1991

To Care for the Dying

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In 1990, three events hit the media with gale force, causing a flurry of analysis and commentary. Most recently, while many of us celebrated and feasted during Christmas holidays, Nancy Cruzan starved to death in a Missouri hospital. Her parents had attended her comatose body for seven years and now, after years of battling, were permitted by that state's Supreme Court to remove the feeding tubes that sustained it. Six months earlier, Janet Adkins died from a dose of poison injected into her body by Dr. Jack Kevorkian's "suicide machine." Having been diagnosed with Alzheimer's disease, she chose to terminate her life in her mid-fifties rather than to face an increasingly debilitated existence. And in the spring, Mary Ayala, a woman in her forties, gave birth to a baby daughter conceived for the express purpose of creating a compatible bone-marrow donor for her seventeen-year-old leukemia-stricken daughter, Anissa.

In each case, these events prompted my family, friends, and acquaintances to ask me, "What do *you* think?" In other instances, such as when gene therapy proved to have positive effects on reducing cholesterol in rabbits or when it was revealed that much of medical research has been biased toward the male population in this country, however, I was not similarly barraged with questions nor was the media response as prolific. These latter events did not elicit the same degree of concern or response either within my immediate community or among the public.

This differential in response stems from two characteristics shared by the former situations but not the latter. These characteristics contribute to their classification as the classic, gripping, poignant, heart-wrenching, tragic dilemmas of medical ethics. First, these events capture our fears, imaginations, and discourse because they come to us in narrative form, as stories of real people negotiating life. They rivet our attention primarily because their mode of presentation enables us to identify with—to put ourselves in the place of—the characters: the mother, the spouse, the daughter, the physician, or the patient. We instinctively want to champion their cause, vicariously championing our own.

This story-form shapes us: it offers us opportunities to learn about ourselves as we examine potential courses of action in vicariously enacting hypothetical scenarios; it introduces us to events and actors in our world of which we might not have first-hand experience; it displays to us the battles we may be asked to face and the weapons available for that fight. Moreover, these stories do not merely describe our world but, more importantly, they embody claims about who we are, who we ought to be, and how we ought to live. They often construe the actors and events in specific relationships in order to end the story with a

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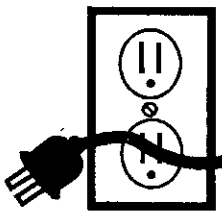


moral or lesson—for example, the right to reproductive choice or the right to die. They reflect certain ideas of what it means to be human—to be autonomous and independent, to stand alone against the world, to possess certain rights such as the right to die. They suggest also that the possessors of these characteristics will live their lives in certain ways—by making one's own choices, by determining one's own future, or by drawing up living wills to protect oneself from technology or from the system.

It is not only their storied form that enables these events to grip our imaginations so powerfully. Although each situation raises different sets of questions and issues, the impact of these stories draws from a common theme: suffering. In each case, the undeserved suffering of a central innocent character is cited to justify the actions taken—the suffering of Nancy's family; how Nancy would suffer if she knew her condition; the suffering entailed by loss of faculties for Janet; the suffering of Mary's daughter.

As a society, we are uncomfortable with suffering and pain. We strive to avoid it in our own experience, and we do not know how to deal with the sufferings of others. We do not tolerate those who manifest imperfections—the aged, the disabled, the retarded, the terminally ill; worse, we often isolate and relegate them to the margins of society—retirement homes, hospitals, institutions.

We are most disturbed by the suffering caused by illness. We can account for some suffering as the logical consequence of certain autonomously chosen courses of action. These kinds of suffering can be given a purpose, a meaning; thus, our callousness toward those we feel deserve their illnesses—especially those who suffer from AIDS. But we are plagued by the suffering caused by illness because of its purposelessness; thus the question is, Why me? or Why this innocent child?

Just as these stories attempt to teach us, the listeners, about who we are and how to live, they also display two important convictions about suffering. First, they reveal that suffering is problematic for us not so much because it is unpleasant or because it hurts, but rather because the specter of our own suffering and the reality of the sufferings of others makes one fact perfectly clear; we are ultimately not in control. This lack of control frightens us the most. While we often forget this fact and live our lives with some semblance of control over our immediate surroundings, instances of suffering reveal to us in graphic detail the myriad of ways in which we do not control our environments, our lives, or those of our families. Suffering challenges our notions of autonomy and independence and reveals to us our deep and enduring need for community.

More importantly, these kinds of stories tend to depict suffering as the enemy; thus, the challenge of these stories is that suffering is to be eliminated through any means, even if that means the elimination of the sufferer. Eliminating suffering restores control to the individual, control that had been usurped by the courts, technology, disease, or convention. Thus, when the debates rage about who is to decide, about patients' rights, or about technology needing limits, these are ultimately questions of control—of who (or what) has the power, the control of the ultimate things. We are fascinated with these cases in medical ethics perhaps because we are watching, hoping that this time humanity has found a way to be in control.

These stories can, however, be told in another way. The Christian tradition offers an alternative set of stories through which we might interpret these and similar events. Moreover, as Christians we are called to be formed primarily by these alternative stories and, if necessary, to allow them to redescribe events as we receive them from the media. The biblical narrative, like the stories of Nancy, Janet, and Mary, powerfully portrays characters with whom we can identify and embodies some clear convictions about who we are, who we ought to be, and how we ought to live. Importantly for our purposes, Christianity provides members of the body of Christ with alternative resources for understanding and responding to suffering.

Like the stories of Nancy, Janet, and Mary, the story of the Gospels also centers on the undeserved suffering of an innocent individual—Jesus. In a similar way, the Gospels accurately describe the impact of suffering, not minimizing or idealizing it. Physical pain and suffering debilitate their victims, rendering them powerless, speechless. The characters of the Gospels, like us, find themselves not in control of their destinies. Here again we see that, for the most part, the world responds to suffering by ignoring or abandoning the sufferer. In the Gospels, the diseased and the mentally ill are deemed unclean and marginalized; Jesus' suffering during his passion is compounded by his abandonment by his disciples and friends.

Here, however, the similarity ends. The challenge presented in the Gospels is not to eliminate suffering; rather, the Gospels challenge their hearers to remain faithful and present to God and to neighbor in the face of suffering, to trust in God, to trust that even if we cannot envision any but the most dismal outcome, the future is in God's hands. Suffering is but one instance, on par with others, in which the actors are called upon to trust in God's presence.

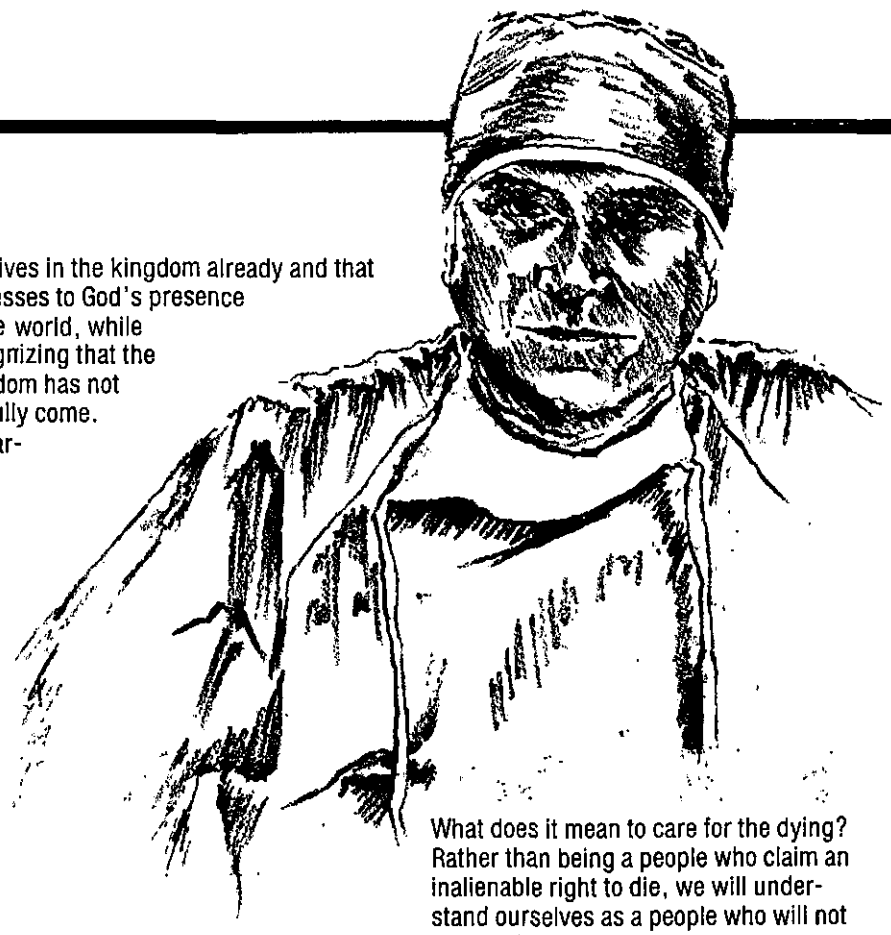
The Gospels justify this challenge by making a number of bold claims about God and about us. First of all, in these stories, God suffers. When God participates in the world, suffering often ensues. God in Jesus suffers economic and religious oppression, betrayal, torture, unjust imprisonment, and death. God knows the pains we suffer. Not only does God share in our suffering, Scripture undeniably witnesses that at times God's presence causes or entails suffering. Neither Jesus nor his mother nor his disciples were spared from suffering by their faith. They suffered the loss of their most beloved one in his crucifixion, persecutions in their evangelizing and mission work, the burden of an out-of-wedlock pregnancy. Worse yet, in Matthew's Gospel, we see the slaughter of the innocents as a direct consequence of the presence of the infant Jesus in Bethlehem. Thus, the Gospels do not argue that God's presence in the world or in our lives offers immunity from suf-

fering, but they do argue that in the face of suffering, God is present. We do not suffer alone.

Thus, the characters in the Gospels strongly embody the conviction that it is more important to be a certain kind of person, a person who responds to God with faithfulness and trust, than it is to avoid suffering. In fact, for these characters, suffering is not the enemy; the enemy is the temptation to be the kind of person that would avoid it at all costs. Their greatest challenge is clearly to choose against the easier path, to choose against the path that would eliminate suffering from their lives, to choose for God. Mary did not opt out of the pregnancy; Jesus did not opt out of his journey to Jerusalem; the disciples did not opt not to spread the gospel. While the consequences of their choices could not have been entirely clear to them at the time, they surely had some sense that their roads would not be entirely pleasant, that some sort of suffering would be entailed. Despite that awareness, the alternative was to them *impossible*.

While suffering stands as only one among many instances in which we are called to be faithful, the Gospels display illness and healing as important moments that witness the presence of the kingdom of God in the world. The evangelists consistently link a trio of activities in Jesus' early ministry: prayer, healing, and preaching the kingdom of God. Jesus repeatedly does all three. Attending to the sick and healing them when possible cannot be separated from the activity of praying to God or from the mission of living the gospel. We cannot attend to God without attending to the sick—paying attention to them, caring for them, being present with them, being compassionate.

We are enabled to do this because, contrary to the story portrayed by the world, the Gospels claim that we are not each autonomous, isolated individuals, each in control of his or her own destiny. Rather, God is always present with us, and the destiny in which we participate is God's. Moreover, more importantly than being individuals, we are members of a people, the body of Christ, a community that lives in the kingdom already and that witnesses to God's presence in the world, while recognizing that the kingdom has not yet fully come. To participate in this community means to realize the depths of our dependence on God—who is our creator, redeemer, and sustainer—and on each other; we cannot be members of this body on our own. When we suffer, then, we are not alone. God suffers with us; others suffer with us; we are called to embody God's presence to our neighbors who suffer.



So just like the stories of medical ethics, the Gospels also display ways of life congruent with their convictions about God and the relationships among God, our neighbors, and ourselves. Some of the practices of this life are the activities of being faithful, trusting in God, praying, participating in the body of Christ, and being present to those who suffer. The shape of this life is called discipleship.

How might this discipleship help us as we think about medical ethics or as we face these kinds of situations in our own lives? Fundamentally, it will mean that we should be cautious about how the questions are articulated and the cases described. It will shape us to give priority to a different sort of question and to offer as valid different courses of action.

Rather than the fundamental question being, Who is to decide? we might suggest that a more important question is, What does it mean to care for the dying? Rather than being a people who claim an inalienable right to die, we will understand ourselves as a people who will not be afraid to suffer illness because we are people who are faithful. We trust our families, our communities, and God and believe that to avoid our lives because we wish to avoid suffering would reveal our lack of faith in them and our lack of faithfulness to them. It is equally a practice of discipleship to allow ourselves to be ministered to as it is to minister to others.

Moreover, in practicing discipleship in the face of the difficult questions of medical ethics, the activity of prayer will be of central importance. It will help us to keep in our minds—in healing, sickness, and dying—where and with whom our destiny lies. It will remind us that our strength comes not from the technologies and tools of medicine, not from our ability to make autonomous decisions and choices, but rather from the fact that God is both with us and beyond any immediate outcomes of events. Finally, in remembering that one of the most burdensome effects of illness is its isolation, one of the primary medical ethical tasks of the Christian community is to alleviate that isolation by reaching out to the sick when they cannot reach out to the community. We are called to be disciples to the sick, embodying God's presence to them. When we can do no more, we can and must still be present. □