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# Hospice Narratives of Good Dying

by Ellen McGee

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*Public attention to assisted suicide and dehumanized technology-managed death has obscured a third paradigm of dying, that offered by hospice care. Through the narratives of hospice experiences, we learn the meaning of "a good death."*

C<sup>urrent</sup> debate over the ethics of terminal illness is almost invariably framed as a choice between two master narratives of dying. The first reflects the dehumanizing anguish of technologically managed hospital death, in which the dying person's last days and hours are spent in artificially prolonged misery. Another narrative, which has recently gained cultural authority by presenting itself as the only alternative, comes to us either filtered through the prism of Jack Kevoorkian's assisted-suicide operation or that prescribed by Derek Humphry in his book, *Final Exit*.

These two paradigms present diametrically opposed visions of the dying process in which the event of death is imagined either as the culmination of passive victimization and progressive loss of self-possession, or as the ultimate moment of active self-control and autonomy. Attention to these two models of dying, both in our popular culture and in the academic community, has obscured the possibility of a third, mediating paradigm, one in which death is reimagined. In this third paradigm, we move beyond the conventional opposition between total loss and total assertion of autonomy.

Although the debate about physician-assisted suicide has raised consciousness about the work of hospice, it has failed to inform the public imagination about the kind of dying that hospice envisions. The public perception is that hospice may provide pain-free dying, but, because the third master narrative is unfamiliar, the public is unaware that dying can be "good."

Hospice offers us unusual stories about "good dying." Sandol Stoddard, in the classic, *The Hospice Movement*, repeats an account of a dying,

fourteen-year-old boy who was hostile and withdrawn. After the hospice team provided psychological, spiritual, and medical support,

The last weeks of his life were made physically comfortable for him; but even more significant was the adult commitment he was finally able to make to those who cared for him. If the quality and not the quantity of life is important then this boy achieved more than many an octogenarian, and if death at any age can be beautiful, then this one was (Stoddard 1992).

The institution of hospice offers a narrative of dying in which care for the terminal patient involves not just symptom control, but also devotion to an ideal of developmental growth in the final stages of life, to the continued significance of human relationships, and ultimately to a quest for meaning that extends beyond the event of death. Hospice narratives reimagine both the nature of the self and of autonomy. The significance of these stories, largely unrepresented in our popular culture and even in the medical ethics community, is that they constitute an alternative to the passive-hospitalized and self-activated narratives of dying. Not everyone will want to choose the hospice paradigm, or will believe that hospice's vision is the "best." However, elucidation and presentation of this model need to be made so that this choice can be a real possibility.

## The Prevailing Narratives

The hospice model is largely ignored on popular television shows such as *E.R.* and *Chicago Hope* that equate medical care with hospitalization. The news media have done little to bring hospice into

the public sphere. Reasons for this failure, which keeps hospice relatively unknown, are not mysterious. Fictional television shows thrive on the tragic-heroic dimensions both of the victimized sufferer and the noble suicide. Dramas need drama of a kind that hospice care does not seem to offer. In addition, news media need another sort of drama, that of a struggle between antagonistic options; a debate framed in terms of the opposition between totally passive death and totally active suicide fulfills this demand.

Publicized narratives of hospitalized dying reflect the fate of sixty percent of the population for whom dying is imagined as a cold, lonely, passive experience. Here the self is an object at the mercy of impersonal, institutional forces. The medical ethics community has responded to this scenario by advocating health care directives. This tradition sees patient autonomy as the primary value. It also defines autonomy simply as the exercise of choice. In this hospital scenario, the patient either opts for technological care and every experimental option that offers any hope for survival, or resigns herself to "the least worst death" (Battin 1983).

In offering advance care directives, the unspoken goal is that the dying patient be able to direct the conditions of dying so as to avoid the unnecessary, painful, expensive, and prolonged aspects of the terminal condition. "Good" is defined implicitly as autonomy, whose exercise prevents suffering and ensures fiscal savings. George Annas, in the Hastings Center study of the SUPPORT project, advises that patients who do not want the impersonal, pain-filled dying of hospitalization should stay out of the hospital. He further suggests that patients resort to legal action to change the behavior of doctors and hospitals (Annas 1995). Nevertheless, as long as "medical hope" is the driving force and the *only* hope that physicians and patients conceptualize, they will continue to opt for any experimental treatment that offers this hope, however slim, even at the risk of increased suffering.

Unless autonomous choice results in actual good, only academics will continue to value it.

Humans cannot live without hope, and medical directives do not offer much. That the tolerable death available through advance directives is not very desirable may help to explain the nonchalant behavior of medical professionals, as reported in the SUPPORT study. Perhaps it is also because of this awareness concerning advance directives that patients, families, and communities have sought alternative narratives of dying and have responded to tales of assisted suicide.

Self-directed suicide seems to offer a more attractive model for dying. In this narrative, the individual takes control of dying, as she has living. The individual is seen as one who understands a meaningful life to be one that is self-created, directed, and controlled; vulnerability and dependence are antithetical to the goods that this individual prizes. Her values are those enshrined in the liberal political tradition. This atomistic individual is respected for rationality and self-direction. The self — its creation, understanding, and direction — is, in this life-story, the focused value. The attention of the medical ethics community to physician-assisted suicide reflects the ascendancy of this model of autonomy and its vision of the good human life. Because this narrative of living declares that the good life is one of independence and control, its narrative of dying emphasizes avoiding the presumed indignity of dependence on others; it directs and manages dying through choosing the time and manner of death.

### Hospice Narratives

Hospice, as a concept of care for people with life-limiting illnesses, suggests another model, one that the model of idealized autonomy rejects. Hospice narratives are drawn from the experiences of real patients and families who view care as a good, rather than as an imposed burden.

It is a fact that as people are dying they often need to be cared for as they did in infancy and young childhood. Caring for babies and toddlers is a burden, but it is also a blessing for families. Families create and sustain themselves around the care of the youngest and the care of their dying loved ones. Your role at present may be the

hardest of all, to passively accept the care that your family and friends need to give you (Byock forthcoming).

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Such narratives challenge the model of idealized autonomy and find it impoverished. The common model of autonomy, from the hospice perspective, is grounded in an incomplete vision of the self. Hospice proposes a different vision of the self, of autonomy and of good dying. Hospice narratives reveal that the way one chooses to die is a kind of self-project, one that completes one's identity. In *Dying Well*, Ira Byock recounts the story of Steve and the personal growth this patient experienced as he was dying.

The biggest thing in the world is saying those five things: "I forgive you"; "Forgive me"; "Thank you"; "I love you"; and "Goodbye." If I hadn't been dying, I never would have cleaned up all the crap in my life (Byock 1997).

The identity of patients has been, and is, essentially created in community. Hospice reimagines care within a more holistic view, where the person, not the illness or symptom, is the patient and the patient includes both patient and family. In this setting, the story is one of human interdependence, where dependency is a valued behavior.

In practice, hospice supports and shapes a different way of dying. Certainly, not all of hospice's patients achieve "good dying."<sup>1</sup> Yet, its stories suggest that there is another way — one between suffering and suicide — of approaching dying. Hospice does not accept the idea that dying has to be a choice between passivity or autonomy. The stories reveal that humans are never wholly

autonomous, and that dying is not a completely unique event that only involves the individual. The stories intimate that our primary good is not egoistic autonomy, but community, and the search for meaning, which is essentially relational. Thus the stories of hospice resonate with the ways ordinary people lead their lives; contemporary men and women find good in the richness of family life, and in the affirmation of the ordinary.<sup>2</sup>

The following man's story of his wife's dying while in hospice care challenges the scientific, rationalistic view of caring for the dying:

Hospice was instrumental in readying me for Marcia's death. Personal anecdotes... along with hospice educational material and recommended reading, allowed me indispensable insights into both the dying process and into the moment of death itself. I came to view death in some respects as a great adventure — a great embarkation ... (Hospice 1995).

Hospice narratives are stories about a way of dying that accepts mortality and resists the control of technology. They portray dependence as a valued part of the human condition and treasure the patient himself, especially in his final hours, rather than his accomplishments. Hospice narratives speak of dying as "an extraordinarily important opportunity...an opportunity for growth" (Byock). These narratives speak of more than a relatively easy and pain-free death; death is not just tolerable. The hope hospice offers is of a time to achieve a sense of completion, of a time for examination and reflection, of relationships and meaning.

### **Narratives of Transcendence**

Hospice narratives are also open to the possibility of transcendent meaning; its practices are respectful of the meaning that can come from opting for ultimate meaningfulness.

The spiritual counselor is an integral member of a palliative care team. Although hospice does not impose a religious or spiritual view and can help patients find meaning solely in generativity,

in concern for guiding the next generation (Erikson 1987), pastoral counseling and spiritual care within hospice foster religious conceptions in those disposed to belief. Hospice's openness to this aspect of the person emphasizes its holistic, nonmedicalized view of care. No discussion of hospice narratives can fail to note the myriad stories of "nearing death awareness." These controversial accounts, described by Dr. Kubler-Ross and the hospice nurses, Callahan and Kelley (Kubler-Ross 1991), are consonant with the beliefs of many religious traditions and fit the world views of many of the dying. Although the validity of these experiences is challenged by the more skeptical, hospice caregivers usually are willing to allow dying people to describe and own their experiences and to be strengthened and comforted by them.

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To create meaning in the final stages of life, hospice caregivers seek to involve patients and families in recalling and telling the stories of their lives and in recording those tales on cassette tapes. Narrative is central to hospice care and to the developmental aspects of dying for both patients and families. Alasdair MacIntyre has emphasized that humans are essentially story-telling animals (MacIntyre 1981), and hospice practice attests to the necessity of story telling for the completion of human life. Hospice caregivers seek to engage patients and families in a search for the narratives of their lives. The Hospice Foundation of America thus provides *A Guide to Recalling and Telling Your Life Story*, a testimony to the central role that narrative holds in human life. The workbook guides patients in recovering and retelling their stories and transmitting their values and traditions to loved ones. The goal is to help patients in the quest for meaning and in the forging of bonds of

community.

A young woman dying of progressive paralysis dictated her reflections on the purpose of life :

A friend and I were considering life and its purpose. I said, even with increasing paralysis and loss of speech, I believed there was a purpose for my life but I was not sure what it was at that particular time. We agreed to pray about it for a week. I was then sure that my present purpose is simply to receive other people's prayers and kindness and to link together all those who are lovingly concerned about me...the wounded man and the Samaritan are inseparable. It was the helplessness of the one that brought out the best in the other and linked them together (Henke 1972).

The patient is a person who has a biographical life that unfolds in relationships, whose influence extends beyond death; hospice, thus, provides care of the patient and family, and offers bereavement care to loved ones after the death. Patients should be offered this positive vision of what life can be like for themselves and their loved ones during the final stages of illness. As a functional corrective to the lack, refusal, or inability to represent such narratives in the popular media, health care professionals should strive to familiarize themselves with the full impact of these accounts.

### **A Substantive Vision**

Hospice proposes an objective view of the good. It holds that an assessment of a person's well being can be made, that substantive judgments can be made about what things make the dying process better or worse. Hospice seeks a good death for its patients, and those words have real content. Etymologically, "good death" derives from the Greek, *Kalos Thanatos* rather than *Eu Thanatos* (Liddell 1990). This translates as "beautiful death," the ideal or exemplary death, and its meaning is not the same as simply dying painlessly and easily, although hospice seeks this, too. Hospice is concerned with enabling the patient

to die nobly, with dignity. Dignity, here, derives from character and is a response to circumstances; it requires virtue in the way a human being faces death, and in the caregivers who accompany him.

Further, hospice's vision of our interconnectedness, of the need to secure and create for patients a network of care and of significant relationships, calls for a communitarian vision of the self, of a self constituted in relationships. Hospice sees community as created in the care we give and receive. It calls for a commitment to valuing human relationships so much that support is provided to the end. Hospice presents an exceptional image of what it is to be human and to flourish. Its model for good dying rests upon an inclusive perception of the human being. The hospice vision is informed by the ordinary lives of patients and families and is more responsive to the implicit values that guide their visions of the good life. The narratives and stories of good home care should be more available to our pluralistic community, since hospice presents an attractive alternative to the prevailing paradigms.

If physicians and medical caregivers become more aware of these stories, they will be better able to help patients find fuller meaning in dying, and more patients will be able to die a good death. "In our experience of moral and practical life, what ultimately carries conviction and activates our moral 'springs of action,' is...our ideas about the possibilities of human life" (Jansen and Tollman 1988). These ideas are most readily available in stories, and these stories, in turn, shape our moral sensitivity. Our ability to choose the selves we wish to be, the lives we wish to lead, and the deaths that end our stories, is enhanced by the narratives of hospice.

### Endnotes

1. While this paper concentrates on idealized stories, hospice also shares stories of dying that are not good.

2. For a much richer discussion of this point see C. Taylor, *Sources of the Self* (Cambridge, Massachusetts, Harvard University Press, 1989), Parts I & III.

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