making, end of life, religious beliefs

The right of competent adults to refuse unwanted medical interventions, even lifesaving treatments, is a well-documented ethical and legal issue. Patient autonomy is a fundamental principle in bioethics, referring to an individual's right to make informed, uncoerced decisions. In health care, a person with capacity has the right to choose whether he/she wants to accept or refuse care. But, does patient autonomy give a person the right to demand care that the health care team considers painful, harmful, or unsafe? What if these treatment requests are based on strongly held religious or spiritual beliefs?

Autonomy, self-determination, and religious freedom are inherent cornerstones in Western society that are protected not only by the US Constitution but also a large body of legal cases.[1] With the noteworthy shift away from paternalism, it is not unusual for health care professionals to come in contact with patients and families who invoke strong spiritual beliefs as the primary reason for continuing with aggressive medical interventions at the end of life.[2]

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This article explores requests for aggressive treatment stemming from strongly held religious beliefs and overarching hope for a miracle. The following case highlights the complexities of religious coping, belief in miracles, and requests for life-prolonging treatment at the end of life. The article closes with a discussion of the ethical considerations and strategies for best communicating with and caring for patients who request life-prolonging medical care in advanced illness.

CASE REPORT

Eduardo Vasquez was a 38-year-old man with a diagnosis of stage IV non–small cell lung cancer metastasized to the liver. Over the course of 1 year, he underwent numerous chemotherapy treatments. He was admitted to the hospital with shortness of breath, unsteady gait, and severe back pain. Scans revealed metastases to the brain and bone. Eduardo expressed anger and frustration with disease progression but was adamant that his cancer could be cured, even though he had been told both at diagnosis and along the illness trajectory that the cancer would shorten his life. He remained focused and determined to continue his cancer treatment. Soon after admission, a family meeting reviewed treatment options and goals of care. A plan was made to undergo palliative radiation to the sacrum followed by whole-brain radiation and ventricular-peritoneal shunt placement for persistent hydrocephalus. The team was clear that these palliative interventions were designed to provide symptom management, without curative intent.

Eduardo was raised in the Dominican Republic by a large, supportive Roman Catholic family. He was married and had a young daughter. Eduardo was a pleasant and engaging man who spoke openly about his devotion to God and his steadfast hope for a miracle. When pressed to explore in more depth, he indicated that he believed God would cure him of his cancer as long as he remained faithful. Eduardo noted that his strong faith decreed that God and only God would decide when he would die; it was Eduardo's job to continue fighting until

that time. Given Eduardo's strongly held belief, he requested that "everything be done" to keep him alive for as long as possible.

RELIGIOUS COPING

Religious coping specifies how a person makes use of his/her religious or spiritual beliefs during stressful life events including health crisis. It is a coping strategy that helps people understand and find meaning in their medical predicaments. Spirituality provides hope in the midst of despair; in many situations, it is considered a healthy adaptation to stress. Religious coping helps people acclimate to stress and can substantially improve quality of life. Positive religious coping (defined as generous religious appraisals, forgiveness, and belief in a partnership with God) is widely associated with enhanced psychological adjustment to difficult psychosocial stressors.[3] Negative religious coping occurs when people feel abandoned by God or believe that illness or tragic occurrence is a divine punishment for a previously committed act. In contrast, negative religious coping predicts that patients experience more severe depressive states, worse well-being, and poor treatment compliance.[4]

Religious coping is also associated with increased preference in cardiopulmonary resuscitation, mechanical ventilation, and other life-prolonging interventions.[5,6] Intensive life-prolonging measures are preferred by individuals with high levels of religiosity (high levels determined by daily prayer, meditation, and/or study). Strong faith significantly influences medical decision making. In a multicenter intensive care unit and emergency room survey, 57% of patients polled thought that God could cure them, even after the health care team indicated that prognosis was poor.[7] Another study revealed that 64% of caregivers of critically ill patients were reluctant to believe physician's predictions of futility.[8] One-third of these surrogates indicated that this doubt was based on personal belief that God would intervene, changing the medical course. Caregivers were subsequently more likely to request continued life-prolonging medical interventions. In another multicenter study, 20% of caregivers felt that their faith in God outrivaled all other sources of prognostic medical information.[6] In this poll, faith was defined as a belief in the power of prayer, prayer circles, and/or presence of God working through the health care team.

Many religious copers choose aggressive treatments in hopes of prolonging life until God heals them. This trust in God also motivates patients to choose risky or experimental treatments because they believe that God will not allow them to be harmed. Religious coping is viewed as a collaborative with God to overcome illness and suffering. Finding meaning or purpose in suffering may allow people to endure more aggressive or painful treatments. The alternate, abandoning belief in God and His ability to cure them by accepting limitations of modern medicine, is regarded as "giving up on God."

Multiple meetings with Eduardo and his family explored goals of care and the clinical team's recommendation for transition to hospice. Eduardo made clear, demanding requests for additional cancer treatment in addition to artificial nutrition and hydration. The medical team countered with concerns regarding poor functional status and disease progression in light of aggressive treatment. Eduardo was steadfast in his focus on treatment. When pressed to explore his beliefs, he responded that he and his family had witnessed several medical miracles in their Dominican community. He believed that God would cure him of his lung cancer as long as he remained faithful and devoted.

WHAT IS A MIRACLE?

A miracle is an extraordinary event that surpasses known human or natural powers and is attributed to a divine intervention. There are many variations and interpretations of miracles, depending on religious affiliation; Christianity, Judaism, Islam, Buddhism, and Hinduism all acknowledge the existence of miracles. Belief in miracles is common not only across major religions but also a frequent belief of the general public. The Pew Research Center Religious Landscape Study exploring religion and public life in the United States, with more than 35 000 people polled on a number of topics related to religious affiliation, reported on worship attendance and religious attitudes and beliefs. In the 2014 poll, 72% of the participants indicated that they believe in heaven, and 58% believed in hell.[9] A 2013 survey by the Harris Poll confirmed that 72% of Westerners believed in miracles.[10] Belief in miracles is a central function in Christianity in part because the Bible describes numerous stories about miracles. Christians are said to remember these poignant stories because the healed are depicted as regular, everyday people with strong beliefs. The Bible and God's work provide Christians with a platform or standard on which to base life and faith. Miracles are seen as evidence that God exists.

Belief in a divine intervention is often interpreted as an expression of hope or optimism about the possibility of recovery, denial of disease progression, and/or anger and disappointment with medical care.[11] This belief also gives patients a sense of meaning, comfort, and control and helps facilitate personal growth while facing mortality.[12] For many individuals, miracles occur when God acts through physicians to cure illness. For others, God is omnipotent, both creating and overriding the laws of nature.[13] For all of these reasons, religious affiliation and belief in miracles are associated with higher preference for aggressive end-of-life

care including cardiopulmonary resuscitation and mechanical ventilation.[14]

> For Eduardo, his strong Catholic faith and hope for a miraculous recovery guided his demands for additional cancer treatment and life-prolonging measures. While hospitalized, Eduardo's functional status continued to decline; he was cachexic and lethargic, with unsteady gait requiring assistance getting out of bed and walking short distances. His respiratory status was poor, and he was on a 100% nonrebreather mask (the most amount of oxygen that can be provided without intubation). The team was unsuccessful in their attempts to solicit Eduardo's end-of-life spiritual needs (last rites, prayer, and/or spiritual guidance from a hospital chaplain or community leader) in addition to asking whether he preferred to die at home or in an inpatient setting. Eduardo and his family were not open to this exploration; they repeatedly demanded aggressive anticancer therapies the clinical team believed to be inappropriate in the setting of end-stage lung cancer.

ETHICAL CONSIDERATIONS

Demands for treatment are deemed inappropriate when they cannot meet the intended physiological goals, do not meet medical standards, and/or result in undue pain and suffering.[15] Medical futility refers to interventions that are unlikely to produce significant benefits and may cause substantial harm. By contrast, appropriate care falls within the bounds of standard medical practice utilized by a respectable number of expert practitioners.

Physicians claim medical futility is a matter of professional expertise and sometimes attempt to forgo shared decision making with patients and families. The concept of futility gives decision-making power to the medical team and is in conflict with the idea of patient autonomy. Looser definitions of futility involve value judgments and should not be used to justify unilateral decisions by the medical team to withdrawal or withholding of treatment. Lo[1] argues that these "looser" definitions of futility are invoked when (1) likelihood of success is very small; (2) no worthwhile goals of care can be achieved; (3) quality of life is unacceptable; and (4) prospective benefit is not worth the resources required.

There are several ethical considerations health care professionals should take into account when responding to requests for aggressive experimental or futile treatment at the end of life. These considerations include core bioethical principles of patient autonomy, beneficence, and nonmaleficence. Autonomy is the right of an individual to make informed, uncoerced decisions. Beneficence obligates medical professionals to act in the best interest of the patient, in essence to weigh the benefits of treatment against the burdens. Nonmaleficence obliges medical professionals to not intentionally do harm or cause suffering. Balancing respect for individual autonomy with the principles of the beneficence and nonmaleficence is at times problematic and difficult to achieve in contemporary bioethics.[16]

DISCUSSION

Eduardo's case illustrates a complicated and all too common patient–health care team encounter. Additional chemotherapy, in the setting of widely metastatic disease coupled with functional decline and decreased respiratory status requiring high-flow oxygen, would have caused great physical harm, without added benefit. After much deliberation as a team and with Eduardo and his family, the request for additional chemotherapy was declined.

When considering medical treatments and interventions, the principle of proportionality is often raised, meaning that the benefit-burden (risk) ratio is assessed by the medical team when recommending and providing treatments and interventions. Clinicians should not do anything that would purposely harm patients without the action being balanced by proportional benefit.[17] In Eduardo's case, it is ethically acceptable for the medical team to refuse to provide treatment. Although patient autonomy is a vital component of bioethics and general patient rights, in this situation it does not override best interest standards. Benefits of treatment should outweigh the risks/harm.

Much has been written about religious requests for additional treatment. Some scholars argue that religious requests for ongoing treatment should be considered separately from other, nonreligious demands for treatment.[18] This argument highlights the extrinsic value of religious freedom, noting that persistent requests that are based on well-established religious beliefs should be honored. Other views state that any "special consideration" of religious requests is discriminatory against atheist and other non Judeo-Christian religions.[19] This position notes that religious beliefs should not be placed above professional practice standards and that no one should receive harmful treatment just because they request it. Still others suggest that physicians are not obligated to carry out aggressive, inappropriate treatment when families make religious requests at the end of life; instead, they are encouraged to explore alternative religious interpretations in hopes of finding compromise.[20] This approach encourages health care professionals to use alternative theological viewpoints to sway patient and family decision making. Manipulation with the goal of convincing patients and families to change their mind is less than optimal. These conflicting recommendations are extreme in nature and do not allow for flexibility and compromise.

Strategies: Communication, Compromise, and Good Patient Care

Patients and families report welcoming a frank discussion with their health care team about spirituality, coping, and religious beliefs.[21] Initial conversations provide a valuable opportunity to identify patient and family expectations in the context of religious beliefs. Acknowledging, validating, and respecting patients' religious and spiritual beliefs are vital steps for the health care team and allow for nonconfrontational relationship building. In addition, validating patient and family's beliefs allows the clinician team to "join in" the hope while also maintaining a health care provider role.[22]

Decisions to challenge requests for inappropriate treatment in the context of spiritual beliefs are not taken lightly. Health care professionals should take time to explore the meaning of the miracle in order to better understand the core perspectives present.[22] Although spirituality is an important aspect of any goals-of-care conversation, it may not be appropriate for clinicians to attempt to reframe religious reasoning. The ability to understand specific religious dynamics and use strategies to assess and grasp the meaning of miracles is not a skill most health care professionals hold.[11] Compromise and understanding can and should be attempted without manipulating families' religious interpretations and beliefs. Whenever possible, conversations should involve outside assistance from a chaplain or other community spiritual advisors. Pastoral assistance navigating complicated religious views and interpretations is invaluable. Hospital and community spiritual care professionals may be able to define religious beliefs differently than patients and families who are emotionally invested in the situation.

Patients and families who demand aggressive care at the end of life in hopes of a miracle may be feeling out of control or experiencing guilt or denial or may interpret the change in treatment plan as a sign of abandonment by the health care team.[23] Sometimes, cultural suspicions including a connection with historical withholding of lifesaving medical treatment or concern that changes are being made because of financial constraints influence patient and family decisions. Exploring feelings along the illness trajectory is essential to identify needs and establish an individualized plan for emotional support.

Open communication between the patient, family, and health care team focusing on the meaning and significance of the miracle will help find common ground to continue care. Negotiation requires understanding and compromise, something that can be difficult at times. After careful exploration of the patient's spiritual beliefs, the health care team can propose a treatment plan that is consistent with both the patient's values and priorities and the team's assessment of the medical condition and prognosis.[24] Often, this plan of care must be re-evaluated as the patient's condition changes. Communication that provides balanced, nonargumentative responses emphasizes nonabandonment and negotiates patient-centered compromises.[25]

> Eduardo and his family were not receptive to hospital or community spiritual support. They were, however, amenable to additional support from nursing and social work. Over the course of several admissions, nursing staff got to know Eduardo and his family well. This alliance ultimately helped guide the health care team in their goals-of-care discussions. A follow-up meeting provided a valuable opportunity to understand the intricacies of Eduardo's hope for a miracle. With the help of nursing staff, this meeting uncovered Eduardo's fear that without additional chemotherapy he would die sooner. In addition, he believed that if he agreed to forgo treatment God would think he was giving up on Him. With this knowledge the team was able to tailor additional conversations to help Eduardo and his family understand the medical contraindications and negative effects chemotherapy would have on the quality and quantity of his life.

> Given poor respiratory status, do-not-resuscitate orders were discussed at length. Eduardo welcomed this difficult conversation and, true to his religious philosophy, chose resuscitation. Some patients and families place more value on prolonged life (quantity) over quality of that time. Eduardo articulated his wishes for life-prolonging measures, and the team honored this decision. Eduardo was intubated a few days later. He died of multiorgan failure in the intensive care unit surrounded by his family.

CONCLUSION

Beliefs in miracles and divine interventions are not unusual and play an important role in the decision-making process, especially at the end of life. Providing spiritual support and allowing patients and families to talk about their specific beliefs not only improve emotional outcomes but also help alleviate conflict. Open, ongoing communication with patients and families helps convey an understanding of and respect for religious beliefs. Inviting patients and families to be a part of the decision making with the medical team can help facilitate compromise and good patient care.

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