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“They wouldn’t pay attention”: Death without dignity

Jack Coulehan, MD, MPH

“Death with dignity” is a common catchphrase, especially in conversations about medical intervention near the end of life. Stripped to a sound bite, it may be used as a rallying cry for physician-assisted suicide and euthanasia or a condemnation of the American way of dying. While the phrase conveys deep beliefs about how persons face—or ought to face—the final phase of life, these beliefs are often not clearly formulated. Since death is a subject we like to avoid, we find it comfortable to use code in speaking about it. “Death with dignity” can serve as one such code. Unfortunately, patients, families, and healthcare professionals may use the code in conversations without realizing that each person involved interprets it differently.¹⁻⁶ In this essay, I explore some of the possible meanings of “death with dignity.”

Case study

She just wanted to die with a little dignity. That’s all she asked for, to die with dignity. But in the end she suffered so terribly. The pain was unbearable. It was

awful, so . . . unnecessary. If only we could have given her the death she wanted.

Not long ago, a friend used these words to describe the way her mother had died. When Joyce Evans learned she had pancreatic cancer, she knew that neither cure nor remission were possible. Mrs. Evans, a retired accountant, made it clear that she wanted to remain as active as possible, spend time with her children and grandchildren, put her affairs in order, and enjoy the blessings each day might hold. Her oncologist supported her decision but, nonetheless, subtly shifted focus by suggesting that aggressive intervention at the outset might give her a better chance to achieve her goals. He recommended that she obtain a second opinion at a major cancer center.

The doctors at the cancer center quickly came up with a comprehensive plan: first debulking surgery, then a complex regimen of chemotherapy. In a matter of days, Mrs. Evans found herself on a therapeutic treadmill. At first she felt obligated to do whatever the specialists advised because they assured her that they, too, had palliative goals. Later, she became so sick from complications related to surgery and the side effects of chemotherapy that she was less able to think coherently. Eventually, she became so

anorexic and weak that her doctors convinced her to consent to a gastric feeding tube “so you can get stronger.” Mrs. Evans suffered unrelenting pain, which, according to her daughter, was treated haphazardly and sometimes grudgingly.

Mrs. Evans tried to maintain a positive outlook, especially when her doctors were present. When her daughter suggested hospice, the oncologists always agreed in principle but said, “It’s not time yet. We don’t want her to lose hope.” Mrs. Evans eventually was referred to hospice nine days before she died. “It was awful,” her daughter said. “She kept getting worse and worse, but no one had time to listen, especially not the doctors. They turned my mother into an irritable, whining old woman. They simply wouldn’t pay attention.”

Surely, Mrs. Evans must have approached terminal illness with ambivalence. By all reports, she consistently expressed a desire for freedom, comfort, functionality, and completion of her life’s work. Yet from an outsider’s perspective, she consistently made the wrong choices. Why? One way of understanding this outcome would be to blame the patient and say she collaborated with her doctors to make dying more difficult and less dignified. She did this because of ambivalence, denial, or an unrealistic

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hope of remission. Either she or her daughter should have taken charge and insisted that her wishes be honored. A second (and more honest) way of understanding the outcome is to acknowledge that the patient and daughter received skewed information, mixed messages, and aggressive vibes from her physicians. It probably is true that if either had been more assertive, Mrs. Evans would have received better care. But neither was particularly assertive. They were ordinary people trying to get through a painful and perplexing situation.

Unfortunately, this story isn't atypical. It contains images, fears, expectations, anger, and desperation common to the current American narrative of dying. Most of us would agree that Mrs. Evans experienced an undignified death. However, each character in this story was, at least consciously, trying to do his or her best to achieve the patient's goals. But how can that be? What about empathy, honesty, and compassion? What about evidence-based decision making? Joyce Evans' story cries out for answers to these questions.

The appearance of dignity

What we understand by dignity depends, to a large extent, on how we view human life in full. Are human beings fundamentally autonomous, or are they members of a community, connected to one another by bonds that reach beyond the purely rational?^{5,7-11} Before examining these two positions, I want to step away from the question of inherent dignity and consider the appearance of dignity and its loss.

On the outside looking in

Without question, most observers would conclude that Mrs. Evans died without dignity. Some might go further and say that she was battered or

tortured by well-meaning caregivers. She experienced sustained and apparently intractable pain. Because of anorexia and nausea, she had a feeding tube inserted, ostensibly to improve her nutritional status, although in fact it caused additional symptoms. Toward the end, she suffered so much that she was reduced to "carping and whining," hence making her family and friends uncomfortable and, eventually, distraught. Clearly, Mrs. Evans's apparent dignity was compromised.

Moreover, these clinical changes paralleled a process by which her personhood seemed gradually to drain away, and she came to resemble an object—a sick person, a cranky old lady, the cancer in room 1341. While this was going on, her family and friends tried to remain connected, but this put them in conflict with the medical objectification of Mrs. Evans and made them frustrated and angry yet uncertain about what to do. Perhaps if they had been willing to fight the system, they would have been able to better safeguard her dignity. But why should families have to fight to affirm their loved one's humanity?

On the inside looking out

What was it like from the inside? Can we imagine how Mrs. Evans felt? Even if she believed that life is sacred, or that she possessed an immortal soul or had a deep sense of interconnectedness with all things, her experience as a dying person did not validate those beliefs. She may well have become so demoralized that pain and hopelessness filled her consciousness, even if, on some other level, she retained a conviction that her life was meaningful or sacred. In such cases, it is understandable that dying persons may experience their lives as having been stripped of meaning, even though the communities of belief to which they belong affirm such meaning.

Dignity as rational choice

Self-determination and dignity

Contemporary bioethicists place a very high value on autonomy and self-determination, suggesting that self-determination is, in fact, an operational equivalent of dignity.^{12,13} Secular bioethics function as a set of guides and procedures for decision making in a culture composed of moral strangers rather than serving as a substantive theory of "the good."^{14,15} Any theory of the good, the argument goes, applies to a given community (or group of moral friends) and must necessarily exclude or alienate people with different moral points of view. Some bioethicists write from the perspective of the good. An example is virtue theory, which holds that health-care professionals ought to develop certain qualities (e.g. compassion, altruism, integrity) to be good healers. However, these works seem quaintly old-fashioned and rarely enter mainstream clinical ethics.^{16,17} Daniel Sulmasy,¹⁰ on the other hand, concludes that freedom of choice is the philosophical basis for secular biomedical ethics, and, hence, is the platform upon which dignity stands.

If freedom of choice constitutes dignity, you'd think it would have been fairly easy for Mrs. Evans to die a dignified death, especially since she was perfectly capable of choosing. Had she decided to fight death against all odds, she might have accepted highly aggressive intervention with integrity and honor, even though it entailed a painful burden and offered little hope. Alternatively, had she preferred a quiet death—as she ostensibly did—she could have chosen palliative care. Although illegal, the extreme option of dignity-as-choice would have been assisted suicide or euthanasia.¹⁸⁻²² Instead, Mrs. Evans presumably chose the quiet version but was manipulated into the "do not go gentle

into that good night” variety. If individual autonomy lies at the base of human dignity, why do we have so much trouble making it work?

Choice: How little there is

Although self-determination as dignity is appealing, the concept is fraught with complications. The first is that choice (as conceptualized here) is historically and culturally specific. Most people throughout human history have died in ways and under circumstances that allowed them no choice. They died of accidents, wars, and plagues. The physical aspects of their deaths were mean and revolting. Today in the Third World, hundreds of millions of people face similar conditions. Millions die of malnutrition and preventable disease. Certainly, if taking charge is a *sine qua non* for death with dignity, most human beings alive in the world today will die undignified deaths as have the vast majority of their ancestors. This means that being fortunate enough to have been born into a wealthy society is almost a requirement for dying a dignified death.

Dignity-as-choice also leaves out people who lack the capacity to choose rationally. This includes infants, children, people with developmental disabilities or serious mental disorders, and persons who suffer from severe dementia. Bioethicists either ignore the dignity aspect of these situations and focus on the process of decision making (who should decide, and by what standards?)²³⁻²⁵ or grant a penumbra of dignity derived from the patient’s association—via affection, memories, and solidarity—with rational persons.²⁶ But to grant a modicum of dignity to a nonrational person simply because of association with others implies that choice merely serves as one marker for a broader concept of dignity.

Dignity as relational

Concepts of human dignity that include content in addition to process (choice) are relational, because they predicate a relationship to a bigger picture—some locus of meaning other than the individual. For example, possessing a soul, an oceanic or cosmic feeling about the universe, a deep commitment to family, and strong solidarity with a social or cultural movement are relational sources of human dignity. These sources have at least three things in common: communication, narrative, and responsibility.

Communication

Relationship places primary emphasis on the ability to communicate; in fact, it predicates a need to communicate. Human development requires a network of connectedness, most of which take place simultaneously at levels more personal (emotional, spiritual) and more detached (social, cultural, economic) than our imagined ideal of communication (i.e., the verbal interchange of rational decision makers). Communication involves touch. It involves sharing the pain of others as well as experiencing their elation and joy. Hence, dignity requires empathy.²⁷⁻³⁰

In our culture, the greatest challenge to nourishing dignity is the drive to expand autonomy by disconnecting us from others—in essence, creating a firewall around the rational incubus within our heads. This attempt is paradoxical, because any moral growth that human beings have achieved in our brief existence as a species depended on expanding empathic understanding to include larger and larger groups, and thereby creating opportunities to interact positively with people from other clans, tribes, or religions. “How do we live with moral differences and yet sustain an overarching community?” asks Jonathan

Sacks in *The Dignity of Difference*.³¹ The answer, he maintains, “is conversation—not mere debate but the disciplined act of communicating—and listening.” And yet the world today seems to be characterized by the reverse process: empathic devolution. The sphere of empathic concern may be shrinking rather than growing, as throughout much of the world we retreat into a variety of new tribes demonizing one another.

With regard to dying, our culture of individualism is ambivalent about communal relationships. We pay lip service to mutual support, friendship, love, and family ties, yet we limit communication about the dying process, often considering it too morbid or depressing for discussion. This is ironic, because “those who cope best with tragedy befalling loved ones are those who are involved in healthy personal relationships that are deeply intimate, even though it is (precisely) this kind of intimacy that made tragedy possible in the first place.”³² Paradoxically, the closer we become connected to others in a way that facilitates mutual respect, the better able we are to cope with their eventual loss and the prospect of our own deaths.

Narrative

For dignity to be meaningful, it has to be understood in the context of story.³³⁻³⁸ While traditionally such stories are religious, they need not be. Take, for example, Camus’ novel *The Plague*,³⁹ which tells a compelling story of how a group of characters create meaning in a world without God; most notably Dr. Rieux, who devotes his entire being to fighting the plague and inspiring others with his dedication and kindness, even though he believes that life is absurd, and there is no one out there listening to our prayers. In essence, the fact that we respond emotionally to Rieux’s story and that it may stir us to act in more

virtuous ways, in some sense creates in us the virtue and dignity that his actions portray. Or consider contemporary stories, like those of Nelson Mandela or Mother Theresa. Our amazement “in response to [Mother Theresa] is not a wonder at her, but a wonder that human life could be as her love revealed it to be.”⁴⁰ There is a sense in which our personal and collective responses to Mother Theresa’s story reveal the dignity of the dying poor of Calcutta and also our own dignity in being able to respond with compassion. In the end, the story is not about Mother Theresa but about the possibility of dignity.⁴⁰

Responsibility

Finally, dignity as relationship implies social responsibility.⁴¹⁻⁴⁴ This concept is embodied in the fictional Dr. Rieux as well as in Mother Theresa, Mohandas Gandhi, Nelson Mandela, Albert Schweitzer, and Paul Farmer. As physicians, we may also find ourselves particularly responsive to Luke’s parable of the Good Samaritan. “What morality restores to an increasingly uncertain world is the idea of responsibility—that what we do, severally and collectively, makes a difference, and that the future lies in our hands.”⁴⁴ Virtually everyone would agree that we have a responsibility to care for the dying, but in our individualistic culture we often fail to appreciate our responsibility to work toward the dying person’s physical, emotional, and spiritual growth as a fellow human being. Moreover, a relational conception of dignity also suggests that dying persons have responsibilities toward others, even though they may be constrained or transformed by illness.

Hospice: Conversation confronts silence

Hospice’s first objective is to alleviate the patient’s physical, emotional,

and spiritual suffering.¹ If this were the complete package, one could visualize patients as passive. The second objective speaks more directly to communication, narrative, and responsibility; that is, to provide circumstances in which dying persons may participate actively in their last phase of life, a phase that involves connection, integration, and personal meaning. In this context, some critics contend that hospice insists on defining “a good death.” If this were true, hospice would rightfully be considered inappropriate for patients who desire symptomatic relief but are not interested in existential growth. Miller, for example, contrasts arguments advocating euthanasia with the hospice model of dying.⁴⁵ He acknowledges that hospice presents “the best approach to dying,” yet contends it is paternalistic to demand that people be virtuous in dying.⁴⁵ However, he misses the point, because permitting opportunity for existential growth is different from insisting on it or specifying its characteristics in a given patient.

Opportunities for existential growth depend on openness and communication. In *The Hour of Our Death*,⁴⁶ a cultural history of dying, Philippe Ariès speaks of our current approach to death as invisible. By that he means we cope with death by splitting the undeniable fact of extinction (which occurs to a dehumanized object behind closed doors) from its personal impact on our lives and that we attempt to blunt its effects or avoid it in various ways (e.g., not talking about it and isolating the dying person from the emotional community). Ariès writes, “A heavy silence has fallen over the subject of death. When this silence is broken . . . it is to reduce death to the insignificance of an ordinary event that is mentioned with feigned indifference.”⁴⁶

Hospice insists, at least, that the silence be broken. Above that, hospice

fosters a relational model of dignity in which all parties meet with mutual respect and mutual responsibilities. Most barriers to good end-of-life care arise from the “heavy silence” that doctors and patients alike have internalized. Usually, as with Mrs. Evans, this silence is unrecognized because everyone—doctors, patients, and family—fill it with a topics that miss the point. This talk is well-intended obfuscation rather than genuine conversation. As with Joyce Evans, suffering goes on behind closed doors—behind a façade of frenetic activity. When a weakened voice does speak up to affirm dignity, the militant structures of medical care deflect the voice by countering it with options, delays, and the subtle suggestion that one can only die responsibly by refusing to give in.

Conclusion

The case of Joyce Evans exemplifies a common problem in American end-of-life care. On the surface, it appeared as if she was fully informed and had control of the situation. The processes of informed consent ensured her dignity as a rational decision maker. Nonetheless, she and her family claimed that she died without dignity because her healthcare professionals didn’t respect or pay attention to her. From the dignity as choice perspective, she was clearly complicit, because her choices continually undermined her avowed goals.

At a deeper level, Mrs. Evans was a victim of the “deep silence” surrounding the reality of death. This silence created a wide gap between the perceived and actual outcomes of medical intervention and, in all likelihood, facilitated the patient’s inability to achieve a dignified and meaningful death. Her world was characterized by dysfunctional communication, loneliness, and perhaps a loss of meaning. I imagine her last few months as being a conveyor belt whisking her along in the wrong direction, but she didn’t

know how to stop it. Unfortunately, her doctors and family didn't know how to stop it either. Better communication, as well as specific palliative care education, might have helped her doctors toss a wrench into the machine, allowing it to stop long enough for a more thoughtful plan to be developed.^{47,48} Had they acted on an understanding of human dignity as grounded in relationship and narrative, as opposed to isolated self-determination, perhaps they would have spent less effort on physical interventions and devoted more energy to assisting their patient to achieve her existential goals.

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