

Spiritual Leaders and End-of-Life Ethics Consultations

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There are a number of barriers that patients and families encounter when facing difficult diagnoses and the prospect of life's end. For those with strong faith practices, the lack of a supportive spiritual leader's presence during end-of-life ethics consultations and important family meetings can be an additional, and unique, obstacle. More than a dozen case studies have shown that patients and families with strong faith adherences can benefit greatly from having a spiritual leader participate in some of the hardest decisions that will ever have to be made.

More often than not, family members and patients enter into conversations with healthcare providers in awe, and with an overwhelming sense of uncertainty. Consequently, families and patients can find it difficult and even impossible to make crucial decisions on their own. Knowing that the body is finite and has limitations is one thing, but accepting such facts when the body of a loved one is failing is a completely different matter. Since spirituality and trust in a spiritual leader continue to be very important to many in our society, a spiritual leader can help patients and patients' loved ones come to terms with mortality.

As a pastor, I have come to appreciate the difference that my presence makes when I pray with or for a congregant before a major medical procedure. The very presence of a spiritual leader during ethics consultations and family meetings about serious life-or-death decisions can make all the difference in the world, both for patients and their loved ones. First and foremost, their inability to act may stem from the fact that often they do not realize that they have options. Second, when facing potential death, most people begin to go through some of the stages of grief. Third, when facing death or severe illness, patients' fear can weigh quite heavily on them and their families. Moreover, surrogates and other family members who find themselves in a position to decide on behalf of their loved ones can feel torn and can have a great sense of guilt. This sense of guilt can paralyze people as they contemplate making end-of-life decisions.

There is a sense of fragility and finality to life that certainly cannot be denied. Spiritual leaders are well placed to speak to those facts. Barnabe Barnes wrote, "A mass of dust, world's momentary slave, Is man, in state of our old Adam made, Soon born to die, soon flourishing to fade." Those who believe in an Orderer or a Creator or a Giver of life embrace the concept that the "dust shall return to the earth as it was" (Ecclesiastes 12:7). Both quotes point to the inevitability of human frailty—that all people are mortal and not exempt from terminal illnesses. Job's sentiment as he laments, "I know you will bring me down to death, to the place appointed for all the living" (Job 30:23), can bring hope and serenity to those who find comfort in the Bible. Yet the prospect of dying or letting go of a loved one can still be daunting and perhaps impossible to bear.

States only recently began to implement laws granting patients and their surrogates the rights to make decisions regarding end-of-life treatments. Before such laws were passed, all major life and health decisions were left to the care providers. Patients, family members, and those who would hold dear the patients' values, wishes, and best interests would have no say in what would happen. Nowadays, however, surrogates and proxies are appointed all the time, and healthcare providers have to consult

patients or their appointed surrogates when important, life-changing decisions are to be made. In 1990, Congress passed the “Patient Self-Determination Act (PSDA; 42 U.S.C. §§ 1395 et seq). The PSDA is a federal law that requires healthcare providers to inform adult patients who are recipients of federal Medicaid/Medicare funds of their right to accept or refuse medical treatment, and their right to execute an advance directive. Furthermore, most states, including California and Massachusetts (130 CMR 450.000: M.G.L. c. 18, § 10 and c. 118E, § 4), have laws that help patients and families to realize a great deal of autonomy through living wills, healthcare power of attorney, and advance directives.

However, being so empowered can become a stumbling block when it comes to decision-making, especially end-of-life decision-making. Many patients and their surrogates struggle with the burden of knowing that their decisions can concretize the inevitable. Far too often, no one really wants to make such a decision. Many do not realize, at first, how great a responsibility it is to decide whether one lives or dies. When presented with various options, patients, surrogates, parents or loved ones may need to be reassured of the options and be informed that they can choose among them—that they can choose one type of care over another, or even choose not to pursue treatments that are futile or harmful.

The presence of a trusted spiritual leader can also be comforting during the phases of grief that accompany the decision-making process. When facing terminal illnesses, many people begin to go through the phases of grief very early. As Bloche rightly noted, “Anger, denial, and other nonrational influences can lock family members into warringstances over whether to treat a devastating illness aggressively or discontinue life-sustaining measures.” Thus, as patients and their surrogates are asked to make critical decisions, it may be that they may not even be in any position to accept the reality of the situation. As surrogates and patients struggle with acceptance, bargaining, denial, etc., it may be too burdensome for them to think clearly enough to make critical decisions alone. The spiritual leader can help to promote understanding, from a religious standpoint, that medicine has its limitations and dying is part of the natural progression of some conditions. The idea of death and the frailty of the body are clearly expressed throughout the Bible.

We are admittedly influenced, to a great extent, by the Greek and Platonic idea that the body dies. The Judeo-Christian and Islamic traditions all adhere to the concept that we all die and to the limitations of the human body (Gen 3:19; Job 14:1,12; Ps 39:5,6; 90:5; 103:14,15; Eccl 3:20, etc.). For patients and families whose spiritual leaders may not be available for end-of-life ethics consultations, all efforts should be made to include a chaplain who adheres to the same faith that the patient and/or family does. Most major medical institutions have chaplains as members of their ethics committee. For instance, a permanent member of Massachusetts General Hospital’s ethics committee, “The Optimum Care Committee,” is an interfaith chaplain, and Columbia University Medical Center has had chaplains on its ethics committees. In fact, the AMA recommends that medical ethics boards include chaplains. They should be well versed in the human body’s limitations and thanatology as it pertains to specific faiths.

A number of case studies have shown that when a spiritual leader actively participates throughout the course of a serious illness or at the end of life, patients and their loved ones can feel relieved of the sense that they have to walk this path alone. The ethics consultation often occurs at a point where life’s journey comes to a crossroads of decisions. Many nurses, physicians, and other care providers concur that most people, patients and surrogates, want a Paraclete, someone to walk beside them as they go through such impossible situations. Ethicists who consider the goals of consultations should recognize that the presence of a clergyperson or spiritual leader can make a real impact. There is a notable difference when a patient or the patient’s surrogate can look to someone whom they trust and be reassured that the body has its limitations and that it is acceptable to let go.

Most major religious traditions are well aware that medicine has its limitations. A spiritual leader is in a unique position to help relieve the fear of the living with the sense of culpability that they did not do all that they could to save, preserve, or prolong their own lives or that of a loved one. Spiritual leaders can only do so if they are part of the process from the very start. They have a special role to play during ethics consultations, when life-or-death decisions are being deliberated upon.

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