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End-of-life discussions

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Medicare recently approved a billing code for end-of-life discussions. I am unsure why this discussion is, other than symbolically, different than discussions we routinely have over lifestyle, nutrition, compliance, or the nature of whatever illnesses or social problems are afflicting the patient. The news media took a different slant, deducing that there will now be a marked increase in end-of-life discussions with patients. I doubt this will occur for several reasons. The first is that I have a hard time believing that doctors are not having these discussions now simply due to the lack of a billing code. We return our patient phone calls although we don’t get reimbursed. We don’t charge extra if a visit exceeds the allotted time. We aren’t lawyers. We serve our patients’ needs once they put their foot in the door.

We know that hospice services are markedly underutilized, which, I think, is true for the same reason end-of-life discussions are apparently not too common. The problem is that these discussions are often painful and delicate. They require an almost “official” change from a medical/scientific practitioner/counselor role to a pastoral role. This is often not easy. It is difficult for most of us to tell a patient or family that the end is near. We worked together, “fought the good fight” for years or decades, but now, as one always knew it would happen, the imminence of death has become tangible. Of course, the patient and the family knew it would happen, but they often never envisioned “giving up,” and sometimes seem surprised that that time has arrived.

Living with illness is often envisioned as a fight, and, in many ways it is. One endures, one accommodates, one takes medicines or other treatments to “fight back.” Patients are encouraged to “not give in.” We read and hear about patients’ courageous fights against cancer and, less often, other disorders. With these metaphors used almost nightly in the television news as we make one “significant” advance against cancer or Alzheimer’s disease each day, leaving the audience wondering why people they know seem to still be dying from these seemingly cured diseases. One can view end-of-life discussions as being focused on “death with dignity,” or as “throwing in the towel.” “I’m not ready to throw in the towel,” is not an uncommon response by a spouse or child. Introducing the end-of-life discussion automatically indicates a prognosis.

There is no “best” way to approach the introduction of a discussion on hospice. In some ways, I think of it as being similar to the discussion of brain autopsies. The best time to get a brain autopsy is at the first meeting, before death is on the horizon, when a patient can take an objective view, envisioning the event as taking place so far in the future that the decision does not seem to really be about him but more about a science-fiction edition, future-him. Once a patient nears his death, I find it quite difficult to request an autopsy. After all, the patient is clearly not going to benefit from it. Hospice care, although quite different, brings up similar issues to the autopsy request, if the autopsy request is made near the end. I have not thought about discussing hospice care early on, partly, I suspect, because I’ve not read suggestions to do so. There have been many articles about hospice and its under-utilization, including articles in this journal, solicited by myself. While I certainly recall being told that we ask for hospice too little and too late, I don’t recall being encouraged to discuss it early on. The development of palliative care provides a bridge, however, towards hospice care, that is much easier to discuss.

Why are end-of-life discussions so difficult? I claim no great expertise in this area, although I’ve certainly given it a lot of thought, but probably no more than most readers of this column. Those of us with clinical practices in adult medicine have experienced the death of our patients. We expect it. Those of us who deal primarily with older patients obviously experience this a lot more...
frequently than the average primary care physician. I often lose one or two patients a week. This has not inured me to the sadness of the loss and the concern that I had been unable to make the last bit of time more enjoyable, or at least, less difficult.

I am aware that I am possibly letting down my patients by not being as forthright as I might be when I avoid end-of-life discussions. From our initial meeting I try to encourage the idea that we are a team, working together to enhance quality of life. In my line of work there are no cures. We “manage” a condition. Part of management requires the patient and family making accommodations as the disease progresses. This usually takes place on its own, just as aging people accommodate to their increasing constraints. I may have to encourage use of a cane or walker, but not usually. I may note the importance of always grasping the railing when walking on stairs, but patients and families already know this. Approaching death is, of course, quite different. The only thing I know is that there is no single “best” way to do this.

I have a firm belief, however, that a new billing code is not part of the solution.

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C a l i f o r n i a r e c e n t l y became the fifth state to legalize physician-assisted suicide (PAS), with the likelihood that other states will follow.

Ninety percent of attempted and 95% of completed suicides occur in persons who have a diagnosis of mental illness and the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) designates suicidal behavior itself as a separate diagnosis. Thus all suicide could be considered an illness. Suicide as a political statement, self sacrifice in battle and similar situations are exceptions. But this categorization does not adequately describe PAS.

The concept of suicide as an illness is of recent origin. Physician-assisted suicide in the context of incurable terminal illness is controversial.

Ancient philosophers had opinions about the morality of suicide, but they did not think of it as an illness. They thought of it as criminal in some cases or justified it in other situations including, but not limited to “shame at having participated in grossly unjust actions” or “extreme and unavoidable personal misfortune” [Plato c.427 BC–C.348 BC].

The development of “institutionalized Christianity” introduced a moral proscription of suicide. St. Augustine (354–430) formalized this prohibition, citing the fifth commandment of “Thou shalt not kill” and applying it to one’s self. This attitude was persistent in Protestants as well, though some suggested that God might forgive.

Some philosophers thought that since the scriptures do not specifically prohibit suicide and since acts such as martyrdom are actually praiseworthy, suicide was not uniformly wrong [John Donne 1572–1631]. The philosopher John Locke (1632–1704) believed that humans possessed God given “natural liberty, but that liberty did not include the liberty to destroy oneself.”

David Hume (1711–1776) concluded otherwise. He stated: “Suicide does not necessarily violate any duties toward other people.” And he believed that “Sickness, old age, and other misfortunes can make life sufficiently miserable that continued existence is worse than death.” Immanuel Kant (1724–1804), however, felt that our morality derived from an inherent “moral will” and that to destroy that is to destroy morality itself.

Although there are situations in which our society mirrors the opinion of Hume and approves of suicide, including the increasing approval of physician-assisted suicide (PAS) in terminal illness, we generally think of suicide in the medical model and assume that persons with serious suicidal ideation are mentally ill. We spend money to rescue persons attempting suicide and forcibly confine them to prevent them from harming themselves. While many suicides are the result of serious mental illness such as depression, others are more situational. A teenager with relationship problems may react by attempting suicide. While this may be an exaggerated situational reaction, it often does not indicate a mental illness.

The AMA prohibition on physician assistance in suicide is based on the premise that physicians should use their medical knowledge and skills only to further the patient’s best interests. Historically, medical paternalism espoused the view that the “doctor knows best.” The concept of patient autonomy has risen rapidly in recent years and puts the patient at the center of medical decision-making. It can be argued that a person with a terminal disease who does not have co-existing psychiatric illness has a right to decide what actions are in his/her best interest.

However, there are respected philosophers who believe that suicide violates basic moral values. Also opposed to suicide are some religions that believe that our body belongs to God and individuals have a duty to protect it.

Suicide, physician-assisted or not, by a terminally ill, mentally healthy person is situational rather than due to a psychiatric illness. The terminally
ill person may believe, for a variety of reasons, that death would result in a benefit to themselves and the community. “Physician-assisted dying,” a term suggested recently in the New York Times, is less stigmatizing. The disease is the real culprit.

The personal belief systems of doctors also are important. Doctors may or may not believe that suicide for any reason is immoral. Doctors may or may not believe that PAS endorses patient autonomy and enhances the public welfare. Doctors should not violate their own conscience or deeply held beliefs. Doctors have no duty or obligation to participate in PAS.

Attention must be directed to the issues of financial incentives influencing both patients and insurance companies. Incentives encouraging PAS should be illegal. Laws permitting PAS should address these issues.

The medical profession should not deny doctors the right to act in the best interests of their patients. But who decides what those interests are? We recognize the right of adult, competent patients to accept or refuse any medically appropriate treatment. The question is whether prescribing lethal medications to a patient with a terminal disease is medically appropriate. We have seen that there is significant support for the view that prescribing lethal medications to a patient with an untreatable terminal disease is medically appropriate when the patient decides that PAS is in their best interest.

Medical professional societies should consider adopting a neutral stance about the morality of PAS. The policy of medical professional societies could mirror the AMA policy on abortion: “to obey the law.” Interestingly, the Rhode Island Medical Society (RIMS) adopted neutrality back in the 1990s and it remains our policy to this time.

[See Heritage, page 88: 1996: RIMS adopts a neutral stance on physician-assisted suicide]

Sigmund Freud (1856–1939), who proposed the view that suicide was due to pent-up aggression, suffered from painful and untreatable oral cancer. He extracted a promise from his doctor, Max Schur, to not “torment me unnecessarily.” Forty years earlier Freud wrote: “I have one wholly secret entreaty: only no invalidism, no paralysis of one’s powers through bodily misery.” He ultimately found himself in exactly that intolerable terminal situation. “Now it is nothing but torture and makes no sense,” he told his doctor. Three doses of morphine, provided with the approval of his daughter, ended his suffering. His biographer, Peter Gay, concluded, “The old stoic kept control of his life to the end.”

Should our patients have the same choice? ✤

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