

A Life-context Approach for Developing End-of-life Decisions

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OVER THE LAST SEVERAL DECADES, end-of-life decisions related to medical care have multiplied rapidly. Patients now are empowered with rights to refuse or to withdraw life-sustaining treatments, including artificial hydration and nutrition. Proxy decisions authorized via advance medical directives have become a part of our medical routine. Organ and tissue donor networks routinely encourage registration. Each of these choices has developed within the tension of technological advances as well as personal and societal values that often have required legal interpretation.

The problem

Although most medical facilities ask patients if they have advanced directives, decisions about complicated medical interventions often are hastily made by patients and families in the midst of crisis during a hospital admission. Speculation about patient values is often the best information *healthcare institutions* have to go on.

In the crucible of hospitalization, families may become embroiled in conflict, which delays treatment decisions and produces a commensurate cost in time, resources and money. The ideal, of course, is for patients and their families to have a concept of, and discussion around, their values before hospitalization occurs. However, few opportunities to formulate end of life values and facilitate discussions with families are readily available.

Piecemeal decision making processes often do not represent the patients' broader values. Family decisions often are based upon generalities such as, "Mother said that she didn't ever want to be a vegetable," or "Dad wouldn't want heroic measures." Further, it is interesting to note that "while about 75 percent of Americans support the use of advance directives, only 30 to 35 percent actually

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This article proposes a conversational way to approach the completion of advance directives. Working with small groups in congregations, the author poses a series of questions related to end-of-life decision making. This process encompasses ethical, psychological, spiritual and financial issues. The list of discussion questions is included.

write them. Even more startling, of that smaller percentage, only about a third are able to find the directive when they *need* it.”¹ In our institution, between 20 and 25 percent of families produce a valid advance directive.

The core questions people face when making end-of-life decisions usually focus on two issues: quality of life and medical futility. Other questions not addressed in most advance directives revolve around sanctity of the body, monetary resources and funeral practices.

Creating a context for discussion

Over the past several years, I have worked with local clergy, congregations and community agencies to approach choices that include these additional perspectives. This lecture series has come at the invitation of local congregations, which have requested my presentation, “Ethical, Psychological, and Spiritual Reflections Influencing End-of-life Decisions,” through the speakers bureau at my hospital. I have found that the best format seems to be a series of three or four small group sessions held either on weekday evenings or on Sunday mornings.

These weekly discussions focus upon several core areas:

- Accepting one’s mortality, i.e., the ability to face this at a gut level.
- Exploring one’s feelings about the treatment of one’s body after death, e.g., autopsy, donation of one’s body to a medical school, organ donation.
- Considering interment or cremation, burial or scat-

tering of ashes and determining the site.

- Deciding what personal values should be communicated to relatives and how best to accomplish this.

Psychological and spiritual issues

Several hours of experiential work are required before people truly enter the dialogue about their own deaths from a position of openness. While wrestling, sometimes painfully, with the core issues, they become aware of the extraordinary psychological, familial and spiritual issues that may influence their choices.

I begin with the most fundamental issue, namely the acceptance of one’s own mortality. As people feel their way into their own death, they begin to move their understanding of their own mortality from a rational head level to a gut level. Using a flip chart as a tool, I move through a series of questions. (See Preferences Questionnaire on p. 25.) This helps to initiate discussion in a nonthreatening way. It also enhances the variety and depth of thinking that individuals may have done previously.

One important component of end-of-life decisions involves the capacity to trust. Advanced directives require individuals to trust that others will comply with stated wishes. Each of us has a capacity to trust others based upon our experience with the world around us. For some, the world has been a place in which the significant people of our life have been trustworthy. For others, relationships have brought a series of disappointments that impair the capacity to trust others. The need to control one’s life sometimes is related inversely to

the capacity to trust. The following are key questions regarding trust from a spiritual perspective:

- In what or whom do you trust? (yourself, others, God, medicine)
- Do you trust others to follow through with your wishes?
- If being in control is an issue, and there are few others you can trust to know your desires, would an advance directive help you to maintain control of your destiny even if you are incapacitated?

Monetary issues and benevolence

An individual’s values regarding monetary resources as well as ethics surrounding the allocation of scarce resources also may enter into end-of-life choices. Consideration should be given as to the amount of money an individual is willing to spend in order to remain alive, especially if there is no healthcare insurance, and to whether this decision should be left to the family.

For some people who have filled their lives with service to others, the concept of organ donation continues to affirm a message about what has given meaning to them. For Christians, the words of Jesus, “This is my body broken for you,” which is used during the communion service, may offer a new perspective of organ donation.

Conclusion

The response to these efforts has been most heartening although there has been little overall effect

upon the number of advance directives individuals have brought to the hospital. Some people have begun to develop life crisis files containing their wills, advanced directives and prepaid funeral arrangements, as well as information about how, where and by whom they wish their funerals to be conducted. Some have designed their own funeral services and provided copies to family members, clergy and significant others.

Many have acknowledged that grouping these end-of-life decisions is a way of putting parentheses—or even an exclamation point—around the end of their lives. They often view this as a commentary about the values under which they conducted their daily affairs.

Obviously, this approach requires, at the very least, a willingness to look seriously at mortality issues. As one might expect, it is especially welcomed by the geriatric population. It also has been well received in religious communities because, at their best, congregations are focused upon the meaning of life and death. Further, this most likely is where the funeral will take place. Additionally, as clergy sit in on the group discussions, they become more capable of assisting families when the time for making decisions actually arrives.

Beyond the obvious public relations implications, producing this kind of program for the community as a public service has significant benefits for patients and their families, for religious communities and, ultimately, for healthcare institutions, which may realize cost savings as life-prolonging treatments implemented while decisions to terminate care are in process may be reduced.

Preferences Questionnaire

Typical answers follow in italics.

1. What does it feel like for you to think about not being here?
I worry about my family! – the thought of nothingness is scary!
2. What is the worst thing about your death that you imagine?
Not being able to say goodbye, dying in pain.
3. What do you fear the most?
Loss of control, not being remembered.
4. If you had a choice, how would you like your life to end?
Slowly, so that I would be able to tie up loose ends. Suddenly, to avoid the pain.
5. If sudden death took away your ability to make your wishes known, who, if anyone, would you trust to make these choices for you? How would you let them know?
Name of a relative. Not sure.
6. Do you have a preference for burial or cremation. Why?
Cremation is less costly.
7. How are funerals traditionally practiced in your family? Do you desire something different?
Three days for a viewing as was practiced in my family makes no sense to me.
8. If burial is your choice, where would you like to be buried? Why?
I would like to be with my husband rather than in the family plot where I was raised in another state.
9. How important is it to you or to your loved ones that your body be whole, i.e., no cremation, donation of organs or autopsy, unless mandated by the coroner?
Extremely important, not at all.
10. What, if any, is your concept of an afterlife? Does your idea about this effect your ability to consider things like organ donation?
I believe in a bodily resurrection and therefore rule out organ donation or cremation.
11. What conditions would make your life intolerable and why?
Loss of limb, sight, mentality, ability to communicate.

Those of us who support families in heartbreaking end-of-life situations may feel more assured that decisions to terminate care have an integrity which is reflective of some anticipatory thought. Most especially, our patients may experience

a much more peaceful resolution to their final moments. ♡

Reference

¹ “Start the conversation now: A guide to end-of-life care,” *Modern Maturity* (September/October 2000).