
Struggle

by Patrick Miller

Providing quality care for seriously ill and dying patients presents personal challenges to health care professionals, summoning them to exercise moral sensitivity, empathy, and compassion.

Recent research regarding care of seriously ill and dying patients indicates that these challenges have not been met (The SUPPORT Principal Investigators 1995). Efforts to change physician behavior by developing the virtues needed to speak forthrightly and compassionately with patients and families about death abound (Solomon 1995). But perhaps the focus here should be on personal, rather than professional, development. Is this, perhaps, a human issue first, and a professional issue second? The virtues in question — empathy, morality, humility, courage, emotional stamina — are shared among all persons, regardless of social or professional standing.

As a young physician, recently out of residency and early in my career as a primary care physician, I am acutely aware of professional development. While my experience grows in caring for seriously ill and dying patients, I am also aware of personal challenges in providing this care — in being compassionate, empathetic, and morally courageous. The struggle to determine “when to say when,” or whether to present a case as having a twenty-five percent chance of success or a seventy-five percent chance of failure, or determining a patient’s goals and values is, I suspect, one shared by most health care professionals. Although providing medical care to seriously ill and dying patients may be a duty unique to health care professionals, the struggles to be compassionate, empathetic, and morally courageous are uni-

versal. An awareness of the elements of these struggles will hopefully lead both to successful ones and to less apprehension in entering into such a struggle.

The following case demonstrates issues with which I’ve struggled in my practice and helps illustrate how personal behavior is at the root of change in caring for the seriously ill and dying.

The Case of C.S.

I began caring for C.S., an eighty-six-year-old woman, when she was admitted to the hospital suffering from shortness of breath. A slight and frail woman, C.S. weighed eighty pounds, only a few pounds less than her normal weight. Examination and testing revealed severe emphysema as well as moderate heart failure. Following a brief hospital stay, she went to a nursing home to regain strength before returning home.

C.S. lived alone in a small home that she had owned for over forty years. She was widowed for seventeen years and had no children or siblings. Her neighbor, Dorothy, who brought her to the hospital, had been managing her finances, as well as buying groceries and taking C.S. to get her hair done. C.S. had done part-time seamstress work but now most of her days were spent worrying and tending to her dog, Lucy. She was consciously aware that her memory was failing, which further exacerbated her

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underlying anxiety. "Doctor, why am I sick?" "I don't know why I'm so sick." "How long have I been sick?" were typical exchanges at the hospital. Although she had poor concentration and poor short- and long-term memory, she was consistent and clear on her desires to make her own decisions and remain independent. When our relationship began, C.S. had capacity to make informed treatment or nontreatment decisions. She indicated to me that a niece in South Carolina was to make decisions for her if so needed.

With care from home health nurses and neighbors, C.S. was able to remain home. However, her failing heart and lungs caused progressive weakness and, despite treatment for depression and anxiety, her cognitive functions declined as well. Several months later she developed a lung infection, which cleared after a second hospitalization. However, because of her deteriorating mental capacity and the progression of her disease, she could no longer return home and live independently.

In addition, her capacity to make treatment decisions had deteriorated such that her niece increasingly was involved in decisions pertaining to C.S.'s living arrangements. Although no formal advance treatment directive document was completed when she had decisional capacity, we did discuss treatment preferences that would apply if and when she lost capacity to make treatment decisions. She did not want life-prolonging or life-sustaining treatments if she could not interact meaningfully with family and friends, or if she could not do for herself. Unfortunately, I did not clarify these general statements, which, in retrospect, could have been done with a few, meaningful questions, for example, "What do you think makes an interaction meaningful?" and "What exactly must you be able to do for yourself and why?"

Surprisingly, C. S. adapted fairly well to her

new surroundings in the nursing home. When I visited her, she recognized me as her doctor, although she no longer called me by name. She showed me around the home but needed help in finding her room again. She still talked of returning home eventually and expressed concern about her dog, who had been adopted by a neighbor. Although she clearly would not be able to return home or regain her desired independence, I admitted her to the hospital for a recurrent lung infection. The antibiotics worked but her cognition suffered because of the change in surrounding. Upon returning to the nursing home, her lucid days were increasingly rare and when, predictably, the infection reoccurred, her niece and I agreed that continuing comfort care with oxygen and morphine in the nursing home versus another hospitalization would be what C.S. would want.

The Denial of Death

The notion of "death as the enemy" manifests itself in the health care profession as we struggle to battle disease and "never say die." Daniel Callahan characterizes this philosophy as a combination of the sanctity of life and scientific progress (Callahan 1993). He continues:

We thereby laid upon ourselves an excessive weight of moral obligation, daily visible in the hesitation and often guilt felt by doctors and families in terminating treatment with the critically ill and dying.

Society is aware of this struggle by providers. The denial of death, along with advancing medical technology, has fueled the patient' rights movement, informed consent, advance treatment directives, as well as the physician-assisted suicide movement. Although this struggle complicates end-of-life decision making for physicians, it is not the physician alone who battles or denies death. Both the health care culture and the broader culture in which we exist must accept death as a limit that cannot be overcome. An individual practitioner may come to accept death as an inevitable

event, but practicing this acceptance in a culture still in denial can be daunting.

I did not struggle in accepting the inevitability of C.S.'s death over the nine months that I cared for her in her dying, even though the scientist in me recalled the early successes of antibiotics.

Their raised eyebrows asked why I wasn't utilizing medical progress to honor the "sanctity of life." Their raised eyebrows also indicated the need for introspection regarding our denial of death.

However, I did struggle with the lack of acceptance by the nursing home staff when I informed them of the decision to keep her there to die. Their raised eyebrows asked why I wasn't utilizing medical progress to honor the "sanctity of life." Their raised eyebrows also indicated the need for introspection regarding our denial of death.

Doing the Right Thing

As I cared for C.S., I constantly struggled to "do the right thing" by initiating treatments that she would have wanted and considered beneficial. In that alone lies a struggle. As Howard Brody points out, "We have an excellent sense of what the physician is not supposed to do in the process of helping the patient but virtually no sense of what he is supposed to do (Brody 1992). When I presented C.S.'s niece with options, how influential should I have been, in this case in the absence of a clear advance directive? The changing patient-physician relationship affects all areas of health care, but with end-of-life decisions this sharing of power is more closely scrutinized.

This struggle to determine "the right thing to do" is what ethics is about. However, in searching for the right thing to do, one needs to

acknowledge the distinction between doing a right thing and doing the right thing. The sense that there is one right and one wrong can belittle the complexities of ethical discourse. An argument could have been made to treat C.S. with supportive care only without that last hospitalization. She had told me that she wanted to be independent and make her own decisions, but she could no longer do this. Would it not have been more consistent with her wishes to provide oxygen and morphine the first time? But she was doing so well in the nursing home! In retrospect, one decision may have been more right than the other, but perhaps neither was wrong.

The Certainty of Uncertainty

Death is clearly the most certain thing in life. In our control-oriented society, the tendency is to strive for certainty in clinical decisions, especially those regarding life or death. Yet, as Eric Beresford explains, "(Uncertainty) is endemic to clinical practice not merely because there is too little information available to the physician or because the available information is inadequately understood, but because of the very nature of the decisions that characterize the practice of medicine" (Beresford 1991). We are struggling, then, for a certainty that can never be achieved. As complex new technologies are developed, the appropriate use of these same technologies becomes less and less clear.

Beresford categorizes this conflict as "technological uncertainty." He then goes on to describe two other types of uncertainty, personal and conceptual. The personal is that which is rooted in the patient-physician relationship. Even with some indication of a patient's goals and values, there remains some uncertainty as to the applicability to a particular clinical circumstance. When a surrogate decision maker is involved, for example, are they truly acting in the patient's best interest? And what effect does attachment between patient and physician have regarding decision making?

In reflecting on conceptual uncertainty, Beresford describes the difficulty in applying

general criteria to specific situations and the problem of incommensurability. Since no two cases are exactly alike and cases rarely present as textbook cases, health care professionals must exercise judgment: “. . . uncertainty is an unavoidable constituent of the particular and context-specific decisions physicians are required to make” (Beresford 1991).

The main technological uncertainty in the case of C.S. was the issue of her rapid decline in cognitive function. Thorough investigation revealed no objective findings and treatment for depression resulted in negligible improvement. Of the few patients who receive some benefit from the drugs used in dementia, might C.S. have been one of them? Are there new drugs or combinations of drugs that are being used that I don't know about? What caused her dementia? In this case, conceptual uncertainty is exemplified by the inability to apply generally accepted standards of therapy or to apply past experiences to a unique and particular case. There will never be guidelines to treat eighty-six-year-old women who weigh eighty pounds, have rapidly progressive dementia, moderate heart failure, severe emphysema, and who own dogs named Lucy.

Compassion

When death is no longer the enemy, when patients and physicians comfortably share power, when the process for doing the right thing is better appreciated, and when uncertainty in medical decision making is accepted, the most deeply personal struggle in providing care for seriously ill and dying patients will remain. Paul Ramsey wrote:

The humanity of such human caring is apt to be more sensitive and mature if we do not lightly suppose that it is an easy thing to convey dignity to the dying” (Ramsey 1975).

And Brody addresses the physician more directly:

To be compassionate in response to the suffering of the patients is therefore one of the most powerful things a physician can do;

but this is possible only to the extent that the physician is willing to adopt a position of relative powerlessness, to acknowledge that the patient's suffering has incredible power over him and that he cannot remain unchanged in the face of it (Brody 1992).

This struggle is shared by all of us; compassion, life, death, and suffering are virtues, events, and emotions that are not unique to the health care profession. Physicians who provide care to dying patients are in unique surroundings however, as their compassion is placed in the context of a dual sense of power and humility (Brody 1992).

Although compassionate care is not exclusive to the care of seriously ill and dying patients, it is of increased importance for such patients. And as its importance increases, so, too, does the feeling of humility or powerlessness in the heart of the physician. When I gave C.S. morphine and oxygen for her shortness of breath and medications for anxiety, I felt I was practicing what little power I had while struggling to accept the powerlessness that peaked as this natural process of dying concluded.

Acceptance

The struggles I have expressed through my care of C.S. exemplify those that build barriers in diagnosing a patient as dying. Problems in making this diagnosis, however, are not the only inadequacies in providing good care to seriously ill and dying patients. For those patients who are identified as dying we have seen that wishes are frequently not honored, pain is inadequately controlled, and psychospiritual needs are not addressed (SUPPORT investigators 1995).

Solutions for improving the ability to diagnose dying and for improving care of the patient's diagnosis have much in common, for example, improving patient/physician communication and increasing the attention paid to a patient's right to self-determination.

Callahan has suggested eliminating this distinction altogether by viewing death as “the nec-

essary and inevitable end point of medical care" (Callahan 1993), while admitting that such a change would take generations to occur.

My struggles in caring for C.S. at the end of her life involved dealing with death as the enemy, doing the right thing, uncertainty in medical decisions, and being compassionate. In some way, I struggled in each of these areas. However, I did not struggle *successfully* in one very profound way in C.S.'s case: I did not share with her that she was dying.

The distinction has been made between making the diagnosis of death and caring for the patient once diagnosed. One very clear component of this care for dying patients is sharing with them that they are, in fact, dying. Some would argue that a patient cannot be treated as a dying patient unless they share in this awareness. Somewhere between C.S.'s initial hospitalization and her death at the nursing home, I realized that her chances of living more than six to twelve months were very low. But I did not share this realization with her, and for that I have regrets. Although I honored her wishes, discussed with her at least some of her goals and values, and provided good comfort care, I now wonder what she missed in experiencing her own dying process. And further reflection causes me to wonder if I really am unable to accept death and, consequently, was not able to share C.S.'s dying with her. Doesn't being compassionate entail open communication and dialogue between doctor and patient?

I have suggested that an awareness of the components in a struggle can lead to a successful one and to less apprehension in entering into such a struggle. Now I also add that understanding such struggles can lead to moral reflection on past struggles poorly done. As the goal of change is my behavior, I believe that empathy, compassion, and moral sensitivity might enhance the often painful process of moral reflection.

As we struggle to improve care of dying patients, each struggle can be addressed in slightly different ways. The denial of death is not isolated to the medical profession and, although change

in the health care culture can conceivably catalyze change in our society, I do not think directing change at individual providers without concomitant change in society will be of benefit. More directed, individual efforts aimed at promoting the acceptance of uncertainty as an inherent component of medical decision making will assist in positive change.

There is irony in writing about a provider's struggle when the struggle of patients dying in our country is at the heart of this issue. The supreme injustice is that we in the health care profession have not struggled enough with the struggles of our patients. Solutions to the struggles of both patients and professionals — struggles of *persons* — have common features. While enhancing a provider's sensitivity, empathy, compassion, and ability to participate in and guide moral choices should improve care of the seriously ill and dying, the methodologies of "behavioral enhancement" will likely benefit from attention to these same virtues.

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