

Inside Patients' Homes: A Metaphorical Analysis of Home Hospice Nurses' Experiences Working With Dying Patients

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Abstract

This study examined the metaphors used by home hospice nurses when describing their experiences working with dying patients. In-depth, semistructured interviews were conducted with 24 home hospice nurses from a midsize for-profit hospice organization that provides services to approximately 230 patients each year. The interviews revealed four main metaphors emphasizing how home hospice nurses conceive and communicate their experiences working with patients: a calling, hallowed ground, going with the flow, and life lessons. These metaphors highlight how home hospice nurses transcend organizational role descriptions, feel empowered to make a difference, appreciate the inevitable unpredictability of their work, and draw upon patient interactions for self-reflection. The findings reveal a consistent emphasis on the positive and rewarding aspects of hospice work and prescriptions about how nurses should perform their role. Metaphors identified in this study could be used to recruit prospective home hospice nurses and strengthen training or education programs.

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The National Hospice and Palliative Care Organization (2013) reports approximately 1.5 million American deaths occur under hospice care. According to a recent study by King, Matheson, Chirina, Shankar, and Broman-Fulks (2013), although baby boomers are living longer due to medical advancements, they are sicker and less healthy than previous generations. As life expectancy continues to rise and health status deteriorates, the health-care industry will be impacted by this growing population. As a result, hospice will continue to meet important end-of-life needs in the American health-care system since approximately 83% of hospice patients are 65 years and older (Han, Remsburg, McAuley, Keay, & Travis, 2006; National Hospice and Palliative Care Organization, 2013).

Hospice provides comfort, not curative, care for terminally ill patients with typically 6 months or less to live. According to the Hospice Foundation of America (2012), hospice services focus on the emotional, psychological, and spiritual needs of patients and caregivers at the end of life, including pain management, respite care, counseling, and bereavement support. Interdisciplinary teams (IDTs) function as the primary means for organizing and delivering hospice care (Oliver, Wittenberg-Lyles, & Day, 2006; Wittenberg-Lyles, Oliver, Demiris, & Regehr, 2009) and typically consist of physicians or medical directors, nurses, social workers, volunteers, chaplains, and counselors. Although each IDT member brings a unique expertise to patient care, hospice nurses provide the highest percentage of direct patient care and have the most contact hours with patients and families (National Hospice and Palliative Care Organization, 2013). Additionally, home hospice nurses must be more assertive, imaginative, and innovative than other IDT members since they have to independently perform duties and make judgments in the private context of the home (Amenta, 1984). Hospice care is offered in nursing home, inpatient, and acute care facilities; however, the majority of patients who receive hospice services are cared for in private residences (National Hospice and Palliative Care Organization, 2013). More importantly, recent cross national research suggests that people prefer to die at home (Gomes et al., 2012).

Research has begun to investigate the end-of-life communication experiences of hospice IDTs (Wittenberg-Lyles, 2005; Wittenberg-Lyles et al., 2013), hospice families (Golden, 2010–2011), employees within hospice facilities (Way & Tracy, 2012), and hospice volunteers (Gilstrap & White, 2013). Beyond these notable studies, however, a thorough examination of home hospice nurses has largely been ignored (Way & Tracy, 2012). Given the frontline nature of home hospice nursing and the central role they play in IDT, family, and end-of-life interactions, the purpose of this study is to examine how home hospice nurses

metaphorically make sense of their experiences working with dying patients to better understand how they enact their organizational role.

The Role of Metaphor in Health-Care Contexts

Metaphors are a useful tool to investigate nurse sensemaking because they provide insight into organizational and role identities as well as employees' expectations and suppositions regarding tasks and role requirements (Heracleous & Jacobs, 2008). Certain realities, such as death and dying, are believed to be understandable only through metaphors (Utriainen, 2004). As a result, the metaphors used by home hospice nurses to describe end-of-life experiences with patients may uncover how they make sense of their organizational role which ultimately impacts on-the-job orientations and behaviors.

Metaphors allow for the understanding of one type of experience in terms of another, structure what is seen and experienced, and influence future interactions, expectations, and actions (Johnson, 1983). Metaphors help individuals make sense of the strange by using the language of the familiar and provide insight into how organizational participants experience their roles (Phillips & Bach, 1995). As such, metaphors can be thought of as an essential avenue by which employees interpret and communicate recurring realities (Pondy, 1983). In organizations, metaphors produce and reflect new perspectives and worldviews, especially when members experience situations that require them to go beyond familiar ways of thinking and acting (Putnam & Fairhurst, 2001). By transforming individual episodes of reality into coherent worldviews, metaphors allow employees to make meaning out of their organizational experiences (Pondy, 1983). In this way, metaphors allow organizational actors to impose order by comparing their new situations to familiar experiences (Lakoff & Johnson, 1980; Morgan, 2006).

To date, metaphors have been used to characterize the nursing experience from a variety of perspectives, including district nursing work (Goodman, 2001), nursing ethics (Wurzbach, 1999), aspects of caring in nursing (Watson, 1987), and patients' interpretations of nurse caring behavior (Jenny & Logan, 1996). Research has begun to address the role of metaphors in health-care settings that deal with death and dying, including metaphor usage of nursing home staff (Moss, Moss, Rubinstein, & Black, 2003), home-based nurses (Öresland, Määttä, Norbertg, & Lützn, 2011), nurse aides (Berdes & Eckert, 2007), hospice volunteers (Gilstrap & White, 2013; Sexton, 1997), and hospice patients (Stanworth, 2006). In addition, metaphors have been examined to make sense of hospice workers' conceptions of death, dying, memorialization, spirituality, and emotional work (Dempster, 2012; Froggatt, 1998; Mercer & Feeney, 2009; Utriainen, 2004; Vivat, 2008). Despite investigations exploring hospice workers' sensemaking, studies have overlooked the specific role-related experiences and metaphor usage of hospice nurses in the care context of patients' homes.

Home hospice nurses experiences are likely to be distinct because their organizational role requires them to simultaneously (a) communicate about the inevitable but often taboo topic of death and dying (Planalp & Trost, 2008) and (b) provide professional care in the informal, privatized context of patients' homes without the aid of common communication scripts that are incompatible with the goals and philosophy of hospice (e.g., cure and rehabilitation) (Griffie, Nelson-Marten, & Muchka, 2004). Since hospice interactions cannot be understood apart from the interrelated interactional tensions particular to the home setting (Gilstrap & White, 2014), this study extends previous work by focusing on how home hospice nurses make sense of their organizational role given their recurring experiences with death and dying in the context of patients' homes. Therefore, the following research question was examined:

RQ: What metaphors do home hospice nurses use to describe their experiences working with dying patients?

Method

Site and Participants

Midwest Hospice Organization (MHO)¹ is a midsize for-profit hospice that provides daily medical, spiritual, bereavement, and social services to approximately 230 patients each year. At the time of data collection, MHO had two offices in a seven-county area with 78 employees, including 29 full-time nurses. At MHO, interdisciplinary teams deliver hospice services with each IDT consisting of a medical director, nurse, social worker, chaplain, volunteer or volunteer coordinator, and certified nurse assistant.

After gaining preliminary access to the MHO through its executive director, the second author met with the nurse coordinator who assisted with the recruitment of participants. The nurse coordinator announced this voluntary research opportunity and distributed an introductory letter from both authors to nurses at staff and IDT meetings. The primary criterion for participation required nurses to principally provide hospices services in private homes versus nursing homes, inpatient facilities, or hospitals. After receiving the names of interested nurses from the nurse coordinator, the second researcher contacted them via phone to explain the study further and schedule individual face-to-face interviews.

The study's sample included 24 home hospice nurses (2 males, 22 females) ranging in age from 28 to 64 years old ($M = 49.6$ years). The majority of participants were women (83%) and Caucasian (96%). Prior to working with hospice, the reported range of nursing experience was 6 months to 27 years ($M = 12.48$ years) with 4 months to 15 years ($M = 7.33$ years) of home hospice nursing experience. All

participants were full-time RNs with four significant organizational responsibilities at MHO: (a) administer initial admission assessment of prospective patients, (b) conduct physical assessment of current patients (e.g., check vital signs, listen to heart and lungs, evaluate pain symptoms, assess patient for pain control), (c) communicate orders and updates to physicians, and (d) manage patient care plans. Participants did not receive compensation for participating in this study.

Procedures

In-depth, semistructured face-to-face interviews were conducted over a 4-week period at private locations convenient for nurses including public libraries, local cafés, and the hospice organization conference room. First, nurses completed an institutional review board-approved informed consent form that described the voluntary nature of participation, guaranteed confidentiality through pseudonyms, and gave permission to audiotape interviews. After the collection of demographic information, a semistructured protocol was used to guide interviews while simultaneously providing flexibility to explore interesting topics initiated by participants (McCracken, 1988). To solicit metaphors, we asked participants to complete the phrase, “Working with hospice patients is like . . .” All participants provided a metaphor in response to our prompt and were asked to clarify their initial metaphorical expressions. The length of interviews ranged from 25 to 56 minutes. All interviews were audiotaped and transcribed verbatim for future analysis. Although theoretical saturation was met at 20 interviews, we continued interviewing participants as part of a larger hospice study (Gilstrap & White, 2014).

Data Analysis

The constant comparative analysis approach was used to analyze interview data (Glaser & Strauss, 1967). First, the researchers independently read and reread transcripts to increase familiarity with the data. Simultaneously, authors individually used open coding to repeatedly sort nurse metaphors into groups until “patterns of metaphors emerged, clustering around recurring ‘main’ metaphors” using analytic memos (Koch & Deetz, 1981, p. 7). Similar to Smith and Eisenberg (1987), dominant and recurring metaphors emerged which “provide[d] a coherent summary of [nurses’] worldviews” within the hospice context (p. 371). Second, both authors collaboratively used axial coding to ascertain relationships between open categories and form metaphorical themes by connecting similar meanings, discussing contrasting opinions, and elaborating interpretations (Strauss & Corbin, 1990). Categories and exemplars were constantly revised throughout the data analysis process until full consensus was met regarding the identification of metaphorical themes and representative participant quotes.

Findings and Interpretation

Four main metaphors highlight how home hospice nurses conceived and communicated their experiences working with hospice patients: a calling, hallowed ground, going with the flow, and life lessons.

A Calling

The most frequently mentioned metaphor highlighted nurse perceptions that they, as individuals, were destined to serve in this role. Their perceived aptitude for home hospice nursing simultaneously distinguished them from others and reminded them of their immediate impact. For example, nurses' self-assessed individual capacity to work inside patients' homes allowed them to discover and articulate where they were "meant to be." Sarah, a 15-year hospice nurse, described working as a hospice nurse as a type of occupational destiny.

The first day I went out and made a [home hospice] visit, I thought this is what nursing is. I will never go anywhere else. It took one day, one visit, and I knew this is where I would be the rest of my life. It's sometimes indescribable really and you know the first day [on the job] whether you can do it and whether you can't do it. [Working with patients] is truly a calling.

Namely, because the role required repeated exposure to death and dying, nurses positioned themselves as different from most others "who can't do it." This organizational destiny also differentiated hospice nursing from other types of nursing they had previously experienced in other contexts. Madelyn, a 7-year hospice nurse, added that hospice nursing "fills that calling in me. I mean working [as a nurse] with prisoners was important but I never felt that feeling, you know, completed. Like my work mattered."

Additionally, the metaphorical expression also emphasized the overwhelmingly rewarding nature of nurses' work, as evidenced in the direct and immediate positive feedback they received from patients and family members. Janice, a 7-year hospice nurse, justified the importance of her role because she knew her work mattered. She said, "It could be 50 [people] you're taking care of and you've touched their lives, just knowing that you've helped them reach the goal that you were there for. It's just very rewarding." The intimate context of the home, therefore, made it possible for nurses to both viscerally impact others' lives and ascertain the ongoing impact of their service from patients and family members who were "always voicing their appreciation of you."

When conceived as the "most rewarding experience you can have in your life" and "the single most important thing I've ever done," many nurses voiced disbelief that they received payment for their efforts. Kaitlin, a 4-month hospice nurse, acknowledged,

[Working with hospice patients is] like having a job that you're getting paid to do that you really shouldn't be paid to do. Honestly, I mean there are days when I go home thinking, I'm getting paid to do this?

Using the language of a calling, nurses transformed their work experiences into service that seemingly transcended organizational labels of work.

Hallowed Ground

Whereas the first metaphorical theme emphasized home hospice nurses' particular individual capacity, the second metaphorical theme highlighted the opportunities associated with unprecedented access. Specifically, this metaphor featured two interrelated aspects of the home hospice nurse role: (a) privileged access in the midst of the dying process and (b) the opportunity to make an appreciable difference during the dying process.

Nurses described feeling honored to be able to interact with patients and family members as a "special" group of people with "unique needs." Part of what made these audiences so special was nurses' contention that hospice patients' needs were too often neglected, shunned, or misunderstood by others. Kelsey, a 1-year hospice nurse, talked about the honor and privilege of

being a part of what life is really about. You get to see the most. You are participating in the most intimate part of a person's life, which has come full circle. We get to be a part of that—that person, that family.

This metaphor's emphasis on privileged access allowed nurses to see and experience an aspect of life few others are permitted to experience in person. As such, nurses described feeling "blessed" because their job provided them the rare opportunity to be a part of the dying process from which most were excluded.

Given their privileged access, the capacity to make a positive difference was also central to this metaphor. For example, Kara, a 10-year home hospice nurse, said,

It's like when somebody's being born and you feel so blessed to be there. That's how you feel when somebody's dying as weird as it sounds. I feel blessed to be a part of what they're going through and [able to] help them.

With the privilege and honor of access came the opportunity to help make the end-of-life experience better for patients and family members. Cheryl, a 15-year hospice nurse, reiterated that her experiences are "like walking on hallowed ground. We're introduced into a situation that is bad. It doesn't have a good ending, and we have the opportunity to take that situation and make it better."

Due to their presence throughout the dying process, this metaphor positioned nurses as essential change agents whose role allowed, and required, them to make a difference in the lives of patients and families.

Going With the Flow

The third metaphorical theme accentuated the unpredictability and uncertainty inherent in home hospice nursing. Daphne, a 4-year hospice nurse, attributed “being able to go with the flow” as an intrinsic work component and an essential qualification of effective home hospice nursing.

It’s just a new day every day. You would think there would be a lot of similarities in your work but it’s just different every day and challenging. I just get up every day not quite knowing what to expect. You kind of know how things will unfold but yet you have to get up and be prepared to deal with whatever that day brings you.

Due to the idiosyncratic needs of patients, challenges of pain management, delicacies of interpersonal relationships among patients and family members, and the informal context of the home setting, nurses voiced a mindset consistent with the overall philosophy of hospice care when describing what it is like working with patients. Ginny, a 3-year hospice nurse, summarized the conditions of the role that require a particular type of orientation:

You never know what you’re going to get. You have all varieties. You have all different diagnoses. You have all the different situations that you walk into. You have no idea when you open that door what you’re going to be walking into—good or bad.

Although this metaphor characterized nurses’ work experiences, it also served as an implicit requirement indicating the need for nurses to possess a high tolerance for role uncertainty. For example, Edith, a 3-year home hospice nurse, characterized home hospice work as “just being able to go with the flow and listen and understand needs. Each patient is so different. You just have to go with each one as an individual.” Even though the inevitable unpredictability of their role was referenced when explaining this metaphor, it simultaneously stressed the individual characteristics nurses believed necessary for effective work performance.

Life Lessons

The final metaphorical theme emphasized how nurse interactions in patients’ homes initiated opportunities for contemplation about their own lives. This metaphor revealed how the impact of the intimate care context inside patients’ homes deeply affected them beyond their organizational role. For example,

according to Kate, a 4-month hospice nurse, caring for hospice patients invited self-reflection.

[Hospice patients] have a lot to offer us and I think sometimes they make us realize what's really important in life that we all take for granted. You know, we're so busy every day and they're just, you know, dealing with living and really making the most out of what they have left. I think it's kind of like life lessons.

Life lessons, however, were not simply a result of working with hospice patients. Valerie, a 12-year hospice nurse, hinted at how the intimate context of the home served as inspiration for self-reflection.

I always like to look at pictures in people's homes. We're seeing that person in their declining condition. This is not the person that has been the ballroom dancer. This is not the person that has been the pianist in front of Carnegie Hall. We take care of wonderful, wonderful people, and then we all get to a certain point and our health becomes bad. We're all the same. We all need help.

Since home hospice nurses only interacted with patients when they were in the process of dying, this metaphor did not frame dying as something out of the ordinary or as something to be mourned. Rather, Beth, a 7-year hospice nurse, described working with hospice patients as "pretty much like real life," adding that dying cannot only be viewed as an end to life but as an essential part of life. In particular, the interactions, observations, and insights gained when working with hospice patients in the home context served as an admonition for how to live their own lives. Paige, a 2-year hospice nurse, said working with hospice patients "makes you realize how fragile life is and just how much, as the human race, we need each other." As a result, caring for hospice patients with 6 months or less to live helped explain their view of the dying process as an integral part of life. Even more, the care they provided inside the intimate care context of the home warranted self-reflection concerning how they should live the remainder of their own lives.

Discussion

The cluster of metaphors and metaphorical expressions identified in this study reveal consistent "symbolic realities" particular to nurses' organizational role and site of care (Pondy, 1983, p. 160). First, each of the identified metaphors highlight the positive and rewarding aspects of hospice work through a framework expressed as (a) meaningful work noticeably appreciated by others (e.g., a calling), (b) unique access to the dying process (e.g., hallowed ground), (c) novel work experiences (e.g., going with the flow), and (d) vital, but overlooked, knowledge applicable to nurses' lives (e.g., life lessons). Although previous research

addressing hospice nurse metaphor usage emphasized the “draining, emotionally negative side effects of hospice work” (Froggatt, 1998, p. 337), this study’s findings demonstrate an overwhelmingly positive tone consistent with the metaphors used by home hospice volunteers (Gilstrap & White, 2013). Role benefits were attributed to nurses’ physical presence in the home, including immediate and positive feedback and the privilege of unprecedented access. When using metaphors to discuss their experiences, home hospice nurses may have used primarily positive metaphors to counteract “widespread social perceptions of dirtiness” associated with interacting with and serving hospice patients who have 6 months or less to live (Ashforth & Kreiner, 1999, p. 421).

Second, our findings support Wurzbach’s (1999) claim that “metaphors often become a self-fulfilling prophecy” (p. 98) and underscore how role descriptions can become indistinguishable from role prescriptions. For example, the hallowed ground metaphor highlights how nurses might feel compelled to act and be responsible for transforming a bad situation into something better for patients. Similar to Mercer and Feeney’s (2009) findings concerning nurses’ representation of death, this particular role orientation might be conceived as a strategy “to resist death, the pain, and the uncertainty and suffering it may bring” (p. 261). Due to this orientation, nurses might feel compelled to act to improve a patient’s situation even when factors beyond their control might inhibit or even make impossible the fulfillment of ideal hospice care (e.g., patient refusal to take medications, subjective quality of pain management, nurse-patient or family disagreements about care). Home hospice nurses’ overall metaphorical orientation, however, did not demonstrate a resistance to death and uncertainty as much as it revealed judgments about the appropriate type of person suited to serve home hospice patients and families (e.g., calling, going with the flow). Home hospice nurse metaphors, therefore, went beyond simple descriptions of working with patients and served as behavioral and moral prescriptions about how they, as individuals, should experience their role.

The metaphors identified in this study should be used to strengthen training and continuing education for prospective and current home hospice nurses. When referring to nursing education, Czechmeister (1994) believes students’ “desire to help others fuels their caring, but they also need the perceptual tools to enable entry into the patients’ world” (p. 1231). The integration of metaphors into hospice training could serve as effective perceptual tools to enhance discussions about recurring role requirements, role expectations, and lived experiences specific to the home hospice nursing experience. The benefits of nurse metaphoric analysis would positively impact the quality of hospice care since metaphorical reasoning “comes out of the experience of human beings situated within a physical and cultural environment” (Johnson, 1983, p. 383). Consequently, addressing role-related metaphors in nurse training would allow

nurses a means to discuss, evaluate, and critique metaphors that will not simply reflect their reality, but, more importantly, create and shape how they experience their role and service in the home hospice setting.

Findings also should be used in the recruitment of novice and practicing nurses to home hospice care. Hospice organizations have been facing recruitment challenges for the last decade (Harris, 2013). Although home hospice care demands are rising, nursing education, to date, is not fully preparing new graduates to play a significant role in this area (Heller, Oros, & Durney-Crowley, 2013). Similarly, acute care nurses often feel greater discomfort initiating conversations about death and dying due to a lack end-of-life training (Mee, 2002; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). Metaphors both illuminate a particular reality and deny other possible realities (Czechmeister, 1994). As a result, role-specific metaphors could be a useful resource to prospective nurses with uncertainties about hospice care or limited experience working with dying patients on a regular basis.

Further research examining the use of metaphors throughout the hospice experience is warranted because the majority of participants were women (83%) so it is unclear if the metaphors articulated were a reflection of their specific orientation and challenges or “linked to an understanding of the role of women in how they manage their work” (Goodman, 2001, p. 111). Future studies could also investigate how metaphors differ and evolve depending on years of service. Finally, since this study was conducted at one hospice with its own organizational culture and norms, comparative studies should further examine how divergent cultural connotations of death and dying impact nurse experiences and role articulation.

Research illuminating the sensemaking function of metaphors is necessary to better understand the “lived experiences of the hospice philosophy” (Mercer & Feeney, 2009, p. 261). As lynchpins to the home hospice experience, the manner in which home hospice nurses orient themselves to their role affects how they interact with patients, hospice team members, family members, and volunteers. The metaphors used by home hospice nurses do not only characterize their individual encounters with death and dying inside patients’ homes, rather they also prescribe ways of acting and interacting particular to their organizational sensemaking experiences.

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