Humanities: Art, Language, and Spirituality in Health Care
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Physicians' Reflections on Death and Dying on Completion of a Palliative Medicine Fellowship

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Editors' Note: *A central focus of the Humanities Section has been to provide a forum for health care clinicians to reflect on various related themes in enfolding their personal experiences with challenge, suffering, insight, and healing. Although many of the articles are reflective, we find it helpful occasionally to include a qualitative, systematic review of what it is we may be experiencing, as exemplified in the following study of first-year experiences of palliative care fellows. This serves to both ground and validate our experiences as well as providing a creative example of how we might look at our work anew.*

Abstract

Context. Patient and family dissatisfaction may result when they are not satisfied with the physician/patient interaction, although the physician may feel he/she worked hard to provide information to the patient and family. New approaches to visual analysis can 1) identify significant insights from physicians' personal and clinical experiences in providing compassionate palliative care and end-of-life care and 2) provide an effective and practical vehicle for communicating with patients, their families, and other professional caregivers.

Objectives. To elucidate palliative physicians' core experiences with their patients' dying and death.

Methods. A qualitative visual analysis was conducted on 75 images created by physicians completing a one year palliative medicine fellowship. These images are part of a larger personal reflections narratives database of images, text, and auditory projects prepared by students, interns, and fellows completing training in palliative care at a large hospice provider. Participation in the personal reflections project is a required part of the training program, with the goal of blending clinical competencies with lived experiences of caring for the dying.

Results. Two categories of visual metaphors underlying the images were identified, with both expressing the relationship and transitional dynamics of life and death: portraits ($n = 30$, 40%) and nature ($n = 45$, 60%). Conventional images representing anxiety, pain, or other dimensions of suffering commonly associated with death and dying were virtually absent ($n = 2$, 0.03%).

Conclusion. We propose the communication of positive, hopeful, even peaceful perceptions of death and dying was likely the result of effective personal and professional skills gained through physicians' clinical experiences during the fellowship. J Pain Symptom Manage 2016;51:633–639.

Key Words
Palliative care, physicians, self-reflection, humanism, visual narratives

Introduction

Over the past few decades, progress in interdisciplinary understanding of pain and symptom management, psychosocial and spiritual suffering, and compassionate communication skills has been made. These developments have reduced suffering while improving quality of life for the dying and their families and increased satisfaction for clinical

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professionals who provide palliative care.[1] However, the personal and clinical experiences of physicians, which are grounded in their relationship with their patients, remain understudied and the least understood for delivering optimal palliative care.

Practicing medicine provides rewards but also includes commonly overlooked personal and professional challenges. For instance, in addition to workload-related fatigue, physicians confront stressors that range from changes in clinical practices associated with increasing organizational bureaucracy to patient care demands to processing enormous amounts of information.[2] Combined with personal stressors from working in often highly emotional circumstances, medical practice can negatively impact physicians' overall health, resulting in increased risk for burn-out and addictive and other harmful behaviors, while reducing the quality of care and safety for their patients.[3–5]

Confronting the existential, psychosocial, and spiritual complexities and uncertainties accompanying dying necessarily presents professional and personal demands on palliative care physicians.[6] There is little doubt about the prevalence of significant emotional costs to physicians providing care to their dying patients.[7–9] Many of these end-of-life experiences are unique and powerful but also intangible, with "smoke-like" qualities.[10,11] However, these challenges also can generate "teaching moments" that result in positive personal and professional growth for palliative care physicians, such as personal reflection skills, more humanistic attitudes toward life and death, and flexible coping skills.[12,13] The literature, albeit sparse, suggests these ineffable end-of-life experiences for palliative physicians are relatively ubiquitous and, therefore, may provide important insights into death and dying, and their personal and professional impact on clinicians.

Visual Storytelling

Medicine has always relied on narratives; for example, medical case histories and patients' first-person accounts of their illness are narratives commonly used in clinical practice. Kleinman[14] and Polkinghorne[15] were early advocates calling for increased attention to patients' illness experiences as sources for significant information for evidence-based clinical practices. Illness narratives are first-person stories organized and communicated through written, oral, and, to a lesser extent, visual texts. They represent ways patients attempt to describe experiences of unfamiliar life disruptions, layers of suffering, ways of coping and adjusting to considerable uncertainty, spiritual and emotional challenges, healing, and their relationships with physicians and other caregivers.[16–18] These stories also actively engage their audiences by inviting them to reflect on the ambiguities, paradoxes, metaphors, and subtleties of illness experiences.[19] Over the past decade, illness narratives have been extended from their original focus on patients' stories to also include clinicians' perspectives and the interpersonal dynamics of patient-clinician experiences. Interactive and contextual use of these stories have played a central role in the emergence of narrative and humanistic medicine, which advocate interpersonal competencies for physicians to promote more sensitive, empathetic, and compassionate skills to the biomedical and nonphysical issues that are part of the patient-clinician relationship.[20–23]

Notwithstanding their use in art therapy, visual narratives are underused compared with their written and oral counterparts in medicine. However, they represent another, and often invisible, component of the illness experience because they are "right-brain" nonlinear depictions of the tacit, intuitive, emotional, and holistic nuances generally referred to as the "aesthetic experience." They make use of visual metaphors to represent new meaning from the more ambiguous and chaotic experiences that can prompt empathy, personal reflection, and transformation.[24–26] Recently, increasing attention has been given to how paintings, drawings, and photographs might be used as visual narratives for providing insights into less visible dimensions of patient-physician relationships. These studies illustrate the potential of visual narratives for triggering reflection to reveal unrecognized features of clinical practices and promote empathetic, compassionate skills that complement and extend clinical practices, for both patient and physician.[27–30] Although oral and written narratives have become generally accepted practices for understanding end-of-life experiences,[31,32] the potential of visual narratives for gaining insights into one of life's most mysterious and challenging events remains untapped. The main goal of this study was to elucidate palliative physicians' core experiences with their patients' dying and death. As many of these experiences are ambiguous, we analyzed physicians' stories of death and dying represented through visual art-based reflections projects.

Methods

Data Collection

This study is a retrospective qualitative analysis of visual reflections narratives created by physicians at the conclusion of a one year palliative medicine fellowship at San Diego Hospice and The Institute for Palliative Medicine (2006–2011). At the end of their training,

fellows were encouraged to express their thoughts and feelings about death and dying through the arts and humanities, including 1) exploring and expressing their humanism, 2) reflecting on core experiences with death and dying, and 3) exploring the intimacy of the physician-patient relationship. Fellows gave signed informed consent to permit use of their projects for educational and research purposes. The projects were photographed and archived by hospice staff.

The 147 available projects included both images ($n = 90$) and written texts ($n = 57$, e.g., poems). This study only used the 90 images collected over the six year period. Poor image quality rendered 15 (17%) unsuitable for analysis, resulting in a final sample of 75 visual reflections narratives.

Data Analysis

Grounded theory principles and procedures appropriate for analyzing the large number of images in our visual narrative data set were used.[33] Our pragmatic approach to coding involved three stages, each of which used procedures to reduce coder bias. First, 12 two-person teams independently used a successive pile-sorting method to code the descriptive content within and across the images. After no new literal content categories could be identified, teams cross-checked their findings with each other until agreement on the basic units that made up the images was reached.[34–36] The coding teams were undergraduate research methods students studying with one of the first authors. To promote intercoder reliability, teams were informed of only the general purpose of the reflections project but were given no specific coding instructions. The second and third coding stages were undertaken by the authors.[2] Using axial coding, the student-generated categories were pile-sorted again into more general categories.[3] Using the general categories, holistic coding was used to identify the two basic themes represented in the visual data. Like the student teams, the authors used sequential cross-checking to reduce bias and error and promote intercoder agreement and interpretive convergence. Grounded theory advocates constructing categories and themes; not as the end products for reporting, but as scaffolding for an interpretive rendering of the meaning being conveyed through the data.[36]

Results

Without exception, student coders reported being initially overwhelmed with the apparent uniqueness and ambiguity of the images. However, after multiple repetitions of the pile-sorting process, the descriptive codes from the teams were remarkably similar; the resulting categories were then used to create a coding taxonomy. Student teams identified six literal descriptive content categories that make up the visual vocabulary found across the visual reflections narratives: oceans, skies, sun, trees, people, and man-made objects (e.g., boats, bridges).

Common overlapping found in the six categories was used by the authors to recode the visual reflections narratives into their two most basic general themes: people ($n = 30$, 40%) and nature ($n = 45$, 60%). Axial coding, including cross-checking coding decisions, was then used to identify five subcategories of types of specific subject matter within the two general themes.

Images in the "people" category were broken into two subcategories: social portraits ($n = 19$, 63%) that included groups of people, such as families and friends (Fig. 1), and individual portraits ($n = 11$, 37%) (Figs. 2 and 3). The "nature" images were organized into four subcategories: "integrated scapes" ($n = 24$, 38%), which consisted of landscapes combined with seascapes ($n = 6$), such as the beach and ocean shore, and abstract representations of nature ($n = 11$), such as a dried wreath; seascapes ($n = 15$, 33%), such as the open ocean or sunsets over the ocean (Figs. 4 and 5); and landscapes ($n = 13$), such as images of trees. The majority of these images did not contain any representations of people or human societies, and nature was the preponderant component in the images that included some type of human representation ($n = 12$, 23%, e.g., Fig. 5).

Discussion

The delivery of palliative care is grounded in patient-clinician interpersonal interactions that in summary become the "illness" experience. The physicians' narratives make use of visual metaphors to express some of the more prevalent yet ambiguous issues that make up these experiences. The work by Lakoff and Johnson illustrates how visual metaphors convey meaning by using bright colors to express

Fig. 1. Social portrait: Prosocial.

Fig. 2. Individual portrait: Transitional pathways.

emotional warmth, spatial depictions of foreground and background express the passing of time, and directions of up express positive hopeful orientations, whereas down represents illness and other negative experiences.[37–39] Notwithstanding expected variations in aesthetic data, the visual narratives include patterns of humanistic insights into the end of life that are worthy of consideration. From the reflections project, one physician reported how important being reflective and empathetic is for both patient and clinician:

> It is important to stop regularly to reflect on how taking care of dying patients is affecting you. Time and space for self-reflections is one thing that maintains my ability to do the difficult job of taking care of patients at the end of life. It helps me … enter [a] patient's room in a more open manner with a clearer mind.

What is expressed and what is absent are equally important contributions to the physicians' stories. For example, in contrast with common stereotypes of death and dying one might expect to see, surprisingly only two images (0.03%) included

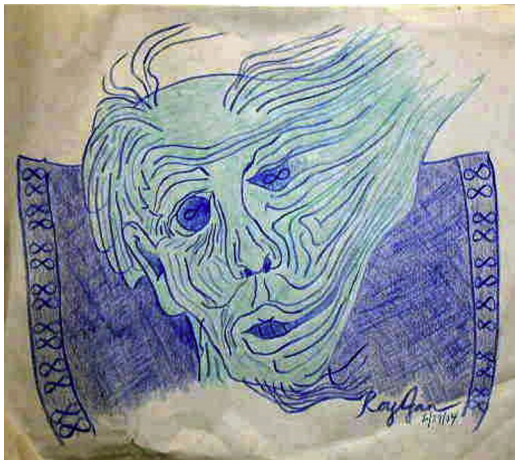

Fig. 3. Individual portrait: Infinite possibilities.

representations of anxiety, pain, or other dimensions of suffering. Signs of clinical medical care are also notably absent. Instead, the visual reflections narratives emphasize humanistic insights by focusing on relationships with people and nature that are positive and hopeful, and death and dying as types of peaceful and spiritual transitions.

Visual metaphors representing the passing of time and the supportive nature of social groups may represent dying as a life transition and the importance of social relationships at the end of life. The unidentifiable, mysterious, and shadowy individual portrayed in Fig. 2 is standing alone and partway across a bridge over a large body of water. The figure appears relaxed, standing in a nonthreatening posture, leaning against the protective fence of the bridge. The bridge offers a wooden walkway and railway track suggesting different ways, speeds, or time it might take someone to traverse to the other side; an unknown and uncertain destination in the far distance. Fig. 3 is also a solo portrait but with the focal point on a lone person's face lying on a soft pillow. Transitional movement is represented by realistic facial features becoming more ambiguous, and that move in an upward direction. Infinity symbols suggest that dying may not result in death as a final absolute state but that the transition itself presents unlimited human potential. Fig. 1 presents a social portrait of a group of soldiers. Because the goal of the reflections projects was to express salient features of dying and death, we infer they are mourning another member of their military community who has recently died. The soldiers form an intimate supportive circle, most kneeling with heads bowed, and their arms around each other, apparently in prayer. The importance of being connected to others, through belonging to a social group, is paramount in this image. In the background is a military vehicle indicating, perhaps, that their present location and circumstances are also transitory. The prominence of prosocial motivations, for an empathetic belonging to a community, is also found among the physicians through the reflections projects as, "… a way of bringing out a deeper part of us, a part of our identity that we do not necessarily express or even always acknowledge, and they helped to bond us into a community of people with a shared purpose."

The second general theme draws our attention to the larger context of our lives: nature. Fig. 4 presents six sequential images of the sun at different positions at the horizon between the sky and ocean. The ocean is depicted as calm, but as the waves indicate, it is in constant motion. It may not be important that we cannot know if the sun's light represents the beginning or end of life. However, the images do convey our lives as inevitably transient, even fleeting. The light is displayed as warm, inviting, and adds serenity

Fig. 4. Seascape: Life cycles.

and spirituality to dying and death in these images. Large-scale images of nature have long been used by painters to represent the sublime and spiritual quality of our lives. Fig. 5 also uses a large body of water in the foreground and a large sun in the background. However, here the ocean is powerful with large waves representing the turbulence and challenges that can accompany the dying process. The boat offers safety, but it is also being violently pitched about. Some of its passengers are ejected from the boat, who are presented as ghost like as they are thrown into the stormy water. Perhaps, this serves to remind us that not all persons have a "good death." Instead, the end of life can involve periods of considerable suffering, such as agitation, emotional turmoil, anxiety, depression, and loneliness. In contrast, human-like figures in the boat are a warm orange color and bathed in a warm bright light that fills the boat as they carry on, in the face of adversity, somehow continuing to manage the sail and rudder, setting a path toward the large radiant sun. The scale of the sun, covering almost one-half of the image, and the intensity of its light suggest more hopeful yet mysterious transformations or spiritual awakenings may lie ahead.

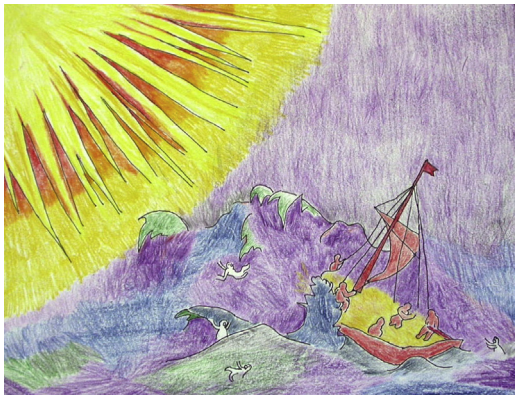

Fig. 5. Seascape: Uncertainty.

Conclusions

There is no doubt that dying patients confront suffering and their physicians face personal and professional challenges while providing palliative care. However, physicians' visual reflections projects summarizing their one year intensive immersion with dying patients do not point to pain and suffering as the central features among the multiple factors that arise in their end-of-life experiences. Instead, emphasis is on the end of life as transitions with uncertain but hopeful destinations; the visual metaphor of dying as another journey for the patient and physician to discover. These insights are not readily observable but can be facilitated through reflections projects. One physician mentor to the fellows noted:

> There is a clinical gestalt when a trainee "gets it." It is enormously difficult to define, let alone measure, "it." Yet, every clinician educator can describe the phenomenon. So many people, inside and outside of medicine, lament that there is something "different" or "missing" in contemporary physicians. I have learned, particularly through the personal reflection project, that every trainee has the potential to "get it"—even the most hardened, cynical, and emotionally unintelligent. The project makes the invisible, visible. Further, it drives personal synthesis into a concrete personal ethic of caring for the clinician.

These positive and transformational nuances of the dying process suggest a resilience has prevailed during confrontations with the fragility of one's mortality, as noted by one physician: "I learned to be thankful to my mentors, co-fellows and teachers; to be more mindful of the spiritual aspect of life; and, of course, improved medical management of EOL issues." This is reminiscent of work by Frankl[40] and Frank[41] illustrating how confronting chronic illness and death can produce a resilience leading to personal development that enriches the meaning of one's life. Within

palliative settings, this resilience serves to enhance patient care and the meaning of clinical practice for physicians.[42] Rather than being rare cases based on individual characteristics, the prevalence of positive themes across the visual narratives supports recent research identifying resilience as a more common occurrence that is often overlooked.[43–45]

Resilience and personal and professional transformations are dependent on how the patient-physician relationship is negotiated over time. The emotional and spiritual features in the physicians' visual narratives reflect the subtle nuances of their empathetic and compassionate relationship with patients. These features support humanistic and prosocial research that argue ineffable and subjective features of relationships become identifiable, and then central to holistic, other-centered interpersonal dynamics leading to positive outcomes, such as improved self-perception and competency, nonverbal skills, sense of responsibility to others and social reciprocity, and patient and physician satisfaction.[21,23,46–48] Through the reflections projects, physicians discovered integrating their clinical skills with their human skills proved to be a rewarding experience. For example, one physician reported, "It gave me an excuse to step outside of usual scientific medicine and to spend time with the other unconscious, human side. I constantly need more reminders to do so," whereas another stated, "It helped me to process my work experiences so that I could be more present in my personal life."

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