Religious and Spiritual Differences Within Families: Influences on End-of-life Decision Making

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ABSTRACT

Religious and spiritual diversity are increasing in the United States. This can present unique challenges at the end of life, especially when individuals within the same family have differing beliefs. There are wide variations in individual interpretations of religious teachings. There is also a lack of homogeneity within religions. Health care providers may find it challenging to understand the nuances of individual religious traditions. Clinicians should approach patients and families with humility. A case is presented of a family with diverse traditions in Buddhism, Catholicism, and a nonreligious spirituality.

Keywords: decision making, diversity, end of life, family dynamics, palliative care, religious diversity

Religious and spiritual diversity are increasing in the United States. This diversity of faith can present unique challenges at the end of life, especially when individuals within the same family have differing beliefs. Diverse religions result when populations migrate around the globe and bring a multitude of beliefs with them. Also, US baby boomers in greater numbers have embraced faiths divergent from their families of origin.[1] In the past, family religious beliefs and customs were more likely to be shared across generations, and today that is not the case.

Individuals may adhere strictly to the teachings of a specific religion, but more often there are wide variations in individual interpretation of faith and teachings. This lack of homogeneity within religions makes it presumptuous to assume any individual's beliefs based only on his or her named affiliation or denomination. Health care providers may find it challenging to understand the wide range of religions in a pluralistic nation and sort out the nuances within individual religious traditions. A basic understanding of religious groups' values concerning end-of-life care and life-sustaining treatment provides a basis for clinicians to discuss end-of-life issues with patients in thoughtful and sensitive ways. Yet, at the same time, health care providers must be aware of individual complexities of faith and religious beliefs.[1]

Religious and spiritual influences are especially important at the end of life. Death and dying are more than biologic processes. Perhaps at no other time are patients' spiritual and religious beliefs more critical.[2,3] Patients can find great comfort in their spiritual beliefs and often seek the counsel of faith leaders when facing serious illness. Families and loved ones also may seek guidance and strength from their faith. When families must face difficult decisions during the end of life of a loved one, they are at risk for uncertainty, doubt, and possible long-term distress. In today's climate of diverse religious traditions, many individuals are choosing a faith that may differ from their families. When there is incongruence between the families' and the patients' religious and spiritual beliefs, questions about end-of-life decisions may be magnified.

Religious rites and practices have the potential to provide comfort to patients and families. However, if there is conflict over religious beliefs, there can be long-term suffering, especially on the part of the survivors who have served as surrogate decision makers. In

a study comparing end-of-life surrogate decision makers and non—decision makers, Webb and Guarino[4] studied the potential for long-term distress among the surviving family members after they have lost a loved one. They report that all deaths have the potential to cause distress for many years and even decades after the death.[4] In some family members, this distress can progress to posttraumatic stress disorder. Surviving loved ones may question their decisions and be left with doubt about their choices.

Intrusive thoughts and memories of a loved one's death can be an ongoing source of distress for survivors. These triggers include visual or auditory and even smell memories. Religious symbols have the potential to become a part of these memories. The presence or absence of religious music, prayers, or chants; and icons, such as jewelry, beads, or pictures, or smells, such as incense, can be important considerations during the dying process.[4] When families have discordant religions, these symbols and rituals have the potential to become a comforting memory or a distressing one. Nurse practitioners (NPs) and other health care providers can help create a more comforting environment to help mitigate some of the distress that results from potentially disturbing sights, sounds, and smells.[4]

The case presented here shows the conflicting views of a family with religious beliefs of Buddhism and Catholicism, as well as 1 nonreligious significant family member.

CASE

James is a 47-year-old man who is in the intensive care unit with a severe head injury sustained in a bicycling accident. He was initially found without vital signs and was resuscitated at the scene of the accident, but he never regained consciousness. James is now supported on a ventilator. His pupils are fixed and dilated. He does not respond to voice or touch. He does not respond to painful stimuli. His partner, Andrew, and his parents, John and Joann, have been at the hospital daily since the accident 4 weeks ago.

Personal and Social History

James was working as an elementary school teacher until his accident. He lives with his partner of 8 years, Andrew. He has no advance directives in place.

Spiritual History

James converted from Catholicism to Zen Buddhism as a young adult. He meditated daily and had a shrine in his home. He attended a temple, which was a distance from his home, every few months and also attended a local Unitarian Church. He spent several weeks each summer on a Buddhist mission providing care to children in underserved areas. James wore a necklace of a dharma wheel with the following inscription: "Move. And the way will open." Andrew is nonreligious but self-identifies as a "spiritual person."

Andrew has declined visits from the hospital chaplain when he is present. James' parents are devout Catholics. They have attended the same church since James was born. They are involved in their church activities and are close to the priest from their church. They believe that since James was baptized as a child, and participated in other religious rites as a young man, he remains a Catholic and should receive the Sacrament of the Sick.

The family has been asked to assist in decision making for James. They will be asked to decide to continue the ventilator to prolong his life or to withdraw the ventilator. They are also facing questions of whether to continue long-term artificial feedings. They are considering whether to arrange to donate his organs after his death. They have been asked to discuss what spiritual support would be most comforting for them and for James at the end of his life. In the absence of a directive or a health care proxy, a family meeting was held to discuss what James' wishes would have been. Because James and Andrew are life partners who are not legally married, Andrew has no legal role as a decision maker. Because there is no health care proxy, his parents would be the assigned surrogate decision makers.

BACKGROUND

Buddhism and Catholicism have differing religious traditions surrounding death and dying. Individuals who are nonreligious may also have important spiritual concerns at the end of life. Whether the religious beliefs are of the patient or the loved ones, they may have implications for caregivers. We will describe each of these three traditions and common