"People Just Don't Understand": Challenges Communicating Home Hospice Volunteer Role Experiences to Organizational Outsiders

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Abstract

Volunteers play a central part in the delivery of end-of-life care. Unlike other interdisciplinary team members, however, home hospice volunteers may face unique communication challenges when explaining their role to organizational outsiders. In-depth, semistructured interviews were conducted with 38 home hospice volunteers from nine different U.S. hospice organizations. Interviews revealed volunteers experience four communication challenges when trying to explain their role to outsiders: we're not special—we're special, we're among the living—we're among the dying, it's enjoyable—it's depressing, and presence is significant—presence is insignificant. Findings demonstrate how role articulation inhibits volunteers from communicating the full scope and relevance of role experiences. Although volunteers used discursive strategies to alter perceptions of stigma, these strategies may also exaggerate insider-outsider differences, inhibit authentic role disclosure, and reduce value of service to personal benefit. Our conclusions highlight the importance of external-based communication training to enhance role identity and connection to the hospice mission.

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Whether it is my family members or people I meet for the first time, they say, "God, how do you do it?" My mom says, "I don't know how you do that? How do you go in there and do that?" From my perspective, it's not that difficult at all. But for people who haven't done it, they just think it's the weirdest or most amazing thing.

—Eric (13-year hospice volunteer)

The National Hospice and Palliative Care Organization (2015) reports approximately 430,000 trained hospice volunteers donate at least 19 million hours of service annually to hospice organizations throughout the United States. The hospice movement is based on a "philosophy of care which recognizes that dying is not just a medical event but a personal one as well" (Gordon, 2016, para. 2). Hospice provides end-of-life care for terminally ill patients with 6 months or less to live and no longer receiving curative treatment. The hospice philosophy focuses on caring, not curing, and strives to "treat each person as an individual and to respect the feelings, beliefs, and wishes of the dying person" (Foster, 2006, p. 24).

Volunteers are central to the functioning of hospice programs because they "provide an important source of unpaid labour" and "bring a sense of 'nonmedicalization' to hospice care" (Dein & Abbas, 2005, p. 58). As part of Medicare requirements, volunteer service must comprise at least 5% of total patient care hours (National Hospice and Palliative Care Organization, 2015). The majority of hospice volunteers (60%) assist with direct care support by enhancing duties of professional interdisciplinary team (IDT) members, spending time with patients, providing respite care, and supporting family members before and after a patient's death (Andersson & Öhlén, 2005; Coffman & Coffman, 1993; National Hospice and Palliative Care Organization, 2015). Although understudied from a communication perspective, scholars have begun examining (a) individual motives and role tasks of hospice volunteering (Baugher, 2015; Egbert & Parrott, 2003; Paradis, Miller, & Runnion, 1987; Starnes & Wymer, 1999), (b) how hospice volunteers make sense of their role experiences (Foster, 2006; Gilstrap & White, 2013; Wittenberg-Lyles, 2006), and (c) the communication difficulties and rolespecific issues volunteers experience when interacting with patients and families (Planalp & Trost, 2008).

Home hospice volunteers' distinct organizational status may make them especially prone to communication dilemmas when attempting to articulate

their role to audiences external to the patient-family care setting. First, the burden of explaining their role in ways others understand and appreciate may be more pronounced for hospice volunteers because, unlike other care team members, they serve in their role without financial remuneration and their organizational affiliation is "primarily symbolic, not material" (Farmer & Fedor, 1999, p. 362). Second, volunteer role articulation may be constrained because outsiders have little patience for work-related complaints, especially when complaints are often "met with advice to simply stop volunteering" (Lewis, Gossett, & Kramer, 2013, p. 414). Third, as vital participants in hospice care, volunteers frequently spend more time with patients than other IDT members (Foster, 2006; Wittenberg-Lyles, 2006; Worthington, 2008), but they have "much less clearly defined roles" than other hospice workers (Dein & Abbas, 2005, p. 63). Thus, hospice volunteer role articulation may be more complicated because, like other volunteers, their role involves "unique temporal and spatial links to the organization, which affects interaction patterns" (Ashcraft & Kedrowicz, 2002, p. 91). Moreover, as "some volunteer jobs are better than others in providing access to the public and garnering external attention for the efforts" (Gossett & Smith, 2013, p. 328), hospice volunteer role identity negotiation may be affected because it is enacted in the private, home setting apart from other volunteers and hospice organizational members (Egbert & Parrott, 2003; Qaseem, Shea, Connor, & Casarett, 2007; Way & Tracy, 2012). Consequently, like other types of employees, volunteers' distinctive, yet isolated, organizational work inside patients' homes may heighten the impact outsiders play in shaping volunteers' "collective construction of a preferred identity" (Tracy & Scott, 2006, p. 29). Just as "physician identity is symbolic and material in that it is constructed out of local talk in social interaction" (Real, Bramson, & Poole, 2009, p. 586), this study expands our understanding of volunteer role construction by examining the communication challenges home hospice volunteers experience when explaining their role to organizational outsiders.

Communicating Role in a Stigmatized Volunteer Context

Role theory examines role perceptions and relational properties between individuals and organizations (Conway, 1988; Schuler, Aldag, & Brief, 1977; Thomas & Biddle, 1966). It provides a framework to investigate role-related discourse because it emphasizes the social elements of behavior, including how individuals use language to construct and enact their organizational selves (Brookes, Davidson, Daly, & Halcomb, 2007; Hardy & Hardy, 1988; Simpson & Carroll, 2008). As a collaborative and communicative process,

role-related discourse serves as a primary means for defining, developing, and negotiating one's organizational role (Apker, Propp, & Ford, 2005).

Brookes et al. (2007) define roles as "description[s] of behaviours, characteristics, norms and values of a person or position" (p. 147). In addition, roles assist in the negotiation of tasks and "offer 'maps' that guide people through their interactions and evaluations of themselves" (Emanuel, Bennett, & Richardson, 2007, p. 160). Finally, roles facilitate role development, support role enactment, and provide social and behavioral expectations of individuals in certain social positions and settings (Biddle, 1979; Lynch, 2007; Montgomery, 1998; Simpson & Carroll, 2008).

Role development is "an emergent process" influenced by role expectations, organizational-specific requirements, the needs of role inhabitants, and "ongoing interaction among actors in a particular role set" (Miller, Joseph, & Apker, 2000, p. 196). Organizational members use communication as a means for role construction through social interactions both within and outside the organizational setting. Examining discourse offers "unique access and insight" into role construction as "organizational actors use role so commonly and readily to explore and explain who they are in their work (and non-work) activities" (Simpson & Carroll, 2008, p. 46). To date, research has concluded communication with others makes it possible for people to "learn, interpret, and accept or reject role expectations" (Apker, 2002, p. 75); however, it has not examined the discursive challenges home hospice volunteers face when interacting with hospice outsiders.

Hospice volunteers' role articulation to outsiders may be complicated by the unique population they serve. Ashforth and Kreiner (1999) pinpoint hospice work as an example of an occupation that highlights how "boundaries between the physical, social, and moral dimensions [of taint] are inherently fuzzy" (p. 415). First, hospice work may be conceived as physically tainted because the role requires participants to "willingly enter into contexts of death and dying" and spend time in the physical presence of dying patients (Wittenberg-Lyles, 2006, p. 51). Although body care is not part of the hospice volunteer role, volunteers may experience taint because of their close proximity to the "unbounded body," thereby participating in process of "remov[ing] patient's dirt, and the patient as dirt, from mainstream society" (Lawton, 1998, p. 138). In addition, residential hospice volunteer work might also be socially and discursively constituted as different because the role necessitates volunteers to be in contact with dying patients amid a culture that often excludes open discussion about death and dying and views death as a tragedy (Foster, 2006; Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reilly, 2008). For example, Snyder, Omoto, and Crain (1999) identify the "social costs of volunteerism" (p. 1176) and

found volunteers working with HIV/AIDS populations were "socially punished for their good deeds" by their social networks (p. 1189). As sources of social support for patients with 6 months or less to live, hospice volunteers "are confronted with a difficult communication situation that is characterized by high uncertainty and social stigma" (Egbert & Parrott, 2003, p. 32), reinforcing the need to examine role-based communication with organizational outsiders.

The role-related communication difficulties of hospice volunteers warrant further investigation to better understand how they may "encounter and discursively respond to perceived stigmas" (Meisenbach, 2010, p. 269). Understanding the communication challenges faced by home hospice volunteers when trying to explain their role to hospice outsiders may (a) further existing research regarding this important, but often overlooked, population (see Egbert & Parrott, 2003); (b) shed light on the communication management strategies enacted by volunteers who may experience stigma through "discursive action" (Meisenbach, 2010, p. 271); and (c) affect volunteer recruitment, organizational identification, and volunteer training. As a result, the following research questions were examined:

Research Question 1 (RQ1): What communicative challenges do home hospice volunteers experience when attempting to articulate their role to hospice outsiders?

Research Question 2 (RQ2): How do home hospice volunteers discursively manage these role-related communication challenges?

Method

Participants

Thirty-eight hospice volunteers (25 women, 13 men) were interviewed for this study. At the time of data collection, participants were actively volunteering at one of nine different hospice organizations located in two Midwestern states. Volunteer coordinators assisted with the recruitment process by sharing our study's purpose and relevant documents (i.e., introductory letter) at volunteer meetings and training sessions. After receiving a list of willing participants from each coordinator, we contacted volunteers to further explain the study and set up face-to-face interviews. Volunteers had to be actively working with patients in a residential setting to qualify for the study.

Volunteers ranged from 21 to 86 years old (M = 63.55 years). The majority of participants were married (74%) with 16% widowed (8% widowers, 8% widows), 8% single, and 2% divorced. Volunteers reported 3 months to 20

years (M = 5.02 years) of hospice volunteer experience and were not given compensation for participation.

Procedures

In-depth, semistructured interviews were conducted at locations convenient for participants (i.e., local café, home, hospice organization conference room). Volunteers signed an institutional review board (IRB)-approved informed consent form which described the study's purpose, voluntary nature of participation, and anonymity of responses through the use of pseudonyms. Following the collection of demographic information, an open-ended interview protocol asked volunteers to describe (RQ1) the communication challenges they experienced when explaining their role to hospice outsiders (e.g., "How do you explain to others why you volunteer to spend time with hospice patients?" and "What aspects of your role do you think are most difficult to explain to hospice outsiders?") and (RQ2) how they discursively managed those challenges (e.g., "How do people react when you tell them you spend time with hospice patients?" and "How do you respond to their reactions?"). The length of interviews ranged from 20 min to 1 hr and 44 min (M = 41 min). Although theoretical saturation occurred at 29 interviews, we interviewed all willing participants who initially volunteered for the study as part of a larger hospice project (Gilstrap & White, 2013). All interviews were audiotaped and transcribed verbatim resulting in 285 single-spaced pages of text.

Data Analysis

A modified constant comparative method was used to code and analyze interview data: data reduction, unitizing, open coding, and axial coding (Corbin & Strauss, 2008; Glaser & Strauss, 1967). First, researchers independently conducted data reduction by independently reading and rereading transcripts to organize data and identify passages specifically related to (RQ1) role-related communication challenges and (RQ2) discursive strategies used to negotiate those role-related challenges. Unitizing occurred by taking data related to each research question and breaking it down into units of analyses ranging "from a few words to complete paragraphs that expressed a coherent idea" (Kramer & Danielson, 2016, p. 108).

We individually created analytic memos from the units to identify preliminary categories through open coding by "breaking down, examining, comparing, conceptualizing, and categorizing data" (Strauss & Corbin, 1998, p. 61). Researchers then collaboratively grouped categories with similar characteristics together, developed new or nuanced categories when differences emerged, and eliminated irrelevant and/or redundant categories. During this analysis, we determined categories related to (RQ1) role-related communication challenges were better understood as tensions experienced during conversation(s) with outsiders (e.g., we're not special—we're special), rather than as mutually exclusive, static challenges (e.g., a context for a calling). In addition, category labels for RQ2 were drawn from existing stigma management research (e.g., denial, reframing) and interview data (e.g., camouflaging, shifting focus). Researchers repeated open coding via phone conversations and email until no additional modifications were needed.

Next, researchers jointly conducted axial coding. Open coding categories were reassessed and rearranged by identifying relationships between categories and joining those with similar traits and features (Strauss & Corbin, 1998). Relationships between categories were evaluated to identify themes. A theme was defined "as a patterned semantic unit in which commonalities and differences among participants' discourses and attendant practices emerged through repeated readings" of the transcripts (Buzzanell et al., 2005, p. 266). Themes for each research question were identified by frequency, repetition of "key words, phrases, or sentences," and the "same thread of meaning" even if different words were used (Owen, 1984, p. 275). We continued axial coding until theoretical saturation occurred and consensus was met. Like Barbour and Manly (2016), to meet consensus and "enhance the rigor of our analysis," we identified examples "that supported one interpretation over another . . . to reconcile inconsistencies" when our interpretations differed (p. 340). Finally, researchers revisited the transcripts to locate participant quotes that best exemplified each theme.

Findings and Interpretation

Hospice volunteers articulated recurring and interrelated communication challenges when attempting to explain their hospice role to outsiders. Our findings represent four interactional tensions volunteers experienced when communicating their role: we're not special—we're special, we're among the living—we're among the dying, it's enjoyable—it's depressing, and presence is significant—presence is insignificant (RQ1). Each communication tension highlighted organizational insider—outsider perceptual disparities, as well as the evolution of volunteers' role-related discourse. Moreover, hospice volunteers used five strategies to discursively negotiate their communication challenges: denial, reframing, redirected identification, camouflaging role experiences, and shifting focus (RQ2). In the following, we report these strategies as they are relevant to each tension.

We're Not Special—We're Special

The most frequent communication challenge hospice volunteers mentioned involved assumptions about who could fulfill the role. Volunteers reported repeatedly receiving individual acclaim when outsiders learned of hospice volunteers' service. This individual praise directed at volunteers, however, was almost always accompanied by the explicit assertion that volunteers had to be different or special because their service asked them to be or do something that they, themselves, could not do. After revealing their role, volunteers said they were often told, "I could never do that because it takes a special person," "I couldn't be a hospice volunteer," and "I can't spend time around people who are dying."

Although volunteers acknowledged being individually applauded, outsiders' disassociation of them from the service they performed was repeatedly cited by volunteers as a significant communication challenge because it contradicted their beliefs about the capability of all people to serve. Such responses discursively constructed volunteers as worthy of acclaim, but at the same time, unique because of their service. Eliza, a 3-year hospice volunteer, highlighted the persistent challenge of describing her role given outsiders' simultaneous admiration and distancing. She said, "most [outsiders] are in awe that you can [be with the dying], and the other half, are negative. They say, 'I couldn't do that. I don't see how you can do that.""

This communication challenge draws attention to the frustration volunteers endured when attempting to communicate that who they are and what they do as home hospice volunteers "is not really anything extraordinary," and the role itself required no special qualifications. Volunteers' insistence that hospice volunteering "is easier than people think" and that "it is no big deal" was often dismissed in lieu of personal attributions of credit (e.g., "You must be a saint"), thereby limiting volunteers' ability to talk about the applicability of the role beyond themselves and their own particular skills. Steve, a 3-year hospice volunteer, provided the ideal example of this tension of simultaneous appreciation and rejection. He stated that when people ask him about spending time with hospice patients, they say, ""It takes a special person to do that,' and then they walk away. It's just like, 'Well, did you want to know or not?"" To manage this recurring communication challenge, volunteers used two primary management strategies: denial and reframing.

Denial. Hospice volunteers recounted initially using a denial strategy when attempting to convince outsiders that the role did not require any special qualifications or capacities that would disqualify others from hospice volunteering. This denial strategy was illustrated by Martina, a 6-year hospice

volunteer, who recalled a typical conversation she engaged in when attempting to dissuade others from presuming that only certain people can fulfill the role:

They say, "What do you do with hospice?" They don't understand, for one thing. And then they will say, "Oh you must be really special to be able to do that," and I'm like, "No I am not!" I am not any more special than anybody.

Consequently, volunteers' denial management strategy was believed to be ineffective because of their perceived inability to persuade outsiders that anyone, in fact, could serve in the role. For example, Marcia, a 6-year hospice volunteer, pinpointed the disconnect particular to this communication dilemma:

Usually, the first thing they say is, "Oh, I could never do that." "Oh you are so special that you can do that," and I am like, "You could do that." But most people have to experience it like you did. But I do have some people I talk to that have experienced it, whose parents have had hospice, and they still say they couldn't do it. So, maybe it is a matter of maturity or something . . . But I think they would surprise themselves if they tried it. It is easier than they think. It's no big deal. I mean, you are just going to visit somebody.

Others' contention that they could not serve highlights the interactive tension that precipitated role rearticulation. Regarding the difficulty of overcoming others' self-professed disqualification from service, Candice, a 6-year volunteer, asked, "I just don't know why more people don't want to do it?" Thus, volunteers' "frustration with people who don't do it" initiated a discursive shift from emphasizing the universality of role applicability to an awareness that their service was, or had to be, framed as a "calling."

Reframing. When continually faced with others' disbelief about their own capacity to serve, volunteers constructed home hospice work as "a gift," "my calling," a "special capability of dealing with dying people," and "something we're good at." This management strategy highlights the discursive reframing of the very unique qualities they had once denied. For instance, Jolene, a 4-year hospice volunteer, explained how her ability to fulfill the hospice role was cocreated amid the interactional context of outsiders' incredulity:

I was talking to someone recently. As soon as I told him what I did, he said, "You have to have a calling or a gift for that." And sometimes I will explain that to people. I'll say, "I just think I have a gift for it."

Volunteers sought to reframe outsiders' attention regarding how the hospice volunteer role accentuated the very qualities that distinguished them from others. Specifically, they refocused attention on their ability and willingness to endure the stigma related to death and dying. Jennifer, an 8-month hospice volunteer, described herself as unique because she possessed "the compassion enough to want to be around them. So I don't see the stigma where some people have got it. I think, too, it is personality because not everybody is cut out to do something like this." Jennifer's compassion, or willingness to serve despite stigma associated with death and dying, was attributed to her personality. Volunteers repeatedly described home hospice work as a calling because of their "capability of dealing with dying people." Emphasizing the distinct skills she possessed that differentiated her from others, Parker, a 2-year hospice volunteer, said, "We all have gifts and [hospice patients] need somebody who doesn't just cry every time someone walks in the room."

This reframing strategy often diminished volunteer choice. Because volunteers were believed to possess the unique willingness and capacity to help, they, alone, became responsible for helping patients. For example, Edith, a 2-year hospice volunteer, recounted how she tells others, "there is a need, and when you see a need, if you are the kind of person that can fulfill that need, than I think we would be remiss not to do that." As a result of this strategy, volunteers frequently minimized their own choices while emphasizing service as a moral imperative, or "the right thing to do," for only those people with particular gifts.

We're Among the Living—We're Among the Dying

The second challenge hospice volunteers experienced when communicating about their role occurred when they attempted to accurately characterize the people they believed they served and the nature of their particular connection with patients. Although volunteers felt they were spending time with the living, outsiders believed volunteers were spending time with the dying. This interpretive schism highlighted distinct insider—outsider perceptions that not only shaped how volunteers oriented themselves to the hospice role, but also challenged outsiders' views regarding who was affected by the dying process.

Informed by their role experiences, volunteers' conception of dying and death impeded role articulation with outsiders in multiple ways. Unlike hospice outsiders who often viewed death as abnormal and worthy of trepidation, volunteers conceived of dying as an essential part of the living process. This perceived conflict between volunteers' views of dying and outsiders' (mis)perceptions of death became the "hardest part to explain." For example,

Nadia, a 20-year hospice volunteer, reiterated that dying is "part of life. Dying is part of living. We're all going to be there one way or another." In addition, Parker felt what distinguished her from hospice outsiders was the ability to "still see that [hospice patients] are very much alive. Just because they are terminal, they are still very much alive. Yes, they are dying, but today, they are here. Today, they need to be heard." This significant difference in interpretation constrained volunteers' ability to explain that spending time with hospice patients was not what others believed it to be. Blake, a 2-year hospice volunteer, added,

I never think of it as being around death. I'm around people who are in their lifetime's last moments or months on Earth. I never think of it in any sort of negative way. Death, it's a friend. I think hospice helps us come to a more healthy appreciation of what dying is all about.

Drawn from their role experiences, volunteers' conception of working with the living, not the dying, made it difficult to explain that their service was not something to be feared. According to Beverly, a 15-year hospice volunteer,

I think generally, people look at sickness and death, particularly, as being a fearsome thing. But you know death is part of life. It's not just moving on and it doesn't frighten me. So that's the hardest part to explain to people who say "I couldn't do that or how do you do that."

Volunteers primarily used the management strategy of redirected identification to negotiate this communication challenge.

Redirected identification. Volunteers' perceived inability to alter others' associations of dying/death with fear was a recurring communication challenge because it was viewed as incompatible with their own understandings and role experiences. Therefore, to differentiate not only whom they believed they were working with (e.g., the living, not dying), but also how they identified with hospice patients, volunteers' redirected their identification to emphasize their connectedness with patients rather than with hospice outsiders.

Volunteers' role experiences and regular exposure to hospice patients contributed to the interpretive distinctions between hospice insiders and outsiders. Unlike outsiders who viewed hospice patients as categorically different from themselves, hospice volunteers believed they were similar to patients because, as Daniel, a 3-year hospice volunteer, said, "We're all dying, I'm dying too." Similarly, Rebecca, a 5-year hospice volunteer, emphasized, "Everybody's dying. You're dying. I'm dying. There's no difference." As

such, dying was not viewed as an unexpected experience that happens to *other* people. Rather, volunteers regarded dying as a common and ongoing source of volunteer–patient identification. Dying was not something that others experienced, it was something that united volunteers and hospice patients because of volunteers' hyperawareness that death was always "knocking on the door." Consequently, when organizational outsiders reacted as if there was "something wrong with him" because his role required being around people who are dying, Reed, a 2-year hospice volunteer, said he often responded by saying "It's not that, we're all dying." Because volunteers saw themselves as strikingly similar to the audiences they served, they found it difficult to explain their identification with patients others had dismissed, rejected, or could not understand. Therefore, they sought to manage this communication tension by recognizing the near-impossibility of convincing, or overcoming, outsiders' views because "their view of death is different from [my view]."

Although the redirected identification strategy was proffered as an attempt to nuance public understanding of who hospice volunteers served, it also blurred the very distinctions between volunteers and hospice patients. When responding to questions about why they spent time around dying people, death and dying were not constructed as something that happens for only some, and not others, nor was it conceived as something that could be quarantined in the future tense. Rather, a shift in volunteer identification was premised on the belief that dying "is a process we're all going through." This management strategy not only collapsed categories of what death and dying might mean and whom might be affected, but it also violated outsiders' beliefs about when dying begins. According to Rebecca, a 5-year hospice volunteer, "Everybody's dying. You're dying. I'm dying. There's no difference. You don't know in this room who's going to die first." Constructed in this way, spending time with patients was not conceived as an anomalous experience, it was expressed as a process everyone is undergoing and/or using to help them prepare for the inevitable. Consequently, volunteers' continued willingness to spend time with dying patients, in spite of outside questioning and concern, disrupted others' distancing of death/dying by demonstrating their identification with patients.

It's Enjoyable—It's Depressing

The third challenge occurred when volunteers attempted to communicate the nature of their interactions with patients. Particularly, home hospice volunteers regularly tried to overcome others' presuppositions that their experiences with hospice patients were reducible to the "sad experience [outsiders]

think it's going to be." When volunteers' work was labeled, and dismissed, as depressing, volunteers found it difficult to communicate the multilayered nature of their experiences.

Upon discovering the hospice volunteer role included spending time with patients who had 6 months or less to live, outsiders responded with characterizations such as "morbid" and "something that should be feared." Bethany, a 7-month hospice volunteer, explained, "I think it is hard for people to think you want to hang out with a dying person. [They think] 'what could you possibly find that is good about that?"" Volunteers voiced concern at the apparent impossibility of explaining how they could enjoy an experience others dismissively portrayed as "depressing," "tragic," and "sad." Even in the midst of spending time with hospice patients who had 6 months or less to live, the good volunteers experienced in their role interactions became a source of exasperation because when communicated, it defied outsiders' preconceptions. Jane, a 7-year hospice volunteer, explained that most people

can't understand that family members and sick people, who are dying, can actually enjoy life. I think they find that hard to understand. They can't understand that family members and sick people, who are dying, can actually enjoy life as long as their pain's controlled.

Moreover, Ethan, an 11-year hospice volunteer, pinpointed the self-doubt he endured when trying to reconcile his hospice experiences with what others believed they should be. He said, "They say it's depressing. I don't find it depressing. Now why I don't? I don't know." These types of replies, and subsequent self-questioning, became more problematic when hospice volunteers tried to explain their choice to voluntarily spend time with hospice patients instead of engaging in other opportunities. According to Steve,

It's most difficult to explain that you are wanting to do hospice volunteering instead of going to the lake. Or that you are doing that instead of going out to the bar. "You are taking that as your first choice compared to doing things fun for yourself? You would rather do that than this?" I think that is where the break seems to be. I say, "Oh, I can't go. I have got a hospice thing I got to do."

Outsider perceptions associated with dying and death, therefore, constrained volunteers' role articulation because they often precluded volunteers from testifying to the "rewarding experience" they had when spending time with patients. Volunteers expressed concern that if they did, in fact, openly express that they enjoyed spending time with hospice patients, others would make judgments about them and question their motives. For example,

Hannah, a 1-year hospice volunteer, recalled the futility of responding to others' questions as to why she would want to volunteer to spend time "around dying people." Notably, "once they find out [I'm a hospice volunteer] they ask, 'Why would you want to do that?' They have their minds set . . . because they [think] death is depressing. Period." When explaining the nature of their interactions with patients amid bounded expectations, volunteers sought to camouflage their role experiences.

Camouflaging role experiences. Unlike outsiders, volunteers discursively distinguished between the process of spending time with patients and the certain outcome of death. Repeatedly, participants identified the difficulty in explaining the possible rewards of spending time with someone, and then finding the means to communicate their heartfelt experiences in light of people's negative associations with inevitable death. According to Paige, it was "most difficult to explain why I enjoy hospice. And then to say that this is what I enjoy." Thus, volunteers sought to manage this tension by camouflaging their authentic experiences with patients and families by silencing themselves, using euphemisms (e.g., "I have a hospice thing"), and avoiding discussions about their interactions with patients and family members. Because volunteers disentangled their interactional experiences with patients from the sadness others conflated with "what is going to happen in the end," they found the "laughter" and "joy" they experienced difficult to communicate when such experiences were incompatible with what outsiders would accept or allow when it was believed "it has got to be sad going in there when you know what is going to happen in the end."

Because of the perceived disparity between what volunteers experienced in their role and what outsiders concluded, communicating that hospice patients "are as much fun to be with as anybody" was not a viable option because others "shut off their ears. They think it is depressing. There is no sense in explaining." Consequently, volunteers expressed that if they authentically and fully disclosed the breadth of their experiences, including the joys and rewards they experienced only as a result of spending time with hospice patients, outsiders would not be equipped to appreciate what they were referring to, and, as individuals, they would be negatively judged.

Presence Is Significant—Presence Is Insignificant

The fourth communication challenge arose when volunteers tried to justify the purpose of their role even though no action on their part would prevent a patient's death. This discursive challenge involved explaining the value of their presence in ways outsiders would understand and appreciate despite the fact that "you know what is going to happen in the end."

To distinguish their role function from other hospice workers, volunteers underscored that their role had nothing to do with the physical care of patients, such as bathing, lifting, or changing diapers. For example, Daniel stated,

We just visit and try to fulfill an emotional need. But other than that, it's hard to say what we do, really. People just don't understand. It's difficult to explain because it's not a material thing. It's something that's intangible.

After delineating what their role did not entail, a recurring source of frustration involved attempts to emphasize role value without being able to point to discernible acts of service. For outsiders, doing was synonymous with service whereas for volunteers, presence was considered sufficient and meaningful unto itself. For example, Lacey, a 2-year hospice volunteer, recounted a common query she received when trying to express the purpose of her role: "You're not doing anything. You just sit there for 5 hours when someone is going to die?" She said she typically replied to such questions by saying, "Yeah, I promise[d] [patients] before they got in that condition that I would be there. I feel like I'm more valuable there." Volunteers found it difficult to communicate the value of their presence beyond the negative connotations associated with merely wanting to "hang out with a dying person." Although outsiders believed something had to be "done" in the company of hospice patients, volunteers attempted to discursively position their physical presence (e.g., holding hands, sitting near patients, reading to patients, talking, listening) with patients and family as the only necessary function of their role. As such, volunteers sought to manage this communication challenge by shifting the focus of outsider attention.

Shifting focus. Faced with others' prejudices concerning the dubious value of their role when acts of service would not make a difference in preventing death, volunteers sought to manage the perceived perception of uselessness by shifting the focus away from what could be *done* and instead, featuring the benefits volunteers received from physical presence during end-of-life experiences. For example, Jaimie, a 2-year volunteer, emphasized to outsiders that her physical presence allowed her access to knowledge and insight not possible during any other time of life:

People think there's something wrong to be around dying people. But I have told others that I believe that when people are close to dying, that they are really close to a spiritual experience and sometimes when you are in the energy

of somebody whose actually dying, and they are in a real positive feeling about it, that it's just almost an enlightenment experience. There's something about the energy of people that have accepted death and are ready to go. It's almost blissful.

By refocusing attention to what they individually gained from their service, rather than what they did for patients, volunteers tried to highlight the role benefits their privileged access afforded them as something markedly different than what could be experienced in everyday communication encounters. For instance, Candice, a 6-year hospice volunteer, highlighted what she has gained from her presence during this unique time:

I think people are so real because it is towards the end of their life and so they are not going to make you feel good. I mean say[ing] things to make you feel good. "This is it, I'm going to tell you what I'm thinking." I'm there, I'm not mincing words. It's just real and I just like that because in today's society, it's not like that.

By redirecting outsiders' attention to what was gained in the presence of hospice patients, rather than what they did for patients, this strategy featured physical presence not only as a means to enlightenment but also as a prerequisite to deeply authentic interactions.

Similarly, when explaining the need for his physical presence in lieu of other social opportunities or obligations, Frank, a 2-year hospice volunteer, demonstrated how the urgency of end-of-life communication with patients required his presence in an exceptional way. When attempting to justify the need to spend time with patients instead of choosing other social opportunities, he said he explains as follows:

This is important. This is a timed thing. It has to be done now. It has got to be done before anything else has to happen. I can go to a movie later. Or I can go have fun later, but this time thing. This guy has this much time left. He has to have this done. He has to have me help him now, because there is no tomorrow when it comes to something. He needs that special whatever it is, right now. It can't wait. It can't wait with hospice.

Although volunteers explained that their physical presence helped make patients and families "less frightened" and provided "assurance they are not alone," they also enunciated what they received from their role by using self-accomplishment and self-satisfaction language. For example, when faced with questions regarding the purpose of his role, Davis, a 2-year hospice volunteer, said he talks about the self-satisfaction he gleans from knowing his physical presence with patients makes a noticeable difference:

You get a good sense you've accomplished something. You've been able to make a difference in somebody's life that day. You know, it's when you walk in, there could be all kinds of chaos going on and when you leave everybody is eating or kind of calmed down a little bit. And there's a little bit more order and peace.

Specifically, volunteers articulated to others the value of their physical presence with patients by underscoring the immediate and discernible results of their service as evidenced by "see[ing] the look on their [patients'] faces or see[ing] them smile." Thus, self-satisfaction was indelibly linked to their ability to discern impact and appreciation in real-time. For instance, Sabrina, a 2-year home hospice volunteer, explained that she tries to make clear to others that she volunteers to be with hospice patients because her presence

makes [patients'] last days more pleasant and it makes me feel good to be able to know that I'm helping them. It's rewarding to know how much they enjoy having people around and giving them attention.

Personal satisfaction, therefore, was attributed to being able to "see the help" their presence and attention provided patients and family members. Physical presence inside patients' homes was believed to be necessary and sufficient to bring about positive and discernible changes in patients' lives as well as their own needs for self-efficacy. When responding to others' questions regarding the purpose of her service, Lacey regularly underscored that "I'm more valuable there. I feel like it's the most important thing I've ever done." The emphasis on the measurable and observable impact of their physical presence was deemed necessary to refocusing attention away from role purpose by clarifying the deep personal satisfaction volunteers received from their unique access to end-of-life communication experiences they believed to be unequaled in everyday experiences.

Discussion

Home hospice volunteers are individually acclaimed during interactions with outsiders, though their public articulation of role is consistently met with misunderstanding, awe, and bewilderment. Volunteers experience discursive challenges when attempting to dissuade others regarding the (a) perceived role-specific skill qualifications; (b) nature of the population they served; (c) prejudices of role-based, interactional experiences; and (d) value of presence as an essential type of service. Specifically, our results indicate volunteers experience four recurring communication challenges when explaining their role to outsiders: we're not special—we're special, we're

among the living—we're among the dying, it's enjoyable—it's depressing, and presence is significant—presence is insignificant. Volunteers attempt to discursively manage these role-related communication challenges in light of ongoing insider—outsider tensions that reduce the communicative breadth and depth of the volunteer role experience. To discursively negotiate these role-related communication challenges, volunteers use strategies of denial, reframing, redirected identification, camouflaging role experiences, and shifting focus. Three major conclusions can be drawn from these themes.

First, hospice volunteers experience challenges when communicating their role to organizational outsiders. Specifically, role articulation is negotiated during interactions and often delimits hospice volunteers from communicating the full scope of role experiences because insider-outsider tensions often defy what others believe can, and should, happen in the company of someone who has 6 months or less to live. Although Way and Tracy (2012) argue hospice employees' acts of compassion "were accompanied by feelings of self-worth and appreciation for their work" (p. 311), our findings demonstrate how volunteers' role articulation is constructed amid bounded acceptance, tolerance, and understanding of service and the dying process. Thus, although hospice volunteers are often individually acclaimed by outsiders, they may be different from other hospice workers because such acknowledgment simultaneously reinforces the perceived (un)naturalness of their organizational role and service (Bolton, 2005). As a result, the praise volunteers receive regarding their willingness and capacity to serve hyperindividualizes the role, making it more challenging to communicate how the organizational role, rather than the person, contributes to the larger mission of serving patients, families, and hospice.

Second, as noted in past research, hospice volunteers use a variety of strategies in response to stigma, including denial, reframing, and avoidance (see Ashforth & Kreiner, 1999; see Meisenbach, 2010). Our findings demonstrate how volunteers primarily use variations of reframing to reduce offensiveness, including recasting role capacity as a calling, redirecting identification to emphasize connectedness to patients, and shifting the value of service away from discernible acts of service to what volunteers gain by access to patients. Although their reframing strategies reflect a desire to alter outsiders' beliefs and responses regarding the perceived incongruity of volunteering to work with hospice patients, such role-negotiation strategies may inadvertently segregate volunteers by maximizing role burden and minimizing choice; exaggerating organizational insider/outsider differences; inhibiting the disclosure of authentic, role-based experiences; and reducing value of service to personal benefit.

Third, volunteers' role-related communication challenges may be pronounced due to their "identification with a role as compared to an agency"

(Gossett & Smith, 2013, p. 329). Particularly, volunteers tend to identify more with hospice patients than their hospice organization or care team. As a result, hospice volunteers may experience ongoing, and simultaneous, tensions as they negotiate insider appreciation from the direct populations they serve *and* outsider misunderstandings. Thus, this study extends our understanding of hospice volunteers' role construction by highlighting the recurring discursive challenges they encounter and management strategies they use beyond individual volunteers' particular "tendencies and characteristics" (Egbert & Parrott, 2003, p. 32).

Volunteer organizations can use the findings of this study in three major ways. First, unlike traditional employees whose perceptions of role negotiation may "sustain employees' sense of hope that unsatisfactory aspects of their roles can be changed with the approval and support of their supervisors" (Miller, Johnson, Hart, & Peterson, 1999, p. 41), hospice volunteers' organizational role status situates them as neither organizational insiders nor outsiders, complicating how their roles can be negotiated and articulated. Because of their ambiguously perceived status within the organization, volunteers may be limited in their ability to draw on "the social resources needed to selectively attend to outsiders and to selectively engage in social comparisons" (Ashforth & Kreiner, 1999, p. 425). Unlike research that concludes hospice volunteers are well-supported by staff, generally well-trained for hospice-specific contexts, and satisfied with their roles (Dein & Abbas, 2005), our themes demonstrate the important function identification plays when managing communication challenges. Although "people may identify most with an organization that provides opportunities to play out their helperrole-identity" (Gossett & Smith, 2013, p. 329), novice and experienced hospice volunteers would benefit from hospice-sponsored training that focuses on role-based communication that helps them more effectively communicate with external audiences, replete with strategies designed to acknowledge and manage possible contradictions. For example, research has identified the importance of using metaphors to explain and communicate experiences in hospice volunteer training and recruitment (Gilstrap & White, 2013; Sexton, 1997). To date, however, communication training for hospice volunteers has largely focused on communication with patients, family, and hospice staff (Hall & Marshall, 1996). This study underscores the importance of supplementing internal-based communication training with external-based communication training to help volunteers proactively voice common, role-based experiences to outside audiences.

Second, training and continuing education programs should teach hospice volunteers strategies for justifying their role as integral members of a professional IDT, including role descriptions that more adequately address their value to patients and families beyond idiosyncratic individual qualities. Although hospice volunteers have been found to be more empathetic than the general population and other health care volunteers (Egbert & Parrott, 2003), empathy is too often conceived as an individualized capacity rather than a skill set drawn forth and cultivated by the role itself. This study provides a significant starting point for pinpointing role-specific aspects volunteers find most difficult to communicate to outsiders. With this knowledge, staff might create rhetorical opportunities for new, ongoing, and prospective volunteers to communicatively transform these recurring communication challenges into role-specific language designed to enhance the articulation of service as a vital part of quality, end-of-life care. By creating such opportunities, hospice organizations may further enhance volunteers' identification not only with the people they serve but also with their respective hospice organization and mission.

Third, hospice organizations may ultimately be placing volunteers in the unenviable position of having to overcome long-standing misconceptions and prejudices as individuals, rather than leaning on organizationally derived sensemaking resources. Because hospice volunteers' work largely takes place in the home, their physical isolation from other organizational employees and peer volunteers may inhibit collective socialization whereby volunteers might be able to engage in "backstage interactions with similar others" (Tracy, 2005, p. 276). Thus, hospice volunteers are particularly vulnerable to role articulation challenges because their service physically isolates them from other hospice workers, especially fellow volunteers from which they might create a shared volunteer-specific culture. Without a common organizational vernacular to account for role, hospice volunteers must borrow language from the mainstream ideology surrounding dying and death, thereby reducing their roles into private, ephemeral experiences. Thus, hospice organizations should seek to create ongoing opportunities for volunteers to socialize and communicate about their role with each other so they might be able to forge a collective, role-based identity.

There are two limitations of this study. First, it relied on volunteers' recall of past interactions with others outside the hospice context. This method allowed us to examine the phenomenological experiences of hospice volunteers and their challenges communicating with outsiders (Andersson & Öhlén, 2005). However, it did not allow for observations in natural settings. Therefore, researchers should continue to explore the multidimensional nature of role negotiation by directly observing interactions between hospice volunteers and organizational outsiders, other hospice workers, and patients and family members. Second, we did not differentiate role articulation in conjunction with years of service during data analysis nor did we make

distinctions among various hospice organizations (e.g., religiously affiliated) that may affect hospice volunteer role orientation. For example, Jennifer, an 8-month volunteer, suggested length of service may be an important issue when she said,

I think [the reason I volunteer with hospice] probably is different from when I first started . . . and how it is now when I just have the confidence to tell [others] that it is something that I am compassionate about.

Future research should examine the construction of role in conjunction with years of hospice volunteer service to examine whether volunteer tenure affects role articulation (see Finkelstein, 2008).

In conclusion, continued research "at the intersection of health and organizational communication" (Real, 2010, p. 457) will provide ongoing opportunities to understand volunteer communication challenges in nontraditional contexts of care (e.g., prisons, nursing homes). If volunteers "evaluate the costs and benefits" (Musick & Wilson, 2008, p. 444) of their service in light of their identity, research examining how volunteers discursively construct role to outsiders provides a window into how volunteers conceive of their service and their organizational value. For organizations that seek to recruit and maintain volunteers who willingly engage in end-of-life care, creating collective and organizationally sponsored sensemaking opportunities is essential not only for volunteers themselves but also for the populations that benefit from sustained volunteer efforts.

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