

Beyond principles: Virtue ethics in hospice and palliative care

Marie J. GIBLIN, PhD

Abstract

Living ethically in the face of death is a major challenge for the ill person, the family, and the hospice staff. Beyond the recognized need for ethical decision-making regarding medical principles, there are decisions about character for all involved: "What kind of person will I be?" "What kind of family will we be?" "What kind of caregiver will I be?" "What kind of community will we be?"

This article is a discussion of virtues that are appropriate in hospice staff and volunteers: compassion/empathy, faithfulness, justice/advocacy, and practical wisdom. The author calls for a wider sharing of their knowledge and experience.

Key words: hospice, palliative care, caregivers, virtue, character, ethics, end of life, care of the dying, spirituality

Introduction

My own experience as a hospice volunteer may have been rooted originally in the sense of loss I experienced after both of my elderly parents died of natural causes, suddenly and only 27 hours apart. Four years after their deaths, I

signed up as a hospice volunteer. I had been thinking of becoming a volunteer for several years but had hesitated. Preparing to teach an undergraduate course in health care ethics finally gave me the courage. Now, grateful for five years of opportunities for service, friendship, and learning from hospice patients, families, and staff, I want to give something back by describing an approach to health care ethics that has special relevance to end-of-life care: an ethic of character and virtue.

The attention given to the emotional and spiritual aspects of care within the hospice tradition is a natural springboard to discussions of character and virtue without narrowing the perspective to a particular religious tradition. The ethical questions occurring at the end of life often are different from those of the typical dilemma of medical ethics: "What should I/we do?" Instead, a palliative care approach raises the deeper and more persistent question, "How can I/we, in this situation with all its complexity, rise to the occasion?"¹ To answer the latter question requires interpersonal skill, imagination, and spiritual resources.

Principles and beyond

Ethical thinking about end-of-life care goes back at least to Hippocrates

and to sixteenth-century church discussions about ordinary and extraordinary means of preserving life. Yet, bioethics as a discipline only emerged in the late 1960s and early 1970s as a response to technological advances regarding life support, organ transplantation, and emerging biotechnology. At first, theologians, philosophers, and clinicians were the participants. As awareness of pluralism in society grew, faith-based perspectives were criticized as seeking to impose their viewpoints on others. A vacuum formed as a result and philosophers stepped in to offer themselves as more neutral guides for spelling out arguments and highlighting what was at stake without committing themselves to particular solutions. Medical ethics then became dominated by philosophical ethics, which sometimes looked for procedural resolutions to ethical dilemmas (for example, by focusing on who should make the decision rather than on the merits of the decision itself).² Other philosophers, most notably Beauchamp and Childress, authors of *Principles of Biomedical Ethics*, described the core of bioethics as a principle-based theory that focused on respect for autonomy, non-maleficence, beneficence, and justice.³ These principles have formed the skeleton of modern western medical ethics. By the early 1990s, this predominance

Marie J. Giblin, PhD, Associate Professor of Theology, Xavier University, Cincinnati, Ohio; Ethics Consultant, Mercy Health Partners, Cincinnati, Ohio.

of principles in ethical thinking had been criticized as too narrow—especially the deductive applications of principles that relied on rationality alone and focused too narrowly on the individual's rights. Total reliance on a principle-based theory was criticized for its failure to allow for the complex human personal and familial drama that occurs in health care settings.

Such criticism leads to thinking about ethics as more than choices in quandaries. Ethics is also about one's character (what kind of person I am becoming) and one's community (what kind of community we are forming).

Beauchamp and Childress, in the fifth edition of *Principles of Bio-medical Ethics*, have moved the discussion of virtue from the last chapter to the second chapter, addressing it even earlier in the book than their four famous principles. They admit that not only principles and rules are important in the moral life:

Principles and rules cannot fully encompass what occurs when . . . physicians and nurses provide palliative care for a dying patient and comfort to the patient's distressed spouse. Our feelings and concerns for others lead us to actions that cannot be reduced to the following of principles and rules, and we all recognize that morality would be a cold and uninspiring practice without various traits of character, emotional responses, and ideals that reach beyond principles and rules.⁴

The moral experience of those who are ill and those who care for them is richer than any one theory of ethics can encompass.⁵ Principles provide tools that can be used, among others, in the effort to sort out moral ambiguity. They ought not to be turned into static ends in themselves that transcend circumstances of time and place

and other particularities.⁶ Human desire for moral certitude can drive people to use principles in ways that disallow the real complexities. To do so undercuts the human capacity to act as a true moral agent, or to bring a full range of human sensitivity to the discernment of moral values. Thinking about character and virtue, in addition to principles, can help us tap that wider range of human sensitivity.

Ethics of character and virtue

Character refers to each person's unique moral identity, or who a person is at the core of his or her being. It is not static, but ever becoming, not only as we grow into adulthood, but as we mature and age as well. Virtue was described by the medieval theologian and philosopher, Thomas Aquinas, as a good habit or a disposition that is productive of good. In more modern terminology, virtue is about human flourishing. Virtues act to some extent as ideals. As one author put it, "for the honest person, virtues are not what we acquire in life; they are what we pursue."⁷

While character and virtue suggest inner, subjective elements, they also have a reciprocal relationship with society, *i.e.*, with social and cultural influences. In one sense, character is formed in the particular contexts within which we develop and live out our lives. The values, virtues, and vices of those familial, ethnic, religious, social, and economic contexts affect our character and our own development of virtue. Our moral identity also can be influenced by workplace and organizational environments. In another sense, our character and pursuit of virtue can actively affect the social, cultural, and organizational environments in which we live and work. Matters of character and virtue have a communal dimension to them as well as a personal dimension. Character

and virtue are not given by nature but formed in community by decisions, commitments, and actions which, in turn, shape the communities in which we live.

How, then, can ethics of character and virtue assist those who take part in hospice and palliative care? Living ethically in the face of death challenges the ill person, the family, and the staff very deeply. There may be less need for the typical decision-making which figures so prominently in the medical ethics of principle, but still there are decisions about character and virtues for all involved ("What kind of person will I be as I face this illness?" "What kind of family will we be?" "What kind of caregiver will I be?"). There are daily choices about actions, words, and tone of personal encounters. In what follows, I will presume the ability to provide competent and professional care. I will propose four virtues (or moral traits) for reflection and discussion by hospice and palliative care staff and volunteers. This selection of virtues is meant to evoke the reader's own thoughtful reflection on these matters, not to present an exhaustive list.

Recently, a psychologist and social worker defined the uniqueness of hospice by highlighting the rare mixture of interpersonal skills, compassion, and professional competence that are needed to help others confront the psychic dilemma of death:

The importance of these characteristics, combined with the central goal of holistic, individualized care, leads to yet another defining difference of hospice care: its dependence on the quality of staff/client relationships to accomplish its social mission. This unique dependence on relationships constitutes the "soul" of hospice.⁸

Relationships are at the center of

hospice and palliative care, and “the kind of person one is” will greatly influence those relationships. Thus, it is fitting to focus on four important virtues of staff and volunteers within this context: compassion/empathy, faithfulness, justice/advocacy, and practical wisdom.

Compassion and empathy

Beauchamp and Childress define the virtue of compassion as “a trait combining an attitude of active regard for another’s welfare with an imaginative awareness and emotional response of deep sympathy, tenderness, and discomfort at the other person’s (or animal’s) misfortune and suffering.”⁹ The definition encourages us to consider the realms of emotion, imagination, and action.¹⁰ Often, the imagination is stirred to consider that this patient might be one’s mother, grandfather, or other family member. In care at the end of life, the response often goes a step further—to empathy. A medical student suggested that empathy means “I could be you.”¹¹ One hospice nurse expressed the feeling of empathy as “thinking of what it would be like to be the one in the bed.” Empathy adds another element: recognition of vulnerability and our sense of sharing the same human condition. Apart from violent or accidental deaths, we will all eventually be sick, and we will all eventually die. Our shared mortality levels the playing field. The obvious vulnerability of the ill person calls us to admit our own vulnerability. This shared vulnerability unites us and opens us up to each other on a deep level. The vulnerability can, of course, be denied and close off communication at this level. It is this vulnerability that our culture works so assiduously to deny.

What is needed often in palliative care is not technical expertise but the ability to give support and to share in the human experience of suffering and

loss as fellow members of a community. That task does not depend on professional roles and can be taken up by a nurse, physician, social worker, chaplain, or volunteer. Instead of playing roles, staff and volunteers can act as caring companions who have the privilege of listening to the experiences and feelings of this unique patient, this specific family. Over time, staff learn from this type of sharing with patients and families, and they become more able to comprehend the suffering and anticipate the needs of their clients.

It would be unfortunate to “medicalize” the dying experience more than it already is, by insisting that specialists and professionals deal with each aspect of the person and carefully delimit what is “my job” and “not my job.” It is very human that an inpatient hospice nurse keeps on her clipboard some simple prayers from the Jewish tradition (with which she is not very familiar) so that she can be ready to provide a prayer from the family’s religious tradition if this would be comforting at a crucial moment. Always waiting for someone else to come (e.g., the chaplain) disempowers everyone and heightens the isolation that the ill person already may be feeling.

One essential element of compassion is support of the hospice patient’s loss of “control,” with an affirmation of dignity and value. Control means different things to different people, yet a sense of its loss is a common area of suffering. Our culture highly values autonomy and control. In terminal illness, losses of this kind are greatly distressing to the ill person. This is why it is so important that hospice staff handle toileting needs with great respect and care for the dignity of the person. Their care is an affirmation of personal dignity and reassurance that this very personal loss of control does not signal any diminishing of the value of the person. Staff can be teachers of this essential honoring of the

sick person.

Compassion is also linked with the ability to listen and sensitively attend to the story of the patient and the family. By being companions in this way, hospice folks are witnesses to the suffering and struggle of ill persons and their loved ones as they tell their story in ways that express its meaning in their lives. It is important that this testimony be heard and understood; and it can only be heard and understood if the caregiver is open to the words of the sufferer through having dealt with her/his own suffering. As a hospice chaplain put it, “Your experience of suffering enables you to be with them in their suffering.” Sometimes this companionship is felt simply through presence, even in silence.

The witness becomes the learner. One hospice nurse said, “Why is it that the most important things to learn are only learned when we’re dying?” But it is possible to learn. The hospice worker’s experience of learning from the ill validates sociologist Arthur Frank’s insight that there is a “pedagogy of suffering,” by which he refers to the ill person’s ability to teach others.¹² The lesson is not just about suffering and the dying process but about living our lives fully and deeply before death.

Faithfulness

In this time of crisis, amidst patient and family fears of abandonment by the medical establishment, faithfulness until the end and accompaniment in bereavement are powerful testimonies to the importance and value of the ill and their loved ones. Faithfulness can be understood in terms of deep human solidarity. For Jews, Christians, and Muslims, it may also serve to communicate God’s love—constant and unending. Dying is a sacred time, a time that emphasizes the mystery of being human, the depth of sorrow, and the strength of love.

One hospice nurse, a Christian, said that she often associates her presence with the dying person with the women's presence at the foot of the cross of Jesus. The faithfulness of God's love is a theme in Christianity, Judaism, and Islam. If we can evoke a sense of that love, then our faithfulness becomes a kind of "sacrament" that points beyond us to the faithfulness of God or, to those without religious faith, to the beneficence of the universe.

Justice and advocacy

Relationships of compassion and faithfulness are rooted in respect and concern for all who are facing life-threatening illness. For this reason, individuals and organizations, hospice staff and volunteers, as well as health care facilities, should look for opportunities to advocate for those without access to hospice or palliative care services. They are many: the elderly in institutions and at home, prisoners (many plagued with HIV or becoming increasingly elderly and ill), low-income people who may be unaware of hospice, the uninsured, and the homeless. Increased reimbursement and fundraising, as well as efforts at making hospice services comfortable for diverse populations, will be required for organizations to reach out to these groups. It is here, especially, that virtue meets community. It is not enough that a fraction of people who need hospice and palliative care services receive them. What kind of a community do we want to form? Not the kind that provides high technology screening, or even treatment, and then abandons those who cannot be cured.

Practical wisdom and prudence

Practical wisdom is admired by philosophers because of its roots in Aristotelian thought. Beauchamp and Childress describe Aristotle's model in this way:

The practically wise person understands how to act with the right intensity of feeling, in just the right way, at just the right time, with a right balance of reason and desire.¹³

This is an ideal that none of us can live up to completely. Practical wisdom operates when a caregiver attempts to identify what needs attention and what human response is needed. For instance, does patient withdrawal indicate a need for privacy or a need for comforting? Practical wisdom may not give us the answer, but provides a desire to gently seek an answer.

Practical wisdom as prudence helps caregivers to be reasonable about expectations. For example, if psychological, spiritual, or social issues are to be addressed, prudence recognizes the need for the patient's active involvement.¹⁴ Therefore, these issues might be touched upon gently with the ill person and the family—so that education is not just about symptom management, but also about possible needs for forgiveness and reconciliation, for touch, for prayer, etc. "Planting seeds," is what one nurse called it. Exercising prudence gives family members a choice, for example, by offering them various opportunities for participating in personal care. Prudence recognizes that often we don't know the complexity of the personal and family story, and we cannot presume to understand it. We do better by proceeding gently, making suggestions, or offering opportunities, while letting people be who they are, supporting them in their struggles to bring matters to a good end. In situations of cultural diversity, prudence can help us to be sensitive, open, and able to learn from others.

Practical wisdom also makes us realize that it is our own life experience that enables us to be present to those who are suffering. All wisdom does not come from work. It comes

from our experience with children, intimate partners, parents, relatives, and friends that we enjoy (and sometimes suffer with). Our own wholeness and humanity need cultivation through good relationships, an ability to receive as well as to give, a sense of humor, other life projects, and play. All of these add to our ability to be present to the ill and their families as fellow human beings.

Organizational climate

The level of commitment and service on the part of professional caregivers is often at odds with an organizational world beset by multiple pressures for efficiency and concerns for documentation and reimbursement. Administrators and managers need to recognize the role of the organizational environment in fostering or discouraging the development of virtue. Under the health care pressures today, there is little time for team members to even see each other, not to mention provide mutual support. Under severe time constraints, the temptation arises to continue with the same routine, to just get the job done, to let go of the real goals of care, and to decline to get emotionally engaged with the ill or their loved ones. These are very serious issues for the continuation of the spirit of hospice. It is not fair to put the responsibility for maintaining this spirit totally on individual hospice workers, by asking them to learn to cope through various attempts at personal adjustment. Systemic and operational changes are happening everywhere in health care. Often they are driven by the demand to cut costs in order to ensure the continued viability of the organization. Given these pressures, more dialogue and proactive creativity on the part of staff and administrators is needed to bring about organizational changes that work in favor of faithfulness, support focusing on true goals, and reward the willingness to

remain emotionally engaged. The effort to make needed resources available (through Medicare payments for hospice care) should be brought to the public as well, since the issue is also political.

Conclusion

In our society, death has become highly technological and very frightening. Education about end-of-life care has barely begun—in medical schools, nursing programs, and in the public domain. Much more remains to be done. A study in 1999 found that fewer than three percent of terminally ill patients received any help from volunteers. The authors also concluded that religious communities and colleagues from work are not engaged in assisting in the care of most dying patients.¹⁵

Not only does fear of death play a role in keeping friends and neighbors from helping, but also fear of intrusion, and, on the part of the family, fear of dependence on others and loss of privacy. Concerns about intrusion/privacy issues should be respected and dealt with sensitively, but they should not eliminate possibilities for greater supportive interaction. We Americans need to rethink how we feel about dependence/independence. Perhaps neither should be the focus; rather, we should try to build a new realization of our human interdependence. We need each other across our life spans, but especially at the beginning of life, at times of illness, and at the end of life. Human dignity is not destroyed but enhanced by interdependence. Our interdependence is the key to joy in the good times and to solace in difficulties. The experience of caregiving is often an experience of

privilege and not of “burden.” When caregiving is perceived this way, we as a culture may begin to realize that accepting help does not spell weakness or humiliation but is simply another aspect of human dignity—one that allows the friend to act with compassion and generosity to uphold the ill person’s humanity.

This discussion will end with a call for education and recruiting of people to participate compassionately and sensitively in the care of persons near the end of life. If the experience could be more widely shared, knowledge and wisdom about the dying process and about the virtues needed could be dispersed more broadly throughout the community. As this wisdom spreads, members of our various communities will be better prepared to participate not only in the dying of others but in their own dying.

The knowledge and experience gained by helping others needs to be brought to bear on in the political and social realm also, so that structural changes in the health care system take place to allow services to be available to all. Both structural and personal change are necessary if we are to have confidence that none of us will be abandoned, but that we will be supported by families, friends, and communities that have practiced and begun to grow in virtues that can help us end our lives with dignity and love.

Acknowledgment

The author wishes to express thanks for the insights shared with her by Martha Binstadt, Jamie Favret, and Audrey Dwyer from Hospice of Cincinnati, Cincinnati, Ohio.

References

1. May WF: *The Patient's Ordeal*. Bloomington: Indiana University Press, 1991.

2. Shannon TA: *Bioethics and religion: A value-added discussion*. In Davis DS, Zoloth L (eds.): *Notes from a Narrow Ridge*. Hagerstown, MD: University Publishing Group, 1999, pp. 129-135.
3. Beauchamp TL, Childress JF: *Principles of Biomedical Ethics*. 5th ed. New York: Oxford University Press, 2001. See also Chambers T: Centering bioethics. *Hastings Ctr Rep*. 2000; 30(1): 22-29.
4. Beauchamp & Childress, *op. cit.*, 26.
5. Churchill LR: Bioethics in social context. In Henderson GE, King NMP, Strauss RP, et al. (eds.): *The Social Medicine Reader*. Durham, NC: Duke University Press, 1997. See also Arras JD, Steinbock B: Introduction: Moral reasoning in the medical context. In Arras JD, Steinbock B (eds.): *Ethical Issues in Modern Medicine*. 5th ed. Mountain View, CA: Mayfield Publishing Company, 1999.
6. Churchill LR: Rejecting principlism, affirming principles. In DuBose ER, Hamel R, O'Connell LJ (eds.): *A Matter of Principles: Ferment in US Bioethics*. Valley Forge, PA: Trinity Press International, 1994.
7. Keenan JF: Virtue ethics. In Hoose B (ed.): *Christian Ethics*. Collegeville, MN: The Liturgical Press, 1998, p. 85.
8. DiTullio M, MacDonald D: The struggle for the soul of hospice: Stress, coping, and change among hospice workers. *Am J Hosp Palliat Care*. 1999; 16(5): 641.
9. Beauchamp & Childress, *op. cit.*, 466.
10. Randall F, Downie RS: *Palliative Care Ethics: A Good Companion*. New York: Oxford University Press, 1996.
11. Spiro HM: What is empathy, and can it be taught? In Spiro HM, McCrea Curnen MG, Peschel E, et al. (eds.): *Empathy and the Practice of Medicine*. New Haven, CT: Yale University Press, 1993, pp. 7-14.
12. Frank A: *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995, pp. 137-167.
13. Beauchamp & Childress, *op. cit.*, 468.
14. Randall & Downie, *op. cit.*, 18-19.
15. Emanuel EJ, Fairclough DL, Slutsman J, et al. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *N Engl J Med*. 1999; 341(13): 962.