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## Voices Yet Unheard

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The voice of the person facing the end of his life sometimes seems to be lost in the current dialogue about improving end-of-life care. This essay addresses clinicians' fears about direct, open communication with the seriously ill patient about death and proposes a lens for viewing the end of life that honors the life still left to live.

Our death-averse culture places the dying individual in the unenviable position of having to find a way to face his end and live each day until death amidst a health care system that is structured to cure him and, perhaps only at the very end, to care comprehensively for his nonphysiologic needs. None of us wants to die—consider the words of Dylan Thomas,<sup>1</sup>

*"Do not go gentle into that good night,  
Old age should burn and rave at close of day;  
Rage, rage against the dying of the light."*

As clinicians caring for persons facing death and their families, we witness their courageous struggle to "beat" the disease that is chipping away at their strength and often we, like their loved ones, implore them to keep the faith, to continue the battle, to rage against the illness that threatens to steal their lives. We struggle with finding the right words to maintain the tenuous balance of truthfulness and hopefulness, fearing that honesty about disease progression and the limitations of medicine and science might launch them into hopeless despair. Our fears about communicating with the dying person may remain cloaked by our puzzlement or conviction about when is the right time to honestly disclose and when should we hedge.

In 1965, sociologists Glaser and Strauss<sup>2</sup> published findings from their extensive qualitative study of how death was managed in the acute care setting. Through interviews and participant observation with patients, their families, physicians, and nurses in the hospital setting, the authors discovered four distinct "awareness contexts," which they defined as each party's awareness of the patient's status and their recognition of the other's awareness. Their research revealed that patients and those around them engaged in complex maneuvers to avoid direct disclosure about a cancer diagnosis. Because clinicians feared and were uncomfortable discussing death, they developed and substituted "personal mythologies" for appraisals of what patients actually wanted or needed. For example, clinicians avoided direct disclosure about the seriousness of illness based on beliefs that the patient would lose hope, give up or be psychologically harmed; that the patient would ask if he really wanted to know more; or that there was no need for discussion, as the patient probably knew already.

When Glaser and Strauss completed their research, it was common for disclosure of the cancer

diagnosis to be withheld from patients for fear that they would lose all hope. Glaser and Strauss found that clinicians often engaged in elaborate "mutual pretense" with patients to avoid confronting the certainty of the patient's death and maneuvered the communication in hopes that patients would "discover" the truth. They described "a systematic tendency among health care professionals in hospital settings to avoid direct communication about dying in hope that the patient would discover it on his own."<sup>2</sup>

Clinicians' reluctance to discuss disease and death openly with patients may be due as much to their own anxieties about death as it is related to misconceptions about what patients want to know and talk about. The awareness of the dying theoretical framework discovered by Glaser and Strauss continues to be relevant to the cancer patient's experience, despite the fact that the work was completed more than 35 years ago. They correctly predicted that dying at a place other than home from the end stage of a chronic illness would become more common in the ensuing decades, making the problem of awareness even more important. Thirty-five years after the Glaser-Strauss study, Stanley<sup>1</sup> observed the continuing existence of a "conspiracy of silence" about dying.

Health care providers often cite concerns about threatening the patient's ability to cope if they were to fully disclose information about the diagnosis and prognosis<sup>4</sup>. Yet recent studies of patients with advanced cancer, AIDS, and other life-threatening illnesses demonstrate their desires for information and capacities for maintaining hope and transcending the experience of life-threatening illness, even when the expected outcome is certain death.<sup>5,6,7</sup> In this author's qualitative study of treatment experience and patients' decisions to enroll in a hospice program, the respondents related examples of how grateful they were to have the opportunity to engage in important work before death, and how they had negotiated a complex path of emotion, fear, and grief to arrive at these new understandings.<sup>7</sup> In the words of one participant,

*"If I were going to write a book, I'd have to call it 'I'm terminally ill and I'm having a better day than you are'".*

Kübler-Ross maintained that hope persisted across every stage of terminal illness, noting that "even the most accepting, the most realistic patients left the possibility open for some cure, for the discovery of a new drug, or the 'last minute success in a research project.'" <sup>8</sup> Likewise, Frankl<sup>9</sup> described the human capacity for optimism that can be maintained in spite of the possibility or even certainty of pain and death. Although useful to an understanding of one facet of hope in the terminally ill, these conceptions of hope focus on the finality of death and seem to diminish the resilience of the terminally ill patient who reconceptualizes hope repeatedly as he approaches the end of life, often finding new ways to live comfortably in the space allotted him.

Hope has been linked to the concept of transcendence. Researchers have illuminated how patients with life-threatening illness transcend the self.<sup>5,6</sup> Patients with cancer in one study found meaning in the experience, enhanced self-esteem, and maintained control over their lives by helping others, accepting help, experiencing pleasure from their environment, and reminiscing.<sup>6</sup> Themes of self-transcendence in a study of gay men with AIDS included similar "give and take" conceptualizations, where the men found meaning by connecting with others and accepting help.<sup>5</sup> In addition, the men found meaning through creating a legacy, letting go of meaningless activities, and living in the present. Decreased distress from the illness and an increased sense of well-being were associated with self-transcendent behaviors.<sup>5,6</sup> Coward<sup>6</sup> concluded that the process of achieving self-transcendence varied according to illness, age, and gender, and that humans find diverse ways of realizing meaning in their lives.

Similarly, participants in this author's study of decisions to enroll in hospice care used the opportunity of foreknowledge of their death to resolve relationships, create legacies, and find a new balance in their lives.<sup>7</sup> One participant related that he was grateful to have time to plan for

the remainder of his life (and his death) and shared a long and poignant letter he was writing to his young son. Another talked about how she was easing her adult children into taking more responsibility for the tasks she used to complete, and was using her time to complete the work that was most important to her, organizing the many family photo albums. She said,

*". . . to me they mean a lot. I thought it (the legacy) might be . . . larger, the house, the car, you know, and it's not, it comes down to photo albums."*

The notion that the end of life offers opportunities for growth and closure is the basis for the hospice movement and a theme in recent literature concerning the end of life. In his book, *The Rights of the Dying*, author David Kessler relates his discussion with the late Mother Teresa, who told him, "a life is an achievement...and dying, the end of that achievement."<sup>10</sup>

How might end-of-life care look different if we were to view the end of life as a time of reflection, achievement, and continued opportunity? First, we might turn our concern to how the patient's opportunities for growth will be limited by our failure to disclose and dialogue instead of fearing the consequences of revealing too much. This perspective could help to answer the question of when we honestly disclose and when we should hedge, allowing us to be more fully present in our own lives as we listen to our patients, learning from them what they want to hear and when they want to hear it.

Next, we could separate the construct of hope from cure, so that the latter is not a necessary condition for the former. Further, we might broaden our notions of healing, so that when patients' underlying disease cannot be reversed nor the status quo maintained, we could offer our wide array of symptom management, psychosocial and spiritual interventions as critical and worthy tools at any stage of the disease. Perhaps we could look to our interdisciplinary colleagues for help when we feel most helpless, recognizing that medicine has limitations, and that some symptoms respond better to nonmedical approaches. We could then become less preoccupied with determining the boundaries of "terminal" illness, and instead focus our energies on assuring that patients receive the help and support they need at any stage of illness.

Finally, we could tear down the artificial wall that separates the "living" from the "dying"—*them* from *us*. The simple acts of being fully present to those in our care—focusing on their faces, ignoring other distractions, offering a gentle touch, and listening deeply—can do much to ease the sense of isolation experienced by the dying. Asking the question, "*Tell me what is most important to you now,*" and then giving them time to respond affirms our commitment to their journey and our respect for their wisdom. If we could view our patients as living until the moment of death, as they wish we would, then we would see them as not so very different from ourselves. As one participant in this author's study related just a few weeks prior to his death,

*"You know, it's just a curiosity . . . why so many good things are happening; so many positive things to just a normal person . . . there is no answer . . . bad days will be here. Good days will be back. But I'm still here and I'm alive."*<sup>7</sup>

It is difficult for any of us to imagine the circumstances of a terminal illness of our own, and perhaps even more difficult to imagine finding a way to live each day fully in the face of impending loss. Perhaps the greatest barrier to improving end-of-life care is our inability to embrace the reality that we too will face the end of our lives. Yet if we became less fearful, we might be less determined to fix, more willing to listen to our patients, and more comfortable with their grief, silence, anger, sadness, and fear. And each step of the way, we could companion our patients so that they are not alone as they face the grief, sadness, and fear that accompanies life's final transition. Then as each other's guides, we could lean into the pain and suffering, not away, helping them to find a way across or through to a place where they could reflect on lives that have been a triumph and legacies that will live on.

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## Notes

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