Culturally Relevant Palliative Care



Richard Payne, мр^{а,b,*}

KEYWORDS

• Culture • Palliative care • Imagination • Narrative competency

KEY POINTS

- Although all persons facing serious illness have individual needs, the foundation for providing quality palliative care is in making connections that focus on universal human needs.
- Clinicians should make considered and reflective judgments that minimize stereotyping and superficial generalizations.
- Clinicians should be open to the perspective of the person experiencing illness and suffering.
- The story of illness should be encouraged and elicited for a fuller, richer perspective of the
 person with illness who is like all others, like some others, and like no others.

"Every person is like all others, like some other, and like no others."

— Adopted from Kluckhohn and Murray, 1948

ONE PERSON—3 IDENTITIES

This proverb or witticism^{1,2} is relevant for all clinicians. Proverbs or writings of this kind can be considered part of a larger genre of "wisdom literature." Perhaps the most famous examples of wisdom literature are the Old Testament books of Job, Psalms, Ecclesiastes, and, of course, the book of Proverbs. By using techniques such as simile, symbolism and allegory—language that likens one thing to another, and makes comparisons to understand the relative values of concepts—these phrases, scripture passages, and secular witticisms provide concentrated nuggets of wisdom to assist with navigating a world that is not black and white, but full of shades of gray.

This particular expression points to a great challenge for clinicians who desire to practice competent, comprehensive care, attentive to the particular human needs of

E-mail address: rpayne@div.duke.edu

^a The Divinity School, Duke University, Box 90968, Durham, NC 27708-0968, USA; ^b Bioethics, Center for Practical Bioethics, Kansas City, MO 64105, USA

^{*} Corresponding author. The Divinity School, Duke University, Box 90968, Durham, NC 27708-0968.

their patients. Analogous to the 3 physical states of water, which can exist as a solid, a liquid, or a gas, and still be constituted of the same fundamental substances—2 hydrogen atoms and 1 oxygen atom—persons experiencing illness exist in 3 interrelated states or identities. Attention to the multiplicity of perspectives of individuals rendered vulnerable by illness is at the heart of providing competent and humane medical care. Recognizing that every person is "like all others" identifies the notion of a shared common humanity and universal needs when facing serious and life-limiting illness. Recognizing that every person is "like some others" acknowledges that we share commonalities with certain tribal and cultural groups and not with others. Finally, affirming that every person is "like no others" speaks to the very important need to individualize care and to assess the specific circumstances of illness and the particular needs of individuals with unique preferences and personal values.

Like All Others

It has been said that "our confrontation with death lays bare the spiritual dimension of the human experience" (Ira Byock, personal communication, 2004). This idea speaks to a nearly universal yearning for understanding of the connection to other peoples, to wonder about creation, and perhaps a Creator, and to find meaning and purpose in life experiences - in the context of serious illness and contemplating a life that is perhaps about to end. The imminent loss of self, or loss of a loved one, often directs one to important spiritual values that transcend racial, gender, class, and geographic boundaries. These spiritual values may be enriched by and interpreted through specific religious traditions and rituals. These values-the desire not to be alone or abandoned during illness, but to be in the company of family and loved ones; the desire to be free of physical pain and avoidable suffering; the desire to reconcile with and say goodbye to family and loved ones-undergird nearly universal human aspirations in the context of serious illness and end-of-life care. These values transcend the common social and political categorizations of human life. Professional caregivers can make valid assumptions that these values and needs will apply to all of those they serve – irrespective of race, ethnicity, religious tradition, and socioeconomic status.

Like Some Others

Although these values and aspirations are shared by the human family, the ways in which these needs and desires are voiced, the meanings attached to these values, and the way people act on them are influenced greatly by the nuances and characteristics that make up the rich diversity of the human species. The great common ground of human concerns that make everyone "like all others" is often confounded in the distinctive cultures of community and the personality that defines ethnic groups and individuals. In this context, everyone is "like some others" in the common cultural patterns that bind people together in community. But even here, there are important caveats. Culture and community often refers to groups of individuals who share a common language, lifestyle, and worldview.⁴ Community may be geographically defined or virtual, unencumbered by physical limitations of space and time. Adding to the complexity, notions of community and culture may overlap and cross boundaries between racial and ethnic categories making conventional categorizations problematic and not at all predictive of the ways in which people are likely to response to serious illness, disease, and loss. In fact, even in the expression and discussion of firmly held medical "facts," clinicians must be sensitive to notions of cultural interpretation. Perhaps the best example of this is the recent controversies concerning the acceptance of "brain death" as the legal and practical criteria for actual death (see VALUES AND CULTURAL PERSPECTIVES DETERMINE THE "RIGHT ANSWER").

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