

Rediscovering Community at the Core of the Human Condition and Social Covenant

BY IRA BYOCK

Community is a core value for end of life care. It could not be otherwise. Dying confronts us with questions that go to the heart of what it means to be alive and human. Looking at these questions, we find that, fundamentally, human beings are social animals. Indeed, humanness may have little meaning without a context of relationships with others. Vanderpool asserted, “Being part of a community is essential for the development of consciousness and individuality and is characterized by communication, mutuality, and the ethical ideals of fidelity, gratitude, reciprocity, justice, and love.”¹

At its most rudimentary level, society is about people choosing an alternative to isolation and competition. The primal social compact is about offering cooperation and accepting responsibility; self-interest rooted in mutual obligation. This fundamental contract—or is it a covenant?—was the initial impetus for society and remains a sustaining force today. Writing in that tradition, philosopher Norman Daniels has identified “equality of opportunity” as the foundation stone of justice and has outlined principles to guide policy decisions and enable a moral assessment of proposed health care systems. Several years ago Daniels and fellow philosopher Dan Brook wrote this about the Clinton administration health plan:

“We are members not only of a national community but also of many other communities that flourish within our society: religious, racial and ethnic, as well as the neighborhoods, towns and cities in which people share a sense of common life. Fundamental to all these different communities is a shared concern and responsibility for one’s fellow members, especially those suffering misfortune and in need of help.”²

Applied to situations of illness-related suffering, disability and dying, these core values suggest basic components of care that we are obligated to extend:

Providing shelter from the elements. Metaphorically, we say to the other person, “We will keep you warm and dry.”

Maintaining hygiene. “We will keep you clean.”

Assisting with elimination. “We will help you with your bowel and bladder function.”

Offering food and drink. “We will always offer you something to eat and drink—and help you to do it.”

Keeping company, non-abandonment. “We will be with you. You will not have to go through this time in your life entirely alone.”

Alleviating suffering. “We will do whatever we can, with as much skill and expertise as available, to lessen your discomfort.”

Obligations and expectations of care find little place within the prevailing contractual framework of patient-provider relations that emphasizes individuals, rights and liberties. If, however, the fundamental social compact is a covenant, by extension, we must incorporate covenantal values and principles within our caring and our ethical analyses. One reason for doing so is that many people prefer for their proxies to make decisions about their care in ways that are, as Joseph Fins has argued, more covenantal than contractual.³

Inherent limitations of a contractual model carry profound clinical and social implications. Fins notes that the contractual decisionmaking is founded on underlying distrust and requires external strategies such as advance directives, which assign responsibilities, rules and restrictions on surrogates. Protection of autonomous individuals from unwanted intrusion is the highest value. This insight sheds light on the “right to die” as a logical extension of the contractual model as applied to illness, suffering, and dying. It is the right to avoid being protected from oneself. In this context, “assisted suicide” seems a misnomer, a contradiction in terms. Suicide is by nature a solitary act. The act of suicide by an ill person (successful or not) represents not only a rejection of care but an attempt to unilaterally sever the social contract.

Traditionally, hospice has operated from an alternative covenantal and community-based approach. Not surprisingly, hospice is often positioned as a counterpoint to physician-assisted suicide in ethics discussions and texts. A social covenant is based in trust and is durable; the connection with community cannot be severed. Within a covenantal approach to illness, caregiving, dying, and grief, people respond to others out of a lived sense of mutuality and because they are motivated by a desire to care. In acting covenantally, I make decisions affecting the well-being of another, conscious that her well-being affects my own.

The hospice model of care seeks to integrate medical excellence within a community approach to end-of-life experience and care. In addition to clinical professionals, the interdisciplinary team typically includes one or more clergy serving as chaplains. Additionally, a variety of trained and supervised community volunteers from

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many walks of life serve patients first and foremost by being present, spending time together and demonstrating that the person who is ill matters to them. Some may help with household chores, or assist with life review, or offer other services, such as a massage or manicure simply to brighten the ill person's day. Volunteers also serve the clinical team, most visibly by contributing observations and insights to the care planning process. More importantly, however, by their time, effort, and presence, volunteers remind busy hospice clinicians of the basic social and community values that professions were created to advance.

Our ability to respond to one another in community is not confined to obligation and recognized problems. We also have "response-abilities" to enhance a person's quality of life and the life of the community: We can bear witness; we can promote opportunity.

Bearing witness. Metaphorically, we can say to the person who may be dying, "We will bear witness to your pain and your sorrows, your disappointments and your triumphs. We will listen to the stories of your life and will remember the story of your passing." Volunteers within hospice or from a variety of both faith-based and secular community organizations amplify and extend clinical capacities in this realm.

Promoting opportunity. The old saw, "People die as they have lived," is only half true. Some people change in ways that are valuable and important to them and their families during the time they are dying. Empiric evidence amply supports the concept of human development at the end of life.⁴ In the developmental work of reviewing their lives, sharing bad news, reconciling (when needed) and completing relationships with others, and exploring existential and spiritual aspects of life, some people value assistance. Contributing to others and achieving a satisfactory sense of completion and life closure are important to patients and families facing life-limiting illness. Beyond the basics of caring, within a responsive community and social covenant, we can encourage others to tell their story as a contribution to the community's collective history.

Extending help with these inherently difficult and nearly universal personal issues fits within a social

covenant that exists before one's birth and extends through one's death. People need not accept this help; they need only know it is being freely offered. So, too, within this covenantal framework of community, I believe that even as we die we retain rudimentary responsibilities to our caregivers, families, and communities. We are obligated to make our needs known and to accept care that meets our needs without violating our values. To the extent we are able, we have a responsibility to complete our affairs and significant relationships. We have, if not a responsibility, at least a socially constructive opportunity to tell our stories.

Assertions of basic elements of care and social responsibilities might seem naïve and sentimental in the contemporary world of health care and public policy, especially in the prevailing climate of soaring health care costs and hard budget choices. However, as revealed by the Access to Hospice Care: Expanding Boundaries, Overcoming Barriers project, they are fundamental to the very moral structure, not only of health care, but also of society as a whole. One of the responsibilities of each profession is to provide leadership to the social corpus on matters within the profession's purview. It is essential that the professions especially, in collaboration with the larger community, balance respect for people's rights and liberties, with a robust sense of responsibility—and response-ability. Hospice epitomizes that response.

1. H.Y. Vanderpool, "The Ethics of Terminal Care," *JAMA* 238 (1978), 850-52.

2. D.W. Brock and N. Daniels, "Ethical Foundations of the Clinton Administration's Proposed Health Care System," *JAMA* 271 (1994), 1189-96.

3. J.J. Fins, "Commentary: From Contract to Covenant in Advance Care Planning," *Journal of Law, Medicine, and Ethics* 27, no. 1 (1999), 46-51.

4. B.M. Mount and J. Scott, "Wither Hospice Evaluation," *Journal of Chronic Disease* 36, no. 11 (1983), 731-36; M. Kearney, "Palliative Medicine: Just Another Specialty?" *Palliative Medicine* 6 (1992), 39-46; I.R. Byock and M.P. Merriman, "Measuring Quality of Life for Patients with Terminal Illness: The Missoula-VITAS Quality of Life Index," *Palliative Medicine* 12, no. 4 (1998), 231-44; I.R. Byock, "The Nature of Suffering and the Nature of Opportunity at the End of Life," *Clinical Geriatric Medicine* 12, no. 2 (1996), 237-52.

ing and acceptance, regardless of class or circumstances. The African American clergy are important sources of strength for sick and hospitalized patients and their families. Belief in immortality is an essential part of the outlook of many African Americans. For them, death is not their final state. These beliefs may conflict with

the concept of "end of life care," which has been defined as the domain of hospice, and regardless of qualifiers such as "compassionate" and "quality," much language about hospice reflects the notion that death is final. In discussing death with African American patients and families, hospice providers therefore inadvertently may

identify themselves with a viewpoint that is antithetical to the beliefs of African Americans.

Still other religious beliefs or practices about the end of life are common among other racial and ethnic groups. For many Hispanics, death is determined by God's will, and suffering is an integral part of the process.