

WHEN HOSPICE FAILS: THE LIMITS OF PALLIATIVE CARE

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ABSTRACT

Hospice is the best-known example of palliative care. Advocates maintain that good palliative care precludes any need for suicide, assisted suicide, or euthanasia for suffering patients near the end of life. This article examines the feasibility of the palliative approach for all patients, showing that reasonable people may refuse even the most exemplary care for themselves or an incompetent relative. Palliative care should always have an important place in medicine. Yet medical realities and the alleviation of pointless suffering necessitate that policymakers consider other options, including "active" euthanasia, consistent with patient autonomy and the right to die.

Palliative care is intended to keep patients comfortable (emotionally as well as physically) and pain-free while they wait for death. Hospice is the best-known example of such care. Hospice advocates maintain that good palliative care precludes any need for suicide, assisted suicide, or euthanasia for suffering patients near the end of life. In their view, pain relief, symptom management, and a supportive environment facilitate a peaceful end and make any desire for a speedier death irrational [1, 2]. Such a request also signals a failure on the part of health care providers and constitutes a challenge to do better [1].

Indeed, many examples of serene deaths have been reported in hospice literature. But are all patients satisfied with comfort care? Does everyone enrolled in a hospice program experience a pain-free, dignified death? If not, do all who will face death in the future want to risk being one of the lucky ones? Is the much-publicized importance of patient autonomy and empowerment to be limited to palliative care because explicit aid in dying is always prohibited by hospice ideology? Does the patient have a duty to live because palliative care is available? These are the critical issues this article addresses.

In 1982, Robert Kastenbaum wrote that “healthy dying”—the notion that the terminal phase of life should be exalting and fulfilling—was “a major fantasy of the public at large” and that many of those attracted to the hospice movement had been “tantalized by the image of a transcendent terminal experience” [3]. Unlike this appealing public image of the ideal death, the reality is that hospice care, and palliative care in general, have important drawbacks that are likely to persuade some people of the benefits of a quicker death—for example, via assisted suicide or a lethal injection from a trusted physician. Reasonable people can, and do, refuse even high-quality palliative care [4]. Hospice practitioners themselves are well aware of the limits of palliation, but claim that unmanageable patients are extremely rare, their numbers insufficient to justify resort to deliberate killing even when that seems the best option for some [2].

LIMITATIONS OF PALLIATIVE CARE

Although unmanageable patients may indeed be rare in hospice experience, this is largely attributable to the fact that patients are highly selected for their likelihood to benefit from hospice’s specialized services. That is, those who are unmanageable or likely to become unmanageable are seldom considered good candidates for hospice. Moreover, the selection process works both ways: patients who select hospice tend to be those who find its goals compatible with their own. Patients with terminal illnesses other than cancer, the severely demented, those who are abusive or violent, and the extreme aged suffering from multiple, overlapping chronic conditions are generally excluded. Were this not the case, the number of unmanageable patients in hospice programs would be much higher.

Hospice cannot accommodate all the old, incurably ill, and dying patients who might conceivably benefit from palliative care. Over two million deaths occur each year in the United States, whereas hospice programs collectively serve only about 200,000 patients annually [2]. But the shortcomings of the palliative approach are far more intractable than sheer insufficiency of numbers. They include the difficulties of pain management and symptom control; the mental incapacity of many patients, especially the elderly, which may preclude any substantive benefit from palliation; the requirements of human dignity and autonomy, which hospice claims to support; the definition of a good death; and the problems inherent in withholding or withdrawing treatment to allow death to come “naturally.”

Pain Management

How accurate is the common belief that pain can be well managed? Sixty percent of all patients are pain-free the day before death, according to a survey

by the National Institute on Aging [5]. For those who experience significant pain, however, adequate control is exceedingly difficult to achieve and requires constant monitoring [6]. In some cases, pain cannot be effectively controlled without making the patient unconscious [7]. Despite the strenuous efforts of caregivers, some hospice patients still suffer intractable pain [8]. Even with an experienced terminal care team, some patients experience such unendurable symptoms that they must be heavily sedated in their last days. According to a recent study, sedation was needed for 16 percent of patients in the last week of life; a similar study found that more than half the patients required sedation [2]. Inadequate pain control in a hospice setting causes considerable tension for workers, such as Montana's Hospice Six, a group of nurses accused of illegally dispensing narcotics to suffering patients when waiting for a prescription would have increased their distress [9, 10].

No individual can be sure that he or she will remain pain-free until death or have pain that can, or will, be medically managed. Pain and discomfort endured by patients who have a reasonable hope of returning to a normal life is viewed very differently from terminal suffering, which is expected only to culminate in death [11]. Even the best pain-relief regimen cannot make the patient well or change the prognosis [4]. Nor is the risk of inadequate pain control the only consideration affecting judgments about the desirability of palliative care. Other relevant factors include the unpleasant side effects of painkilling medications, the symptoms of the underlying diseases and conditions, the psychic pain accompanying dependency and loss of control of one's body, the frustrations of being confined to bed or having one's freedom of movement severely curtailed, and the suffering that one's dying causes for significant others. Virtually everyone will experience one or more of these problems, and they may be impossible for caregivers, however dedicated, to remedy.

Symptom Control

Irene Robinson was paralyzed on one side, unable to speak or eat, and was fed through a nasal tube. The doctor said she would never walk or talk again, but could continue in her present state for another ten years. How could palliative care make Mrs. Robinson's life tolerable? Aware of her condition, she decisively conveyed her wishes to her son, Frank: repeatedly, with her one good arm, she held an imaginary gun to her head and pulled the trigger, signalling him to end her misery [12]. Are we justified in assuming that people like Irene Robinson are irrational in rejecting comfort care and requesting a quicker death? Should palliative care be imposed on such patients contrary to their expressed wishes?

Palliative care does not always preclude aggressive medical interventions aimed at alleviating suffering before death occurs. Invasive procedures (including amputations and other surgery), radiation therapy, and chemotherapy may be used

to relieve symptoms or prevent their development. An effort is made to weigh benefits and costs before such aggressive remedies are tried, but this is a difficult undertaking; such measures may cause patients anxiety, discomfort, or pain [13]. Prior experience of hospitalization, surgery, and other treatments (both curative and palliative) may also predispose some people to elect a quicker death. An example is a patient described by Dr. Timothy Quill. Dr. Quill was well-acquainted with palliative care through his work as director of a hospice program and explained its benefits to his patient. Unconvinced, she declined palliative care and asked him to help her kill herself. In an article in the *New England Journal of Medicine*, the doctor explains why he complied [14].

How successful is hospice in achieving high-quality palliative care for patients who do choose this option? Researchers have attempted to measure the quality of life of dying cancer patients, who comprise the great majority of hospice enrollees. They used such indexes as the patient's ability to manage personal care, feeling very ill, being unconscious, seriously confused, or depressed. They found a relatively low quality of life for about one-third of patients (34.2%) five weeks prior to death. This proportion increased to 42.8 percent three weeks before death and rose again, to 63.2 percent, one week prior to death. There were no significant differences in quality of life between hospice patients and those in conventional care settings, leading the investigators to conclude that "hospice interventions did not alter the quality of life . . . in either the physical or emotional arenas" [15].

But how are we to interpret the many reports of patient and family satisfaction with hospice services? Do such reports constitute evidence of hospice's merit and belie claims that palliative care, however well-intentioned, may fail some patients? Undoubtedly, some patients and families are quite satisfied with the hospice choice. But, on average, hospice patients are no more satisfied with their medical and nursing care than patients in other care settings [15]. Recall also that hospice patients are highly selected, admitted to hospice precisely because they are deemed most likely to benefit from the program's services. Further, reports of satisfaction with hospice inevitably reflect the respondent's ignorance of alternative outcomes: since the patient dies only once, no one can know what her experience of dying with conventional care would have been like. For patients unable to respond to questions during their last days of life, reports of satisfaction with the care received reflect the opinion of a proxy, usually a close relative, who can only guess at the patient's opinion rather than know it with certainty. Finally, the only comparisons that have been made have been between hospice and conventional care, not between palliative care and a quicker death with lethal drugs, for example. That some are pleased with hospice services, then, does not conclusively demonstrate the desirability of that regimen for every patient. Nor does the existence of satisfied patients allow us to conclude that other alternatives, such as physician-assisted suicide, might not be deemed more desirable than palliation were they to be offered.

Mental Incapacity

Coping with severe dementia and mental incapacity constitutes a serious challenge for both proponents and providers of palliative care. For example, as Alzheimer's disease slowly destroyed his wife's mind, seventy-nine-year-old Hans Florian cared for her at home, with the help of his son. In order to keep her clean and well-fed, they had to bathe her, change her clothes several times daily as she wet and soiled them, and pry open her mouth at mealtime. Yet, for nearly two years, unless she was heavily drugged, Mrs. Florian screamed almost constantly, often waking her caregivers. She screamed only two words, the German words for "fire" and "pain." Finally, for all their sakes, Hans moved her to a nursing home. There the screaming grew worse, terrifying other patients, and he was asked to remove her [16].

Johanna Florian's dilemma illustrates the fact that comfort care is clearly wanting if, at best, it can only control symptoms by inducing unconsciousness. Other than maintaining them indefinitely in a deathlike state (heavy sedation), what can palliation offer such patients? How do palliative efforts in these cases affect families and the professional caregivers who provide them to an uncomprehending, and perhaps abusive and combative, patient who is unable to appreciate their help? Research indicates that lack of positive feedback from patients is stress-inducing for hospice staff and contributes to burnout and job turnover [8, 17, 18]. In fact, recognition of their inability to help such patients die a better death leads most hospice programs to reject patients who are mentally incapacitated [19].

Human Dignity, Autonomy, and the Good Death

Throughout history, people have distinguished between good and bad deaths. A good death is neither premature nor delayed. Hence both sudden, unexpected deaths, especially those of children and adults in the prime of life, and lingering deaths are highly disvalued [20]. Because of its long duration and the loss of personhood its victims experience, Alzheimer's disease has come to epitomize a bad death [20]. Nursing home residents often express a wish to be done with their suffering, and others become weary with the uncertainty surrounding their actual time of death [21]. In the words of one hospice patient, "The worst thing is not knowing the when. I know that it's going to happen, but I don't know when and I don't like this. There is no control. No way of being able to say I have this amount of time and then I'll die. I lie here and think about it all" [8]. Such worries detract from the quality of one's remaining lifetime.

A good death, in contrast, is under the dying person's control and gives that person time to settle debts and fulfill obligations [22]. Achieving "closure" is important. The term refers to settling differences, healing wounds, and closing gaps in human relationships [23]. Closure is difficult or impossible when the

timing of death is uncertain or when the patient is too physically frail or mentally impaired. To most people, a death without closure is a bad death. Closure is also a compelling matter for family members, friends, and professional caregivers, who must live on with a sense of failure if it is not achieved. To the survivors, words left unspoken and feelings that were never expressed are cause for deep regret and guilt, because it is too late to make amends [23]. Yet when only palliative care is available, both patients and their caregivers must endure considerable uncertainty in the wait for death.

Many people also distinguish between having a life (a biographical concept) and being alive (a biological notion) [24]. Having a life encompasses an awareness of oneself as a unique individual, with the ability to love, learn, and laugh; remember yesterday and plan for tomorrow; have hopes and dreams; and interact with others. To have a life in the biographical sense obviously requires life in the biological sense, but the reverse is not true. If a person's biographical life is over, many see no point in prolonging his or her biological life. Hence those with serious health problems that the medical system cannot sufficiently alleviate may reject even exemplary palliative care, or a family member may reject it on their behalf.

Most individuals wish to avoid not only a lingering death but a dying process that is undignified, "degrading," or "disgusting" and to spare their friends and relatives from watching it [25]. These apprehensions reflect fears of pain, helplessness, dependency, institutionalization, and being a burden to others. Family members dread having to watch the slow, painful dying of a relative. The pain of watching helplessly as a loved one deteriorates is sometimes so severe that some families must be discouraged from visiting an institutionalized relative [26]. Hospice staff are often highly distressed by witnessing patients' inexorable decline and lingering death [8].

To many dying persons, altruism may be an integral part of a good death. Insured or not, most patients worry about the financial effects of their illnesses on other people. Many reports have cited the immense cost of the life-prolonging treatments provided to some people in the last stage of life and the plight of their families. As in the case of expensive curative treatments that promise little benefit, some patients may decide that palliative care is not sufficiently beneficial to warrant its costs. They may wish to avoid impoverishing the family or dissipating an estate to pay for care. For example, a husband may worry that his wife will not have enough money to live on after his death if their life savings are expended on care that is likely only to prolong his death rather than make him tolerably well again. Other patients may wish to free up funds for more productive uses in the larger society. Evidence of poverty, neglect, and preventable suffering are all around us. Some individuals wish to respond to these concerns, perceiving in their timely death a final way to be useful [27]. In rejecting physician-assisted suicide and lethal injections for the terminally ill, the palliative approach precludes these choices.

If death is inevitable, many patients feel that it should come quickly, out of consideration for their family, their caregivers, and society generally. Long death watches are very trying for the participants. In a court case, for example, a wife's request to have her husband's feeding tube removed was granted on the grounds that if he could have spoken, he would have wanted it removed. But it took eight days after the removal for death to occur [28]. One must question whether this lingering death, and its toll on his family, is what the dying man wanted. Long death watches also create stress for professional caregivers, including those with special training in dealing with the dying. As a patient lingers, staff stress inevitably heightens, creating discomfort over the patient's inability to let go and grief over a hard death [8].

The hospice movement has long championed individual autonomy, patients' rights, and a commitment to maximizing the quality of life even if it means a quicker death (for example, through rejection of medical treatments with only a small probability of success). The movement "has worked to empower patients and their families to make choices about their medical care and has emphasized that these choices include all forms of intervention" [2]. Hence the patient and family are nominally in control of all care decisions. However, this is not strictly true. Choices are in fact limited: "active" aid in dying, in the form of physician-assisted suicide or euthanasia, is not on the list of options. However, since "passive" euthanasia is acceptable, even desirable, to proponents of palliative care, does this too not preclude any need for "active" aid in dying?

Shortcomings of "Passive" Euthanasia

Some ethicists and health care workers distinguish between "active" and "passive" euthanasia. In their view, "active" euthanasia means literally killing the patient, for example, with a lethal injection, whereas "passive" euthanasia involves withholding or withdrawing treatment in order to allow a patient to die "naturally" due to his or her underlying illness. Other experts maintain that such distinctions are meaningless and point out that "passive" aid may increase the patient's suffering [24]. Nonetheless, many hospice proponents and other advocates of palliative care regard "passive" euthanasia as morally acceptable but draw the line at "active" forms.

But "passive" euthanasia is a poor option for some patients. First, death does not always occur quickly or with dignity when treatment is withheld or withdrawn. For example, it may take a week or more for a patient to die of starvation after a feeding tube is removed. Similarly, death does not necessarily follow quickly or easily when a respirator is disconnected, as one man discovered when his father endured an "agonizing battle to breathe" for twelve hours before death ended his ordeal [29]. Likewise, when another patient persuaded doctors to remove the ventilator keeping her alive in a hopeless condition, her family endorsed her

decision and gathered around her for a final farewell. But, dismayed at the bitter irony, the woman found herself still alive the next morning [30].

"Passive" approaches to dying may also entail waiting for months or years until a life-threatening crisis occurs and then withholding treatment. An example is waiting until a patient contracts pneumonia and, at that point, withholding the antibiotics that would cure it. Such passivity ensures prolonged suffering. As one writer described his mother's situation: "Heart and lungs are working, whatever is wrong with spine and limbs and mind. There is no respirator to be unplugged. No doctor can pronounce her a terminal case. The only sure prognosis is constant pain and misery as long as she lives." He asks, "Can't we put my mother to sleep?" [31]. Given the current murky legal situation in the United States, the answer is "No." But the lingering death that such patients die is one that few would willingly choose for themselves or allow a loved one to endure. Although a decision not to oppose death has been made in these cases, the passive way in which death is "allowed" is morally repugnant to many, incompatible with human dignity, and a violation of practitioners' responsibility to do no harm to their patients.

CONCLUSION

Americans have the right to refuse any and all life-sustaining treatments; this is equivalent to the right to choose death even when continued life is possible [32]. Lawyers, health care professionals, and policymakers agree that treatment refusals by competent patients should always be honored. Moreover, the courts have allowed such choices to be made by guardians for incompetent patients [33]. Suicide is no longer illegal. However, helping another person to die is illegal in many states and of doubtful legality in others, even when the assistant is a physician with a longstanding relationship with the patient. Hence the right to die is encumbered by unresolved issues limiting how that right may be implemented—palliation and passivity are endorsed while "active" aid in dying is forbidden.

Many Americans eschew these artificial distinctions and wish to control the timing and circumstances of their death. Public attitudes have been shifting toward greater approval of physician aid in dying, such as lethal injections for the terminally ill [34-36]. Derek Humphry's explicit suicide manual, *Final Exit*, became a best-seller in 1991. In Michigan, which until recently had no law against assisted suicide, Dr. Jack Kevorkian has openly helped twenty people to die. Instead of condemning the doctor, his patients and their relatives are grateful for his help [37]. Legislation to legalize physician-assisted dying is on the horizon in several states, with groups like the Hemlock Society in the forefront of the death control movement [38-41].

Physicians' views on "active" aid in dying are also changing. For example, when twelve physicians published a report on providing care to the terminally ill in 1989, ten of them agreed that it was not immoral for doctors to help in the

suicide of such patients [42]. Interviews with physicians suggest that, with experience, most intervene less aggressively with elderly patients and become more concerned about the undue prolongation of life [43]. For example, Dr. Howard Caplan recommends legalizing "active" aid in dying because "ten years of practice in geriatrics have convinced me that a proper death is a humane death. That's either in your sleep or being *put* to sleep" [44]. A survey of hospice physicians in 1991 showed that one in four agreed that "there may be situations in hospice care where under appropriate guidelines, assisted suicide would be a viable alternative"; in the same survey, an additional 15.4 percent of physicians agreed that such interventions would be appropriate in other care settings [2].

Although most hospice workers are opposed to "active" aid in dying and maintain that hospice care makes it unnecessary, 38 percent would support "active" euthanasia if it were decriminalized and reasonable safeguards were devised; an additional 18 percent were unsure, and only 45 percent were opposed [2]. Support for patient autonomy and recognition of the limitations of palliative care underlie the stance of these workers. Note that hospice workers are highly selected for a strong orientation to palliative care, and thus constitute a group among whom one would expect almost universal *resistance* to "active" euthanasia.

In summary, the evidence suggests a clear rejection of palliative care in some circumstances on the part of patients, their families, professional caregivers both inside and outside the hospice movement, and the public at large. Palliative care should always have an important place in medical practice. Certainly it should always be offered before considering more extreme measures, and patients who decline it should be questioned and counselled to ascertain their true wishes. Palliative care may well be the best choice for some. But it should not be the *only* alternative. Medical realities and the alleviation of pointless suffering necessitate that policymakers consider other options consistent with patient autonomy and the right to die.

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