

Exploring Human Suffering: Why the Reluctance?

by Timothy E. Quill

For many reasons health care professionals, patients, their families and society are often challenged by suffering. This essay suggests why clinicians, in particular, are unwilling to journey into suffering with their patients and proposes how they might overcome these barriers.

Medical clinicians seem reluctant to explore their patients' suffering with the same intensity and caring that they apply to their patients' underlying biological problems. In this essay, I speculate about reasons for this reluctance beginning with a story of extreme suffering told to me by a long-time patient.

Bill¹

Bill was a physically fit, energetic man in his mid-seventies who still worked part-time when he wasn't playing tennis or golf. He lived life fully and was a joy to be with because of his thoughtfulness, sensitivity and wit. His first encounter with serious illness came when he suddenly lost the vision in the center of both his eyes from a disease called macular degeneration. He became legally blind and was unable to read, drive, or enjoy sports that required fine hand-eye coordination. Though he was devastated by this loss, he began to adjust and develop new skills to get around his deficit.

Several months later Bill was found to have cancer in his throat. Because the cancer had already spread to the lymph glands in his neck, Bill was not a candidate for operative treatment. Instead, he was offered radiation treatment which he was told had a good chance of controlling the disease. To take advantage of this chance, he would have to tolerate a sore mouth, difficulty swallowing, and perhaps temporary hearing trouble. With little hesitation or questioning, he began radiation treatment.

The reality of the radiation treatment was unfortunately harder than he imagined. He permanently lost most of his hearing and could not swallow any solid foods. Though the tumor shrank, the hearing loss and the inability to eat solid foods persisted. He adjusted as well as he could to these severe losses, though his energy and joy of life never fully returned.

Over the subsequent eighteen months, Bill lost weight, had constant headaches and walking short distances left him exhausted. His cancer began to grow rapidly making it difficult to swallow liquids. It had also spread to his sinuses and his brain. Large amounts of

drainage from his nose forced him to wear a pad under it to keep himself dry. Bill found the drainage from his nose and mouth to be humiliating, a constant reminder of his physical degradation. This once active, joyful, proud man was now legally blind and severely hearing impaired. Copious quantities of mucous drained constantly from his nose, and he was unable to swallow most of his own secretions. After two years of progressive loss and misery, it would only get worse.

A long-time patient of mine, who was a retired nurse and a former hospice worker as well as a Hemlock Society member, was also a close friend of Bill and his wife. As a friend of the family with special knowledge and experience, she was called on for advice because of Bill's rapidly deteriorating condition. Bill's wife confided, with tears streaming down her face, that he was now thinking about committing suicide. When asked, the friend agreed to talk to Bill. His first words were, "I suppose you're going to try to talk me out of it, too." When she said no, Bill spoke openly of his anguish and helplessness, and about how he was comforted only by the release that would come with death. He now dreaded the process of dying much more than death itself, and he could no longer stand the indignity of living. He talked at length about his love for his wife and of the unbearable frustration of being a burden for so long.

After several daily visits with Bill and his wife, there was no doubt in my patient's mind that Bill would take his life with or without anyone's approval. He never faltered in his belief that it was his only realistic option. Bill's wife gradually came to accept his decision, though she felt overwhelmed by both his dying and by his continued living under current circumstances. When they began to discuss methods, Bill brought out a shotgun and discussed how he intended to use it. They also explored using an overdose of medications as recommended

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by the Hemlock Society. Bill had enough potentially lethal medication for the suicide provided he could swallow it all, and provided that someone would assist with the plastic bag if the overdose was insufficient (this is a backup measure of a Hemlock Society suicide described in their literature). My patient's understanding and compassion for Bill now superseded her concern about her own legal liability if her role in his suicide were discovered. She was committed to being with Bill and his wife until the end, no matter where it took them.

Bill intended to take the overdose on his own the next day. If necessary, my patient would assist with the plastic bag. Plans were made for notifying the authorities

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and deciding what to report. Once Bill was dead, they would remove the bag and call the doctor to report that Bill was found dead of "natural" causes. My patient went home that night not sure what the next day would bring, but certain that Bill believed that death was his best choice.

When my patient returned the next day, Bill told her that after deliberating all night, he had decided not to involve her in his death. He was worried about the legal vulnerability that she and his wife might incur if their assistance in his death were discovered. Despite my patient's protestations that she was willing to take this risk, he would not change his mind. "I love you too much to risk your future." After a long conversation, Bill excused himself to go to the bathroom. Within minutes there was a loud gunshot. Bill's wife and my patient ran to the bathroom where they found Bill gruesomely wounded in the head, half-dead and half-alive.

An ambulance and the police arrived and rushed Bill to the hospital. His wife was numb, unable to think clearly or speak. My patient, powerless and overwhelmed, remained at the house with Bill's wife. After Bill was evaluated and resuscitated in the emergency department, a physician called the home to inform the family that they might not be able to save him. Bill's wife said, "Please don't try. He's suffered enough." The physician agreed, promising to give Bill something for his pain and to keep him comfortable.

Bill died three hours later.

Bill's wife probably will never recover, or forgive herself.

My patient will never forget and is more frightened than ever about the potential of unremitting end-of-life suffering.

This is a sobering tale. When disintegration and humiliation occur prior to death, especially when we cannot avoid or ameliorate it, we are challenged as persons, professionals and as a society to find a better way.

Three myths unfolded in Bill's story that confound clinicians' approaches to human suffering, and our willingness to explore it openly.

Myth 1. *If I live healthily and use medicine judiciously, I will not be sick (will not die).* Death and severe illness are blamed on the doctor (should have been picked up earlier or treated more effectively) or on the patient (should have lived a healthier lifestyle). Bill lived life fully and took excellent care of himself. He also received the best medical care, yet still found himself dying in pieces from the relentless progression of his illness. He also experienced statistically improbable, but devastating, complications of his treatment through no fault of himself or his doctor.

Myth 2. *If doctors use hospice care more effectively, particularly when treating physical pain and depression, intolerable suffering prior to death can always be avoided.* Though doctors must learn how to use pain relieving techniques more effectively and to address psychiatric co-morbidity, the notion that Bill's dilemma would have been made tolerable with a better doctor or more hospice care is highly unlikely. Bill had no physical pain, but he had other physical symptoms that in aggregate were largely untreatable. To imply that hospice has all the solutions to such overwhelming and degrading physical losses, to say nothing of associated existential or spiritual losses, is naive and dishonest, and disavows the depth of despair and violence to which some suffering persons are subjected. Bill clearly would have benefited from an open discussion of his wish to die with his doctor,² though it is unlikely that his wish and resolve would have weakened with this exploration.

Myth 3. *I don't have time to explore these issues.* This is a false issue reflective of the simplistic belief that the doctor's only important job is to cure or fight for life. Most clinicians have little difficulty finding the time and energy for other "death defying" medical acts, even when the odds of success are small and complex psychosocial issues are raised. Yet fully exploring a dying patient's suffering, to lessen the aloneness that accompanies it or to see if it can be ameliorated in any way, is approached

with less enthusiasm and energy. Though there is substantially less reimbursement for such discussions and interventions when compared to acute care, I don't think this is the central factor.

Other Sources of Reluctance

1. *Exploring the suffering of a fellow human being can be frightening and painful for patients, families and clinicians.* The hesitation on the part of families and clinicians may be a variation of "There, but for the grace of God, go I." It is especially difficult for those who have had little personal experience with suffering, or who have had extensive personal experiences that have been unexplored or traumatic. For some, exploring another's suffering may cause a confrontation with mortality for the first time. For others, this reflection may shake faith in an all-powerful, beneficent God. For still others, it may be the first awakening of medicine's potential to cause serious harm as well as to heal. Witnessing true disintegration or humiliation of a dying person is fundamentally disturbing and may permanently change the world view of the witnesses.

Patients struggle with many of these same issues. Sometimes talking about death or unrelieved suffering makes it more real to the patient and may undermine denial which can be an effective coping mechanism. Others who are aware of the problem may be reluctant to burden, frighten or disappoint the clinician or the family whom they feel obligated to protect.

Exposure to the suffering of human beings is very difficult, but it is also humanizing for witnesses, provided they have the opportunity to share their perceptions and reactions with others. Without such processing, these experiences may be frightening and result in a withdrawal from the suffering person. In hospital-based medical training, severe patient suffering is palpably present, yet largely unacknowledged. The covert message is clear: the fight for life against all odds is more central to the role of the clinician than a compassionate, creative approach to suffering.

2. *Traditional medical teaching leaves learners with the impression that if they hear about a problem, they must fix it.* Medical clinicians are "fixers" by temperament, and this tendency is encouraged in training. We are exposed to a narrow view of healing that emphasizes intervention and curing, and de-emphasizes the importance of acknowledging and exploring suffering, or of being a witness, fellow traveler and friend. Similarly, we are trained to treat diseases much more thoroughly than we are prepared to take a comprehensive approach to suffering. Cli-

nicians show a reluctance to explore other aspects of the human condition that are associated with strong feelings and severe suffering, but are not easily fixable (family violence, sexual abuse, alcoholism, depression). Some of the reluctance to look into suffering stems from the same pitfall: "I am not sure what to do with it once it is uncovered."

3. *There is a large gap between idealized medical ethics and clinical reality.*³ The feelings and reactions of clinicians are not usually acknowledged in the idealized discourse of medical ethics. Physicians are routinely chastised for undertreating physical pain in persons who are dying, yet if they even remotely acknowledge purposefully helping a person die, they are admonished for having crossed a line between healing and killing. Medical ethicists and philosophers often prefer to avoid the complex, messy realities faced by suffering human beings and their families and doctors, remaining instead in the ab-

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stract world of theoretical dilemmas and artificially created patient scenarios. Solving isolated, ethically complex situations does not always prepare one for the continuous series of ethical challenges posed by dying patients in the future.

4. *Many clinicians fear being asked to assist severely ill, suffering patients whom they care about to die.* It is certainly safer not to care and not to hear about the suffering. Imagine yourself being Bill's "ideal" doctor, a skilled clinician who also cares deeply about him as a person. Imagine further having witnessed and participated indirectly in Bill's gradual disintegration. You have experienced and empathized with Bill's loss of most of what had meaning for him, and understand his despair as he waits for the next humiliation, knowing that death will provide his only relief.

If you are confused about your responsibility, you are not alone. Most ethicists and clinicians would agree that openly exploring his suffering and his request is imperative, for it will lessen isolation and may lead to alternatives that don't involve assisting death. But if there are no alternatives, what are the physician's responsibilities? There are at

least two levels to consider. The first is personal: is it morally acceptable, given one's own values and beliefs, to assist a patient in this way? If not, then the clinician must explain his or her beliefs and values and continue to search for mutually acceptable alternatives. If the clinician's beliefs support assisting a patient to die, then he or she must consider

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the ambiguous legal environment within which such activities are considered. Generally assisted suicide is not legal and is against many codes of professional ethics, yet it is also tolerated and condoned provided it is carried out with compassionate intent and kept secret.

In the midst of this ethical and legal conundrum, doctors and family members must respond one way or the other. When one has been a caring witness the decision is emotionally wrenching no matter which way it goes. Ideally physicians could discuss specific cases with trusted colleagues, so they are not acting alone. Unfortunately such consultations are rare in our current legal environment. Because intense involvement with patients entails both personal (fear, grieving) and professional (legal prosecution, professional second-guessing) risks, it is not surprising that many clinicians avoid the issue by not hearing about the suffering and not caring personally about their patients. In doing so, they miss out on the potential of a rich experience: the opportunity to form a helping relationship with a fellow human who is suffering.

Recommendations

The following are recommendations to help physicians deal more effectively with patient suffering:

1. Clinicians must become students of the human condition as well as treaters of disease. Beginning in medical school, they must be exposed to patients in all phases of the life cycle, following individual persons through the latter phases of treatment, through failed treatment, and through the anticipation of death and bereavement.
2. There must be an environment in which students, residents and practicing clinicians can safely and nonjudgmentally explore the suffering they are witnessing. Physicians' responses to their own suffering must be examined if they are to address the suffering of others.
3. Clinicians must be taught to explore suffering and requests for assisted dying, even if they cannot fix the problem or accede to the request. The healing potential of a witness, the potential to alleviate or lessen aloneness, and the possibility of uncovering avenues of response other than assisted death are compelling reasons to encourage this exploration.
4. Clinicians must try to bridge the gaps between idealized ethics, unclear laws and complex clinical realities. In the current environment, the safest course for the clinician is to avoid the patient's suffering and continue a blind fight for life, treating diseases rather than patients. Ironically, exploring and understanding the realities of suffering faced by patients may hold the key to humanizing all three domains.

References

1. This story was initially presented in Timothy E. Quill, *Death & Dignity: Making Choices and Taking Charge* (New York: W.W. Norton, 1993): 117-120.
2. Timothy E. Quill, "Doctor, I Want to Die. Will You Help Me?" *JAMA* 270 (1993): 870-873.
3. Timothy E. Quill, "The Ambiguity of Clinical Intentions," *NEJM* 329:14 (September 1993): 1039-1040.