
ORIGINAL ARTICLES

Dying other, dying self: Creating culture and meaning in palliative healthcare

CHRISTOPHER J. MCCANN, M.A. AND HECTOR Y. ADAMES, PSY.D.

Chicago School of Professional Psychology, Clinical Counseling Department, Chicago, Illinois

(RECEIVED April 3, 2012; ACCEPTED April 12, 2012)

ABSTRACT

Dying is an act of creativity, and we each die as cultural beings. Culture helps us create the meaning death requests of us. However, the dominant culture of the healthcare system views death as a failure of modern medicine, an event of unspeakable terror and taboo. Palliative clinicians must honor each dying person's cultural identity (as well as the person's family), not subject it to the dominant discourse of Western medicine. This article offers practical guidelines for palliative clinicians to do so, as well as a case vignette.

KEYWORDS: Palliative care, Culture, Meaning, Multicultural issues, Death and dying

INTRODUCTION

Death seizes us. Death calls us. Death, as we approach the unknown, asks us to weave together strands of meaning. We move toward death, cross that ultimate threshold, simultaneously alone and together. Death is larger than us; it engulfs and overcomes us. We all die as cultural beings. Culture is the warp and the weave we use to sculpt death in a way that we can ingest, metabolize, and express. Culture forms our response to death; at times consciously, at other times simply by adoption and without question. Cultural conditions surround how we face, cry over, arrive at, court, and even conquer death. Culture and death are not separate. We narrate death and death narrates us.

This article tells the story of the hazards of dying in an institutional cultural framework that presses death into the domain of shame, taboo, disgust, fear, and failure. For many, dying has been institutionalized. Institutions are organisms with culture, a culture that the dying person becomes subject to. This article provides recommendations for palliative care providers to be aware of how the institution of dying

is rooted in Western majority culture, and how they can allow patients their own unique ontic expression of death. The authors will do this by offering four thematic domains (i.e., Focal Point, Continuum, Flourishing, Possibility) and a case vignette that illustrates an example of incongruence between a patient's cultural values and those of a palliative care unit. Dominant Western culture, as this article defines it, tends to be composed of monotheistic religion, whiteness, socioeconomic power, and rational scientism. When taken comprehensively, these recommendations, although not oriented toward sustaining policy, will provide clinicians with a greater ability to conceptualize their patients, and a heightened degree of interpersonal awareness. It is also necessary to mention that this article primes the reader for a deeper and more sophisticated textual inquiry; hence, it is meant as a general introduction to these ideas.

FOCAL POINT

First, it is recommended that palliative care providers have a working understanding of the existential focal point of death as it pertains to dominant Western culture.

Western psychology has long viewed death as a carrier of profound anxiety (Yalom, 1980). The tradition of existential psychology, which arose in

Address correspondence and reprint requests to: Christopher J. McCann and Hector Y. Adames, The Chicago School of Professional Psychology, 325 North Wells St, Office: MM-4116, Chicago, IL 60642. E-mail: acme.letter@gmail.com or hadames@thechicagoschool.edu

contrast to the traditions of psychoanalysis, behaviorism, and cognitive therapy, seeks to address ontological focal points such as meaning—meaninglessness, relationship—isolation, freedom—choicelessness, will—fate, being—nonbeing (Cooper, 2003). Existential psychology presupposes that these themes present universally, at times consciously confronted and undertaken, other times avoided. In addition, existential psychology assumes that an individual's confrontation with these universal human experiences is pervaded with anxiety. Therefore, each person facing this anxiety must individually grapple with being situated in these themes, crafting life from this constant dance. Becker (1973) stated that culture and character intertwine to enable this heroically creative play. Death itself, understood by this tradition, is often seen as the ultimate boundary situation, as a powerful agent of fear, and consequently, of the capacity for self-transformation (Yalom, 1980).

Palliative care providers undoubtedly encounter this fear on a daily basis. This fear is deeply woven into the fabric of dominant Western culture. But does this inherently traumatic core of fear manifest in all people, regardless of cultural difference, equally? It is no longer acceptable for dominant forms of sociocultural discourse to speak for everyone when it comes to death. Palliative care, as a product of the dominant discourse, cannot be a one size fits all model. In diverse and heterogeneous contemporary societies, people must be able to freely express their own cultural narratives without being caught in the trappings of the overruling social hegemony.

In Western medical systems, death is seen as both a failure and a taboo (Gibbins et al., 2011). Medical systems provide multiple symbolic defenses against the lived corporeality of the body, and thus function as an agent of separation between the body's creatureliness and cultural standards of death denial. As Goldenberg et al. (2000) state, the human body constantly reverberates death and animality; and our established cultural practices of modification and regulation of the body serve a similar separating function. In order for palliative care providers to extend their treatment into the diverse fabric of contemporary populations, the death discourse they embody must be consciously seized upon and opened for revision. Palliative healthcare systems can no longer monopolize the symbolic space of the body.

CONTINUUM

Second, it is recommended that palliative care providers understand the following cyclical continuum: death ⇔ meaning structures ⇔ worldview ⇔ culture (circling back to death), and implement its use within patient conceptualization.

This cycle begins with death, as unknowable. Death emits uncertainty, requests creativity. As unknowable, individuals propelled toward death seek the creation (or unquestioned adoption) of meaning. Meaning is the sense we make out of the condition of death. This sense-making crafts the experience of death into an experience of creativity, which superimposes the organization of a worldview onto the total uncertainty of death. A worldview, as such, contains ideas about who we are, why we are here, what the world is, and finally, how the world is. According to Spinelli (2007), the process of constructing a worldview is largely an interpretive act between us and what it is we relate to. In this way, this interpretive crafting (pulling on all of our capacities to think, feel, learn, imagine, and relate) constellates together into a meaningful organization of personality, perception, patterns of behavior, and self-concept. Our meaning-saturated worldview is not separate from our identity (Adames & Fuentes, 2011; Fuentes & Adames, 2011). Our worldview can be considered a first-person perspective; our identity is a second-person perspective. These two perspectives meld and intertwine. My identity is inseparable from the concepts I construe from the fluctuating event horizon of my sensory field.

We are interrelated beings in every conceivable facet of our existence. Individuals partake of the meaning ⇔ worldview exchange in a co-constructing way with others. In this way, we organize ourselves around existential nodes that are punctuated by networks of culture. Our race, ethnicity, gender, age, sexual orientation, socioeconomic status, and able-bodiedness all contribute to the thematic complexes of our worldview.

Then, by scaling along this continuum, we find ourselves back to death created, crafted, and shaped, as it were, by this dynamic process. By tapping the power death provokes to awaken our most human capacities, the process does not lead us in avoidance away from death but *further into its orbit the more we shape it into a culturally unique image.*

FLOURISHING

Third, it is recommended that palliative care providers recognize the contrasting institutional worldview of the healthcare system and the worldview of the dying patient. It is recommended that palliative care providers seek to honor the way of dying of the patient within the larger worldview of the medical institution, allowing that patient's singular and unique dying to flourish.

Palliative care providers encounter the dying as an encounter with the Other. This encounter must be recognized as a relationship that cannot be stultified by

monochromatic assumptions of sameness. However, this assumption is likely, and may resemble this: *In death, we are all the same. Death is universal, and as shared human animals, we all die (and feel, conceive, anticipate) death in the same way.* However, by recognizing the previous death-culture continuum, palliative care providers may recognize that it is not just a “person” who is dying, not just biological processes that are failing, but an entirely comprehensive way of being that is crossing a previously untouchable threshold. In meeting this dying Other, it is crucial that by explicit or unrecognized implicit assumptions palliative care providers do not overtake the dying Other’s way of being with the institutional structures of meaning (death as tragedy, taboo, failure; death as inherently traumatic, unspoken, feared). In contrast, a palliative care provider may allow the meaning of the dying Other’s worldview to arise in a process of sanctification, as stated by Frosh and Baraitser (2003). Sanctification, taken in this context, is devoid of religious meaning. Instead, by sanctification the Other is honored as important precisely because that Other is different (Frosh & Baraitser, 2003). Frosh and Baraitser’s (2003) sanctification may therefore become the medium of relationship between the palliative care provider and the dying Other. One may have various forms of connection with the Other within this relationship, yet the Other cannot be overtaken. The dying Other always extends beyond the institutional definition of that Other.

But what may prevent the adopting of this open stance? When we encounter the Other we do so from within the matrix of our own culturally developed worldview that is rich with personal and socially informed biases and assumptions. These biases, drawn along the lines of power of a given society that upholds discriminations, prejudices, and oppressions, are intended not to keep the Other just as other (an element of vital difference), but to keep the Other as less than oneself. The dying encounter of the Other within the palliative care encounter is not exempt from this all too human habit. Therefore, it is recommended that palliative care providers become crucially aware of how they are relating to the dying Other as an Other of difference.

POSSIBILITY

Fourth, it is recommended that palliative care providers caution themselves against a rigidity or homogeneity of perception that may occur in their Other-centered learning.

Palliative care providers may attempt to creatively engage their own worldview so that they become increasingly able to integrate new information emit-

ting from *each* dying Other they encounter. In doing so, a complex and nuanced openness may arise that can allow a truly respectful and compassionate treatment to unfold. The outlines of the Other as less than oneself are continually being drawn by the dynamics of the society at large outside the healthcare institution, and palliative care providers, as any other members of the society, fall under these collective influences. In addition, the palliative care provider runs the risk of forming more assumptions from encountering two or more dying Others of a shared cultural identity. Therefore, it is recommended that a palliative care provider must strive to provide treatment and conceptualize the dying Other slightly beyond what that provider has previously known or categorized. Although it is not possible to completely renounce one’s biases and assumptions and set aside a particular worldview in its entirety, it is possible for one’s worldview to become highly fluid, creative, and organized around questioning and curiosity rather than notions and certainties.

MARIA

Maria was a 70 year-old, divorced, Latina female. Initially, Maria presented with a reported history of gradually progressing memory difficulties. Prior neuropsychological testing revealed executive dysfunction, reduced attention and cognitive slowing, and impairment with new learning including retention of information.

Prior to Maria admission to hospice care, she would often not know the reason for her appointment and adamantly denied problems with her memory and thinking. At the time, Maria reported that her “only complaint” was “finding her car.” However, her daughter reported a 5 year history of gradual cognitive decline that had significantly worsened over the past 3 years. The daughter reported that Maria would easily lose her train of thought, had difficulty following conversations, and continuously repeated stories from decades prior. In the past, Maria had gotten lost while driving in their neighborhood. Moreover, she had a history of forgetting where she had parked her car. The concern that brought them to seek evaluation and treatment initially was an incident in which Maria drove her car into the garage door. Reportedly, Maria did not know that she had the car in “reverse.” During this same period of time, Maria had difficulties recalling names of her friends and her grandchildren. She became increasingly disorganized, frequently misplacing important items (e.g., eye glasses, wallet, keys). In fact, she often searched for items (glasses) only to find that she was holding them in her hands. She also had

difficulties with grooming/dressing. Suspected etiology was a neurodegenerative disease process, most likely dementia of the Alzheimer's type.

Maria's daughter denied any significant changes in her mother's personality, and had not noticed any inappropriate behaviors. For the past 5 years, Maria's daughter had managed all of the household bills and finances, since Maria has had significant difficulties completing this task.

Maria's health continued to decline. She had difficulty eating and swallowing, and required full-time assistance and care. Furthermore, she had lost the ability to communicate with words and experienced a number of infections including various episodes of pneumonia. Given the required 24-hour assistance needed, and the lengthy and delicate journey that is involved in the late stage of Alzheimer's disease, the family was advised to seek outside care. This round-the-clock care can be difficult for caregivers; therefore, health providers typically recommend moving the person to a residential care setting. Given that Maria was estimated to live <6 months, the family was specifically recommended to seek hospice care. The underlying philosophy of hospice care is the focus on quality and dignity of the affected person by providing comfort, care, and support services for the individual with a terminal illness and that person's family.

Unique to Maria's case was the fact that the family did not have an understanding of what hospice care entailed. Initially, they thought it was a place where Maria might "get better." As it would be expected, the family still had hope that their mother, their grandmother, their aunt, their Maria would come back. They were hoping for a miracle that never materialized. The family was uninformed and confused regarding the fact that they had choice in the care that Maria would receive (e.g., refusing, starting, limiting, or ending medical treatments; making the change from treatment to care that is focused on comfort). Maria did not have advance directives and the family grappled with making decisions consistent with what they believed Maria would have wanted. Such experience created a sense of guilt and confusion within the family. The daughter expressed concerns about believing that she might be a part of her mother's death, an act that went against their cultural norms. The daughter also had concerns about making decisions pertaining to aggressive medical care (e.g., respirators, feeding tubes, intravenous hydration, cardiopulmonary resuscitations) and often wanted to give the decision power to Maria's health providers.

Finally, the family did not want to engage in discussion about a brain autopsy. All of the abovementioned difficulties created family conflicts. It

highlighted the family's cultural belief and value of celebrating life, planning for living was incongruent with the messages and tasks that the hospice staff were recommending. Overall, the staff struggled with how best to care for the family unit.

INCLUSION

In order to craft truly compassionate and humane treatment, those who work with the dying must consider the role that culture plays in shaping a person's understanding, preparation for, and process of dying. The culture of the institution of modern medicine, in concert with dominant North American culture, presents only a fragmented view of the dying Other. Practices of open questioning and inclusion must be favored over avoidance, shame, and anxiety. Palliative care providers are asked to take responsibility for understanding their own conditioned perceptions of death and dying, and how those perceptions affect their ability to attune to the difference of the dying Other. By following this path of sanctification, coalescence arises between the dying Other and the presenting self of the palliative care worker (see Table 1). The deathbed itself becomes the cultural grounds of inclusion. Culture, when uniquely honored and expressed, prepares us to become the unknown.

Table 1. *Dying Other, Dying Self Assessment (DODS-A).*

Dying Other (and family)	
•	What are your experiences with death?
•	Have you ever had a loved one in palliative care before?
•	What are your wishes for your loved one (or yourself) who is dying?
•	How can we bring your cultural beliefs, practices, and ceremonies into this process?
•	Who from your community can we invite into this encounter to make this happen (e.g., clergy, folk healers, artists, musicians)?
Dying Self (reflections for the provider)	
•	How do I understand death?
•	What does it mean to die?
•	What do I want for my death?
•	How does this compare or contrast to the patient?
•	How can I empower the patient to die in their unique manner?

This table provides a list of questions divided into two domains: Dying Other and Dying Self. The first set of questions may assist in assessing patients (Dying Other) and family members' previous experience with death while welcoming their cultural practices, beliefs, and values into the palliative care milieu. The second set of questions serve as reflective questions for palliative care providers (Dying Self).

REFERENCES

- Adames, H.Y. & Fuentes, M.A. (2011). Having a voice and being heard: Exploring the impact of multiple social identities on the self. In *Experiential Activities for Teaching Multicultural Competency in Counseling*, Pope, M., Pangelinan, J. & Coker, A. (eds.), pp. 49–51. Alexandria, VA: American Counseling Association Press.
- Becker, E. (1973). *The Denial of Death*. New York: The Free Press.
- Cooper, M. (2003). *Existential Therapies*. London: Sage Publications.
- Frosh, S. & Baraitser, L. (2003). Thinking, recognition, and otherness. *Psychoanalytic Review*, 90, 771–789.
- Fuentes, M.A. & Adames, H.Y. (2011). The social cultural profile. In *Experiential Activities for Teaching Multicultural Competency in Counseling*, Pope, M., Pangelinan, J. & Coker, A. (eds.), pp. 153–155. Alexandria, VA: American Counseling Association Press.
- Gibbins, J., Mcoubrie, R. & Forbes, K. (2011). Why are newly qualified doctors unprepared to care for patients at the end of life? *Medical Education*, 45, 389–399.
- Goldenberg, J.L., Pyszczynski, T., Greenberg, J., et al. (2000). Fleeing the body: A terror management perspective on the problem of human corporeality. *Personality And Social Psychology Review*, 4, 200–218.
- Spinelli, E. (2007). *Practising Existential Psychotherapy*. London: Sage Publications.
- Yalom, I. (1980). *Existential Psychotherapy*. New York: Basic Books.