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Navigating the Transition from Advanced Illness to Bereavement: How Provider Communication Informs Family-related Roles and Needs

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ABSTRACT

Person-centered, family-oriented services are integral to palliative and end-of-life care. Effective communication with providers informs the quality of the dying experience for patients and how families fare in bereavement. This paper reports findings from a study exploring how communication and care in the later stages of an advanced illness influence family caregivers' well-being in bereavement. A concurrent triangulation design was used to analyze data collected during semi-structured interviews with 108 recently bereaved caregivers from a single hospice agency in Western New York. Findings from this study suggest that family caregivers assume the role of interpreter and advocate while engaged in both formal and informal communication with health care providers at the end of care-recipients' lives. Findings also suggest that families are more likely to feel emotionally prepared for loss and grief when health care providers are available to communicate in a concise, consistent, and compassionate manner. The results illuminate the important connection between communication during the transition from late-stage illness to end-of-life care and preparation for bereavement. The paper concludes with a discussion of how findings from this study align with recent concerted efforts to establish standards and competencies for social work education and practice in palliative care.

KEYWORDS

Family caregivers; communication; end-of-life; bereavement

Introduction

Person-centered, family-oriented care in both palliative and end-of-life programming has been identified by the Institute of Medicine (IOM, 2014) as a critical area for improvement within current health care systems. Effective communication between health care providers, patients, and families that supports advance care planning ahead of medical crises is regarded as an essential component to achieving high quality end-of-life care (Carr & Luth, 2017). Yet prior research suggests that provider-patient-family

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communication about prognosis, goals of care, and decision-making is limited (Fischer, Min, Cervantes, & Kutner, 2013; Waldrop & Meeker, 2012; Zwakman et al., 2018).

Approximately 30–50 percent of all American adults have documented their end-of-life wishes (Carr & Luth, 2017). When care preferences are not documented, patients have a greater likelihood of dying in a hospital (Nicholas, Langa, Iwashyna, & Weir, 2011), higher frequency of receiving unwanted and aggressive interventions (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014), and lower chances of their wishes being both understood and honored at the end of life (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). However, there is a growing body of research to suggest that documentation alone does not provide sufficient guidance; rather, timely communication between health care providers, patients, and families is necessary for achieving desirable outcomes for both the care-recipient at the end of life and the caregiver in bereavement (Fischer et al., 2013; Moriarty, Maguire, O'Reilly, & McCann, 2015; Zhang et al., 2009).

The emotional preparation of caregivers for the end-of-life trajectories of care-recipients has been found to mediate risk factors for distress in bereavement (Becqué, Rietjens, Geertvan, Agnesvan der Heide, & Witkamp, 2019; Hovland & Kramer, 2019). Feelings of regret, anger, loneliness, anxiety, and hopelessness can contribute to mental health issues in bereavement, especially when caregivers experience miscommunication with health care providers related to their family member's prognosis and plan of care (Ishida et al., 2012). High quality end-of-life care and communication have been found to positively influence adaptation in bereavement (Higgins & Prigerson, 2013). A longitudinal study of patients with advanced cancer and their informal caregivers found that interventions aiming to minimize caregiver distress, encourage advance care planning, and improve the quality of the dying experience contribute to better outcomes for caregivers (Garrido & Prigerson, 2014).

Family meetings are one such intervention for achieving these desired aims and outcomes. During these meetings, social workers are uniquely positioned to support the dying person and/or the surrogate decision-maker to articulate end-of-life wishes and advocate across the interdisciplinary team for advance care plans to be upheld. Social workers are also well trained and educated in the provision of psychosocial support to caregivers and family members who are anticipating or preparing for the progression of the end-of-life trajectory (Black, 2007; Wang, Chan, & Chow, 2017). Prior research has articulated best practices for facilitating effective communication during family meetings, including how interdisciplinary teams comprised of social workers, nurses, and doctors can facilitate

person-centered, family-oriented care across health care settings (Ngo-Metzger et al., 2008; Curtis et al., 2001).

Little is known about what family members perceive their roles to be in family meetings, nor is there much guidance within the available literature as to how health care providers can meet the expressed needs of families to ensure greater emotional preparedness for both death and bereavement. The overall purpose of this study was to explore how communication, advance care planning, and care in the later stages of advanced illness influence family caregivers' well-being in bereavement. Specifically, this paper focuses on the nature and quality of communication in late-stage illness and at the end of life and how that informs family transitions in roles.

Methods

Study design

Data presented here were drawn from a causal-comparative, longitudinal study with three waves of data collection. A concurrent triangulation design was employed to collect and analyze quantitative and qualitative data at 4, 10, and 16 months following the death of an individual who died in hospice care (Creswell, 2018). This paper presents Time 1 quantitative and qualitative data collected concurrently during interviews with bereaved caregivers. Quantitative data were collected to ascertain the frequency of in-person family meetings concerning the end stage of the care-recipient's terminal illness and the perceived quality of communication with health care providers. Qualitative data were collected to elucidate the dynamics of this communication, including how provider communication informed decisions about health care utilization, outcomes at the end of life, and well-being in bereavement. The project was developed in collaboration with the Research Department and Bereavement Services Program at [blinded] in [blinded]. The study was approved by the [blinded] Institutional Review Board.

Sample

A sample of 108 bereaved caregivers was drawn from a single hospice provider agency in Western New York. This setting was purposefully selected due to its ability to facilitate access to recently bereaved surrogate decision-makers, thus maximizing understanding of their roles and needs both before and after the death of the care-recipient (Onwuegbuzie & Collins, 2007). All caregivers who were over the age of 18 years and able to consent were eligible for inclusion.

The Bereavement Services Program of [blinded] informed all recently bereaved caregivers of the study and sent the principal investigator an encrypted list with contact information for the primary caregivers monthly throughout the recruitment period. Informational letters and mailed response forms were sent to 325 recently-bereaved caregivers three months after the death. The recruitment period lasted for three months until the desired sample size was reached; all eligible participants who received the letter, returned the response form, and consented to participate were interviewed.

Data collection

Time 1 interviews were conducted in-person or by phone as per the participant's choice approximately 4 months following the death of the care-recipient to maximize recall while minimizing intrusion during the early stages of acute grief (George, 2002). The principal investigator in collaboration with the Research Department at [blinded] developed a semi-structured interview guide that included quantitative (e.g., demographics, rating of end-of-life experience, bereavement symptom indexes) and qualitative (e.g., history of illness, description of end-of-life experience) items.

The focus of this paper relates to data obtained from participants in response to two quantitative questions asked during the interview: (1) Did the patient and you have an in-person family meeting with one or more health care providers about the end stage of his/her illness before his/her enrollment in hospice? [Nominal, Dichotomous; Yes/No]; (2) Please rate the quality of communication with the patient's health care providers before his/her hospice enrollment. [Ordinal, 5-point Likert Scale; Clear/Understandable/Needs Met to Unclear/Not Understandable/Unmet Needs]. Four additional qualitative questions were asked to elicit narrative descriptions of the dynamics of family meetings, end-of-life experiences, and bereavement: (1) If you did have an in-person family meeting, when, where, and who did you and/or the patient meet with?; (2) Can you please tell me about the time leading up to and after the patient's passing?; (3) Were you expecting the patient's passing?; and (4) Do you believe that you had enough time to prepare emotionally for the patient's passing?

Interviews were conducted by the authors and lasted between 45 and 120 minutes. Interviews were audiotaped and professionally transcribed with permission. If a participant declined audiotaping, field notes were taken by the interviewer. Gift cards to a local supermarket valued at \$10 were offered to all participants at each interview as a token of appreciation for their participation.

Table 1. Participant demographics.

Characteristic	Caergivers (n = 108)
Age–mean (range)	61 (32–88)
Gender–n (%)	
Male	31 (28.7%)
Female	77 (71.3%)
Race–n (%)	
Caucasian	92 (87.6%)
African American	8 (7.6%)
Hispanic	2 (1.9%)
Asian or pacific islander	2 (1.9%)
American Indian or alaskan native	1 (1.0%)
Unreported	3 (2.8%)
Marital status–n (%)	
Married	52 (48.1%)
Widowed	34 (31.5%)
Divorced	11 (10.2%)
Single	9 (8.3%)
Partnered	2 (1.9%)
Religious preferences–n (%)	
Catholic	53 (49.5%)
Christian	31 (28.7%)
Spiritual	4 (3.7%)
Other	1 (0.9%)
No affiliation	19 (17.6%)
Educational level–n (%)	
>High school	3 (2.8%)
High school diploma	21 (21.3%)
Some college	23 (24.2%)
Bachelor's degree	31 (28.7%)
Advanced degree	17 (15.8%)
Unreported	13 (12%)
Relationship to care-recipient–n (%)	
Spouse/partner	33 (30.6%)
Adult child	57 (52.8%)
Sibling	6 (5.6%)
Extended family member	9 (8.3%)
Friend/Other	3 (2.8%)

Data analysis

Consistent with the concurrent triangulation design, quantitative and qualitative data were analyzed separately and then combined to facilitate a richer understanding of the dynamics of communication at the end of life, particularly as it relates to the roles and needs of caregivers and families (Creswell, 2018). Quantitative data was entered into SPSS v.21. Descriptive statistics were calculated for demographic data and categorical questions exploring both the frequency of family meetings and the rated quality of communication with health care providers (Table 1).

Interview transcripts were entered into Atlas.ti v.9 for qualitative data management and co-coding. The authors engaged separately in *open coding*, or the process of understanding the dynamics of provider communication through line-by-line examination of the bereaved caregivers' transcribed interviews. Next, transcripts were subjected to *systematic coding*, or the examination of narrative data using a start list of concept-driven

Table 2. Study themes and definitions.

Themes & categories	Definitions
Family Meeting	<ul style="list-style-type: none"> An in-person meeting between the family caregiver(s), care-recipient, other involved parties, and one or more health care providers about the end stage of the care-recipient's illness.
Family-related roles	<ul style="list-style-type: none"> Family caregivers translate information from providers and care-recipients and then often back-translate it to other involved parties.
<i>Interpreter</i>	<ul style="list-style-type: none"> Family caregivers ensure care-recipients' day-to-day needs were met and end-of-life wishes are upheld.
<i>Advocate</i>	<ul style="list-style-type: none"> The clarity and understandability of communication with health care providers, such that the needs of the care-recipient and caregiver are met.
Quality of communication	<ul style="list-style-type: none"> The information that is delivered and the style in which it is delivered by healthcare providers to family caregivers and care-recipients.
Family-related needs	<ul style="list-style-type: none"> The continuum of family caregivers' preparedness for the end-stages of the disease trajectory and lasting implications of this preparedness in bereavement.
<i>Provider communication</i>	
<i>Emotional preparation</i>	

codes that emerged through consensus building by the authors. Each code represented a key tenet of the research question. Example codes included family-related roles and family-related needs. Patterns emerged and codes were collapsed to create categories. For example, family-related roles fell within two categories: (1) interpreter and (2) advocate; and, family-related needs fell within two categories: (1) provider communication and (2) emotional preparation. *Axial coding* was then used to define and specify the properties of each category and sub-category (Padgett, 2008). The definition of study themes and categories are presented in Table 2.

Findings

Participants

The 108 participants in this study were the primary caregivers to care-recipients who died from: cancer ($n = 54$, 52.4%); congestive heart failure ($n = 12$, 11.4%); Alzheimer's disease ($n = 9$, 8.6%); stroke ($n = 7$, 6.7%); COPD ($n = 4$, 3.8%); and other chronic conditions. The care-recipients' average length of stay in hospice was 76 days ($SD = 146.83$, $Mdn = 21$). Bereaved caregivers ranged in age from 32–88 years of age ($M = 61.5$, $SD = 10.3$). Participants were predominantly female ($n = 77$, 71.3%) and Caucasian ($n = 92$, 87.6%). All but three were providing care to a family member; adult children ($n = 57$, 52.8%) and spouses ($n = 33$, 30.6%) were the most common familial relationships represented in the study sample. The majority of participants were married ($n = 52$, 48.1%) or recently widowed ($n = 34$, 31.5%). The demographic characteristics of the care-recipients and caregivers in this study are consistent with national trends in hospice utilization (National Hospice & Palliative Care Organization, 2018).

Family meetings

Quantitative findings from this study suggest that the majority of participants ($n = 61$, 57.5%) recalled having an in-person family meeting with one or more health care providers about the end stage of the care-recipients' illness. As one adult child recalled:

They used to have quarterly and semi-annual meetings at the nursing home about basic game plans, how she has been doing, what kind of treatment she had, the medical attention she had, what kind of medication she was on and everything. At the hospital, she was in the Intensive Care Unit first and then went to a room. We did have a representative come before she was admitted to Hospice. They sat down with myself and my two sisters.

Qualitative responses regarding the nature of these meetings suggest case-specific variability in when and where they occurred and who was involved. Family meetings frequently preceded a status change or care transition, or followed a predetermined timeline according to the standards and practices of a given setting. Participants described meetings in long-term care, hospitals, and hospices, where meetings were held in private conference rooms, at the bedside, and along hallways. Participants reported that some combination of doctors, nurses and social workers attended. Care-recipients and other involved family members were also invited. However, 1:1 meetings with the primary caregiver were most common when other family members were long-distant or the care-recipient lacked capacity.

More than one-third of participants recalled no meetings, primarily because providers did not initiate this type of communication. Participants described attempting to decipher the care-recipient's prognosis through direct observation and informal communication with providers. As an adult child noted, "I don't recall any specific meetings, just knowing that I could see the decline." Several participants reported that family meetings were not facilitated because these conversations were undesired by the care-recipient and/or caregiver. When asked if there had ever been an in-person family meeting, one widow firmly stated, "No, never. It's just a big N-O." She went on to elaborate, "No, because it was our business. His and mine." Another adult child recalled:

If there was [a family meeting], it was with my older sister because she was in town but I'm not aware of it. That was mom, 'If there is anything you need to know missy, I'll inform you.' The nurse would come in and say, 'Are there any questions?' And I would just say, 'Nope.' I knew that my mom was in control and she would take it as a form of disrespect or that is how I took it as.

Participants suggested that, while family meetings were common, there was wide variation in how they were conducted.

Family-related roles

Analysis of the qualitative narratives of bereaved caregivers suggests two emergent roles: *interpreter* and *advocate*. As interpreters, family caregivers translated information from providers and care-recipients and then often back-translated it to other involved parties. As advocates, family caregivers ensured day-to-day needs were met and end-of-life wishes were upheld.

Interpreter

Caregivers frequently reported having to interpret the meaning of communication with providers. As a bereaved sibling recalled, “I think the doctor would talk in a little bit of coded language.” Another bereaved spouse identified her daughter as the family’s designated interpreter at a family meeting:

My oldest daughter was there. She was pretty much doing all the research prior to the meetings, and she was explaining to us what was happening. A little better than the doctors did, actually. She’s not a medical person, but she knew more than we did so she was able to fill in that buffer, that gap where we weren’t sure but she had already done the research on it. I think having an advocate in your own home like that really enhanced communication with the doctors.

Caregivers often assumed the role of interpreter to both better understand the prognosis of the care-recipient and engage in informed decision-making with health care providers.

Family caregivers were also uniquely positioned to interpret both the needs and wishes of the care-recipient; they reported being able to identify status changes before they became evident to health care providers. As one widow noted, “He was 91 years old. He wasn’t 56 or 80 or something. He was 91. From the time I was 17 and he was 25, we could read each other like a book.” Another adult child recalled being initially dismissed:

Well, she was in the hospital and they finally decided that they were going to discharge her. And her primary care doctor at that time was not her doctor but one of the staff. He came through and he said she was okay to go get discharged. I said, ‘Well, I don’t think she is.’ I said, ‘She’s still not feeling well ... and not eating.’ He said, ‘I don’t know why, that’s just more or less the way it is.’ So, I said, ‘Well, we’ll get her dressed and we’ll go home that day.’ Well, while we were sitting there getting her dressed, she had another stroke.

As an interpreter for the care-recipient, the role of family caregivers was often to articulate critical information to sometimes skeptical providers to ensure that accurate diagnoses were rendered and appropriate care was delivered.

The primary caregivers frequently recalled serving as interpreters for their own family members; in this capacity, they would translate information derived from the providers and the care-recipient to others to ensure

that everyone was informed and understanding of decision-making. One adult child recalled, “We called her brother because we knew it was pretty bad. He lives in [a city approximately 3 hours away]. And my sons came over. We shared what the team told us and everybody agreed. They said, ‘Well, it sounds like a reasonable plan.’” Another adult child noted, “My sister was only a phone call away. We communicated by text constantly, although she didn’t agree with keeping her home and she wouldn’t have done that. She did honor my wishes and was there for me.” Participants’ reported that streamlined communication helped to ensure that they felt supported when decisions needed to be made on behalf of the care-recipient.

Advocate

Family caregivers advocated for the basic needs of their loved ones, especially when the end stages of their illnesses warranted out-of-home care. An adult child recalled the collective efforts of all involved family members, “Yes, her needs were met because we made sure. We were close where we would go and visit, and ask questions. We knew what my mother wanted and how she wanted to exit life.” Generally, the bereaved caregivers who participated in this study recalled providers being responsive to their advocacy. However, there were some caregivers who reported variability in the quality of providers’ responses and the intensity of advocacy required to ensure the care-recipients’ needs were met. One adult child of a care-recipient who had Alzheimer’s disease reflected:

There were times when the communication was really, really good and then I felt like at other times they weren’t listening to what I was saying and they weren’t getting him what he needed. Because during his agitation stage, I was really, really lobbying for them to give him something just to take the edge off. And I thought that they didn’t really get it. He was so agitated. He never slept. He was just pacing the halls. Literally, he never slept. I finally said something like, ‘How would you feel if you were wandering the halls of your house, you woke up every day after sleeping two hours or an hour here and there, you didn’t know where you were, you didn’t know who you were, you didn’t know anything about your life and then the day started all over again. How would you feel?’ So I fought with the doctors because I felt like he wasn’t getting what he needed. And, finally, they did give him something.

In bereavement, those family caregivers who assumed the role of advocate appeared to regard these interactions as acts of service to benefit their dying family member.

Similarly, family caregivers assumed the role of advocate when articulating and engaging in health care decision-making. Primary caregivers, often in coordination with the care-recipient and other family members,

advocated for known or documented end-of-life wishes. An adult child recalled how she and her sister worked collectively to advocate for the wishes of their father during family meetings and in other settings when decision-making was required:

Even though my sister was the first person on the health care proxy, we would always go together and she would always say, 'Do you agree with it?' When my dad was at [nursing home], one time he was lying in bed and it was one of those days where he was having a good day and I was on one side of the bed and my sister was on the other side of the bed. He said, 'I could sit here for hours and listen to how the two of you talk because you just get along so well.' Then he took my sister's hand and he took my hand, and he said 'As long as I have both of you, I know I'll be okay, because you'll make the right decision.' I think I always remember that I knew in my heart and she knew in her heart it was what he wanted.

Many participants reported feeling more affirmed in their advocacy when wishes were known and/or documented in advance of the end of life. One adult child recalled how advance care planning was integrated into their family dynamics, "We talked early. Ever since she was 60 years old, from 60 to 80. You bring it up at the appropriate time; it's not dwelled on. If people wait too long, then it tends to be dwelled on." Many caregivers reflected on how prior experiences informed the wishes of the care-recipient. One adult child recalled:

They had pre-arranged this a while back that she didn't want any resuscitation. In other words, if it was her time to go, she was going to go and she didn't want to be hooked up to anything. This was all taken care of before anything happened. Because my father had Alzheimer's and he was also 95 when he died, but we learned a lot from his illness and everything was pre-arranged.

At four months after the loss, these narratives suggest that many family caregivers continued to grapple with their role as advocates particularly as it related to health care decision-making. Some questioned their effectiveness in advocating for their family members' wishes while others ruminated on whether or not they ultimately made the right decision, especially when wishes were not known or documented.

Quality of communication

Quantitative findings from this study suggest that the majority ($n=62$, 57.4%) of bereaved caregivers regarded their communication with health care providers as clear and understandable thus resulting in the needs of the patient and family being met. Only 18 participants (16.7%) reported unclear communication and unmet needs. The remaining 28 participants (25.9%) rated the quality of communication somewhere in between.

Family-related needs

Analysis of the qualitative narratives of bereaved caregivers suggests that they needed to engage in effective communication with the interdisciplinary team in order to be emotionally prepared for their family members' passing and their own bereavement. For recently bereaved caregivers, *provider communication* involved both the information that was delivered and the style in which it was delivered. For these participants, their *emotional preparation* for the death fell along a continuum and often had lasting implications through the end-stages of the care-recipients' disease trajectory and into bereavement.

Provider communication

Family caregivers in this study frequently acknowledged the volume of new information they had to both receive and understand to effectively support the care-recipient at life's end. As one bereaved nephew concisely noted, "We all had to do a lot of learning." Another adult child highlighted the challenges that emerged when families were not provided with critical information:

This is the first time we did this, as family members. Hospice would come in, but we were the hands-on care. And I don't think we were prepared for that. We did it; I would do it again. I love my father. But we didn't know that the hallucinations were expected. There were some things that could have been better communicated.

In bereavement, some family caregivers questioned whether insufficient information impeded their ability to provide quality care to the care-recipient at the end of life.

Participants reported needing clarity for effective communication to be achieved with health care providers. One widow noted, "There were times when things were unclear. Where we were like, 'Um, what was all that again?'" A lack of clarity was often attributed to the use of clinical jargon or misrepresentation of the care-recipient's prognosis. One sibling experienced both and recalled:

I think it was a little too much with false hope. I don't think they were forthcoming with how severe it was. They were trying to sugar coat it. A lot of people don't understand a lot of the medical terms and a lot of what's going on, so I think they try to explain it a simpler way but then they get too vague.

Those who did experience effective communication with their health care providers often attributed it to clear information about the plan of care. One adult child reflected, "The provider was pretty good. She would always mention to us what her plan of action was going to be, what she planned on doing, and what was always open." The bereaved caregivers favored clear and direct communication, particularly as it related to the care-recipients' diagnosis and prognosis, even when that information was challenging to receive.

In addition to the clarity of language used, participants emphasized the importance of consistent information from the interdisciplinary health care team. One adult child noted, "It was a constant problem. It seemed like everybody was not on the same page." Another widow recounted a specific example of inconsistency among health care providers in a hospital setting:

I said [to the palliative care physician's assistant], 'A doctor just came in; he told us he has two months to nine months to live if he has treatment.' She said, 'He's lying to you. Well, he's not telling you the truth.' That's how she put it. He doesn't want to be the bad guy. He only has two days to live. It's like, 'What the hell are you talking about?'

Others participants, however, experienced consistent information from all members of the health care team or had a trusted provider who could deliver a coherent message that was encompassing of the different perspectives represented on the team. For example, one adult child recalled:

I felt as though there were an awful lot of doctors that were seeing her. I mean the very first day, I think she saw 10 doctors. I felt like every doctor was compartmentalized within their own specialty and that there was not a lot of communication in between people. The only doctor that was very open and honest with me was the doctor that we had initially seen in the ER. On the very last day before we transferred her to Hospice, I said to her, 'I'm sorry, but I don't have a big picture yet. I have little pieces of the puzzle, and I need them put together for me.' So she, at that point, that doctor did.

In bereavement, many participants continued to question how communication across the interdisciplinary health care team impacted the end-of-life experiences of their family members.

Participants in this study frequently acknowledged that the communication style of their health care providers was equally as important as the information they delivered. The bereaved caregivers interviewed for this study favored providers who were available in person or via telephone on both a routine basis and as needed when there were changes to the plan of care. One adult child recalled the availability of her mother's provider:

He would even call me up every day, the doctor in the morning after he saw her. He would explain things to me. There was only one incident that he didn't get in touch with me, and I blew my coop. It was when they were giving her a medication that I did not recognize, and she did not recognize. I said, 'She's not taking it until I find out.' I called the doctor, and he called me right back and apologized for him not calling and telling me he put her on an antidepressant.

Those who encountered providers who were less available often attributed it to the busyness of the setting (i.e., a hospital during an influenza outbreak) and scheduling issues (i.e., provider rounds before visiting hours). Several participants cited hospitals as particularly challenging

environments for consistently engaging with providers. One adult child recalled:

There was one doctor, one floor doctor. He called me one night when he was on rounds and I said, ‘Oh, thank you so much for calling.’ He said, ‘Oh, well it’s all over the chart that we have to call you.’ And I’m thinking then, you’re the only one that has read her chart, because you’re the only one that has ever called me when I have not been there. I had everything with big bold letters on her chart that I wanted to know every single thing that was done, every single thing that happened and I didn’t. It didn’t even matter that I had it on there. They weren’t telling me unless I asked, unless I specifically went and asked, I was not being told.

Generally, those bereaved caregivers who regarded their providers as available had a clearer understanding of the care-recipient’s end-of-life trajectory and perceived their needs to be met during the dying process.

Participants reported positive experiences with providers who were compassionate when communicating with the care-recipient and the family about the end stage of the illness. One adult child recalled the following encounter with the doctor who delivered her father’s prognosis:

The biopsy was done on a Monday and on Tuesday, the [doctor] came in, sat down, took my father’s hand, and said, ‘I’m sorry to tell you this, but it’s cancer of the esophagus, the stomach, the liver.’ It was like basically everywhere. He hugged my mother, he hugged me, he had tears in his eyes. He was the most compassionate. He talked to my daughter; my daughter’s husband is a physician and her father-in-law in a surgeon. He talked to them. He took the time.

Alternatively, the absence of compassion at this point in the disease trajectory was particularly upsetting to caregivers. The same participant recalled an exchange with another provider around the same time period:

Another doctor came back again on Tuesday and she said, ‘There’s nothing more we can do for him here.’ And she was nasty. She said, ‘We can’t keep him here.’ I said, ‘Wait a minute. Do you realize we haven’t wrapped our head around that my father is dying? Obviously we can’t just take him home and care for him by ourselves. We want him home though.’ She said to the resident, ‘Go call hospice.’ And she left. If I was more in my right mind because she had all her residents there, I would have taken them out and said, ‘Just so you know, this is not the way you treat a family.’

Participants also cited the importance of compassion from providers in their bereavement. One widow reported the following encounter with her husband’s oncologist after his death:

When he passed away, would you believe that man called me from New York City? He was at a conference and he told me, “I couldn’t let it go. I had to call you now.” He said, ‘I’m so sorry.’ I thought that was so wonderful. I mean, how many doctors would do something like that?”

Another bereaved spouse had a distinctly different experience with her primary care physician:

I don't even feel comfortable going to my family doctor after 30 years. I went there one time since [my husband] passed away, because I hurt my elbow. And he had no compassion whatsoever. Never mentioned [his] name, that they're sorry or anything. They acted like they didn't even know me. He could have showed a little more compassion. He probably has a lot of patients that died, but I thought I was special, because I went to him for 30 years. I guess I wasn't.

The style of communication utilized by health care providers varied. Those who found the communication clear and understandable such that their needs were met described providers who were concise and consistent in their delivery of information and compassionately available to all involved.

Emotional preparation

Recently bereaved caregivers were asked retrospectively about if they had expected their family member's passing and if they had sufficient time to emotionally prepare for the death. A qualitative analysis of their responses suggests that participants self-identified along a continuum of feeling fully prepared to entirely unprepared for the loss.

Family caregivers who felt emotionally prepared for the care-recipient's death often identified as having their needs met by their health care providers. They reported receiving sufficient information to understand the diagnosis and prognosis, including the symptoms that would likely accompany end of life. One widow recalled the following experiences:

Yes, every step of the way I received enough information. Because I was trying to prepare myself, I kept on asking the nurses, 'Where are we? You've had this experience before, where are we in this process?' The nurses were really forthcoming with telling me. Like when he first started with hospice, the nurses said he was by no means at the end of life yet. And when he did reach the point of being at the end of life, the nurses actually did tell me so. They explained that there is a process of dying, what happens.

Caregivers sometimes assumed responsibility for their own emotional preparation, reporting having engaged in advance care planning with the care-recipient, providers, and other involved family members. An adult child, when asked if she felt emotionally prepared for her mother's death, recalled:

Oh my god, yes, definitely. My mom, for years had been saying, 'I know. I'm not stupid, I'm not going to be here for my next birthday.' We had totally prepared everything as far as her cremation, everything was done, and financially everything had been done. My half-brother, his mom is an attorney and he's the one that actually drew up all of the paperwork. It was pretty easy.

One caregiver who felt she was emotionally prepared for the death of her husband reported the following experiences in bereavement:

Yeah, I think I was prepared. When it was over, I was seeing a counselor at hospice. I think I went four times and at the same time, I was reading a book by Tom Brokaw. It was about him growing up in South Dakota, and he was running for Student Council or Class President or something. He thought he was doing a pretty good job, and his favorite teacher pulled him aside and he said, 'Brokaw, you're a big phony. You're telling everybody what they want to hear.' And I thought about that. Am I telling people what they want to hear? I was trying to be strong for the family, but I don't think I was really a phony. But I read that sentence probably 15 times; I think it straightened me out so that if I did have negative thoughts, I wasn't afraid to express them.

For those who felt emotionally prepared, the death sometimes came with a sense of relief. One adult child reflected, "After it happened, you are glad that they're gone. You don't want to see him like he was—not brushing his teeth, not combing his hair, not shaving. So, you're kind of glad because basically my father wasn't there." The narratives suggest that participants who felt emotionally prepared for both the death and their own bereavement had no unmet needs.

A subset of the sample reported having received enough information from health care providers to meet their needs yet being emotionally unprepared to witness the progression of the care-recipient's advanced illness. As one widower stated, "Ya know, you're never really emotionally prepared, but there was enough time. We knew. I knew. She knew." Another adult child reflected on the information received and how it was processed:

I knew when the palliative care doctor was called in; I knew it was going to happen. They kept saying days to weeks, and then it was hours, literally hours. I know that some of medicine is guessing; I realize that. But I was thinking like after I knew it was just hours, I was just thinking how can they possibly say days to weeks? I just felt like, when they said days to weeks, I had extra time and that maybe things could turn around. And maybe that was just my own way of putting myself in denial.

The death of the care-recipient often marked the first intimate encounter with death for those who felt only somewhat emotionally prepared for the loss. One participant whose extended family member had in-home hospice care at the end of life reflected:

I don't think it could have been any different, but it did come as a surprise in a way nonetheless. It shouldn't have. White, middle class people in America don't grow up with the experience of death around them all the time, though. So, my sister and I didn't have that. We didn't have siblings who died and death all around us. When it had happened, it had been isolated in hospitals. So, it was kind of a new experience.

The cognitive dissonance between understanding that death was imminent and feeling emotionally unprepared continued to reverberate into bereavement. One adult child reflected:

I think I had enough time. She was in hospice for several days; they told me it was probably within the next 12–24 hours. I knew it was coming. Part of me said, I won't be spending tonight and the next night in the hospital. But, I don't know, that was in April and this is September. There are times when I find I still have difficulty comprehending. I can't believe I'm not going up to nursing home to see her.

Even when family-related needs were met at the end of life, some primary caregivers' narratives suggest that both unfamiliarity with death and the profoundness of the loss made it challenging for them to emotionally prepare for the death and their own bereavement.

Another subset of participants felt entirely unprepared for the death of the care-recipient. For some, the rapid progression of the advanced illness challenged the capacity of families to receive and process sufficient information to have their needs met. One adult child whose father was admitted to the hospital for acute symptoms of pneumonia but was later diagnosed with cancer recalled:

It was pretty cut short. We went to the funeral parlor on Saturday, and he died on a Monday. And then we had to go back there on a Tuesday. Everything was happening so fast. We still hadn't wrapped around our heads that he was going to die. Because in our mind, he still had pneumonia.

For others, the absence of sufficient information and/or the capacity to make sense of the information from health care providers contributed to feelings of unpreparedness. One adult child recalled the following exchange with a hospice provider at the end of her father's life:

He was just getting weaker by the day, and I called them and said, 'I'm really alarmed. He's really, really weak. He's having a hard time just getting up and going to the bathroom.' And the woman sort of said to me, a little bit abruptly, 'Well, you know, that's the nature of cancer.' I just thought, 'Oh, I don't know why but you didn't mention it, and I didn't make the connection.'

The loss of an intimate partner contributed to many participants stating that there is "never" enough time to prepare emotionally for the death. One bereaved widow stated, "No, I would have taken another 100 years." In bereavement, participants who felt emotionally unprepared for the care-recipient's death often wished for additional time and reported a continued sense of disbelief. One widow reflected:

Me? No. I am still not prepared for it. Even though he's gone, I'm not prepared. I'm not ready to let him go. I expect to see him anytime. It's like a dream; it never really happened yet. I know it has, deep down I know it has and mentally I know it has. Emotionally, I don't think so.

When family-related needs were not met, participants' narratives suggested that they felt emotionally unprepared for the death and bereavement.

Discussion

This paper provides specific reflections on the road that is traveled between late-stage illness and bereavement and the ways that provider communication functions as a global positioning system (GPS) to help family caregivers navigate uncertainty and the unknown. The perspectives and recall of 108 bereaved caregivers of people who died in hospice care illuminate how the presence/absence and quality of communication with providers influence family-related needs and roles through the important developmental transition of losing a family member.

The study's findings build on and extend knowledge about the importance and influence of provider communication in advanced illness and how it informs the experience of adjustment to bereavement, which has been found to begin before death (Schulz et al., 2003). Previous studies have identified the important elements of provider communication across settings to be family-centered and include discussion of the illness experience, family emotions, decision-making, and maintaining comfort and dignity in the dying process (Levin, Moreno, Silvester, & Kissane, 2010; Radwany et al., 2009). The style of provider communication in this study often depended on the busyness of the setting and the clinical priority (curative vs. palliative) of the unit, which has been conceptualized as a "philosophical divide" for people who are at the end of life and hospitalized in an acute setting in which palliative care is not the priority (Chan, Macdonald, Carnevale, & Cohen, 2018).

Caregivers have been found to have significant needs for information, communication, and consultation about decision-making, without which they often feel adrift as death nears (Wee, Adams, & Eva, 2010). In this study, family caregivers needed to serve in the roles of interpreters of life experiences for health care providers while simultaneously interpreting medical information for a family member who is dying. Caregivers also served in the role of an advocate by voicing the person's wishes when they are unable to do so. The family role transition from adult child, spouse, or sibling to interpreter and advocate also has implications for adaptation in bereavement, including significantly increased risk for mental health problems (Moriarty et al., 2015).

At its best, quality provider communication is far more than information dissemination and affords an important opportunity for caregivers to prepare for the death of a family member while also facilitating the transition to bereavement. Support for family caregivers who are commonly seen as "hidden patients" is a key element of palliative care, yet caregivers often receive unsystematic and incomplete support (Hudson et al., 2015; Veloso & Tripodoro, 2016). Study participants who felt emotionally prepared spoke about how healthcare providers supported wayfinding in the form of

prognostication and descriptions of the signs of an approaching death. However, for some, this information was not sufficient to prepare them for death when it occurred and resulted in an experience of cognitive dissonance. Notably, many reflected that there is no way to ever be ready for a death.

Emotional preparation for a family member's death underscores the strong and essential continuum of end-of-life care which has been found to involve: (1) accepting reality; (2) knowing death is near; (3) getting your "house in order"; (4) saying "what you need to say"; and (5) giving permission to die (Hovland-Scafe & Kramer, 2017), in addition to the transition to bereavement care that involves acknowledging and incorporating the reality of the loss. Caregivers who felt unprepared for a death have connected that experience to intense stress and been found to be at greater risk for mental health issues in bereavement (Moriarty et al., 2015). While the bereavement literature has begun to explore the associations between patients' end-of-life experiences and caregivers' subsequent risk for mental health issues, much more is yet to be discovered from bereaved caregivers' lived experiences (Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008; Teno et al., 2004; Wright et al., 2008). Encouraging advance care planning conversations and improving patients' quality of death appear to be promising possible interventions that may contribute to improved caregiver adaptation in bereavement (Garrido & Prigerson, 2014). Caregiver mental health before death (Boerner, Schulz, & Horowitz, 2004; Stroebe, Schut, & Stroebe, 2007) together with preparedness for the death (Hebert, Dang, & Schulz, 2006) and the perceived quality of the patient's life in the last week of life (Wright et al., 2008) have been associated with mental health issues in bereaved caregivers. Participants in this study illuminated the central connection between their experiences near the death of a family member and their varied perceptions; clearly, one size does not fit all.

Notably, the confluence of caregivers' comprehension of the progression of an illness, management of a dying person's transition from independence to dependence, and the ways that caregivers make meaning of the journey from end-of-life caregiving to bereavement aligns closely with Aaron Antonovsky's Sense of Coherence Theory (1979). Making sense of a loved one's serious illness and approaching death is one of the most stressful of all human experiences. The Sense of Coherence is a global orientation that reflects a person's capacity to respond to a stressful situation and the theory posits that people develop a narrative about illness through the relationship between the Manageability, Comprehensibility, and Meaningfulness of a situation (Antonovsky, 1979; Lindstrom & Eriksson, 2005). *Manageability* is the extent to which a person perceives that resources are at their disposal and are adequate to meet the demands posed by the stimuli that bombard

them. *Comprehensibility* refers to the extent to which they perceive the stimuli that confront them in internal and external environments as making cognitive sense in that the information is ordered, consistent, structured, and clear. *Meaningfulness* refers to the extent to which a person feels that life makes sense emotionally; they perceive problems and demands as worth investing energy in, committing and engaging with, and regarding as challenges rather than burdens. Together, this global orientation reflects a person's capacity to respond to stressful situations (Antonovsky, 1979; Lindstrom & Eriksson, 2005). The study's findings support the need for provider communication that attends to caregivers' comprehension of transitions on the trajectory of an illness, recognition of the needs that accompany care transitions, and the meaning that transcends family processes from the late stages of an advanced illness to bereavement (Milberg, Olsson, Jakobsson, Olsson, & Friedrichsen, 2008)

Limitations

While the findings presented in this paper extend knowledge on family-related roles and needs in palliative care, there are limitations to the study. The sample was purposively derived from one provider agency in Western New York, which may limit generalizability to other settings in which the meso- and macro-level context of provider communication and end-of-life care may vary. Yet, partnership with this agency ensured access to a sufficiently robust sample of bereaved caregivers willing to share the narrative experiences of their recent loss and grief. Further, the study sample was somewhat homogenous across demographic characteristics, particularly race/ethnicity and religion, although participants were generally representative of the hospice and palliative care population nationwide (NHPCO, 2018). This paper focused on data derived from a longitudinal study of 108 bereaved caregivers; mixed-methods were used in the collection and analysis of semi-structured interview data. The size of the study sample at Time 1 contributed to the authors' decision to limit quantitative analyses to descriptive statistics. However, the sample exceeded the size necessary to reach saturation in the analysis of qualitative results. This, coupled with the concurrent triangulation design, supported the rigor of the analysis.

Conclusion

Challenges with medical providers have pervaded caregivers' experiences when a family member is dying (Aoun, Kristjanson, Currow, & Hudson, 2005). Many challenges have been found to be grounded within current

health care systems (Chandran, Corbin, & Shillam, 2016). Social workers are most often tasked with being liaisons in facilitating participation and dialogue among patients, families, and providers. Accordingly, social workers are called on to provide context about the variation in human and family dynamics for interdisciplinary team members. The social work presence on a team affords opportunities for enhanced quality and effectiveness in both interactions and patient outcomes (Russell, 2015).

Consensus-derived competencies have been developed to direct generalist-level palliative social work in the United States, including improved training of social workers in end-of-life care using a curriculum framework and evaluation tools (Glajchen et al., 2018). Competencies include a focus on the connections among communication, emotional preparation, the end of life experience, and bereavement. Addressing structure and processes of care, social workers are expected to use best practices to communicate with other providers, patients, and families. Addressing the social aspects of care, social workers are expected to assess the amount of information that a patient and family are able to comprehend and communicate information in a clear and logical manner. Competent social work care at the end of life involves supporting the patient and family in participation in shared decision-making and educating patients and families about palliative care and hospice (Glajchen et al., 2018).

Recent concerted efforts have also yielded the development of important standards that guide social work education and practice in palliative care. Moreover, specific standards have been created that address communication, preparation, and bereavement. The Advanced Palliative Hospice Social Worker Certification handbook addresses death preparation and death with 10 specific competencies. Palliative hospice social workers are expected to assess and support patients with preparatory grief and the family/caregiver with anticipatory grief. In fulfilling these practice competencies, social workers are expected to support the family and caregivers at the time of death by providing education about options for care and signs and symptoms of impending death. Social workers advocate for the patient's after-death preference while balancing the patient's and family's preferences for place of death (Social Work Hospice & Palliative Care Network [SWHPN], 2018).

Provider communication to the family on a journey of serious illness creates a space for caregivers to understand family members' progression toward the end of life, especially when it may not be immediately obvious. Sensitivity about emotional preparation for the end of life, even when it is not imminent, is critically important to help caregivers navigate their family-related roles and needs in this life-changing transition.

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