

# The Clash of Meanings: Medical Narrative and Biographical Story at Life's End

By Sharon R. Kaufman

Though death is of course a universal biological fact, the dying process, like all life-course passages, is culturally patterned. Today in the United States, most deaths occur in the acute-care hospital. The widespread understanding that death there is “problematic” is a response to the fact that the end of life is conceived largely (though not entirely) in a medical idiom that seeks to diagnose disease *while* dying occurs and to prolong life for as long as possible with the best technology available. The notion of “death with dignity” is a cultural response both to the use of high-technology hospital medicine and to the institutional press toward curative and restorative therapies regardless of the patient’s biography and nearness to the end of life. Grassroots community efforts to ensure that deaths take place at home, innovations in medical school teaching that view death as inevitable and not as failure, and palliative care services in hospitals are all efforts to provide end-of-life care without technologies for life prolongation—so that a “dignified” and “meaningful” death will be produced. Those efforts

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are by now a well-articulated rebellion against the pervasiveness and dominance of a model perceived to have run amok (SUPPORT, 1995).

One difficulty in addressing concerns related to end-of-life care is the lack of clarity among health professionals, patients, and families alike, about when the actual dying process begins. For all its diagnostic acumen at the end of the twentieth century, medicine, as system of knowledge and clinical practice, is seemingly unable to consider, first, whether a particular medical crisis is the last one for an individual and, second, whether or not a person is dying. Physicians are not expert at determining whether patients are in the last stages of illness or when death will occur (Lynn et al., 1997; Lynn, Teno, and Harrell, 1995). One common result of not knowing and not acknowledging when dying begins and not knowing when death is likely to occur is the press to continue treatments, sometimes almost to the moment of death (SUPPORT, 1995). Moreover, medicine in the United States generally does not allow for a transition, a process, a pas-

sage between life and death except in the most perfunctory way. Thus medical ideology cannot account for what that process might look like and what its range of variation is likely to be, and medical practice cannot consider new forms of action appropriate to a time for dying. Knowing the precise moment or the specific clinical signs that determine “the beginning” of the dying transition can only be posited as necessary or as a solution to the problem of death in an affluent society where the right to advanced and ongoing medical care is considered a given, hospitalization to sustain old and frail lives is frequent, and a variety of life-prolonging biotechnologies exists.

I turn to two narratives of old age, decline, and death as exemplars of the problem of death for many Americans. I use the term *narrative* in a well-recognized sense, meaning accounts from individuals that portray their subjective experience, including a sense of intention, explanation, and emotion. Social scientists have borrowed the concept of narrative from the traditional humanities and view it as an expansive tool through which to articulate how individuals construct meaning and negotiate their worlds. Narrative representations of aging, illness, and dying provide a way to explore the multiple meanings and voices that are expressed during life-course transitions.

The examples that follow are not of high-technology medicine, intensive care unit treatments, or “heroic” intervention, aspects of the problem that receive a great deal of consideration. Rather, these narratives are about a different feature—slow senescence and the kinds of concern and suffering it produces when dying is not acknowledged and a dying role for the patient is not recognized. I suggest that no cultural models or ideals for these sorts of deaths are available, just as there are no models for extreme old age itself. From a cultural narrative standpoint, as we shall see, American society offers no way of understanding death without a clear terminal diagnosis (such as cancer or AIDS), a staged trajectory of dying (as Elizabeth Kubler-Ross has proposed), and an aware and expressive dying person at the center of the story (Seale, 1998). Yet in reality, those kinds of deaths are not the norm in late life. Much decline in

advanced age is not heroic, dramatic, or purposefully directed by the deteriorating individual. The case studies below are drawn from a larger study of how dying and death are approached and understood by health professionals, patients, and families and how dying and death occur among older adults in one community hospital.

#### CASE 1: ‘FAILURE TO THRIVE’

Mrs. A, age 85, was admitted to the hospital for malnutrition and “failure to thrive,” while her only child was out of town. A hospital physician provided me with some background information: Mrs. A was a very “high functioning” person who had been “declining.” She had spinal stenosis, or constriction, and lower extremity weakness. She was not eating, and was taking antidepressant medication both for depression and to stimulate her appetite, and was in great pain. At home, where she lived alone, she had hired caregivers for twelve hours a day. The physician informed me that the in-hospital medical team had put her on a morphine drip to reduce her severe pain, and the medication had made her very sleepy. Now she needed to be awake so the staff could “get her nutrition up.” The physician also told me that the family was in a transitional moment, facing the end of her life.

I met Mrs. A’s son, a professional man, on the second day of her hospitalization. He talked to me at great length about his mother’s life and career as a talented musician, her illnesses and decline over a four-year period, his own heavy involvement in her care and deep concern for her well-being, and the strain and guilt he felt in his attempt to care adequately for an ill mother while at the same time working, raising three children, and caring for a deteriorating in-law. When I asked him what had led to his mother’s hospitalization, he replied that this was one of a series of setbacks, part of a long process of illness and decline that began with a stroke four years before. He said that his mother had not been eating and was becoming more and more dehydrated, less alert, and less oriented. This situation had frightened the paid caregivers, who were not able to make her eat, and they had decided that she needed to be hos-

pitalized. The son said, "She was feeling a kind of physical, biological depression . . . That's what the doctor saw in the hospital, and it certainly was true."

At the time we talked, the son was trying to determine whether his mother's undernourishment was a decision on her part, "even if it's kind of a passive decision, 'to stop living.' If she's had it, and in many ways she has, she's said so." But he was not sure, and he said he felt that her inability to eat was perhaps the result of physical problems: "Well, then that's not a decision at all, it's something that is happening to her," he said. "If we could help that, then maybe she could have more time . . . But every time she loses something, it's a little death."

Several days later, diagnostic tests revealed an infection, which the medical team, patient, and family agreed to treat. Mrs. A's primary hospital physician told me that Mrs. A was in pain. The physician also said that the infection was being treated with intravenous antibiotics, which required that Mrs. A be fed through a nasogastric tube, "because you can't treat with antibiotics and not feed. She needs food to improve. You either have to treat fully, or decide not to treat at all. The patient agreed to treatment, but passively." The physician addressed the conflicts that arise when putting a feeding tube in someone who had been refusing to eat. "Dropping a feeding tube into a woman who doesn't want to eat seems really barbaric," she said. "Had Mrs. A said 'Do not treat this infection. I won't take the feeding tube,' that would have been a pretty clear message. But she was agreeable to the therapy and the tube feeding."

On the twenty-eighth day of Mrs. A's hospitalization, she was still on the nasogastric feeding tube. She was not more alert or awake. Oral pain medication had replaced intravenous morphine. The next day, Mrs. A was discharged to a nursing home without a feeding tube of any kind, and the son was aware that she would die if she did not eat. Two weeks later, Mrs. A died in the nursing home.

#### **CASE 2: DOOMED TO DEATH IN LIFE**

Mrs. B, age 87, was admitted to the hospital because of a stroke. Her daughter informed me that her mother's decline had begun approxi-

mately three years before. A very spry and active woman well into her 80s, she had become "more tottery, more prone to falls," had given up driving, and had begun to use a cane. It took her a long time to do things. The daughter summed up Mrs. B's condition prior to this hospitalization: "She was in ways kind of losing ground, and unhappy about it. . . . But mentally she was still quite with it." Moreover, she had been brilliant, had had an outstanding and path-breaking career as a writer, and was an intellectual resource for family and community. "So when the stroke robbed her of everything that had to do with language," her daughter said, "it robbed her of her very being."

Three weeks into her hospital stay, Mrs. B needed total physical care and could not speak or swallow. It was unclear whether she understood anything or could communicate at all. The primary issue for the family was her quality of life. The family questioned whether Mrs. B wanted to live like this. She had told her family that she never wanted to be a burden to them. The daughter and son-in-law asked themselves whether they should withdraw nutritional support, which had been given in the form of a nasogastric tube as part of standard hospital practice. If they were to take out the tube, how, they wondered, could they let her die with dignity and end her suffering?

The family's conference with members of the medical team on Mrs. B's twenty-third day in the hospital stood out for the daughter as a memorable, awful moment:

I had said to the doctor, 'What do you predict out of all this, what do you see?' and he said, 'I think she may learn to swallow, but she'll always be at risk for aspiration. I think that she will be able to communicate some way, but not fluently. I think that she'll be able to go from bed to chair.' But he was not clear if that was with help or not . . . And part of my asking this was because there was constant pressure to put a stomach tube in. I felt pressured by the nurses, who said, 'This is uncomfortable. You really want to get that nose tube out of there because it's so uncomfortable for her, so much more comfortable to put it in the abdomen.'

The family remarked that they were alone in making decisions because the medical staff had

one perspective—to save life—and they had another—to consider their mother’s existential condition. They decided that under no circumstances would they authorize a stomach tube for Mrs. B, regardless of the pressure they perceived and, in fact, they wanted to remove the nasogastric tube and not replace it with anything. They spoke with the chaplain, still wondering if their wish to remove nutritional support was “the ethical thing to do.” When they received support for their decision to stop it, they informed the doctor, who was supportive. The family decided to bring Mrs. B home and “let her go.”

The daughter reported, “I started calling people and started to line up round-the-clock care and all of that. That was Friday morning. Friday afternoon I got a phone message from the speech therapist saying, ‘Wonderful news, she can swallow.’”

The son-in-law chimed in: “And we looked at each other. Wonderful news? We were prepared to clean up the house, have hospice come in, and four weeks and her suffering will be over.”

The daughter continued, “And there you are in this horrible situation where you’re thinking, ‘how can you be a good person and not rejoice that she’s improved enough to swallow?’ We felt two-faced, going to the hospital, watching the joy of the staff and then thinking, that is just prolonging a horrible situation. I went away and said, ‘She’s doomed. She’s doomed to what she doesn’t want.’”

Mrs. B was discharged to a nursing home, where she learned to swallow so she was not at risk for aspirating. But she was not talking, was extremely uncomfortable when she was out of bed, was paralyzed on one side, could not respond, and the family was not sure how good her hearing or vision were. They said, “She’s depressed. She’s given up. She’s cognitively less there than she was—less animated.” They told me that, looking back, if they had known they could have withdrawn the nasogastric tube, or never had it inserted in the first place, they probably would have made that choice. The daughter said, “I think that no one looks at it in terms of the risk of having to live a non-life versus putting the nose tube in and maybe there’s a chance of improvement.” She

concluded our conversation about her mother by saying, “The last thing she wanted was what happened to her.”

#### INTERPRETING THE NARRATIVES

These case studies illustrate the clash of two discourses: the biomedical discourse, which often extends biological life through medical means, versus the existential discourse—the search for the authentic self and its desires in the midst of the illness. In both these cases, the insertion of the nasogastric tube located the families in the common medical story of not giving up, of “choosing” to extend the life of the body. That story frequently trumps other stories in the American hospital setting. The feeding tube also anchored both stories in the larger medical and bioethics debates about whether or not artificial nutrition for frail elderly people constitutes appropriate medical care, basic humane care, or futile treatment.

The stories of Mrs. A and Mrs. B lie outside the idea of “a good death,” promoted first in the United States by Elizabeth Kubler-Ross, in which individuals not only confront and verbally acknowledge their end, but also create their own deaths by directing the action of caregivers. Through those means, it is thought, others can know the dying self and can allow a last opportunity for the person to achieve a meaningful experience (Kubler-Ross, 1969; Seale, 1998). Neither Mrs. A nor Mrs. B could express what she wanted about extending the life of the body in the absence of the life of the self. Neither woman could create or control her own end. Most important for their families, neither could authenticate a meaningful identity in a period of decline. Both were consumed by an all-pervasive illness as well as by the medical narrative—discrete disease treatment and the management of bodily life extension. Neither Mrs. A nor Mrs. B could enter a dialogue with family or the medical team. Neither could speak the self into the medical narrative in order to live a different story of dying.

In the case of Mrs. A, medical and psychosocial modes of explanation compete to structure the story of her decline. The competition between medical and psychosocial modes of knowing the patient resulted in a narrative

standstill. For four weeks, the story did not move along. Neither Mrs. A's son nor the health professionals could dictate or even discern the appropriate direction of this narrative because Mrs. A herself could not participate in its construction or articulation. So the story remained in limbo, stuck between survival and death. Without Mrs. A's active participation in the story, an ingredient necessary for the ideal "good death," the quality of her dying could only be interpreted as unsatisfactory.

Mrs. B is defined by clinicians solely in a medical idiom. Her future is plainly described. Her biological body will be able to function, but only marginally and only under strict surveillance, with a stomach tube in place. The family wanted to subvert that story. They agonized over how to act so that the clinical scenario would not be realized. They decided to remove the feeding tube, thus assuming the story would move toward a well-orchestrated and peaceful death. If the patient's intelligent and creative self could not be salvaged, an appropriate death was, for the family, the only story worth pursuing. But their plans went astray when Mrs. B began to swallow spontaneously. Her daughter and son-in-law felt terribly guilty because they did not want the medical narrative of surveillance, dependence, and extended bodily existence to continue. Feeding a living body in the absence of an expressive self for an indefinite future was not a story they wanted to dwell in. They wanted to be "good," that is, to share and live the values of medicine. But the tragedy of an ongoing death-in-life became the more powerful story.

#### CONCLUSION

Thirty years ago, before the feeding tube (or the intensive care unit), a cultural expectation of waiting for death characterized the responses of health professionals and family to dying. The watchful attention of a generation ago has been replaced largely by either active battle or moral conflict as patients, families, and health professionals face the dying transition. Today, even among the very old, death is viewed as *not necessarily inevitable this time*. Decline and death can be, and regularly are, controlled. But therein lies the difficulty. There is scant admission that

this time, this hospitalization, may be the right time for dying.

These case studies raise the question: What does supporting or assisting the dying transition actually mean? The cultural discourse on "death with dignity" and control over the dying process assumes that everyone involved in a dying patient's care will know what to want as well as how to act. That discourse also assumes that the dying person knows what to want when faced with pain, infection, and disability and has the ability to communicate effectively about her desires. Unfortunately, those cultural assumptions gloss over the very real conditions of many old patients and the microdecisions and actions that are produced in medical institutions and which patients and families face, usually unexpectedly and without prior experience. Both Mrs. A's son and Mrs. B's daughter, like most family members I spoke with in the course of this study, did not know what kinds of treatments their relatives wanted within the medical story that was being constructed for them, even when they did know how their relative wanted to live. The discrepancy between the medical narrative unfolding before them and the biographical story they tried to discover or extend was the cause of significant despair.

In American society today, there is no narrative about what is good for the patient (Mattingly, 1991; 1998) when the patient is an old person in decline. Significant for the construction of that narrative, there is no cultural script about what is good in the science and art of medicine generally (Brody, 1992). In fact, various observers of clinical medicine have noted an essential lack of clarity about medical goals in an aging, individualistic society (Brody, 1992; Callahan, 1987). These case studies illustrate conflict, resistance, ambivalence, and the complexity of hospital death, even in late life. They illustrate the fact that the "problem" of death is composed of stories—resisted or willingly entered, avoided or hoped for, thwarted or proposed. A serious grappling with the problem of death will have to take its narrative features into account. ☺

*Sharon R. Kaufman, Ph.D., is professor in residence, Institute for Health and Aging, University of California, San Francisco.*

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