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The Dialectics of Care: Communicative Choices at the End of Life

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Communication at the end of life poses important challenges for patients, families, and care-givers. Previous research on end-of-life communication has concentrated on areas including the provision of bad news and clinical and personal decision making. In this study, we turn our attention to the processes through which caregivers provide comfort in palliative care. Our ethnographic and interview study of spiritual communication among hospice workers and their patients is guided by a dialectical framework. We find a central dialectic in which hospice workers recognize the tension between "leading" and "following" patients and families in discussions of spirituality at the end of life. Our analysis reveals that though some care providers choose one pole of this dialectic, most workers try to manage the dialectic by shifting between leading and following in different situations or different points in time or by transcending the dialectic and addressing the multiple goals of interaction.

Death is inevitable, and while there is no way out, there is a way through. (McPhee, Rabow, Pantilat, Markowitz, and Winker, 2000, p. 2513)

The desire for a "good death" is perhaps universal, though such a wish might mean different things for different people. The idealized version of a "good death" is, perhaps, death during sleep, a quick and painless death, or death surrounded by loved ones at home (see, e.g., Meador, 2005; Wittenberg-Lyles, 2006). A number of forces in the United States have increased the need to evaluate end-of-life concerns and focused our attention on ways in which the process of dying can be improved. For example, the population of America is aging. In 2005 there were 36.8 million people over the age of 65 years (12.4% of the U.S. population), and by the year 2030 this number will grow to 71.5 million (20% of the population) (Administration on Aging, 2007). In addition, Americans increasingly die of chronic diseases. For example, of the 10 leading causes of death in the United States reported in 2004, most were chronic conditions requiring long-term end-of-life care (National Center for Health Statistics, 2004). Further, as family size decreases and mobility increases, we often turn to professionals to help us through the final stages of dying. For example, patients served by hospice increased from just under 500,000 in 1997 to 1.3 million in 2006 (National Hospice and Palliative Care Organization [NHPCO], 2007). This is not to say that families are not intimately involved in end-of-life care. Indeed, Piercy and Chapman (2001) note that "despite persistent myths that families abandon their aged relatives to nursing homes and other care facilities, reviews of research findings show that family members provide the majority of assistance needed by their dependent elders" (p. 386). However, it is clear that individuals and family members are not always equipped to deal with the difficulties of end-of-life care. Thus, it is of little surprise that recent years have seen an increase in research attention to ways in which individuals, families, and professionals cope with the variety of challenges faced during the final months of life.

In this article, we consider these challenges through a study of end-of-life communication with hospice professionals and

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volunteers. We begin by briefly considering the literature on communication at the end of life, pointing to the importance of additional research studying the communication of comfort care. We then propose a research question that we investigate through a dialectical analysis of observations and stories of professionals and volunteers working with dying patients.

COMMUNICATING AT THE END OF LIFE

Scholars in communication and health disciplines have considered important issues of end-of-life communication for many years. For example, there is extensive literature on ways in which health care professionals provide "bad news" to patients. Early research on "death-telling" (e.g., Clark & LaBeff, 1982; Davis, 1991) suggests that practitioners can use several "delivery tactics," and that issues such as support, empowerment, and provision of information all contribute to patient satisfaction. More recently, scholars have argued that communicating bad news requires a variety of complex communicative choices (Gillotti, Thompson, & McNeilis, 2002), that health professionals should tailor their messages to the needs of individual patients (Sparks, Villagran, Parker-Raley, & Cunningham, 2007), and that communication regarding a terminal prognosis should involve team-based and family communication and a variety of topical approaches (Wittenberg-Lyles, Goldsmith, Sanchez-Reilly, & Ragan, 2008).

Other scholarship considering communication at the end of life has concentrated on the array of decisions required as death approaches. This work tends to take one of two approaches. First, some research considers aspects of clinical decision making (particularly involving health care professionals) at the end of life. For example, Barton, Aldridge, Trimble, and Vidovic (2005) describe the stages of end-of-life discussions in a surgical intensive care unit where talk moves from general descriptions of status through holistic decision making and to a discussion of the logistics of dying. Studies also consider the clinical decision to withdraw life support and treatment, arguing for ethical frames that account for both medical and nonmedical factors (see, e.g., Barton, 2007). In contrast to this clinical emphasis, other studies place more attention on the decisions made by patients and families, particularly in the area of formulating advanced directives (e.g., Hines, 2001; Young & Rodriguez, 2006).

These areas of research have considered important concerns that face individuals, families, and health care professionals as they deal with end-of-life issues. However, this research also illustrates the attention often paid to factors such as "decisions" and "bad news," rather than a focus on issues that are both more mundane and more meaningful. For it is becoming increasingly clear that the most important issues at the end of life are not decisions about treatment, funeral plans, or estates, but concerns with comfort, spirituality,

and life significance. For example, a study of factors considered important at the end of life by patients, families, and providers found that "whereas physicians tend to focus on physical aspects, patients and families tend to view the end of life with broader psychosocial and spiritual meaning, shaped by a lifetime of experience" (Steinhauser et al., 2000, p. 2482). The work of Maureen Keeley and Julie Yingling (Keeley, 2007; Keeley & Yingling, 2007) looking at the "final conversations" that the dying have with their loved ones illustrates this point. Their research reveals five themes in these final conversations—love, identity, spirituality, everyday talk, and relational difficulty—and Yingling and Keeley (2007, p. 95) note that these "final conversations demonstrate that the communication that occurs at the end of life involves more than pain, caregiving, dying and funeral arrangements. They tell us that communication at the end of life is as valuable to the surviving partner in the conversation as it is to the dying one." Similarly, Ragan, Wittenberg, and Hall (2003) have called for increased research on concerns of "meaning" in palliative care, arguing that "all patients, terminal or otherwise, want pain and other noxious symptom management, but patients and their families and caretakers also realize that there are other, equally important concerns at the end of life" (Ragan et al., 2003, p. 221).

Scholars have begun to address these concerns. For example, several recent reviews of literature in this area point to the importance of existential and spiritual concerns at the end of life (Kaut, 2002), and argue for integrating discussions of spirituality within other clinical conversations (Sinclair, Pereira, & Raffin, 2006). There is also some writing that provides care professionals—especially physicians—with advice about how to best address psychosocial and spiritual issues at the end of life (see, e.g., Holmes, Rabow, & Dibble, 2006; Lo et al., 2002; Quill, 2000). Indeed, Holmes et al. (2006) note that physicians are becoming increasingly inclined to provide various kinds of spiritual care to dying patients. However, most of the work in this area still concentrates on the role that meaning and spirituality may play in helping patients and clinicians make decisions about care. For example, in a table considering "What to Include in Most End-of-Life Discussions" (Quill, 2000), most issues concerned clinical choice points (e.g., DNR [do not resuscitate] orders, other life-sustaining therapies). Only two subpoints in the table note the importance of considering "relief of psychological, social, spiritual, and existential suffering" and "creating opportunity to address unfinished business" (Quill, 2000, p. 2505). This focus on clinical decisions is not surprising, as most practitioners believe that "the roles of physician and spiritual counselor usually are best kept separated" (Lo et al., 2002, p. 751).

However, physicians and other caregivers are often faced with the task of providing comfort to dying patients and their families. For example, Elaine Wittenberg-Lyles and her colleagues have examined published narratives of health

care professionals and the stories of hospice volunteers to document the central role of comfort communication at the end of life (Wittenberg-Lyles, 2006; Wittenberg-Lyles, Greene, & Sanchez-Reilly, 2007). In a recent correlational study of hospice patients, Prince-Paul (2008) found strong positive relationships between self-reports of communication regarding love and gratitude and social and spiritual well-being. These studies clearly point to the importance of communication in palliative care, but do not address specifics about the process of communicating comfort at the end of life. Our goal in the current research project, then, is to continue in the direction of these investigations by considering the process through which health care professionals and volunteers communicate and provide comfort to patients and families about important issues of meaning and spirituality. Because of the limited research that has considered the process of communication in palliative care, we take a descriptive approach guided by this general research question:

> *General Research Question:* How do caregivers communicate in providing comfort to patients and families at the end of life?

In approaching this general research question, we were confronted with the need to make several critical conceptual choices. These involved the issues of "who" we should consider in our study of end-of-life caregivers, "what" kind of communication content would be the focus of our research, and "how" we would frame our analysis of care and communication at the end of life.

In considering the question of "who," we immediately turned to the hospice movement. The use of hospice services has increased dramatically in recent years—as of 2004, more than 3,300 hospices were operating in the United States (National Hospice and Palliative Care Organization, 2004). The hospice movement, founded by Dame Cicely Saunders, has its roots in the belief that dying patients require utmost respect in their final days. Mackay and Sparling (2000) identify six basic principles followed by hospice including (1) affirming life and viewing death as a natural process; (2) neither hastening nor postponing death; (3) providing relief from distressing symptoms and pain; (4) integrating spiritual and psychological aspects of care giving; (5) offering a support structure to assist patients in living as actively as possible until death; and (6) offering a support system that helps families cope during the patient's illness and their bereavement (p. 460). Thus, the concerns of hospice are in line with our focus on the communication of comfort during the end of life. Further, hospice workers are generally regarded as successful in their end-of-life communication. For example, in a study of hospice patients, Pevey (2005) found that an overwhelming majority of respondents were satisfied with hospice communication and found great comfort in interaction with hospice workers.

In considering the "what" of our research question, we decided to turn our attention to communication regarding spiritual concerns at the end of life. Spiritual concerns are clearly of central interest to dying patients and their families. Further, within hospice, spirituality is seen as a critical component of care, though the concept of spirituality has evolved from a monotheistic approach based on Christian theology to a view emphasizing concepts of meaning and connection (Bradshaw, 1996). Dame Saunders was clear, however, in stating that "spiritual care was not an 'optional extra'" (O'Connor & Kaplan, 1986, p. 53). This focus in hospice follows a growing trend in many health care settings. Daaleman and Vandecreek (2000, p. 2515) note that "although there are multiple interpretations of spirituality within health care settings, constructs of meaning or a sense of life's purpose have been suggested as primary components." However, most care providers find issues of spirituality difficult to wrestle with (see, e.g., Lo et al., 2002; Quill, 2000). Many caregivers have little training in spiritual issues and are uncomfortable in discussions of existential concerns that are fraught with the possibility of misunderstanding. Thus, a consideration of spirituality in end-of-life communication is likely to reveal many of the more difficult challenges faced by caregivers.

Finally, in considering the conceptual question of "how" we would frame our analysis, we were struck by the complexities of end-of-life communication. There is no rulebook for interacting with dying patients and their families, and scholars repeatedly note that these interactions are complicated by factors ranging from health status to culture and ethnicity to personal belief systems to family dynamics. Given the complexity of the process, we were drawn to concepts from relational dialectics (Baxter, 1990; Baxter & Montgomery, 1996), an approach that emphasizes the messiness of communication in personal relationships. Central to a dialectical approach is the concept of contradiction, or "the dynamic interplay between unified opposites" (Baxter & Montgomery, 1998, p. 4). These contradictions may involve, for instance, the tension between autonomy and connection or between concealment and disclosure in relationships. Whatever the contradictions, a dialectical approach suggests that these tensions are not necessarily resolved, but are coped with in the give and take of interaction and in the over-time change and development of relationships. These dialectical tensions are likely to be particularly apparent in end-of-life interaction, as patients and their families cope with competing forces of connection and separation, of stability and change, of openness and privacy, of life and death.

Thus, given these conceptual choices about the framing of our general research goal, we pose the following specific research question:

> *Specific Research Question:* How do hospice workers and volunteers manage the dialectics of interaction in discussing issues of spirituality with patients and families at the end of life?

METHODS

To address our research question, we analyzed data drawn from a 5-month ethnographic study[1] of hospice care provision. Ethnographic methods have been suggested as an ideal approach for research on topics like this in which major concerns revolve around meaning making and interpretation (Gonzalez, 2003; McRoberts, 2004), as these methods allow for prolonged interaction, opportunities to forge relationships, and the chance to probe for underlying understandings of situations. Data collection for the ethnography was completed by the senior author, and both authors participated in discussions regarding the analysis and interpretation of results. Ethical concerns made it impossible to actually observe interaction between hospice workers and volunteers and the patients and families to whom they provided care. However, by establishing trust with members of the organization, through long-term immersion in the day-to-day activities of the hospice, and by carefully listening to caregiver stories, we feel confident in our understanding of how caregivers approach their interaction with patients and families.

Research Context and Participants

Central County Hospice (CCH)[2] is a mid-size hospice in the South with two offices serving 17 counties. CCH was chosen for this study partly because of its commitment to holistic end-of-life health care, including palliative, emotional, and spiritual support to the patient and the entire family. Care is provided to all people in need without regard to race, age, faith, diagnosis, or ability to pay. CCH serves an average of 600 patients per year, with an average daily census of 77 patients. The hospice care team includes the patient's physician, hospice physician, skilled hospice nurse, medical social worker, certified hospice care aid, chaplain, volunteer coordinator, bereavement coordinator, and community volunteers. CCH has 65 full-time employees located in two offices. In addition to paid staff, CCH is supported by strong volunteer support (24,000 annual hours of volunteer service).

Data Sources and Procedures

Over the course of 5 months, the senior author spent 230 hours as a participant observer at CCH, attending functions including interdisciplinary team meetings, bereavement groups, community memorial services, staff retreats, and volunteer trainings. This observation period included job shadowing in several areas of the hospice including social work, medical records, bereavement, and reception, participation as a counselor at a day-long camp for bereaved children, and four day-long "ride-alongs" with the marketing liaisons, a nurse, a social worker, and a chaplain. These observations generated 239 single-spaced pages of field notes.

The second major source of data is 42 semistructured in-depth interviews. Interview participants included social workers, nurses, volunteers, care aides, bereavement staff, the organization president, the volunteer coordinators, medical records staff, receptionists, marketing staff, and the chaplains. All members of the management staff were interviewed and at least one representative of each organizational division was interviewed. The interview protocol was semistructured and included a wide range of issues regarding spirituality in the workplace and interaction with patients and families. The protocol and interview procedures were designed to encourage the sharing of narratives about hospice and the care process. All interview audio recordings were transcribed, yielding 419 single-spaced pages.

Finally, we also analyzed a variety of organizational documents, including training manuals, website postings, annual reports, newsletters, brochures, and articles about CCH in the local newspaper. These documents totaled over 400 pages.

Data Analysis and Interpretation

All transcripts, notes from organizational documents, and field notes were uploaded into Atlas.ti, a qualitative software analysis program. This program was used to sort, separate, and categorize the various data sources using the constant comparative method of data analysis (Strauss & Corbin, 1990). This initial sorting generated a number of major categories related to care provision, organizational and personal spirituality, and stress management strategies. The specific data, stories, and comments relied on for this article came from a variety of these categories, but especially the category of spirituality and patient care. Data were analyzed through the process of axial coding, wherein codes and categories are compared to find connections and themes (Strauss & Corbin, 1990). Several strategies were used to verify the trustworthiness of the qualitative data: prolonged engagement (over 230 hours spent in the organization), triangulation (use of multiple data sources and methods), and member checks with two key organizational members.

RESULTS

Our analysis of observations, interviews, and archives regarding communication at CCH showed that the provision

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[1]This research is part of a larger study on organizational spirituality, communication, and care in hospice settings. This paper highlights issues of care provision in interaction with patients and families. All procedures were approved by the university's Institutional Review Board.

[2]To protect anonymity, pseudonyms are used for the organization and all participants.

of comfort at the end of life involves a complex set of inter-actional choices. Hospice workers provide physical, emo-tional, and spiritual support for patients and families in the most difficult of situations. Though a variety of "classic" dialectics might be considered in an analysis of these com-munication patterns (e.g., tensions related to autonomy or disclosure), the data we considered led us to concentrate on one central dialectic that enabled and constrained the provi-sion of care. This was the dialectic between "leading" and "following" in communication, especially regarding issues of spirituality. In this section, we first discuss the two poles of the dialectic and then consider the ways in which care providers at CCH negotiated the dialectic in interaction with patients and families.

Hospice Workers as Followers

At hospice, patients and families are viewed as care experts and hospice workers as novices. During volunteer training, Steve, the chief executive officer (CEO) at CCH, shared a story illustrating this philosophy. The story begins as hos-pice staff members enter a hospital room and see a husband caring for his wife. He puts a fan at the bottom of her bed and wipes her face with water to keep her skin moistened. The staff members note this and then walk to the next room where they find another wife caring for her husband. In this room, she puts a scarf over the lights because their bright-ness hurts her husband's eyes. The staff members move on to the third room where they find an elderly man wrapping newspapers in towels and placing them under his wife's legs to protect her paper-thin skin from the bed. The staff members in the story then go back to their offices, put on their badges, and collect their degrees. Then they recreate the stories from the families and sell them as medical news. They attach big words to the simple acts of love, suggesting the use of dimmer lights to protect eyes from photophobia, or sterile positioning pads to pamper sensitive skin. In con-cluding this story, Steve states, "We learned and we still learn every day from the families." This story clearly places patients, and especially families, as key knowledge holders in the care provision relationship.

Because patients and family members are the experts, hospice workers must learn from them how to meet their needs for comfort and spiritual care. Steve teaches this as a process of "walking the stepping stones." He states:

> I've said, "People lay down the stepping-stones that they want you to walk." So when you walk in the house or when you pull in the driveway and there is one of those bird bathtubs and it has Madonna in the middle of it, you have a clue, you have your first clue. Then they will use vernacular. They'll start saying, "Oh I'm glad you are here. You are just like the Holy Father or the Holy Mother" and this or that. So, and it is not only the religious terms. They will lay down and say things and you, your responsibility is to listen . . . Then you've really demonstrated responding.

Michael, the hospice chaplain, teaches a similar philosophy to volunteers. During training, we were provided a handout of the "Three H's" of spiritual care: "Hang around, Hug 'em (if they are open to being touched) and Hush." "Hanging around" entails spending time with patients in an effort to develop a connection. The bracketed caveat after "Hug 'em" clearly illustrates the need to first determine the patient's wishes. Finally, "Hush" is a reminder that most of the job of comfort care is accomplished through listening to the patient.

With regard to spiritual care, this philosophy of begin-ning with the patient's needs is guided by an understanding of spirituality as both potentially helpful and potentially harmful. Certainly, spiritual meaning-making can be important in the face of death and spirituality may be a powerful source of coping. Steve states, "I think we try to acknowledge spiri-tuality because you realize that it is a source of energy, it is a source of coping." Unfortunately, spirituality can also be used as a source of judgment and condemnation. It is the fear of the latter that worries the CEO and affirms the need for a strong organizational rule regarding spiritual care.

Thus, CCH's organizational rules—and the training provided by organizational leaders such as the CEO and chaplain—pull care providers toward the following side of the dialectic. In some circumstances, however, the stepping-stones may not be present and care providers are forced to adapt. In order to provide comfort and spiritual care at the end of life, they might have to lead the patient. Care provid-ers may also be drawn toward the leading side of the dialec-tic by their own belief system or by the patient's family members. In the next section, we examine the factors that pull hospice workers toward the leading end of the dialectic.

Hospice Workers as Leaders

While family members are experts in their own individual circumstances, hospice workers are experts when it comes to the death and dying process. In a world in which no one likes to talk about death and dying, this expertise can become crucial to families at life's end. At the most basic level, hospice workers are experts—and hence called on to lead interaction—in the medical management of the dying process. They know what interventions bring the most com-fort and which medications work best for particular dis-eases. However, hospice workers' expertise is not limited to the medical management of the dying process. Hospice workers also have extensive knowledge about the spiritual and emotional processes of both patients and family mem-bers, and they may find themselves called to lead in these areas as well.

This leadership role is clearly illustrated in discussions of death and dying. In talking about death, Maria, a nurse, states, "It's like the elephant in the room. Everybody knows it's there, everybody can see it. It's very, very obvious but nobody wants to talk about it. I think the first thing that

I normally see when I'm going in for the first time is fear. That's when I start talking about it. I do. That was hard to start talking about death but once you start talking about it, it's like they really open up." Many caregivers noted that providing openings for conversation is particularly important when it comes to spiritual care, because if a patient isn't facing up to death, the person is probably also avoiding the spiritual processing that often accompanies the dying process.

Also pushing care providers toward the "leading" side of the dialectic is the knowledge that patients may have a difficult time bringing up spiritual issues. Susan, a nurse, noted that many patients have visions of heaven or loved ones who have died, but don't talk about them because they are afraid that others will think they are "crazy." However, in this nurse's experience, once the door has been opened to these discussions, patients often have lots of questions and stories and are relieved that they can finally talk about these issues.

Care providers may also feel called to lead in these discussions by their own personal spiritual beliefs. Janet, a nurse, states, "I know I've accepted Jesus as my personal Savior because I believe without a relationship with Him you can't enter heaven. I really believe without a shadow of a doubt that I'm saved and that's where I'm going and I want to bring some more people with me." In this care provider's view, death is a crucial point at which an individual's eternal destiny is decided, and she feels called to take action to do as much as she can to make sure the patient is going to heaven.

Finally, care providers may feel pressured by family members to "lead" discussions about spiritual issues. Greg, a social worker, tells us, "The part that was the hardest for me is having a couple of patients who have been atheists, and the family really wants them 'fixed' before they die." This comment highlights the fact that end-of-life communication is not a simple relationship between care provider and care recipient, but is embedded within larger family and organizational systems.

In sum, care providers' own spiritual beliefs, their expert knowledge of death and dying, and pressure from a patient's family may push them toward the "Leading" side of the dialectic while organizational rules and the hospice philosophy may push them toward the "Following" side of the dialectic. In the next section of our analysis, we consider the ways in which hospice workers and volunteers negotiated the tension between leading and following in interaction with patients and families.

Managing the Dialectic

Balancing and negotiating dialectical tensions in interaction is never easy. However, managing relational dialectics in the hospice setting is particularly challenging, as the imminent reality of death puts significant pressure upon family and care relationships. In other relationships, we may operate with the perceived luxury of time, believing that we can always apologize later or undo our relational mistakes. In hospice relationships, the future is tenuous at best, and Steve took care to make sure all volunteers were aware of these issues during training. He told them, "You can make a mistake with medicine, you can bruise someone during catheterization, you can misdiagnose a decubito. You can even drop them on the floor when you're moving them to a commode or something and those things happen and there is a comeback, there is a cure, there is a resolution to that, but, if you screw up someone's spirituality in the last few hours of their life, you've messed them up for eternity and that is unforgivable." As we move forward in examining these dialectic management strategies, we need to remember that for all the participants involved, these choices may literally feel as if they are about eternal life and death. Our analysis revealed three main techniques for managing these dialectics. First, care providers may select one side of the dialectic and deny the other. Second, care providers may use processes of segmentation and spiraling inversion as they vacillate between the two poles of the dialectic. Finally, care providers may attempt to transcend the dialectic by managing multiple goals.

Selection and denial.   One common way to manage relational tension is to choose one pole and operate as if the other doesn't exist (Baxter & Montgomery, 1996). A small minority of hospice workers chose this management strategy. One hospice volunteer always chose the strategy of leading patients by offering to pray with them as Ashley, the volunteer coordinator, describes:

> One volunteer in particular, David, he is a retired missionary and he is just so sweet and sensitive. He never leaves the home without asking a family if he can have a prayer with them. Now, regardless of what religion you are, most people say, "Oh I'd love for you to pray for me." Most people really want prayer, so he will pray for them.

In this case, the "following" pole of the dialectic is delegitimized because the underlying cause for the organizational philosophy of "leading"—the fear that bringing up one's own spirituality could be offensive—is believed to be unfounded. This quote suggests these fears are unfounded for two reasons: the volunteer's "sweet and sensitive" nature and the fact that "regardless of what religion you are, most people say, 'Oh I'd love for you to pray for me.'"

In contrast, one care provider was much more comfortable with the "following" strategy because of her personal experience and organizational mandate. Susan states, "I really don't get into that because I don't really know what everybody believes. I'm not going to overstep bounds or anything like that. I'm just there to reiterate how they believe and make sure they're comfortable with all of that . . . People are so funny about religion anyway. They want religion but they don't want something pushed upon them. It's got to come from within."

Segmentation and spiraling inversion. A second method for managing these dialectics is by switching between leading and following in interaction depending upon the situation, the time, or the topic (Baxter & Montgomery, 1996; Tracy, 2004). Segmentation involves choosing one strategy for one topic area or individual and the opposite strategy for another. For example, some care providers would lead during discussions about medical issues (where they had strong expertise), but follow during discussions about spiritual issues.

Another method of segmentation was to lead the family, but to follow the patient. This strategy was common in managing reactions to patients' visions. Twenty percent of patient stories told described an incident in which care providers witnessed or discussed visions with patients or family members. In these cases, care providers would always follow the patient. When patients said they were seeing deceased family members or images of people in white, care providers would encourage them to share the visions and ask for more information. While it was easy to follow the patient in affirming these visions, often the family had to be led to be supportive. Amanda, a social worker, argues, "I don't think families should go, 'No, that's not Aunt Ruth over there, that's the lamp.' I think if they're there and they are saying, 'Ruth's over there in the corner,' well then we should say, 'What's Ruth doing?' or 'What's she saying to you? What does she want?'" When family members were afraid of these visions, care providers tried to educate family members about the dying process.

Care providers may also segment the dialectic by following the family, and leading the patient. The following story from Tina, the bereavement coordinator, illustrates this approach:

> There was another nurse that I worked with and she had been with Hospice forever . . . She was talking about one time this guy that was dying, she said he was just horrible. It was just like he was scared and he would call the wife. He would hang on to her and say, "Don't let them get me" and it was like he was terrified. She said it was just scary and [the nurse] was saying that he has to believe in God so he can be at peace with this, and the wife said, "How do I do that?" She quickly told her, you know, that he has to believe that he can ask for forgiveness for whatever he has done. He did, and suddenly he had peace and she said he died like that night, you know.

This story also illustrates another common process of segmentation in which leading and following were segmented in terms of initiating and engaging the topic of spirituality. These care providers waited for patients to lead by providing some sort of opening to discuss spiritual issues. Once patients had initiated spiritual conversations, care providers felt more comfortable in leading the content of the conversation to a particular solution. This solution might be the subsequent visit of a chaplain or it might be a comment based on the care provider's personal convictions. One of

the volunteers, Leona, was directly asked a difficult spiritual question. This "leading" question from a patient provided the volunteer with an opportunity to share her own beliefs.

> About three to four weeks before he died, one day he was sitting there and we were watching the news. We didn't talk really about religion or God. You know you have to feel your way because we cannot bring it up, it has to be their idea . . . This man was 90 years old and had been in the Marines during World War II. This one day he was sitting up there and he said, "You know I wonder if God's going to hold us responsible for the lives we took during war time?" Well I blinked a couple of times and I said, "Lord I need help here." He didn't say anything else and I waited for awhile thinking there would be more of this conversation . . . I finally said, "Well Mr. Davis, I don't think God is going to hold anybody responsible for killing a person who was trying to take away their freedom of existence or their freedom of religion or anything that is really good."

In sum, care providers might segment the dialectic by leading in discussions about medical care and following in discussions about spiritual care, by leading families and following patients, by following families and leading patients, and by leading in content of spiritual discussions but only when patients provide an "opening" to follow.

The next management strategy is spiraling inversion. Spiraling inversion involves an "ebb and flow" between each pole of the dialectic over time (Baxter & Montgomery, 1996). Most care providers spent the majority of their time following patients and family members, but special circumstances would cause them to choose to lead. Following was considered essential, especially in the early stages of relationship development, as Tiffany, a care aide, recounts,

> I would sit back and listen, quietly listen. I would sit in the corner and listen to this family and each person who was talking and the person who was going to be there every day or every other day or whatever. I would listen and kind of get a feel of how this person was going to react to this that or the other. Some of them, you could go meet them and it was really lively and it was OK, and with others you had to be very quiet . . . You'd hear things and just go. You could be bubbly one day and the next day "I don't want to do this." You have to adapt, and read the family; read the person you're going to mingle with.

Once care providers had developed a relationship with patients, they felt more comfortable leading the interaction, and perhaps engaging them in spiritual discussions. Maria, a nurse, states, "Now the ones I do get closer to are the ones who believe like I do. You can talk more freely, you have a connection. That does play a part in this." Kassidy, a care aide, feels the same and says, "When you found a spiritual based family that can relate to what you are saying, that's you know, a Christian family, it puts a little more into it because you relate better to them."

In addition to time, in some moments care providers' "intuition" might push them toward the leading side of the

dialectic. Tina, the bereavement coordinator, tells a story about giving direct advice about intense family issues. She initially notes that "as a social worker I had always been taught, you know, you never say 'this is what you need to do.' You just lead them, like what are your options and what do you think, and that kind of thing." But when Tina was confronted with a dying patient whose husband wanted to bring an estranged son back into the family fold, she went against this professional training. "I do not know what led me, maybe God led me to say it, and I said, 'This is what you need to do.' I said, 'You need to just go ahead and call him, and tell him that Hospice says she is dying, and it probably won't be more than a couple of days, and say if you want to say anything to her, you know, this is the time.'" Tina saw a happy ending to the story, as the son came to his mother's bedside. Her intuition—or her faith—suggested a deviation from the professional training that dictated "following" in much end-of-life care.

Managing multiple goals.   Finally, some care providers used creative communication strategies to transcend the leading-following dialectic. One of these strategies was to "lead" with open-ended questions that would allow the patient or family to talk about a variety of issues, including spirituality if desired. For example, Mary, a nurse, states, "You can always ask and you say it in such a way that it is not pushy. What is it that you need? What do you want to tell me about how you're feeling right now? . . . Most everybody lets their hair down and they'll tell you what they need."

A second strategy in which hospice workers helped lead patients in processing their spiritual issues without leading in terms of content was to answer patients' questions with more questions. Greg, a social worker, illustrates this technique:

> I had a minister on services . . . He had ALS, which is terminal, there is no cure, but he had his whole congregation praying for him and they were praying for a miracle. The wife knew he was going to die, the wife knew the stages of the disease progression, and he just refused to acknowledge that. So they sent me out there to address these end-of-life issues with him. So the way I handle it, I did not know what I was going to do until I got there, and it was so "What if what you have planned is not really what God has planned for you? What if this isn't really the way it is going to go? What have you done to prepare for that? So what is your plan B?" We just kind of took this back a step and I think faith and hope and all those things are wonderful things, and you should keep praying and, yes, miracles happen, but what if it really is your time? How do you make sure your life is taken care of?

By responding to the patient's and wife's questions about the dying process with more questions, Greg was able to deflect the conversation away from Greg's personal beliefs and focus on the beliefs and concerns of the patient and family. In this technique, the care provider assumes the leading role of processor or counselor, but does not give direct advice or offer answers.

The strategies of segmentation, spiraling inversion, and managing multiple goals capture the fluid notion of care provider–care recipient relationships and allow for significant adaptation to different circumstances. Although this process was very comfortable for some care providers, adaptation was difficult when there was a disjuncture between a care provider's beliefs and his or her organizational role. This created a paradox in which to obey the dictates of one role was to disobey the dictates of another. Dialectical tensions become pragmatic paradoxes when individuals perceive them as double binds (McGuire, Dougherty, & Atkinson, 2006; Tracy, 2004). The tensions faced by one Christian nurse caring for an atheist patient illustrate how the hospice injunction to follow the patient can become oppositional to the evangelical dictate to lead people to Christianity. Amy, a supervisor in the office, relates the story that had been shared with her by a nurse:

> [The patient] wasn't religious. He didn't want to see the chaplain, and I remember that nurse giving a report when he died. She went there, and he said, "It's hot, my bed's on fire. It's hot, it's hot, it's hot. The Devil's in here, it's hot, it's hot." That just forever sticks with you because he, of course, the nurse who was there couldn't see anything. But he was just like, "It's hot, it's hot, and it's hot. There's fire under me. There's fire under my bed." This man had a real bad history, you know, he beat his kids. I know it's just like gosh, those stories they do stick with you.

In responding to this situation, the nurse stayed firmly in her organizational role at CCH and provided the patient with more morphine to ease his pain. Her feeling was that the man had clearly expressed his spiritual wishes by declining the hospice chaplain and she felt bound to follow that request. While this solution was clearly justified when framed within the hospice rules, when she interpreted her decision later according to her spiritual belief system, the nurse experienced significant distress and she went to her Christian friend Amy for social support. This story demonstrates the difficulties that care providers can have meshing their own spiritual belief system with organizational policies.

SUMMARY AND DISCUSSION

In summary, this analysis incorporated dialectic theory as a lens to explore the process of end-of-life care as enacted by hospice workers. Analysis of patient care stories, observations, and archives demonstrated that care providers must manage the dialectical tensions of leading and following as they seek to comfort patients and family members. Pressures to follow came from organizational rules and the hospice philosophy, while pressures to lead came from patients' family members, care providers' spiritual perspectives, and care providers' expert knowledge. This leading–following dialectic was managed through the processes of selection

and denial, segmentation, and spiraling inversion. In some cases, care providers attempted to transcend the dialectic and manage both goals by leading the process of spiritual discussions, but allowing patients to direct the content. Finally, some care providers experienced the dialectic as a pragmatic paradox causing them to experience significant role conflict.

The finding that "leading and following" is a central dialectic in end-of-life care is in line with some of our widely held ideas about health communication. For example, in considering issues of patient-centered care, scholars point to the patient's expertise in experience and the provider's expertise in medical matters and suggest that providers should "follow" the patient in eliciting information about the patient's life world (e.g., Bennett & Irwin, 1997; Vanderford, Jenks, & Sharf, 1997). In this area of research, patient participation in medical consultations is seen as providing valuable benefits in medical decision making (Street, 2007). Models that recognize varying spheres of expertise are also represented in the literature on end-of-life care. For example, Quill (2000, p. 2506) points out that "the physician must ultimately guide the discussion to the most critical medical aspects of the decision," but Lo et al. (2002, p. 753), in discussing spirituality concerns, argue that physicians "should respect the patient's views and follow the patient's lead in exploring how these issues affect their decisions about medical care, cause distress, or provide comfort." These writers would probably not be surprised about one basic finding in our study—that providers often led discussions in medical matters but followed in matters of spirituality.

However, our discussions with and observations of hospice workers revealed that managing the leading and following dialectic was not as simple as these prescriptions would suggest. Indeed, decisions about leading and following were also influenced by family members, by the care provider's own belief system, by organizational norms, by the ongoing development of the relationship, and by the moment-to-moment movement of the conversation. In many ways, these hospice workers followed the pattern noted by Miller (2007) in her study of a variety of workers in "compassionate careers." These individuals described compassion work as involving processes of noticing, connecting, and responding. Processes of noticing are analogous to the hospice idea of following the stepping-stones—looking for clues about care recipient needs and following the agenda the care recipient sets. Then, in the processes of connecting and responding, care providers make the complex decisions about the best way to relate to the specific patient and the ongoing communicative choices of interaction.

Our findings provide important directions for future research and practice. With regard to scholarship, this study provided an initial descriptive look at how hospice workers manage the complicated process of providing comfort at the end of life. Though past research (and our experience in this hospice) suggests that these workers are largely successful in their efforts to provide care, future work should look more specifically at how patients and family members feel about the ways in which comfort care and spiritual guidance are provided. Further, our study revealed that these choices were often viewed as challenging and paradoxical by the care providers; these complex issues could be further explored by considering issues of identity and authenticity in the workplace (Tracy & Tretheway, 2005).

Finally, our results suggest ways in which training can be provided for care providers working with patients and families at the end of life. The medical literature provides several models designed to help physicians and other caregivers deal with issues of spirituality at the end of life. For example, the "FICA" model for taking spiritual histories (Puchalski, 2002) suggests that professionals and volunteers should ask questions about faith and belief, the importance of spirituality, membership in a spiritual or faith community, and how the patient prefers to have spirituality addressed during care. Evans, Tulsky, Back, and Arnold (2006) provide oncologists with several communication strategies at the end of life, including an "ask–tell–ask" policy that suggests a purposive balancing of leading and following in interaction with patients. It is clear, though, that there is not a single "cookie-cutter" approach to leading and following in conversations about spirituality and meaning as death approaches, and our results point to some of the complexities and choice points that could be covered in ongoing training. Caregivers should know that a simple dictate to "follow their lead" is not always possible or desirable. Rather, caregivers should be pointed to ways in which information about family and the ongoing development of the relationship can guide decisions about the management of these difficult conversations. Further, caregivers should be trained in specific communication strategies that might help to "transcend the dialectic" by responding to multiple goals and should be aware of the influence of their own belief systems on decisions about communication in palliative care. Katz and Genevay (2002, p. 338) suggest that when caregivers are aware of their own feelings and vulnerabilities they can "grow in awareness and in [the] capacity to be more effective helpers." This is never more important than when facing the challenge of providing comfort at the end of life.

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