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Health Decisions: The Value of Advance Directives

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The 21st century dawns with two major realities colliding together in the health care environment. Medical technology is advancing at a rate far ahead of our ability to learn how to be good stewards of it. Sometimes this technology can meaningfully prolong life, but sometimes it also has the opposite effect of prolonging the dying process unnecessarily. At the same time, patients increasingly are faced with health care decision-making that is guided both by a desire to minimize suffering in the face of terminal illness, and an attempt to somehow wade through the myriad of issues related to the use of technology, managed health care spending, and limits on or even lack of insurance coverage. Without contrary indications, hospital medical staff are required by law, and doctors by the Hippocratic Oath, to provide the full range of available treatment and life-sustaining technology to those admitted to the hospital.

ADVANCE DIRECTIVES

One instrument designed to amplify the patient's voice with respect to the use of technology is the Advance Directive. There are two types of advance directives (AD). Instructional ADs offer direction for care by the patient, determined while competent, to be used when decision-making capacity has been lost. Included in this subset are living wills and documentation limiting the use of resuscitation. Proxy ADs, on the other hand, name alternative persons, called surrogate decision makers, in the event that one is found to be incompetent to make his or her own decisions.

Advance directives, including the role and function of proxy decision makers, vary by state or province. For example, the state of Connecticut specifies two different roles for surrogate decision makers. A Health Care Agent makes decisions only in the area of withholding or withdrawing life support measures, while a Durable Power of Attorney for Medical Decisions makes all other health care decisions except that which the Health Care Agent decides. One person can fill both roles. A surrogate decision maker is best empowered when preferences have been shared and discussed by the person he or she is to represent.

State laws have been drafted regarding ADs. As of 1994: “In the United States, all 50 states have passed laws on either instruction directives, proxy directives or both. Forty seven states have laws supporting the use of instruction directives; those that do not are Massachusetts, Michigan and New York. Forty eight states have laws supporting the use of proxy directives; those that do not are Alaska and Alabama.”...In Canada there is legislation supporting ADs in the provinces of Nova Scotia, Quebec, Manitoba, Ontario and British Columbia” (*Journal of Palliative Care*, 10:3,1994,111-112).

In addition to state laws, the US Congress passed the Patient Self Determination Act (PSDA) in December of 1990. This legislation requires health care institutions that receive Medicare and Medicaid funding to inform patients at the time of hospital admission of their right to accept or refuse treatment and to prepare ADs. This policy was mandated to be implemented in November of 1991. Four years later, only between 4% and 17.5% of the general population had actually completed an AD (*Chest*, March 1995, p. 752).

General reasons for this continued low percentage of completing ADs are twofold. First of all, patients without preparation are hit with a barrage of questions, information, and ADs upon being admitted. This often results in patients avoiding discussion of this issue while in the midst of the uncertainty of hospitalization. Surprisingly, little has changed here since the new legislation for ADs. Hospitalization can be an overwhelming experience, and this often predisposes patients against discussing end-of-life issues. Secondly, physicians are, for the most part, reluctant to engage patients in discussing issues germane to establishing ADs.

CASES

Mildred

Mildred was over 90 years old, hospitalized with terminal cancer, and began to fill up with fluids. She was largely unresponsive to any stimulus in the room. Her children, a son and daughter, recognized her as their rock, and would not hear of the doctor's invitation to move toward comfort measures only. Mildred's daughter was a doctor herself, and knew the regulations regarding continuing full treatment—which she demanded remain in place. One morning, as Mildred's children were gathering around the bedside, Mildred stopped breathing. Her daughter flew into action, flagging down staff. A code was called, meaning that all available means would be employed to restart Mildred's heart and breathing. The last twenty minutes of Mildred's life were spent being assaulted. Some staff were pounding on her chest, others injected her with all kinds of medications to induce her heart to beat again, while others were dispensing medications and equipment from the crash cart. Still others simply stood by and watched the clock. The room was full, and after twenty minutes all left except for the nurse and Mildred's children.

Scott

Scott was a middle-aged man who lived life pragmatically. When he learned about advance directives in the course of his annual physical, he immediately set out to authorize surrogate decision-makers to act if he were unable to consent to his own treatment. In addition, he asked in his living will for comfort measures only to be administered should he become irreversibly and terminally ill. His wife and family grew weary of his seemingly tireless efforts of preparing himself and them to act upon his AD.

Several months later, Scott was preparing for work one morning, and began to complain of chest pain. He was having a heart attack. He was rushed to the hospital. Staff informed Scott's wife that they were trying to stabilize him, and later would prepare him for angioplasty (inserting and inflating a small balloon in the blood vessels leading to the heart) and possibly bypass surgery. She would not leave his side, becoming increasingly frantic. "You're just going to let him die!" she exclaimed. The bewildered nurse looked in the patient's chart, saw the AD that was meticulously completed, and immediately returned to Scott's wife. "Are you worried that Scott's AD will prevent us from treating him?" "Yes," she replied. "He made us promise to follow his wishes in the case of terminal illness, but he is too young to die!" The nurse sat her down and explained that his condition was far from terminal, and that they would do everything in their power to help Scott stay alive.

Diane

Diane's life was a seemingly endless flow in and out of the hospital. She had been diagnosed as bipolar (a psychiatric illness where one's mental status uncontrollably vacillates between depression and mania), and occasionally had psychotic episodes (an extreme and sometimes extended break from a sense of reality), leaving her unable to make good decisions regarding her care. Moreover, sometimes she got tired of taking her medication and turned to self-medication through heavy drinking.

One day she was talking with her social worker. She had been in an inpatient treatment program and was feeling much more herself. In addition, she felt as though she had been treated as a real person in this setting, not like the one where she had been taken on a number of other occasions, where they treated her and other patients as non-beings. Her social worker sent her home with some information on advance directives for mental health treatment.

Diane knew her parents thought psychiatric illness was just an elaborate hoax, but Diane had a brother who had actually read quite a bit about her illness and supported her through her peaks and valleys. When she was feeling better, she approached her brother about being a surrogate decision-maker, and expressed a desire to include specific instructions that, should she need to be admitted again, the first choice be the facility that seemed most supportive of her care. She underwent special competency tests prior to executing her AD. Diane felt so relieved when all was arranged, knowing that her wishes would be followed even if she were unable to express them. This gave her a renewed sense of investment in staying well.

DISCUSSION

Each of the above cases raised some important points that bear further reflection. They underscore the importance of discussing advance directives before crisis occurs. A common problem when crisis occurs is the narrowed decision-making capacity on the part of the patient; the ability to consider decisions from a number of perspectives is reduced. At the same time, crisis does not have to spell disaster. Instead, moments of crisis can lead to new growth and insight for patients who are supported by family, clergy, or caring medical staff. In fact Advance Directives can help to bring together those making difficult decisions with those

who can be prepared to stand with them in the midst of an ever-changing health care environment.

Advance Directives And Those Who Are Terminally Ill

Mildred is an example of a patient who is terminally ill. Her cancer was well advanced, complications were increasing, and the assault occurring during the final moments of her life was plainly excessive. Palliative care, a term denoting pain control and comfort measures, can replace full and aggressive care, and should do so especially in cases of end-stage terminal illness.

It is often the case that family members', and in some cases even physicians', recommendations or decisions do not match the patient's own. Here Mildred's voice is not heard. Maybe she lived a full life and prepared for her death. Her children had plainly not arrived at a sense of peace or letting go. Differences can also be caused by multiple faith traditions within the family system, some of which hold opposing perspectives on end-of-life care. Had she named a proxy decision-maker, that person's voice is understood as speaking for the patient. In the absence of a proxy, family members' voices are ranked in an order of priority as designated by institutional policy. For example, if a spouse, brother, sister, or children are present, the hospital would choose first the spouse, then others according to the hospital's policy. Oftentimes this is where a struggle ensues. If family members do not agree on how to proceed in caring for their loved one, the patient's voice is lost, and medical staff are held up in providing care while attempting to sort out the disagreements.

What if Mildred had survived cardiopulmonary resuscitation (CPR)? She would have been among the few to do so. An analysis of several studies in a recent issue of the *Canadian Family Physician* notes: "For patients whose cardiac arrest is not caused by simple cardiac conditions, the likelihood of success and return to function is low" (April 1995, p. 656). More specifically, for patients suffering from cancer, neurological disease, kidney failure, respiratory disease, or sepsis (organisms in the blood stream), the overall success rate is less than 10%, with most less than 7%. Moreover, for survivors the increase in life expectancy can be complicated by post-resuscitation complications including: pneumonia, congestive heart failure, gastrointestinal hemorrhage (all occurring in greater than 40% of cases), seizures (30%), and others (p. 656). These facts reveal important insights when considering the decision to continue full aggressive care for those terminally ill. Medical statistics can't always accurately determine

patient care, but it is important to know, as a patient, the potential risks and complications one may face as a terminally ill patient with respect to the use of CPR.

Perhaps this helps explain why more than 50% of persons older than 60 years of age with complications related to terminal illness report having completed advance directives rather than the low rate reported earlier. In an article recently appearing in the *Annals of Internal Medicine*, 400 hemodialysis patients were surveyed. Seventy-nine percent of respondents had discussed end-of-life decisions with family members, and 51% had completed an advance directive. Even more telling is that greater than 97% identified a surrogate decision maker, 93% chose a family member, 88% wanted to include additional family members, while about 36% wanted to include their physician (May 18, 1999, pp. 826,827).

Advance Directives And Getting The Fullest Care

The vignette about Scott raises a fear that is often expressed regarding ADs. Some people wrongly perceive that if an AD has been formulated, it means the person may not get the care she/he needs. In fact, an AD can be changed or even revoked at any time as long as competency is not an issue.

A recent study conducted at a community teaching hospital compared a number of intensive care patients responding to two questions: whether or not an Advance Directive had been made (Y or N), and whether or not an order was written to limit resuscitation (Y or N). Among the respondents, those responding yes to both questions were among the eldest participants. Those who had no AD but did have a DNR order had the highest mortality rate and spent the most time in the hospital. Among those responding yes to an AD and no to a DNR, there were no interventions made (no need to invoke the AD), and these patients on average spent the least time in the intensive care unit (Chest, March 1995, p. 753). Formulating an AD does not necessarily mean one is taking an action to hasten death.

Advance Directives And Those With Psychiatric Illnesses

Diane is certainly not an anomaly in our communities today. Family members agonize over how to care for their loved ones who suffer from psychiatric illness. Beyond the stigmas attached to this illness, our current managed care system in the United States places the most restrictions on this group of patients, including

number and length of hospitalizations, and choices available to them regarding treatment options. ADs are not a well-known resource in the area of mental health as they are a recent phenomenon. However, the process of discussing care issues here necessarily brings together patient and family members. This is a far better scenario than what more often occurs. Family members are scrambling to keep up with decisions being made for their loved one who is hospitalized. They may also be some distance away, and/or ambivalent about being “involved” with their chronically ill loved one, and therefore have difficulty responding in a timely fashion. Additionally, patients who have exacerbated symptoms often cannot clearly process health care decision-making.

A final note of consideration here includes the contribution that the formulation of ADs may offer psychiatric patients. Diane chose to include a specific facility that empowered her to feel like a person throughout her treatment. With this decision-making authority expanded across the country, institutions will need to become more tolerant of psychiatric patient autonomy, and will need to assess the level of restrictions placed on their patients. In other words, institutions that admit psychiatric patients will need to focus more attention on their patients’ experience of hospitalization in order that patients like Diane will feel cared for enough to want to return to their facility.

BASIC ORTHODOX TEACHINGS ON END-OF-LIFE DECISIONS

Before moving to some steps toward the exercising of Advance Directives, let us first reaffirm some basic Orthodox teachings around end-of-life decision-making. First of all, the Orthodox Faith opposes any kind of euthanasia, or acts that are undertaken to end one’s life. In addition, terminal or palliative care is an important factor in the dying process. This includes pain management and “comfort measures,” even though the former can, through the principle of double effect, hasten the dying process. Some pain medications, when taken in large enough doses to reduce pain, can actually suppress the body’s normal functioning even to the point of death. The aggressive practice of palliative care is morally appropriate, without which patients would face death with intractable pain and anguish. Finally, Orthodox ethicists do affirm that in cases of end-stage terminal illness, withdrawal of life support equipment can be viewed as compassionate. In terms of brain-death, this action can become a moral imperative, as the person is no longer alive in any religiously significant way, even though heart function, breathing, even food and hydration can be sustained almost indefinitely. (Please refer to the bibliography for some sources of further in-depth discussion of these issues).

*If you have read to this point, hopefully your question is “**What can I do?**” or “**Where do I start?**” Here are some simple steps.:*

1. Anyone can pay a visit to his/her physician, local hospital or long-term care facility, and ask for a copy of current Advance Directive materials. Pastors are especially encouraged to do this, in order to become familiar with the regulations that unfortunately do vary by state or province. Spend some time reflecting on your own responses to the questions raised in the materials.

2. Identify persons in your parish community who may be able to offer further insight into the use or function of ADs. This includes physicians, social workers, nurses, and pastoral counselors. You may also wish to consult with staff from area hospitals or extended care facilities. Work together in exploring options to educate the parish faithful on these issues.

3. Offer an educational program in your parish community. Sometimes staff from the local hospital or long-term care facility are willing to come and talk to your parish community. The parish priest can then include information on ADs specific to the Orthodox Faith. You may be surprised at how many are struggling with these very issues, and yet are afraid to raise them for any number of reasons. Sometimes case examples can serve to provide significant distance from one's own situation, yet shed light on the important issues.

4. Pastors, be available, along with other identified parish members, to speak to your parishioners and their family members. Sometimes simply being a listening presence can assist family members in hearing one another when discussing these emotionally charged issues. Also, pastors can be a significant resource for hospitalized parishioners, having heard directly what wishes might be significant. This can become vital when family members are enmeshed in agonizing over how to proceed, or are conflicted due to differing faith perspectives or wishes.

5. From time to time, offer educational resources, including sermons, referring to the sanctity of life, and that all stages of it, from birth to death, rest firmly in God's hands. Stewardship is more than managing time, talent, and treasure. We are further called to be stewards of the very gift of life that has been given to us by God.

It is hoped that this article has at least stimulated your curiosity and interest. Now the rest is up to you. Don't wait to make these decisions in the heat of the moment, or worse, leave them up to others who may not know your wishes and/or Orthodox practices. You, and those around you, may find peace in discussing and documenting Advance Directives. Real preparations for a Christian death can lead to a better life!

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