

Research Article

Challenges and Strategies for Hospice Caregivers: A Qualitative Analysis

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Abstract

Purpose: Family caregivers of hospice patients are responsible for the day-to-day care of their loved ones during the final months of life. They are faced with numerous challenges. The purpose of this study was to understand the challenges and coping strategies used by hospice caregivers as they care for their family members.

Design: This study is a secondary analysis of data from an attention control group in a large randomized controlled trial testing a cognitive behavioral intervention with hospice caregivers.

Methods: Audiotaped interviews were coded with initial themes and combined into final categories of caregiving challenges and strategies for managing the hospice caregiving experience.

Results: Caregivers shared narratives discussing challenges that included their frustrations with patient care issues, emotional challenges, frustrations with various health care systems, financial problems, and personal health concerns. They also discussed coping strategies involving patient care, self-care, and emotional support. The coping techniques were both problem and emotion based.

Implications: There is a need for interventions that focus on strengthening both problem-based and emotional-based coping skills to improve the caregiving experience.

Keywords: Caregiving, Hospice, Qualitative methods, Coping, Challenges

Hospice is a service designed to help individuals live as comfortably as possible until they die. In the United States, hospice is provided to individuals with a life expectancy of less than 6 months; more than 1.6 million individuals were enrolled in 2014 ([National Hospice and Palliative Care Organization, 2015](#)). The [National Alliance for Caregiving \(2015\)](#) reports that unpaid family caregivers of all patients provide an average of over 20hr of care per week to their family member; administering medications (including opioid pain relievers), maintaining equipment, and assisting with activities of daily living. The caregiving tasks take a toll on family members

who worry about performing tasks safely ([Caregiving, 2015; Institute of Medicine, 2014](#)). Unlike traditional health care that focuses primarily on the patient, hospice supports the patient and their family as a unit of care, providing holistic care not only for the dying person but also for their family.

In the United States, hospice is primarily delivered in a patient's place of residence; it is designed to assist families in keeping the patient comfortable in their preferred setting until death. This is often made possible because family caregivers accept responsibility for providing day-to-day care during the final months of life. A family caregiver may

be a spouse or adult child, friend, or other individual who agrees to provide the care to the hospice patient.

Caregiving can precipitate adverse health effects that increase caregiver morbidity and mortality (Andrews, 2001; Bevans & Sternberf, 2012; Gaugler et al., 2005; Sherwood, Given, Doorenbos, & Given, 2004; Vedhara et al., 1999) including anxiety, depression, issues in social relationships, and physical symptoms (Given, Stommel, Given, Osuch, et al., 1993; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; McMillan, 2005; Pinguart & Sörensen, 2003; Stenberg, Ruland, & Miakowski, 2010; Toseland, Blanchard, & McCallion, 1995). Among older caregivers, the emotional distress of the expected loss of a friend or family member, the physical demands of caregiving, and the biological vulnerability of older age combine to increase the risk for health problems and early death (Doorenbos et al., 2007; Kim & Schultz, 2008; Vedhara et al., 1999).

Coping strategies to manage these negative effects are important. Some work has been done looking at ways caregivers manage the stress associated with caregiving. One study found that family caregivers of patients with cancer receiving hospice care found that keeping busy, thinking positively, and learning more about the problem were effective coping strategies. Talking the problem over with family and friends also was found to be an effective strategy (Steele & Fitch, 1996). Similarly, Cagle and colleagues (2011) looked at the preparedness of caregivers for their role and identified multiple sources of support including family, friends, neighbors, spiritual beliefs, education, information, and enhanced communication as essential for preparing and supporting caregivers (Cagle & Kovacs, 2011). However, many of the studies on coping have been retrospective studies, interviewing caregivers after the caregiving experience.

The purpose of this study was to better understand hospice caregivers' challenges and coping strategies associated with their caregiving role while they were actively providing care to their family member. To do so, we first explored the following research question: "What challenges are commonly faced by hospice family caregivers?" Next, we asked, "What strategies do hospice family caregivers employ to cope with these challenges?" Finally, to tie our findings to the broader field of stress and coping research, we asked, "Are the coping strategies used by hospice caregivers primarily problem-based or emotion based?" This study builds on existing research on caregiving stress and coping by focusing specifically on the end-of-life caregiving stage and by incorporating firsthand narratives of hospice caregivers while they are actively caregiving, rather than reflecting upon their caregiving experiences after becoming bereaved.

Conceptual Model

This study relies on the theoretical construct of resilience and coping in the interpretation of hospice caregiver narratives. Resilience is broadly defined as the capacity to recover from negative experiences (Lavretsky, 2014). Walsh (1998)

focuses on resilience as a characteristic of families, describing family resilience as inclusive of the ability to make meaning of adversity, have a positive outlook, engage spiritual resources, be flexible, draw on connections with each other and the community, and access adequate economic and social resources. Resilience has been found to be related to caregiver burden; as resilience increases, caregiver burden decreases (Scott, 2013). Caregiver resilience has been found to be bolstered by years of caregiving experience, the ability to distance oneself (both physically and emotionally) from stress, physical exercise, hobbies, support, religion, philosophical beliefs, and humor (Ross, Holliman, & Dixon, 2003). A clear relationship has been found between resilience and coping strategies (Fiori, Smith, & Antonucci, 2007; Kleinspehn-Ammerlahn, Kotter-Grühn, & Smith, 2008; Mayordomo-Rodriguez, Garcia-Masso, Sales-Galan, Melendez-Moral, & Serra-Ano, 2015).

In an effort to inform resilience, Lazarus and Folkman (1984) identified cognitive and behavioral efforts as components of resilience in managing overwhelming situations. Specifically, they identified two types of coping. The first involved behavioral actions to manage problems and was thus called problem-based coping. The second involved more cognitive responses for emotion-based coping, choosing a positive response to a negative situation. Understanding of the nature of challenges and coping type used by caregivers can help inform future interventions. Problem-based or emotion-based interventions in response to specific challenges faced by caregivers may help improve the quality of the caregiving experience. This study aims to address this gap by providing insight into the challenges and coping strategies of hospice caregivers.

Methods

This study is a secondary analysis of data from an attention control group in a large randomized controlled trial testing a cognitive behavioral intervention with hospice caregivers (Grant number R01NR012213). Data were collected from caregivers whose patients were enrolled in one of two large hospice programs in the U.S. Pacific Northwest. The study was approved by the University of Washington Institutional Review Board.

Upon consent, caregivers were randomly assigned to either an intervention group or an attention control group using a random number assignment protocol. The attention control group participants received "friendly" phone calls from research staff and were asked general questions regarding their caregiving experience (Table 1). Caregivers received a total of four phone calls, lasting between 15 and 30 min. The sample included all participants in the attention control group who were actively caring for a hospice patient. Those caregivers whose patient died while they were still completing the series of calls were not included, as we wanted to understand strategies of active caregivers rather than those who were bereaved.

Table 1. Attention Control Visit Script

Each visit lasts approximately 15–30 min.

It is OK to use small talk to break the ice (e.g., talk about the weather).

- Tell me more about you, your background.
- Would you like to tell me your story? How long have you been a caregiver for your loved one?
- What are some of the challenges or problems you face as a caregiver?/Are there things you are struggling with as a caregiver?
- Do you have family or friends who are helping you with this role?
- Are there any other things you want to talk about? I am here to listen.
- Anything you need to get off your chest?
- Are you making any plans for the summer/ the holidays/ [seasonal reference]?
- How did you (and your family) learn about _____'s illness?
- What led to your involvement with hospice?
- How does your family support your caregiving efforts?
- How would you describe your loved one's experience throughout this illness?
- If you could, what would you change about the way that doctors or nurses talked to you and your family?

Interactions with the research staff were audiotaped and reviewed by three members of the research team. Narratives relevant to the research questions were transcribed and coded. An initial coding frame was developed from studies identifying various caregiving challenges (Given et al., 1993; Haley et al., 2001; McMillan, 2005; McMillan & Mahon, 1994; Pinquart & Sörensen, 2003; Stenberg et al., 2010; Toseland et al., 1995). Two researchers coded 10 interviews together and developed joint definitions and a common coding perspective. Another 10 interviews were then coded separately by the coders and compared. Separate coding of the same interviews resulted in intercoder agreement of only 40% (calculated by dividing the number of coding agreements by the number of coding agreements and disagreements combined). Conflicting codes were compared and definitions were once again refined. A second set of 10 interviews were then coded separately and compared once again, resulting in 80% agreement. The remaining interviews were split between the two coders and coded separately.

The first author then reviewed all coding and sorted and combined codes to develop themes. We reached data saturation, as no new codes were identified in the final 25% of the sample. After the final themes from the narratives were outlined, a second-level coding analysis was done to identify problem-based and emotion-based strategies based on Lazarus and Folkman (1984).

The final themes were reviewed by all authors and agreed upon by the research team. Trustworthiness was established with prolonged engagement in the hospice agency by the research staff (4 years) who also served as coders, a detailed audit trail of analysis, and peer debriefing by the research team (Krefting, 1999).

Results

Table 2 summarizes the demographic variables for the sample. The sample included 52 caregivers who participated in a total of 205 phone calls (average of 3.9 of 4.0 per participant) for a total of nearly 58 hr. Each interview

Table 2. Characteristics of Caregivers and Patients ($n = 52$)

Characteristic	<i>n</i> (%)	
	Caregivers	Patients
Women	40 (76.9)	34 (65.4)
Age, mean (<i>SD</i>)	62.1 (14.1)	81.9 (14.4)
Race/ethnicity		
White, non-Hispanic	47 (90.4)	47 (90.4)
Asian	4 (7.7)	4 (7.7)
Multiracial	1 (1.9)	1 (1.9)
Relationship to patient		
Adult child	29 (55.8)	
Spouse or partner	13 (25.0)	
Other relative	10 (19.2)	
Employed	19 (36.5)	
Caregiving > 20 hr/wk	29 (55.8)	
Caregiving > 1 year	40 (76.9)	
Diagnosis		
Cancer		18 (34.6)
Dementia or related illness		11 (21.23)
Cardiovascular disease		9 (17.3)
Other		10 (19.2)
Unknown		4 (7.7)

averaged 33 min and ranged from 2 to 60 min. Caregivers were an average of 62 years old, primarily female (77%), white (90%), and were most often adult children of the patient (56%). The majority had been caregiving for more than 1 year. Patients were an average of 82 years old and predominately female (65%). A third of the patients had cancer diagnosis and nearly a fourth had a diagnosis of dementia or related disorder.

Table 3 summarized the codes as they were initially identified, the ending themes with their definitions, coping type, and an exemplar of the theme. The most common challenges were related to patient care (92%) and emotions (86%) for the caregivers. Challenges concerning social support (62%), financial issues (58%), health care system concerns (48%),

Table 3. Summary of Codes, Themes, Definitions and Exemplars Challenges to Caregiving (n = 52)

Theme	Codes	Definition	Coping type	Exemplar
Challenges				
Patient care challenges: 48 (92%) identified	Help needed; Patient pain/symptom issues; Patient safety	Challenges directly associated with caring for their patients		<i>I'm really fighting, I never really had a problem with bed sores ... and she's lost so much weight she must have lost 40 pounds, and her hips sticking out to an extent that every time I roll her onto her hip ... I told the nurse that I've got to find a way to fight these bed sores, I can't turn her any more than I already am.</i>
Caregiver emotions: 45 (86%) identified	Anger; Anxiety; Feeling unappreciated; Grief; Loneliness; Overwhelmed; Regret, guilt	Emotions articulated by caregivers		<i>You're tired all the time ... exhausted. You feel ... very alone ... you have no idea when it's going to be over, you have no idea how it's going to be over ... you can make no plans; and I would say with that not only can you not make plans for the future, because you don't know when your future is going to start again, often you can't make any plans for the day. Because I have no support and I don't really have any family that supports me ... something that really upset me My mom told people [family members] that I was struggling ... and yet nobody ever called me to see how I was doing. It was almost worse ... it was devastating; I felt like they all abandoned me.</i>
Social support: 32 (62%) identified	Family support; Lack of social support; Social support burden	Social support identified as a need or as a burden		<i>I get worried about ... how I'm going to live after [patient] dies and what's my health going to be like and I do live with some fear of not wanting to be ... wanting to have enough money to take care of my needs ...</i>
Financial: 30 (58%) identified	Financial	Challenges related to finances		<i>I still don't have a handle on [Hospice A] I did call them and I requested all the case notes but there never has been the one person to oversee her case, it's a different nurse all the time.</i>
Health care system: 25 (48%) identified	Experiences with various settings (hospitals, clinics, hospice, nursing homes) and physicians	Challenges encountered with various parts of the health care system		<i>I'm taking care of everything and that means changing her every two hours. I can't do it all night and I can't take care of people and then not sleep ...</i>
Caregiver health: 24 (46%) identified	Seeking medical care for themselves; Caregiver Medications; Caregiver Fatigue	Personal health concerns identified by caregivers		
Strategies for caregivers				
Patient care Strategies: 52 (100%) identified	Seeking help; Placement; Respite	Strategies used to assist in assuring their patient is safe and cared for when they have challenges doing it alone.	Problem-based	<i>I have (private caregiver) ... I feel like there's a plan in place if something goes wrong and I'm not as likely to do something wrong that could cause him harm. I realize I'm living with less stress...less adrenaline ... I'm getting a chance to slowly decompress.</i>
Self-care strategies: 45 (86%) identified	Time alone; Drawing on previous caregiving experience; Acceptance; Assertiveness; Awareness; Positive self talk; Social time; Exercise; Work	Strategies to take care of themselves so they can keep caregiving.	Both problem and emotion based	<i>I think about what my life will be like after this, which is also a good coping mechanism because when she passes, when she dies, I won't die and I have to remember that. This is not what she would want for me, she would not want me to lie down in a hole beside her and stop living.</i>
Emotional support strategies: 43 (83%) identified	Communication; Family; Friends; Support groups; Professional Counseling; Spirituality	Emotional support sought out or provided by friends, family or others to assist with the emotional demands of caregiving.	Both problem and emotion based	<i>... you learn a lot by going to the support groups or talking to people that are in the field. You learn a lot your self and it makes you thankful that our case isn't as bad as other people have it. You just appreciate the simple pleasures ... and you know it isn't going to get any better, you learn that over the time period ... it's a learning experience for the whole family really.</i>

and caregiver health (46%) followed. The most common coping strategy involved patient care, as all 52 caregivers (100%) shared strategies for obtaining assistance of some type. The second most common theme (reported by 86% of participants) involved self-care, namely ways participants managed their own needs while caregiving. Strategies to deal with the emotional and social challenges faced by caregivers were noted by 83% of caregivers.

The narratives regarding coping exhibited both problem-based and emotion-based strategies. Problem-based coping strategies addressed patient care challenges. Both problem-based and emotion-based strategies were used to manage caregiving emotions and self-care strategies.

Challenges for Caregivers

Patient Care Challenges

This theme was defined as any concern that was expressed related to the care of the patient. These included pain and symptom management issues, the need for additional caregiving assistance, and patient safety concerns. A daughter caring for her mother shared one example:

We're still working on the pain. For a couple of days and nights we had total control and this morning she woke up pretty uncomfortable so we're just going to have to readjust a few things.

Likewise, another daughter shared:

I finally got some friends to come in occasionally to spell me so I could go work out or do shopping. At some point in time I'm going to need some supplemental help and it's not going to be friends this time I'm going to have to hire some professional help.

Caregiver Emotional Challenges

Caregivers noted numerous emotions tied with their caregiving responsibility. These challenges are evidence to the emotional strain that accompanies the physical responsibility of caregiving. Emotions included anger, grief, being overwhelmed, and feeling unappreciated. A wife shared her realization in caring for her husband:

But the reality that this isn't going to get better, there's no light at the end of the tunnel on this one and those things all weigh heavy on a caregiver. And I don't know that everyone is mindful of that when they're caregiving.

Another example is a daughter caring for her mother who stated:

It's ok to be mad, it's ok to be angry about it, it's ok to feel angry about it, you're putting your life on hold for someone and it's ok to be mad about that ... your brain is going through something horrific ... the stress of it will do horrible, irrational things to you ... it'll pass, it's a good thing that you're doing ... it's ok if you can't do

it ... especially with women, there's a lot of guilt associated, shame and expectations and these society pressures that get attached to caregiving ... and I've got a lot of that ... you have to be an advocate and it's ok for you to start screaming at people there's no shame in that.

Social Support Challenges

While often thought of as helpful, social support can be burdensome. This theme noted both the need for additional social support, as well as the challenges and burdens sometimes found with social support. A wife and a daughter shared these examples:

They visit me less (friends and family) since he's been on hospice, which is a phenomenon you should look at. What it says is we're afraid of death. People on email write me a note and proclaim their friendship but they don't show up here.

In fact I had a friend from the church come over and visit yesterday and I kind of assumed she would only be here for a short time ... and she left about 5:30 ... and I was exhausted ... I was just amazed at how tired I was after just a visit and we were sitting the whole time just visiting. You know this is another area where you think in terms of not visiting too long for the sake of the person who has the health issues; a long visit can be exhausting for the caregiver as well.

Financial Challenges

Over half of the caregivers experienced financial challenges. These issues related to not only their current financial struggles involving the medical expenses or the loss of work but also the future concerns of lost income once their patient dies. A wife stated:

and I need to look at what I'm going to live on after Jim dies and there's no income I'm still employed except I've run out of vacation time which means my pay checks are all done ... I still have insurance coverage but when I run out of family medical leave, very soon, I will have to switch to COBRA which will be \$1200 month in addition to the \$9000 a month for the home

Health Care System Challenges

Nearly half of the caregivers identified frustrations and problems encountered with various parts of the health care system. These frustrations resulted from experiences with hospitals, nursing homes and hospice agencies, and communication with physicians and other health care providers. One son caring for his mother discussed:

The surgeon never warned her of the consequences of doing radiation in the surgical area. As a result she has a hole in her shoulder ... that will never heal. So that's part of my job is to replace the dressings on that everyday.

Caregivers Health Challenges

Although the smallest number of caregivers noted the effects of caregiving on their health (46%), it was still a very common problem as it was reported by nearly half of all participants. They noted the worsening of conditions because they could not attend to them, the need for medications, fatigue, or the toll of caregiving on their health. Fatigue was the most common complaint. One wife with children who was also caring for her husband noted:

Basically I probably have pneumonia. It's probably about the third or fourth time I've had it since he's gotten cancer because I can't rest or do anything ... I woke up Thursday and I was so ill ... he can't even get out of bed to watch the kids for a minute so I don't get a chance to lay down or anything and if I don't sleep well, so he called and asked (grandparent) to come for a little bit and she came like two hours thank God and I laid down. But it was awful... It was just one of those days where it's like I just want it to be over with.

Coping Strategies Used by Caregivers

Patient Caregiving Strategies

All caregivers discussed strategies to obtain assistance of some kind in caring for their patient. They identified ways to receive assistance from another person and ways to maintain patient safety. Problem-based strategies included hiring necessary respite and other assistance, getting help from family, changing residence for themselves and/or the patient, and placing the patient in a nursing facility or adult family home. These strategies were employed when caregivers became physically or emotionally exhausted and realized they could not provide the care alone. The narratives illustrate the extent of the challenges of caregiving as they discuss the physical toll of caregiving and the difficulty they had in asking for and accepting help from others. Whether they hired help, solicited family assistance, or made decisions to move or place a loved one in a nursing home, these strategies arose from necessity and often desperation.

One wife discussed how she and her husband decided to move in with their children in order to get additional help. Her story is but one example of the physical toll experienced by the caregiver. She stated,

We moved in here with the kids ... it just got to a point for me where it was just too hard. I felt very isolated with his condition deteriorating. I sort of needed more help, and my own health was deteriorating ... I really needed more help and more support.

Similarly, a wife shared how helpful it was to have her family help, noting they came to realize how difficult caregiving was, clearly validating her struggles. She reported,

It's a life changing experience ... my stepson came here and took care of his dad full time and finally got the

inside picture of how difficult it was ... he said, "wow, that's a lot." He realized that it was a 24/7 job.

Self-care Strategies

Caregivers were aware of the need to take care of themselves, so they could continue to take care of their patients. They employed both problem-based strategies such as exercise, as well as emotion-based strategies to reframe their stress and make it manageable. A daughter caring for her mother noted,

I've started exercising just within the last week, and all I'm doing is getting on my treadmill and watching Netflix, and I do feel better.

They exhibited emotional acceptance with an awareness of the reality they faced. An example of positive reframing was provided by a daughter who stated,

I guess there's a method to the madness. I just remain positive. I mean there are just days when it's like ... I've been kind of feeling like there's only so much I can do.

The following statement from a daughter summarized the feelings discussed by many participants:

I have no other choice because I can cry all my tears and I can throw all my hissy fits but it's not going to stop the process. And do I want to get in that deep an emotional pit before I really need to? It's going to get worse. It's not going to get better, it's going to get worse, and in my mind it's kind of stupid to cry all my tears ahead of time.

Emotional Support Strategies

Most of the caregivers also discussed both problem-based and emotion-based strategies to find support to manage the stress they were experiencing. Problem-based strategies most commonly involved getting support from friends and family, support groups, or use of professional counselors. Emotion-based strategies included the use of a spiritual faith or meditation. They shared how this support was not only valuable for them but also for the patient. Two participants stated,

My stepdaughter ... has been very supportive ... She's managed to find a way to come a lot. She's managed to work it out, and when she comes, she comes for the whole day and she talks to her dad and she gets out his yearbooks... and asks questions and all that sort of stuff.

While the use of support groups was not widely reported, those caregivers who attended them reported generally positive experiences. One participant explained,

I think that the support groups are probably the most important because I think, for me, going to the support

groups, I heard people sharing their information, their techniques ... [that] was probably the most helpful ... those groups are really good ... help you stay focused.

Finally, several caregivers noted their spirituality as a source of strength. One wife shared,

... read the bible ... be true to your faith, spend time in prayer, quiet time ... then you're able to keep caregiving.

Discussion

The caregivers in our study described similar challenges as those reported in previous studies. Narratives discussed emotions including anxiety, depression, stress, and relationship issues, all found in former research (Given et al., 1993; Haley et al., 2001; McMillan, 2005; Pinquart & Sörensen, 2003; Toseland et al., 1995). Additionally, caregivers reported adverse health effects documented in other studies. In regard to hospice specific caregiving studies, we found similar themes to the study by Cagle and Kovacs (2011) of caregiver preparedness and support. They found hospice caregivers reporting caregiving as an obligation, a series of personal sacrifices (including financial), and health care system disappointments. Their data differed in that they also identified some positive feelings toward caregiving with the sense of giving back and gratitude for hospice and positive social support.

Our data did not identify these positive themes but rather contributes to the evidence of social support as a burden (Wittenberg-Lyles, Washington, Demiris, Parker Oliver, & Shaunfield, 2013). While social support is generally perceived as helpful, it can also contribute to stress when visits become too long or require too much attention and energy. Frustrations with hospitals and nursing homes for hospice and palliative care providers have been documented (Beng, Guan, Jane, & Chin, 2014; Parker Oliver et al., 2014), but our study also found frustrations with physicians and hospice providers.

Our data also documented caregivers' coping strategies, often generated by their own creative problem-solving or emotion-based coping techniques. Although it is not uncommon to think about caregivers facing patient care challenges, their emotional challenges are often less obvious as the attention of medical providers, friends, and family is so often focused on the needs of their patients (Parker Oliver, 2013). The evidence that both problem-based and emotion-based strategies are being used suggests that comprehensive interventions should enhance both coping type skills.

There have been recent interventions focused on improving the caregiving experience. These studies have focused on developing specific interventions, such as problem solving or involvement in care planning, to teach caregivers coping skills to manage their experiences (Cagle et al., 2015; Demiris et al., 2012; McMillan & Small, 2007; Parker Oliver et al., 2010). Despite these few recent intervention studies, the emotional needs of individuals caring for dying

persons at home continue to receive too little attention. The National Institute of Nursing confirms this position and after a review of the state of the science suggested there are too few tested interventions that offer support to informal caregivers who are caring for dying patients (Aziz, Miller, & Curtis, 2012). These data can provide support for the building and testing of interventions to strengthen problem-solving and emotion-based strategies.

Synthesizing the existing research on family caregiving at end of life is challenging, particularly given the equivocal nature of findings on its outcomes. The existence of caregiving rewards, while often overlooked, does not negate the serious challenges faced by family caregivers. On the contrary, the promise shown by recent interventions, coupled with research indicating that positive caregiving outcomes are indeed possible, highlights the importance of providing support for caregivers and of understanding how they survive—perhaps thrive—in the face of significant stressors. Although our data did not uncover any narratives discussing the positive aspects of caregiving, interviews did not include questions specifically focused on positive experiences and perceptions.

Although data saturation was achieved, we cannot generalize to a broader or more diverse population from these data alone. Because this is secondary data collected for a larger trial, we are unable to connect specific challenges to specific coping strategies in these narratives. We also focused the study on the challenges and coping of caregiver's role. However, this pilot work presents significant data for consideration in the design of future interventions targeting hospice caregivers.

Implications for Practice and Research

The coping strategies employed by these participants are noteworthy and can serve as a guide for others who find themselves in this situation. Additionally, hospice programs can learn from these narratives and identify additional ways to recognize, validate, and share these ideas with others. These caregiver strategies are evidence of resilience, and they are all implemented as a result of caregivers facing significant challenges and burdens.

These data demonstrate a need for hospice staff to embrace the patient and their family and assist hospice caregivers in creating and implementing these and other coping strategies. Clearly caregivers are facing significant challenges and hospice staff should assure those challenges are a part of all comprehensive plans of care. Interventions to enhance both the problem-based and emotion-based coping skills would be beneficial for caregivers. Specifically, problem-based skills to address common patient care issues would be beneficial as nearly all participants noted them as challenges. Additionally, emotion-based techniques to manage the feelings associated with caregiving would be helpful. Consistent with Cagle and Kovacs' (2011) findings that caregivers are seeking additional information, it appears there is tremendous need for hospice staff to enhance their

communication and educational efforts regarding patient care issues.

These data inform not only practice but also research. Evidence on the effectiveness of practice interventions using problem-based and emotion-based solutions is needed. Interventions designed for specific challenges and the use of specific coping techniques to meet those challenges need further testing. Successful coping needs further exploration and attributes for caregivers with positive caregiving experiences need to be further understood and integrated into caregiving interventions. Additionally, our data demonstrate the need for tailored interventions as despite the common themes across a large group of caregivers, every participant had their own needs and preferences and faced unique circumstances. Further research into personalizing interventions in order to maximize their effectiveness and identifying these caregivers who will benefit mostly from an intervention will enable the translation of these research interventions into practice. The caregiving experience for those walking the end-of-life journey with their loved one can be improved with practice innovation and additional research.

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