

Faith in Practice

End-of-Life Care and the Catholic Medical Professional

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Abstract

Theological discussions on appropriate courses of care for the very ill can be more difficult if information on options and outcomes is lacking. This article provides an historical review of a change in the paradigm of care in the United States and similar developed countries. End-of-life courses can vary based on underlying disease processes and health system resources. The purpose of this article is to help readers to better appreciate the limitations of medicine, and so be able to make a more informed decision about interventions that may be offered at the end of life. While there is also some discussion about ethics and physician-assisted suicide, this is not intended to be a theological treatise on Catholic doctrine related to the sanctity of life. Additionally, the following paragraphs will describe the current state of living and dying in America, contrast this with the way people wish to live until they die, discuss the role of the caregiver, provide insight into physician-assisted suicide and misconceptions about medicine, provide insight into the physician's role in end-of-life care, and explain what medicine can reasonably be expected to provide or prognosticate. Finally, there is an attempt to allay misconceptions about the extent of the effect of medical interventions. Medical intervention is inextricably linked to human

fallibility and shortcomings in clinical knowledge and achievement. Recognizing when human intervention can no longer provide cure, prevent decline, or even slow the course of disease is crucial in making end-of-life care decisions.

Changes in the Medical View of Death

A discussion of medical care at the end of life should be put into perspective based on recent history. In the early 1900s, the average life expectancy in the United States was about fifty years of age.¹ Childhood mortality was high, and even adults who survived beyond their sixties were unusual. When death came, it was usually quick. Prior to antibiotics, infections and accidents were principally responsible for one's demise. It was a time when much of medicine focused on comfort and caring, and, with a few cultural exceptions, most deaths occurred at home.

The latter half of the 1900s saw a shift in the focus of medicine to far more aggressive care aimed at cure. Death had become the enemy ... something to be defeated. It became common to equate death with failure.

End-of-Life Course

The end of life generally follows one of three courses. In one course, a person lives being relatively healthy until a sudden event precipitates his or her death. Graphically this is represented in figure 1a. Accidents, sudden catastrophes, e.g., a massive stroke, a large lung clot, or a sudden myocardial infarction (heart attack) can all fit such a scenario.

The second course is more gradual. In this scenario, there is a steady gradual decline in health until finally death occurs. This is depicted graphically in figure 1b.

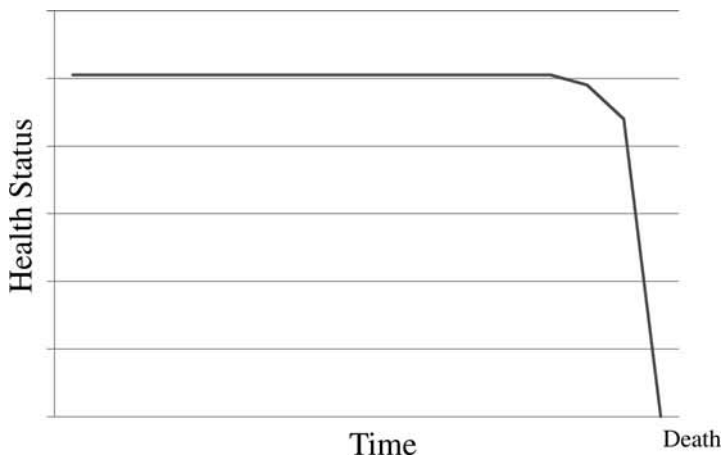


Figure 1a. Sudden death, unexpected cause (<10%).

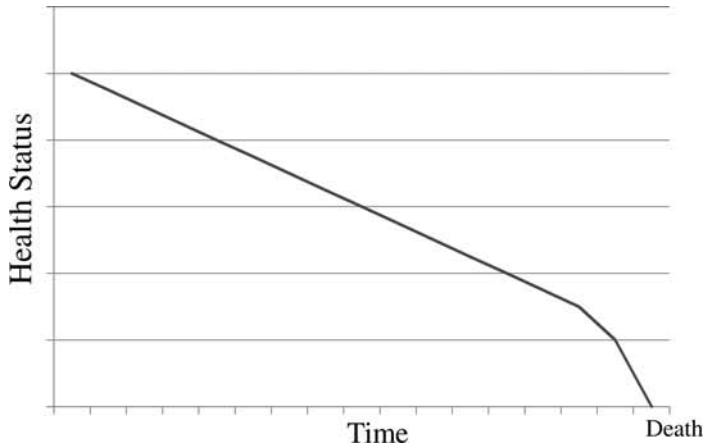


Figure 1b. Slow, gradual, and continual decline.

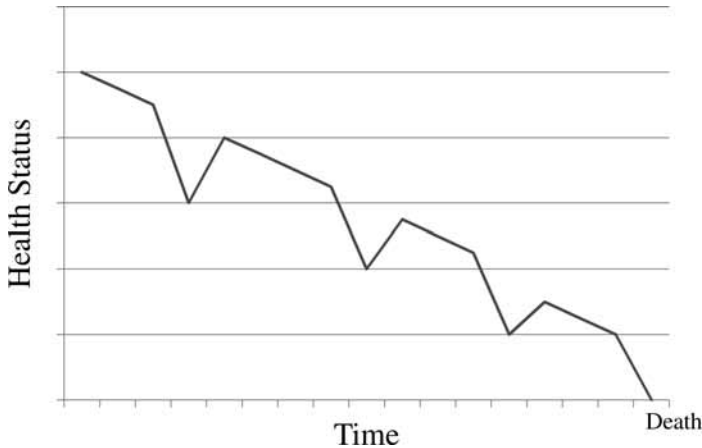


Figure 1c. Gradual decline checkered by acute exacerbations and partial recoveries.

The last course is probably the most common. In this scenario, health gradually declines, but is punctuated by acute episodes with partial recovery. Ultimately, after multiple episodes of acute decline and recovery there is a final catastrophic event from which there is no recovery and death ensues. This is illustrated in figure 1c.

During the 1990s the National Hospice Organization (now the National Hospice and Palliative Care Organization, NHPCO) commissioned a Gallup poll to identify personal preference regarding location of death.² It is likely not surprising that 90 percent of respondents chose home as the preferred location for their last moments in life. Unfortunately, what people prefer is not reflected in reality. In 1949 about 50 per-

cent of deaths occurred in the home. By 1958 that number fell to only 32 percent, and currently about three-quarters of deaths in the United States occur in an institutionalized setting, primarily in the acute hospital or nursing home.³ Many of these deaths are anticipated and could occur at home if people were adequately prepared. The lack of familiarity with the process and the discomfort with death itself provide obstacles that are often too difficult for most people to overcome.

Inadequate Health Professional Training

In 1997 an American Medical Association public opinion poll showed that 74 percent of those surveyed felt that their doctor was “open and able to help you discuss and plan for care in case of life-threatening illness.”⁴ The reality is that many physicians are uncomfortable discussing poor prognosis or conveying bad news. There is generally a lack of skill and training on negotiating goals of care or treatment priorities. The changing pace of medical practice also discourages time-consuming discussions. Additionally, many physicians do not have a clear appreciation of the concept of medical futility and are ill-trained in identifying when procedures and interventions no longer will provide benefit or actually are more likely to harm an individual.

Without formal training, physicians can feel impotent in addressing the palliative needs of end-stage patients. In 1998 one in four of 126 medical schools offered formal course training in end-of-life care.⁵ Fortunately, most, if not all, medical schools offer formal end-of-life training. The caliber of that training continues to vary substantially and many graduates remain inadequately prepared. Even with the better training in recent years, a reality is that most physicians currently in practice did not have the benefit of such a curriculum. Consider the words of one clinician providing care to a dying man:

They said there was “nothing to do” for this young man who was “end stage.” He was restless and short of breath; he couldn’t talk and looked terrified. I didn’t know what to do, so I patted him on the shoulder, said something inane, and left. At 7 A.M. he died. The memory haunts me. I failed to care for him properly because I was ignorant.⁶

When cure is not an option, there remains a need to address the symptoms associated with end-of-life conditions, e.g., pain, nausea/vomiting, constipation, breathlessness, weight loss, weakness/fatigue, loss of function. Pain is particularly troubling. While we have excellent tools to provide pain relief, there remains a large gap between mechanisms to control pain and actual implementation of effective pain relief measures. In the early 1990s the Eastern Cooperative Oncology Group showed that inadequate pain assessment, a fear of using some drugs, e.g., opioids, and inadequate knowledge accounted for the bulk of physician reasons that pain was inadequately managed.⁷

Cultural Changes Impeding End-of-Life Care

Some changes in our society have changed the end-of-life dynamic in recent years. Family size has decreased, leaving fewer children available to help with aging parents. The shift to dual income families has hampered the ability for many to have someone remain at home to provide care for a dying relative. Americans are more likely to spend their older years living alone. Family members are more likely to leave their roots and establish homes long distances away from their childhood homes. Obligations and priorities are often shifted from caring for the aged and frail, despite another Gallup poll that showed that 90 percent of Americans feel that caregiving is a family responsibility.⁸ When it does fall to family members, it is usually to a small number of people (usually female) who are not trained adequately to provide such care.

There are other devastating financial constraints that come into play as well. Twenty percent of family members who provide care will quit work to do so. In 31 percent of cases there will be a loss of family savings, and 40 percent of families will become impoverished.⁹

Coping Strategies

Coping strategies vary tremendously, but data indicate that spiritual people cope with dying better. Unfortunately, such events can also be quite destructive, and suicidal ideation may develop, or patients may seek euthanasia or physician-assisted suicide (PAS). Such movements have grown as people are living longer with chronic diseases that lack cure and the dying process is often prolonged. For some, life or living acquires altered worth. The thought of life not being worth living is becoming one of the great tragedies in modern culture.

Physician-Assisted Suicide

At the time of this writing some states have banned physician-assisted suicide, but two, Oregon and Washington, have statutes that permit this action. One has to wonder, "Why is physician-assisted suicide more acceptable than suicide?" Would physician-assisted bank robbery be O.K.? Is physician-assisted murder acceptable? The other questions that must be asked are these: "Do things always go as the physician plans?" and "Do medications always work as the physician expects?" The answers to these last two questions are, of course, "No!" Oregon has been collecting information on its physician-assisted suicide cases. Fifty percent of patients became unconscious within five minutes of ingestion of the lethal medication and the same percentage died within twenty-six minutes of ingestion. However, the range of time from ingestion to death was from five minutes to nine and a half hours, when death actually occurred! One recipient, who ingested the prescribed medication in 2005, became unconscious twenty-five minutes after inges-

tion, then regained consciousness sixty-five hours later. This person did not obtain a subsequent prescription and died fourteen days later of the underlying illness (seventeen days after ingesting the medication)!¹⁰ This is an important lesson on the imprecision of medicine and the fact that medicine involves art and science. It is often the case that we have far less influence on medical outcomes than we sometimes believe. Interventions often have unintended consequences.

The Oregon Experience

At last count, in Oregon about twelve physician-assisted suicides occurred per ten thousand deaths. Thus about one in eight hundred deaths among Oregonians in 2005 resulted from physician-assisted suicide. Of those who requested physician-assisted suicide, eight in ten patients had at least three concerns. The most frequently mentioned were as follows:

- a decreasing ability to participate in activities that made life enjoyable
- loss of dignity
- loss of autonomy

This concern that people express about being a burden to others is often expressed in dying patients even when not considering physician-assisted suicide. For many, when asked, “Have you ever done anything helpful or nice to someone in need?” the answer has been, “Of course!” or something similar. When asked subsequently, “How did it make you feel, when you made such an effort?” the answer is always along the lines of “I felt great about helping out.” “Why would you want to deprive someone else of such a good feeling?” is an enlightening follow-up question. Having the ability to recognize that as a dying person who becomes dependent on others, one is confronted with an opportunity to help someone else in such a way is often a very helpful perspective and draws much from one’s spirituality.

As if to acknowledge a discomfort with what they have allowed in Oregon, the statute specifically states, “Actions taken in accordance with [the statute] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law.” Instead, instructions are that they “would refer to the terminally ill patients who ask physicians to help them die as ‘persons who use the Oregon Death with Dignity Act.’”

Figure 2 gives a graphic representation of the number of prescriptions for lethal drugs and the number of physician-assisted suicides in Oregon since the law was enacted in 1998.

Organized Medicine and the Catholic Church

Ethically, the larger, more established medical societies have held a relatively solid stance against physician-assisted suicide. Consider this

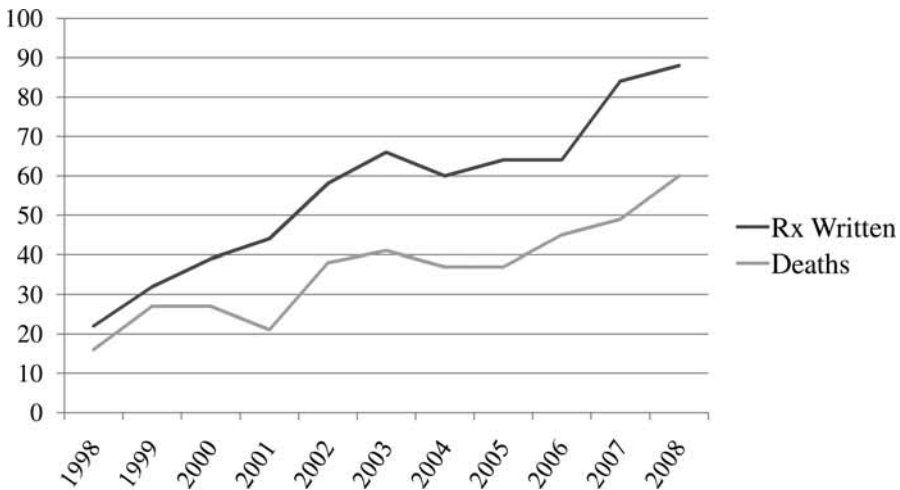


Figure 2. Number of PAS scripts and deaths by year.

passage from the American Medical Association *Code of Ethics*: “However, allowing physicians to participate in assisted suicide would cause more harm than good.... Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.”¹¹ Contrast this to the address given by John Paul II to the participants in the International Congress on “Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas”:

“By *euthanasia in the true and proper sense* must be understood an action or omission which by its very nature and intention brings about death, with the purpose of eliminating all pain”; such an act is always “a serious violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person.”¹²

Misconceptions

Oftentimes discussions around advance directives and end-of-life care decisions are predicated upon false assumptions. Fears, fantasy, and worry are driven by experiences of others or media dramatizations. This is understandable since most people spend little time around dying people, and few have extensive medical training and an ability to interpret data from controlled clinical trials. Misinformation typically surrounds aspects of the primary illness, adverse effects of medications, therapeutic benefit (e.g., tube feeding), intercurrent illness, and the impact of interventions, e.g., CPR. For example, with artificial feeding, there are no studies showing overall benefit or even survival in prolonged artificial feeding in conscious patients. There are data showing poor outcomes with tube feeding in individuals who have documented aspiration (inability to keep food from being swallowed into the lungs).¹³ Intravenous (IV)

hydration is also recognized as being fraught with complications, especially for any extended period. These complications usually outweigh any benefit over time. Not only is extended IV hydration lacking in benefit, it is likely to be harmful.¹⁴ Cardiopulmonary resuscitation (CPR, forceful compression on the chest) rarely has the outcome often seen on television, i.e., complete return to normal. Outside of a monitored setting, the process is rarely beneficial. With frail, older patients, rib fracture is a likely outcome, but again survival is exceedingly rare in such settings. Far less than five percent of heart-attack patients survive CPR, and far fewer than one in one thousand survive CPR in a nursing home or out in the community.¹⁵ The setting most likely to result in successful CPR is in the hospital where the heart is being actively monitored.

Hospice and Palliative Care

When cure is not an option, hospice and palliative care programs can offer aggressive intervention to facilitate comfort and dignity. Hospice programs typically have an unusual (for medical care) emphasis on spirituality. In the 1970s, the concept of hospice came to America.¹⁶ By 1993 about 11 percent of deaths were estimated to occur in some type of hospice program. Estimates from the National Hospice and Palliative Care Organization indicate that about a third of deaths in the U.S. may have been associated with hospice in 2006. Nonetheless, the median duration in a program (where people are entitled to entry when a six-month prognosis exists) is only about three weeks nationwide.

The role of hospice goes beyond direct symptom management and supportive care. Hospice also places an important focus on spiritual care. Hospice even extends beyond the patient with bereavement counseling after a patient dies. Experienced hospice workers and experts who refer to hospice will tout the hospice experience as being unintentionally life prolonging, but even if not, it does seem to improve the living experience for many in the final days of life on earth.

Recognizing the sanctity of life and the fallibility of humanity, one has to appreciate the option of palliative care through formal hospice programs or other programs that emphasize comfort and dignity in care when human beings are unable to provide a medical cure. The next challenge is to recognize when cure is not an option and when to implement palliative interventions to aggressively pursue comfort and dignity at the end of life.

Summary

Preservation of life and respect for its sanctity brings the Catholic Church in concert with mainstream medicine. Many people struggle with decisions about intervention or withdrawal of treatment because of a misunderstanding of the actual benefits that some interventions can provide. Often, as is the case with prolonged use of feeding tubes in

conscious patients or the use of extensive intravenous hydration, there are misconceptions of the merits, not only among the general population, but oftentimes with well-intentioned healthcare professionals. In part this article should help those with an interest in adhering to the tenets of the Catholic Church to recognize the limitations in life-preserving interventions. All of us will die. There is a catholic, in the universal sense, obligation to provide an aggressive caring and comforting environment that assures dignity to the end of this life for every human being. In every setting, prayer that invokes the Holy Spirit as tough decisions on care are derived should always be encouraged.

Notes

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