

When All Else Is Done: The Challenge of Improving Antemortem Care

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Recent findings from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) reveal that Americans are receiving antemortem care that is highly technical and interventional, but poorly consistent with patients' wishes. A growing body of research in palliative medicine describes a manner of care that restores the possibility of a "good death" to the vast majority of patients. By familiarizing themselves with the medical, psychological, legal, and existential aspects of antemortem care, primary care physicians can offer excellent palliative care, changing the landscape of postmodern medicine for the benefit of all patients—including ourselves.

(*Primary Care Companion J Clin Psychiatry* 1999;1:146-153)

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In the last 3 decades, an increasing focus has been placed on the care patients receive at the end of their lives. The expanding technological advancement of medical care, the shrinking pool of financial resources, and the growing number of aged patients in the American population intersect at a focal point of growing controversy in postmodern medicine: What sort of care should the terminally ill receive?

The disparate opinions over what manner of care should be delivered in the antemortem period (and the passions with which they are espoused) have been highlighted in recent offerings by the media. Derek Humphrey's *Final Exit*,¹ a how-to manual for patients desiring to commit suicide, has become an underground best-seller. Similarly, the performance, on prime-time television, of euthanasia by a prominent Michigan pathologist spurred enormous interest.² Figures such as Humphrey and Kevorkian are vehemently praised or vilified (according to one's philosophical position), but they are not ignored. They serve as ethical lightning rods, conducting the volatile currents of the debate surrounding end-of-life care. The reticence of the traditional medical community to sensibly address patient concerns regarding antemortem care has left a

vacuum of leadership, in which figures such as Kevorkian loom larger than life. When the public cannot find those who will rationally debate their concerns, the issues they desire to be addressed do not die. It is then that the voices of zealots rule the day.

OPENING PANDORA'S BOX: THE RISE OF RESCUE MEDICINE

How did such passionate differences arise in the way we view care? As we have observed, the current controversy is of relatively recent origin. Until the very near past, the care delivered to patients at the end of their lives had been largely unchanged since the time of Hippocrates and Galen. Palliation was the focus of care, and most patients' deaths were swift and uncomplicated by technical intervention. For example, in 1906, William Osler³ studied 486 consecutive deaths at Johns Hopkins Hospital. His findings reflect the swiftness of death in the pre-antibiotic and pre-resuscitation era: "Ninety suffered bodily pain or distress . . . eleven showed mental apprehension. . . . The great majority gave no sign one way or the other; like their birth, their death was a sleep and a forgetting."^{3(p18)}

With the development of antibiotics, cardiopulmonary resuscitation, and artificial ventilation, however, antemortem care underwent a revolution. The high success rate (70%) originally reported for cardiopulmonary resuscitation (CPR)⁴ generated enthusiasm for training house officers in resuscitative techniques. Although CPR had been initially successful in a carefully defined patient subset (i.e., previously healthy patients suffering an acute myocardial infarction or mechanical trauma), it was assumed that the efficacy of resuscitative techniques would be transferable to a more generalized, chronically ill population. Soon it was considered the standard of care to begin CPR on any hospitalized patient found without spontaneous respirations or a pulse.⁵ Aggressive techniques of nutrition and medication delivery were developed to support patients kept alive by cardiopulmonary support, but unable to ingest materials by mouth. This model of rapid, intensive intervention has given rise to a type of medicine (Thomas Shannon calls it "rescue medicine"⁶) that works phenomenally well in certain settings (namely, in that of acute pathophysiologic insult uncomplicated by terminal illness). However, it fails to meet the needs of patients

with inexorably progressive diseases. In this setting, rescue medicine “tends to conflate the value of the sanctity of life and the technological imperative, rendering the acceptance of death morally suspect.”^{7(p284)}

Although such rescue medicine may be perceived by some physicians to be the standard of care, it is clearly *not* the kind of care that many Americans want to receive at the end of their lives. They envision a death surrounded by family and friends, in a familiar setting, without multiple technical devices attached to their bodies. The first living will, written by a Chicago attorney in 1967, was designed to assure this freedom from unwanted procedures. By 1976, these competing visions of antemortem care clashed in an actual case: that of Karen Quinlan, a young woman rendered comatose by an automobile accident. Her parents desired to disconnect artificial respiration, in accordance to what they perceived to be her previously expressed wishes. Her medical staff disagreed. In a landmark case, the New Jersey court ruled in the Quinlans’ favor. The right of families to stop life-sustaining therapies was expanded when, in 1986, the wife of Paul Brophy (a man left comatose by a burst aneurysm) was allowed to discontinue administration of nutrition via a gastric feeding tube. In their ruling on the case, the majority judges stated: “In certain, thankfully rare, circumstances, the burden of maintaining the corporeal existence degrades the very humanity it was meant to save.” Mr. Brophy was entitled to what the court called a “death with dignity.”⁸ In a similar case, the family of Nancy Cruzan won the right to disconnect their daughter’s gastric feeding tube.

The growing body of legal decisions endorsing limitation of interventional care at the end of life was interpreted by many Americans to constitute a “right to die”; specifically, the right to die in the manner (or even at the time) determined to be acceptable to the patient (or his/her proxy). Fueled by the increasing intrusion of highly technological care into the dying process and the retreat from the reality of death by the medical establishment, the right-to-die movement gained momentum, until the Supreme Court (in 1997) heard 2 cases where it was argued that the so-called “right-to-die” was constitutional. The Court ruled that there is no right to die *per se*; there is, however, a right to refuse treatment, derived from the principle of autonomy and expressed in the legal prohibition of battery. In other words, patients have a right to bodily integrity, which allows them to refuse medical treatments (a so-called “negative right”). They are not, however, guaranteed by the Constitution the right to determine the timing or manner of their deaths, by demanding intervention to hasten their demise (a “positive right”). The Court did allow, however, that individual states could pass laws enabling patients to seek death-hastening actions by physicians. Thus, Oregon’s Death With Dignity Act, allowing passive euthanasia to patients determined to be medically competent by 2 physicians, was allowed to stand. In Or-

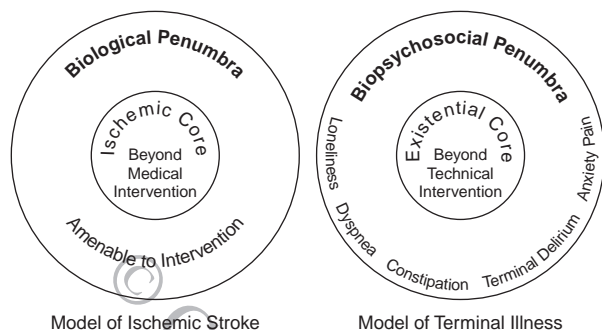
egon, a physician may prescribe medication sufficient to kill, with full knowledge that the patient intends to use the drug for this purpose.⁹ A referendum to create a similar law in Michigan was defeated in the fall of 1998. The Hyde-Nickles bill, currently being considered in the Senate, would make it possible to revoke the Drug Enforcement Administration (DEA) licenses of physicians who knowingly prescribe medications intended for use in passive euthanasia in this manner.

DEFINING THE “GOOD DEATH”

Despite caution from religious leaders, ethicists, and medical societies, public support has been enthusiastic for measures lending more control (even ultimate control) to patients with respect to the setting of their deaths. Patient advocacy groups have proclaimed that they were seeking for patients a “good death.” But what can this mean? How do we determine what is or is not a good death (or is there even such a thing)? Rather than arguing over the means to achieve an appropriate end to patients’ lives, we might do well to begin by attempting to describe it.

A survey of 126 terminally ill patients reveals how patients themselves defined a good death. Their chief concerns were avoiding inappropriate prolongation of dying (61%), strengthening relationships with loved ones (39%), relieving the burden placed on family members by their illness (38%), achieving a sense of control (38%), and receiving adequate pain and symptom management (22%).¹⁰ The results are somewhat surprising, in that pain control was the variable of least concern to patients (the teleological futility of intractable pain is invariably used by proponents of voluntary euthanasia as an argument for the practice). Indeed, studies of terminally ill patients show that only 5% to 11% of patients requesting physician-assisted suicide are motivated by pain.⁹

It is worth pausing here to distinguish between pain, experienced by the body, and suffering, experienced by the person as a whole. Pain may contribute to suffering, and as such, should be eliminated whenever possible. However, some amount of suffering is inevitable during the process of death and cannot be obliterated by physicians. This suffering is due to the difficulty of coming to terms with core issues concerning the meaning of life and mortality. As such, it does not admit to eradication with biomedical intervention. Borrowing from our understanding of the pathophysiology of ischemia, Daniel Callahan⁷ has offered a brilliant model for communicating this concept. He refers to fear, anxiety, and pain as the biological and psychological “penumbra” of illness, but designates existential questions as belonging to the core of the death experience. Just as physicians may intervene to alter the course of disease in the penumbra, but cannot change the morbidity secondary to tissue death in the core of an ischemic stroke, so it is with death. We should intervene in any

Figure 1. Callahan's Model of Antemortem Care^a

^aBased on Callahan.⁷

way possible to alleviate the anxiety, pain, and loneliness of patients, but we are not properly equipped (nor ever will be) to completely relieve the burden of a patient's mortality (Figure 1).⁷ When we fail to realize this distinction, we tend to move further toward the "antimortal" end of the antemortem care spectrum (Figure 2), and attempt to dissolve the existential suffering of death by seeking to control its timing and manner.

OBSTACLES TO THE "GOOD DEATH"

Limiting the scope of the moral imperative to "relieve suffering" is helpful, in that it brings to focus those aspects of suffering that are amenable to physician intervention. The literature, however, seems to show that we fail to discharge even this limited responsibility with a reasonable degree of excellence. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a large, multicenter trial sponsored by the Robert Wood Johnson Foundation, confirmed that patients' expectations regarding antemortem care are not being filled. This study followed prospectively the care of over 9100 hospitalized patients with 1 of 9 terminal diagnoses (defined as a condition known to have a 6-month mortality greater than 50%).¹¹ According to interviews with patients' families, the care delivered was plainly substandard. During the last 3 days of life, 55% of patients were conscious; of these patients, 80% suffered pain, dyspnea, and fatigue. A full 40% endured "severe pain" "most of the time." Of the total cohort, 40% received a feeding tube, 25% received artificial ventilation, and 11% underwent a final resuscitation attempt—interventions which were clearly at odds with the patient's and/or family's wishes in many cases.¹² Approximately one third of patients' families endured significant financial hardship because of medical bills incurred during the antemortem treatment.¹³

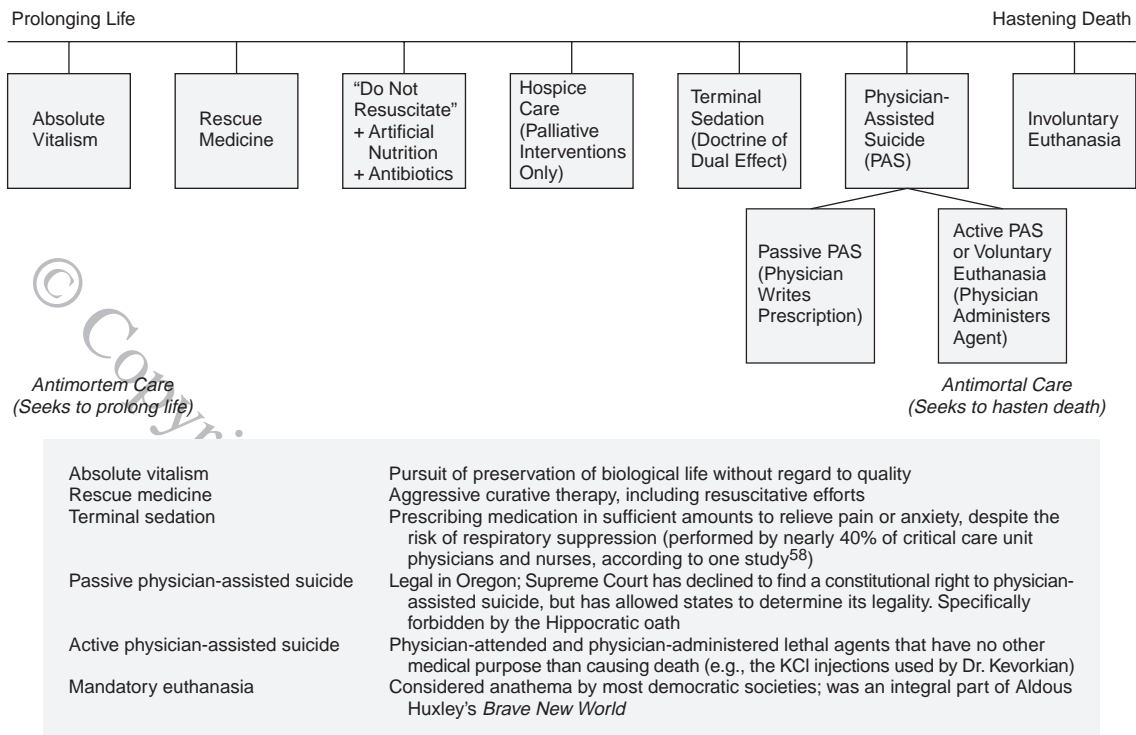
The message from the SUPPORT study is clear: the delivery of antemortem care in America is in need of sig-

nificant improvements. But to do so, several challenges must be overcome. In many cases, the wishes of patients are not known, as a substantial number are no longer capable of making medical decisions and have left no advance directive. When living wills are present, their language is often so ambiguous as to render them useless in typical clinical contexts. When no durable power of attorney has been specified, the physician is sometimes at a loss to determine which family member is to speak for the wishes of the patient. Especially in larger families, this circumstance can result in disagreement as to the best course of care, with the usual consequence of more aggressive care being delivered to the patient.¹⁴ Achieving consensus is made more difficult by the large number of medical staff associated with terminal patients' cases and the frequent absence of an identifiable primary care physician who is willing to coordinate care. Even when the patient clearly expresses his/her wishes (and those wishes are effectively distributed to the medical team), it is sometimes not clear whether the desire to limit treatment is ego-syntonic or is the result of a pathologic state of depression.¹⁵ In the fortunate case when a patient's wish is clearly expressed (by the patient or by proxy) and determined to be made in the context of competence, it can still be thwarted because the physician fears legal consequences or simply refuses to "give up the fight" against illness.

Considering the obstacles inherent in eliciting the wishes of a patient regarding antemortem care in the inpatient setting, it seems logical that such discussions should be initiated in the outpatient setting, remote from crisis. A recent survey of 883 ambulatory patients¹⁶ has shown that this is their preferred model. In general, they wanted their primary care physicians to begin antemortem care discussions early in the physician-patient relationship and early in the course of the patient's disease. Patients also expressed a desire that detailed information be presented, including outcome data of potential interventions, and that loved ones be included in the discussions.

The current literature, however, demonstrates that we are failing to meet this educational challenge. Only 10% to 25% of all adults¹⁷ (and fewer than 20% of elderly patients¹⁸) complete an advanced care directive. This percentage can be substantially lower in some populations (one study of 200 African American patients over age 65 identified an existing living will in only 2%).¹⁹ Rather than receiving open, honest communication from a physician they trust, most patients rely on secondary information about the choices available to them near the end of life, including portrayals by the popular media. Schonwetter et al.²⁰ reported that 92% of the patients they surveyed received the majority of their information about cardiopulmonary resuscitation from television. This type of information can quite often be *misinformation*; television medical dramas typically depict the success rate of CPR

Figure 2. The Spectrum of Antemortem Care



to be 60% to 70%,²¹ a figure far in excess of the actual success rate in hospitalized patients.

The failure of primary care physicians to communicate with patients effectively regarding the planning of antemortem care is attributable to a variety of reasons. Not the least of these is the time crunch. The “fifteen-minute hour”²² is greatly compressed to begin with, and adding existential discussions to a busy schedule can become an exercise in frustration. In addition, physicians are typically poorly trained in the medical aspects of antemortem care and express anxiety about forwarding such discussions. They may avoid addressing end-of-life care because they fear causing the patient anxiety or are concerned about potential conflict with the family. They may be loathe to face their own limitation of the power to cure or their own mortality. They may also face particular cultural barriers that hinder frank exchanges regarding patients’ preferences.²³ Unfortunately, even when the aforementioned obstacles are overcome and an understanding is reached, those outpatient documents often fail to reach the hospital in the case of an admission.²⁴

THE WAY FORWARD

Despite these obstacles, there is much that physicians can do to improve the treatment of patients at the end of their lives. Obviously, we must better communicate with

our patients regarding their wishes with respect to antemortem care and adequately document that communication in such a manner that it is relevant in real time to all care team members. Increasing the number of patients with valid advance directives is obviously a laudable goal. However, having patients fill out a form is not enough to influence the quality of antemortem care; the completion of a living will alone has been repeatedly demonstrated to fail to improve compliance with the wishes of patients and their families.²⁵⁻²⁷ What is wanted is a commitment by physicians to a *process* of engaging patients regarding antemortem care issues, not a reliance on a “one-shot” conversation that leaves a vaguely worded document tucked deep in the recesses of the patient’s clinic record.

Secondly, once patients have expressed their wishes, physicians must commit to carrying them out (so long as they meet the standard of medical reasonability). Physicians must become proactive in providing for patients’ antemortem care that avoids the maximally invasive, highly technological interventions associated with “rescue medicine.” As we have observed, this type of intensively interventional medicine has been phenomenally successful with regard to the treatment of acute pathophysiological conditions, but is ill suited to meet the unique needs of terminally ill patients. Typically, it involves alienation from family and friends (by introduction of acute care settings

with limited exposure to visitors), fragmentation of care into organ systems (each with its own specialist), and diminishment of personhood (by its emphasis on the case, not the patient).²⁸ Rescue medicine tends to view death as a failure of skill on the part of the caregiver, an unseemly aberration to be avoided at all costs. At best, this model introduces multiple interventions and choices to terminally ill patients and their families, which are difficult to manage. At worst, it offers “technological violence disguised as care.”^{29(p6)}

Limiting Antimortem Care

Recent discussions in the literature have defended the right of clinicians to attempt to prevent their patients from receiving such aggressive intervention aimed at biological cure (i.e., antimortem cure). Many authors have called for physicians, when discussing with patients their options regarding antemortem care, to not remain absolutely neutral, but to move toward the prescriptive end of the spectrum.³⁰ By doing so, physicians can potentially reduce the patient’s (or the family’s) anxiety or guilt when they wish to limit treatment.³¹ Cogent arguments have also been forwarded that resuscitative attempts should not be considered mandatory, even in the absence of a do-not-resuscitate (DNR) order. Rather, physicians should, when such attempts have been demonstrated to be futile in the context of the patient’s diagnosis, withhold CPR without obtaining “consent” from the patient or his/her family.^{32,33} In this context, “futile” does not imply a burden of proof reaching certainty (an impossible standard with reference to predicting a clinical course), but one reaching merely a standard of reasonable belief, given available data.³⁴ Of course, even when the physician makes an a priori decision to withhold certain types of care, the patient (or family, if the patient is no longer coherent) should be informed, as a matter of courtesy.³⁵ To protect against the dangers of paternalism, it is best if such decisions are made in consultation with another physician (or a medical ethics advisory team), rather than unilaterally.³⁶

Some have argued that physicians may even withhold resuscitative attempts in the face of family requests to the contrary. This assertion represents a significant shift in the climate of the debate concerning antemortem care. Initially, antemortem discussions centered around the fear (on the part of patients and family members) of overtreatment at the hands of the medical staff. Now many medical caregivers (and *a fortiori*, the administrators who write disbursement checks³⁷) are expressing concerns regarding overtreatment attributable to inappropriate demands from patients and family members. When such demands are made, the patient or family must come to terms with the fact that what is *wanted* matches ill with what is *warranted*.³⁸ In this model of deliberation, the patient’s *preferences* are primary, and the physician’s *knowledge* is primary. When these considerations conflict, caregivers must

lead patients into the delicate arena of compromise, where they must demonstrate “the subtle interplay of empathy and integrity.”^{39(p7)} The courts have not rendered a clear indication as to what balance of professional integrity and patient autonomy they will allow physicians to strike. In some cases, such as that of Helga Wanglie,⁴⁰ judges have denied medical teams the right to refuse futile treatment when a health care proxy demanded it for the patient; in others, such as that of *Gilgunn v. Massachusetts General Hospital*,⁴¹ physicians have been allowed to deny futile treatment, even though it was requested by family members. Again, in areas of such ethical delicacy, consultation with another physician (or better yet, the ethics team) can be of immense value. They not only avail the individual physician of additional support and expertise, but can initiate process-based protocols that simultaneously incorporate individual values (those of the members of the medical staff, family, and patient) with justice (each patient’s case undergoes the same steps of evaluation in the protocol).³⁶

Limiting Antimortal Care

I have made the case that physicians should limit antimortem care, i.e., they should refrain from retarding death in the terminally ill. Should physicians hasten death in this circumstance? For a number of reasons, I maintain they should not. Physician-assisted suicide is expressly forbidden in the Hippocratic oath.⁷ Perhaps this is because the decision that life is not worth living is too weighty a decision for one person (even the patient) to make. It seems impossible for a physician to endorse this choice (or worse yet, to choose *for* a patient). As Leon Kass says:

For the physician, at least, human life in living bodies commands respect and reverence—by its very nature. As its respectability does not depend on human agreement or patient consent, revocation of one’s consent to live does not deprive one’s living body of respectability. The deepest ethical principle restraining the physician’s power is not the autonomy or freedom of the patient; neither is it his own compassion or good intention. Rather, it is the dignity and mysterious power of human life itself, and therefore, also what the oath calls the ‘purity and holiness’ of the ‘life and art’ to which he has sworn devotion.⁴²

Although popular enthusiasm for physician-assisted suicide is currently high, this central philosophic weakness gives rise to a dual paradox that will almost certainly expose it as an unwise (and unethical) practice. Firstly, although physician-assisted suicide purports to “protect” patients from the increasing “control” of modern medicine, the desire for physician-assisted suicide is rooted in a desire to *control* the timing of death. Thus *personal* control is substituted for *institutional* control (admittedly, a limited good), but the thirst for mastery of the core ambiguities of life (and death) remains (hence, the term

antimortal care). In the word image of Callahan, physician-assisted suicide enthusiasts are trying (futilely) to heal the core, and not the penumbra.⁷ Secondly, the physician-assisted-suicide movement cloaks itself in the principle of patient autonomy, but by giving physicians the power to kill, it may actually undermine patients' rights of self-determination. The checkered history of our long century speaks ominously as to the folly of placing the weakest members of a society at the mercy of a technological class acting in what is presumed to be the interest of the general good. Finally, authorizing physicians to kill threatens to compromise the trust of patients that is essential to a therapeutic relationship. In the words of a recent JAMA editorial,

The very soul of medicine is on trial . . . if physicians become killers or are even licensed to kill, the profession—and therewith, each physician—will never again be worthy of trust and respect as healer and comforter and protector of life in all its frailty.⁴³

If these arguments are accepted, it should be readily apparent that the practice of “terminal sedation” is permissible only when the primary goal is to relieve pain, not to hasten death. The Supreme Court has endorsed the legality of terminal sedation if it is used in this manner.⁴⁴ This leaves the physician with wide clinical latitude to choose from a number of styles of care for the antemortem patient, depending on patient (and family) preferences, certainty of diagnosis and/or prognosis, and severity of symptoms. A clinician may choose aggressive resuscitation, hospice care, or terminal sedation; only the interplay of the patient's illness and his/her preferences can determine the “right” choice (invariably, the “rightness” of this choice will be quantitative, rather than qualitative). If a patient (or his/her proxy) continues to disagree with a physician as to what type of care should be provided, the physician is advised to consult appropriate colleagues, call on the help of institutional ethics committees, or (if necessary) arrange for the patient to be transferred to the care of another physician.⁴⁵

Promoting Palliative Care

Even if all agree on the course of treatment, however, death poses a most disagreeable event. The physician, therefore, should by no means attempt to help a patient negotiate these difficult pathways alone. Instead of an exclusivistic physician-patient dyad, one should encourage the input of family members or other medical staff. Thus, the physician underscores the validity of substituting “the collective art of caring for the individualized science of curing.”⁴⁶ Rather than evaluating success by physical cure of disease, the physician rates achievement by assessing the attainment of a number of goals. These include palliation of physical and emotional distress, support of function and autonomy, planning of care in ad-

vance, reduction in medically futile interventions, patient and family satisfaction, maximal achievement of patient quality of life, reduction of family burden, achievement of reasonable time of survival, maintenance of physician continuity and skill, and support during bereavement and “rituals of withdrawal.”⁴⁷

The list of tasks is long; any individual physician not intimidated has probably underestimated the need and overestimated his/her abilities. Considerable clinical fortitude and communicative skill are wanted in the physician who endeavors to excel in antemortem care. But even that is not enough. Dying patients need the type of “intensive caring”⁴⁸ that has high attendant emotional costs. The word itself derives from the Gothic *kara*, meaning “to lament.” To bear the burden of such care, a patient needs not a super-physician, bravely going it alone, but a community of caregivers (led, yes, by the physician) whose purpose is to help the patient achieve the aforementioned care goals as he/she prepares for the end of life.

This concept of communal antemortem care, popularized by the hospice movement, seeks neither to hasten nor to prolong death. The focus is on palliative care that shields the patient from pain, anxiety, loneliness, and fear (the Latin for *palliate* literally means “to place a cloak around”).⁴⁹ Palliative care is not simply adult internal medicine for the terminally ill; it is not problem-based or intervention-oriented. Rather, it is more analogous to newborn care, in that it focuses on psychosocial issues simultaneously with medical issues and involves the family as well as the patient. The hospice model entails more than mere symptom control; it embraces the facilitation of progression of the patient through developmental stages in his/her coming to terms with illness and death.⁵⁰ Although still not well utilized overall (80% of deaths in America occur in nursing homes or hospitals⁵¹), hospice care is increasingly requested by families or recommended by physicians.

As care of the antemortem patient continues to evolve, the need for well-trained, highly competent primary care physicians can only grow more critical. A physician conversant with critical/acute care, proficient in hospital management, well acquainted with community resources, and capable of meaningful and culturally sensitive interaction with the patient's family is essential. Achieving and maintaining competence as this type of “womb-to-tomb” physician are daunting tasks, requiring the cultivation of empathy, morality, humility, courage, and emotional stamina.⁵² It is no coincidence that these qualities have more to do with compassion than they do with cognition. In the process of properly attending the care of the dying patient, physicians are invited to reach beyond their role as scientists to reclaim their (chronologically and ethically prior) role as comforters. As it is quintessentially human to suffer, it is equally central to our humanity that we attempt to heal. Surely we heal best when we lay down

attempts to be like gods (by controlling mortality) and instead focus on being humans (by alleviating suffering, insofar as we are able).

During my training in a family medicine residency, instructors often encouraged me to follow in the steps of a fully qualified family physician. As part of that process, they continually referred to a list of “core skills,” which included delivering babies, setting simple fractures, providing hospital care, and other tasks of the generalist physician. The final step, however, is (in my estimation) the most challenging of all: “When all else is done, comfort the dying.” A moment’s etymological reflection reveals an important truth about the breadth of that task. The word *comfort* entered the English language as *comforten* (1286), meaning to “cheer up” or to “console,” but the word connotes more than a mere attempt to improve another’s mood. It derives from the Latin *com*, meaning “altogether,” and *fortis*, meaning “strong.”⁵³ Recalling that a central concern of dying patients is that they are not abandoned by caregivers, both medical and familial, it becomes obvious that a committed primary care physician can significantly alter the course of a patient’s death. By bridging the gap between a patient’s disease and a patient’s illness (as experienced by the patient and his/her loved ones), a physician ensures that a patient proceeds not alone, but in the company of others. Perhaps this comfort is the most humane “therapy” that we as physicians have at our disposal.

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