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Walking the Narrow Bridge: Religion, Spirituality and End-of-Life Decision-Making

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Eight serious medical professionals stood by my father's hospital bed discussing "the case": a 79-year-old man suffering from a mysterious infection, diabetes, coronary artery disease, dementia and injuries sustained in an in-home fall.

Not once did any of these professionals address my Dad. Not once did they ask my brother or me about Dad's wishes, values or dreams. It did not seem to occur to anyone on this medical team that here was a person—someone with goals and priorities—who could guide decisions about the myriad life-extending treatments they were deploying.

The process of making decisions for older adults at the edge of life is difficult and complex. The choices to be made can be wrenching, especially within the framework of our modern healthcare system, which has an ever-growing arsenal of treatment options—but a dearth of wisdom and discernment.

When we must decide about medical care for our elders, we stand on the narrow bridge between life and death: We feel suspended without moorings, and we desperately need guidance in order to make wise choices. The furor of the recent political debate over healthcare reform has done nothing to bring clarity or comfort to this frightening terrain that eventually we all must traverse.

Where, and to what, can we turn for help? I suggest that religion and spirituality are invaluable resources in grounding end-of-life decision-making.

ANATOMY OF A DIFFICULT DECISION

What makes this decision-making so fraught? First, the availability and use of ever-expanding medical technology confounds treatment decisions. In a 2004 issue of *The Gerontologist*, anthropologist Sharon Kaufman noted that choice is elided as life-extending treatment becomes "routine." Patients, families and even physicians feel guilty if they do not pursue these treatments.

Second, the medical picture of frail older adults is ambiguous—often, they do not die from one ailment, but from multiple systems failing over time (aka "death by falling apart"). It is difficult enough to identify when a person is dying, not just ill or failing, but it is even harder because of our culture's pervasive denial and obfuscation of death. Often, we do not want to acknowledge when we or our loved ones are standing on the narrow bridge between life and death.

And yet, most everyone has witnessed the limits and burdens of treating those who are at the end of a long life: the cancer surgery for the 90-year-old man that results in extended life, but with months of pain and indignity; or the 85-year-old woman who spends her last months of end-stage dementia being shuttled between nursing home and hospital, beset by continual infections.

We have seen the pain and indignity. And, worse, we perhaps have missed the opportunity to face death, to say goodbyes. We realize intellectually that because treatment is possible and available does not necessarily mean that it benefits an individual. Nonetheless, guiding medical treatment for the very ill can feel like a runaway ride on a train hurtling downhill—nothing stops the momentum and no one questions the ultimate destination.

THE DELICACY OF DISCERNMENT

Discernment about life-extending medical treatments is essential, yet largely absent. We can all gain from bringing perspective to this often distressing journey. Patients and families could have an opportunity for a good death—one in which an individual's wishes and aspirations are heard, and comfort, dignity and physiological impact are considered when determining the benefits versus burdens of treatment options.

Careful discernment about the fit between treatments and patients' values and goals may well result in decreased use of life-extending medical resources. A 2009 study in the *Journal of Clinical Oncology* found that end-stage cancer patients whose healthcare teams supported their spiritual needs were three times more likely to receive hospice care and five times less likely to receive aggressive care.

These patients also were found to have 28% higher quality of life scores at the end of life than those who had no attention given to their spiritual concerns. Our society can benefit if we can save these costly medical resources for the times when their impact will truly be welcomed, not just when it is *possible* to use them.

LIFE, DEATH AND SPIRITUALITY

In the often bewildering transition between life and death, religion and spirituality can play three vital, clarifying roles in helping to frame end-of-life treatment decisions, face mortality and offer hope.

Treatment decisions for frail elders are never just about physiological conditions and responses. Framing these choices around religious and spiritual values can be enormously helpful. A 78-year-old woman experiencing a metastatic recurrence of cancer was offered chemotherapy and radiation, but with little hope for long-term recovery. As she reflected on this option with family and friends, she decided that her central value was to consciously approach death. Unafraid, she chose in-home hospice care, spending her remaining days with her loved ones instead of facing taxing treatments and side effects.

Frail adults' downward descent toward death can be a confusing process. But acknowledging and facing the prospect of dying can shape decisions along the way, helping to identify fears and concerns about the end of life. Patients and families often have unfinished business and, while contending with physical symptoms and incapacities, it can be bracing for patients and families to realize what "business" they wish to and can complete.

Unearthing what is most frightening can also provide guidance; in pastoral care practice, I have found that people do not so much fear death as they fear being alone or in pain at the end. Ritual (such as prayer, anointing of the sick, the deathbed confessional) can offer solace as individuals and families face the ultimate passage.

When my beloved grandmother faced her final illness, a wise physician told our family, "You need to figure out what you are aiming for here, because we doctors can always try to do the next *something*, but that may not be the help you want." Physicians sometimes offer treatments to patients so that they and their families can find hope. But the hopes found in religious and spiritual life may be surer anchors. An older adult facing death can find hope in a sense of connection that will not physically die; in her beliefs about afterlife; in the legacy of her deeds or kin; and in the belief that she is supported by a being, a power or a presence greater than herself.

How can patients and families draw upon religion and spirituality as they navigate in our fast-paced, action-driven healthcare system? Professional chaplains can be invaluable additions to healthcare teams. With their skill and training they can help elders and their loved ones to reflect on their quandaries in the light of their values, beliefs and traditions. Christina Puchalski, in her 2006 book, *A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying*, shows that physicians and other healthcare professionals can be trained and empowered to encourage patients and families to draw upon spiritual resources.

Older adults facing life and death decisions should not be cared for only by a team of medical professionals talking exclusively with one another: The team should include the patient, a chaplain or ethicist, family and close friends.

I dream of a process in which end-of-life decision-making will be guided by a patient's values, faith, hopes, dreams and fears. Girded by religious and spiritual resources, the choices made could be wiser—and the walk on that narrow bridge might be less terrifying. ❖

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This article, the final installment of a four-column series covering vital topics in religion, spirituality and aging, is a collaboration of ASA members Jim Ellor, Dayle Friedman, Don Koepke, Harry Moody, Ron Nakasone, Jim Oberle and Steve Sapp. **Aging Today** *thanks them for their fine contributions to this thought-provoking series.*

