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Reciprocal Suffering: Caregiver Concerns During Hospice Care

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Abstract

Context—For many hospice caregivers, the constancy and difficulty of caregiving impact their physical quality of life and cause depression, psychological distress, guilt, loneliness, and restrictions on social activities.

Objectives—Deviating from traditional unidimensional research on hospice caregivers, this study explored the transactional nature of reciprocal suffering by examining caregiver concerns through four dimensions: physical, psychological, social, and spiritual.

Methods—Researchers analyzed audiotapes of intervention discussions between hospice caregivers and research social workers.

Results—Results indicated that of the 125 pain talk utterances, the majority referenced psychological concern (49%), followed by physical (28%), social (22%), and spiritual (2%). Reflections on concerns revealed a global perspective of caregiving, which highlighted the patient's needs juxtaposed to the caregiver's recognized limitations.

Conclusion—By examining the reciprocal nature of suffering for caregivers, this study reinforced the need for assessing caregivers in hospice care, with specific emphasis on the importance of providing caregiver education on pain management.

Keywords

Caregiver; pain management; hospice; suffering; caregiver burden; caregiver quality of life

Introduction

The majority of hospice care in the U.S. is provided in the patient's home, leaving direct care needs in the hands of informal caregivers who are often family members or friends of the patient (1). With little or no formal training, caregivers are responsible for knowing when to contact hospice for assistance with patient care and are expected to administer medications under the direction of hospice staff, who typically provide these directions over

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the phone (2,3). Ensuring pain control becomes an important task that impacts the quality of life for both the patient and their informal caregiver (4). If the caregiver fails, the patient suffers (5). The reciprocity of this role is influenced by perceived patient suffering (6) and establishes informal caregivers as “second order patients” with their own care needs (7). The goal of this study is to understand reciprocal suffering that emerges during hospice caregiving.

For both the hospice patient and informal caregiver, there is the intrapersonal concern of coping with the suffering of self, and the interpersonal concern of coping with the suffering of the other during hospice care (8). Based on the concept of total patient pain as articulated by Dame Cicely Saunders, the founder of the modern hospice movement (9), reciprocal suffering is the combined physical, social, spiritual, and psychological distress among informal caregivers of hospice patients. The rewards of caring for a terminally ill relative can simultaneously produce profound psychological effects, increase anxiety and depression, cause deterioration in other relationships, and suppress professional roles and involvement in personally-fulfilling and healthy activities (10,11). Anxiety, fear, and the search for meaning can be distinct from pain and represent the suffering that can accompany a shared illness experience with a terminal patient (12).

Prior research has established that caregiver burden and patient symptom distress are related (5). The more demanding the caregiver’s responsibilities, the greater the amount of emotional stress and suffering the caregiver experiences (13). The caregiver’s ability to effectively relieve symptoms with pharmacological interventions requires the successful use of skills related to teamwork, organization, symptom knowledge, medication knowledge, and personhood (understanding and responding to the patient’s needs) (2). Anxiety often results for informal caregivers who struggle with these skills and who observe their loved ones suffering from physical pain (4). In one study of hospice caregivers, 80% had witnessed the patient in severe pain and 30% had mistakenly thought the patient had died (14).

While the reciprocal nature of the patient-caregiver role is evident, the majority of hospice caregiver research has been unidimensional, focusing on issues isolated with the caregiver and neglecting the transactional influence of the patient. Although hospice patients are comprehensively assessed for physical, spiritual, emotional, and psychological pain, little is known about how caregivers are reciprocally impacted. The goal of this study was to capture reciprocal suffering that emerges during the caregiving role. Specifically, this study sought to explore: 1) What types of concerns do hospice caregivers identify? and 2) In what ways are hospice caregivers’ concerns reflected in discussions of the caregiving experience?

Methods

This paper draws from a larger pilot equivalency clinical trial funded by the National Institute of Nursing Research (R21 NR010744-01). The larger project aims to demonstrate the feasibility of delivering a problem-solving intervention framework called ADAPT (Attitude, Define, Alternatives, Predict, Try) via videophone technology and comparing this delivery to face-to-face delivery of the same intervention (15–17). The intervention is designed to help caregivers be effective in solving problems pertaining to the caregiving experience by 1) creatively dealing with obstacles, 2) optimistically and realistically involving their patients in the process, 3) developing a plan, and 4) making use of expert information. Hospice patients and their caregivers were randomly assigned to receive the problem-solving intervention either face-to-face (intervention group 1) or via videophone (intervention group 2). The project presented here explores audiotaped discussions of the problem-solving intervention between hospice caregivers and research social workers in

both face-to-face encounters and videophone calls. Data analyzed for this study consist of both control and intervention groups; differences between the two mediums were not explored, as caregiver talk about caregiving was the focal point for the study. The study was approved by the University of Washington Institutional Review Board.

Setting

Data were collected from consenting hospice caregivers in one urban hospice program in the Western U.S. The program is Medicare and Medicaid certified. In 2007, the average daily census for home hospice was 510 and the average length of stay for the program was 65.2 days.

Participants

Participants were hospice caregivers. Caregivers enrolled in the study had to be 18 years or older, have access to a standard phone line, without functional hearing loss, no or only mild cognitive impairment, and at least a sixth-grade education. The study data for the project presented here were collected between February 2009 and July 2009.

Procedure

Upon admission to hospice, caregivers were presented with the research opportunity by hospice staff. Contact information for caregivers interested in learning more about the study, and who fulfilled eligibility criteria, was sent to the research coordinator. The research coordinator visited the caregiver and obtained informed consent. Caregivers were asked to prioritize common concerns using a checklist (see Appendix). Additionally, in order to individualize the intervention material, caregivers were allowed to define problems not included in the list. Finally, the research coordinator tentatively scheduled three upcoming visits (face-to-face or via videophone depending on group assignment). Each of the three visits/video-calls focused on one of the caregiver's concerns as previously identified on the concern list. During the first visit/video-call, the researcher worked on steps one and two of the ADAPT model, the second visit covered steps three and four, and the third visit focused on the last step, which involved trying out a solution and determining if it works. All of these discussions were audiotaped and serve as the corpus of data for this study.

Data Analysis

Qualitative data analysis software, Nvivo 8 (QSR International, Cambridge, MA), was used to analyze intervention discussions between caregivers and research social workers. A member of the research team (SB) listened to the audiotapes and transcribed caregivers' concerns by pain talk within the interaction. Pain talk is defined in this study as any utterance that pertains to the patient or caregiver's concern based on Saunderson's concept of total pain (physical, spiritual, psychological, and social) (18). This coding scheme has been used in prior studies (19). An a priori coding scheme centering on these four aspects of pain was used to code the data. Two members of the research team individually coded 20% of the data into one of the four categories. Inter-coder reliability was compared and was above 0.85 on all categories. The transcripts were then jointly reviewed to determine differences and the two coders derived strict coding criteria and then one researcher coded the remaining data set. Once data were categorized by concern type (physical, spiritual, psychological, or social), the research team used a constant comparative method to discern themes from within the categories.

Results

Audio recordings of 85 intervention discussions were captured for 30 hospice caregivers. Demographics for both patients and caregivers are summarized in Table 1. The mean age of patients was 84 years, whereas the mean age of caregivers was 62 years. The majority of patients (87%) did not have a cancer diagnosis. An overwhelming majority of caregivers were women (77%); however, patients were more evenly split, as 57% were female and 43% were male. More than half of the caregivers were educated, with 20% having a two-year college degree, 37% with a four-year college degree, and 17% with a master's degree. The majority of caregivers were adult children of the patient (43%) and one-third of caregivers were the spouse/partner of the patient (30%).

The number of intervention discussions for an individual caregiver ranged from 1 to 3. Four caregivers in this sample did not complete the intervention because of the death of the patient. Of the 85 discussions, 29 (34%) did not consist of caregiver pain talk (i.e., concern regarding physical, spiritual, psychological, or social issues). In the remaining 56 intervention discussions, a total of 125 pain talk utterances were coded. Caregivers predominantly discussed problems emerging from psychological concerns (49%), followed by physical concerns (28%) and social concerns (22%); few caregivers discussed spiritual concerns (1%). The infrequency of spiritual concerns is predominantly because of the absence of spiritual concern on the checklist originally presented to caregivers as part of the intervention.

Thematic analysis of the data focused on the second research question related to the caregiver's concern and the caregiving experience. Psychological concern was manifested by recognition of the volume of responsibility, a contrasting desire for care responsibilities to end, acceptance of hospice, and fear. When talking about physical concerns, caregivers overwhelmingly focused on experiencing the patient's physical pain and only three of 35 coded references on physical concern included direct discussion about the caregiver's own physical pain. Next, social concerns centered around the demands of caregiving that limited social activity, and the absence of a social network and open communication. Finally, spiritual concerns were only mentioned once by two caregivers. Table 2 summarizes the concern type and themes. Themes within each concern type are described below. Although themes are presented by frequency, frequency rates are based on the small sample size in this study and do not take into account the magnitude of emotion associated with some concerns.

Psychological Concerns

The Heaviness of Caregiving—Caregivers described being overwhelmed by caregiving tasks and depicted psychological concerns with a comprehensive portrait of the caregiving role. In problematizing their role, caregivers emphasized the stress of caregiving as a whole rather than focusing on specific nuanced tasks. The pressure of managing their loved one's care revealed the heaviness of patient dependency. One caregiver explained, "This has been the most stressful, and the most painful, and the most... dealing with her and everything related to her that I've had to deal with... than anything I've ever encountered."

Caregiver burden also was depicted as a catalyst for psychological concern that emerged from emotional burnout. Tasks and responsibilities were highlighted as main concerns, leaving little effort and energy expended towards emotional care. Several caregivers talked about being challenged by their patients, specifically about the consistent expression of love during caregiving. However, caregivers described these patient needs as cumbersome given the plethora of tasks to manage. When asked by her father if she cared about him, a caregiver recalls saying to the patient:

What? Of course I care about you, but I only have so much to give... (crying)... it's pressure I guess... and I just put other thoughts there with my job plus caregiving, I'm way overtaxed. Now I have to add these feelings and there's an extra thing to solve and I can't do more.

To manage this request, the patient's feelings were compartmentalized as an additional caregiving task. Managing these emotions is compounded when the caregiver has traditionally relied on the patient for emotional assistance; as one woman caring for her mother explains: "I told my therapist at one point, I said you know, I need my mother to help me deal with my mother, but she's not there."

Desire for the End—The struggle to provide care and at the same time desire the patient's death produced psychological concern. Such dissonant feelings materialized as guilt and caregivers described being aware of these feelings yet did not know how to manage these thoughts. A caregiver explains:

I don't see the end of the tunnel. I don't see the clear end of the end of the tunnel... I have a very hard time with that, because it's already a year and half. And that's terrible when I say it that way, when I say that... It makes me sound like I'm a terrible.... I'm awful wanting it to end. I don't want him to die, but I'm thinking about myself, too. How much longer can I cope with this?

The difficulty of simultaneously providing self-care and hospice care at home for a loved one was an obvious struggle; this struggle was depicted as a conscious understanding that their own care could once again be prioritized when the patient died. This challenge was exacerbated in situations where the caregiver felt obligated to provide care, as one woman confided:

I'm not proud of it, but I'm now honest about it. I'm very resentful of all this. I did not ask for this, and I don't want it. And I have no alternative, so I just have to understand it is temporary. And that life will not always be like this, and that I need to try to make the best of what I can. He probably did the best he could. But that's just how it is.

Psychological distress for this caregiver emerged from the awareness that she doesn't want to provide care, but does anyway. Caregiving becomes an awkward social responsibility heavily influenced by the relational history between the two family members.

Accepting Hospice Care—Caregivers also described the emotional difficulty of moving from curative treatment to hospice care. A limited understanding of the concept was expressed by several caregivers who struggled to recognize the difference between the two approaches. As one caregiver recalls, the transition between the two types of care was not clearly understood:

One of the things... I ended up being very confused about my dad's medication program because they took away the (inaudible, name of medication), but they didn't take away everything, and I didn't understand why. I didn't understand why last week he couldn't have certain things to eat or drink, and this week now he can have anything he wants anytime he wants it. It seems like to me that it may exacerbate his condition. Maybe it wouldn't matter or not, I don't know, but I didn't understand that.

This lack of understanding caused her further anxiety about her father's care, and the transition to full responsibility in the home and under her supervision left her feeling confused about her role. Additionally, several caregivers talked about problems with hospice

care, highlighting high staff turn-over and poor communication between themselves and the hospice team.

Fear of the Future—Caregivers did not express worry or concern over the upcoming death event of their loved one and instead were distressed about impending grief and bereavement. They explained that they were psychologically prepared for their loved one's death yet worried about what their life would be like afterwards. Thinking about the bereavement period caused incredible anxiety, as one caregiver describes:

I get very fearful. Fear sets in and then I'm [a] mess and then I have to really talk to myself, and I have to pray to God and ask him to take the fear away. And then I'm ok for a little bit and then it comes back again and that's why I've been so upset for the past couple of weeks...really upset because of that, because I worry about that... because when he does die, am I going to be able to enjoy myself then? What's it gonna do to me?

The anticipation of what life will be like without their loved one provoked anxiety, angst, and nervousness during hospice caregiving. These feelings left caregivers even more uneasy when the death event was expected and didn't come, leaving caregivers saying heartfelt good-byes several times. Described by one caregiver as an emotional roller coaster, she adds, "I don't know if we have him for another day, a week, or a month, and that is starting to get weird, because I had said goodbye as well. So that is very tumultuous right now."

Physical Concerns

Caregiver concerns about patient's physical pain centered on patient care and were characterized by the caregiver's role in pain and symptom management and the subsequent experience of witnessing the patient's physical changes. Challenges to patient pain management included apprehension over giving too much or too little of prescribed pain medicines. Apprehension gave way to uneasiness as one caregiver describes the ubiquitous balancing act that often accompanies facilitating pain management:

Right now, we're trying to balance it [constipation] and that's the problem. I talked to (inaudible) about this, and my concerns were that she had gone four days, and now we're trying to address it with a number of constipation pills, so we didn't create a major problem. So it's a real balancing act.....So it's not only a mind game. You can hurt her by making the right [sic] decision.

Although caregivers did discuss and synthesize issues surrounding the patient's physical pain, there was little discussion about caregivers' own physical pain.

Bearing witness to physical changes as their loved one declined also was difficult for caregivers. A wife describes her husband's condition: "His breathing has just been very, very problematic. He's just gasping for air. It must be awful. He's suffocating to death." Caregivers shared that observing these changes were difficult, but also contributed to their understanding of the process. One caregiver's account of her mother depicts this difficult bystander role:

I think she did have another stroke. She was sitting on the toilet and all of a sudden, her head just went down, and she was unconscious. I would lift her head and would call "Mama, Mama." At one point, I thought she was gone. Her eyes, when they opened, they kind of rolled back up, and I thought... Then she began to drool a little bit, and gurgling, horrible gurgling in her throat. The nurse said "I'm sure it was another little stroke."

These difficult events also included active participation in their loved one's decline, as one caregiver explained the difficulty of observing and participating:

So it's her confusion, I think, that's a challenge for me... it's trying to play along and not making her anymore anxious... Last night she wanted to know... she felt I needed to get a hold of her brother. Well, he died two years ago.

In their role of managing the patient's physical pain, caregivers experience anxiety over the administration of medication and anguish over shared experiences of physical decline.

Social Concerns

Many caregivers expressed concerns about the impact the situation had on their interpersonal relationships and opportunities for social activities. Several caregivers described experiences wherein family and friends would enter and re-enter the picture, which usually created more stress for the caregiver rather than providing relief. A caregiver's devotion of large amounts of time and resources to a hospice patient often had undesirable effects on the caregiver's social relationships and well-being. One participant described the constant demands involved with keeping several other people aware of the patient's status:

I think that's probably still it, because any issue, any problem that comes up with my grandma triggers me linking to like four different people and informing them and getting their feedback. And then talking them through their processing of whatever I'm telling them. I find that burdensome.

This caregiver, like several others in the study, expressed frustration with the amount of time and/or resources her caregiving tasks required. Likewise, when caregivers do find time to do things outside of their caregiving duties, they often feel limited or anxious to return to the patient's side. One caregiver explained how these demands made her feel as if her own life was on hold: "I think that identifies an inability to leave and go do things, and it... the need to do something quick and hurry back. The constancy of that care and limiting social activities as well as tasks."

For many caregivers, this problem of social limitation is compounded by the fact that they are the only ones taking care of the hospice patient. In other words, many caregivers have few or no family members or friends with whom to share tasks and responsibilities. For example, the daughter-in-law and primary caregiver of one patient confides that her husband's family has left her with the care responsibilities:

The fact is, number one, is that they're completely non-existent. They will not help. They will not help! At all! Unless you pay them! They are so stupid (whispering). No, they really are. They're not on the same planet as most people are!

Many caregivers expressed the desire for more involvement from others in the form of support for the caregiver and/or the hospice patient. Meanwhile, other caregivers reported experiences wherein family members were involved and attempted to provide support, but on a temporary and fleeting basis. For example, one participant described how family members rallied around the patient when death seemed imminent, but did not continue their support after the patient received more hospice care:

I feel his kids... at least one of them has [abandoned me], and his wife I do... And they all came around when they knew it was almost a sure thing that he was really gonna die, but now it's been going on so long that it's like he's ok. They just don't come around that much, except one son does. This morning I noticed that the layperson that brings over communion hasn't been around for a long time now, so I guess I have to call him. See? As it gets to be old, so to speak — it's probably a

terrible way to put it — people fade away. They only react when it's right there, and it's almost like a duty. “Come, oh my gosh, they're dying, I need to get over there.”

Although caregivers experience varying degrees of concern in regard to the social aspects of their lives, many found it challenging to maintain the same level of social activity and involvement as they did prior to providing care for the hospice patient. And while many caregivers receive support from others — whether consistent or temporary — some feel isolated from and abandoned by family, friends, and/or their own social identities.

Spiritual Concerns

Although spiritual concern was present, it was the type of concern expressed least often by caregivers. The intervention checklist utilized in this study to prompt caregivers to talk about their concerns did not include spiritual concerns. Still, two participants described an experience in terms of a spiritual challenge or struggle. One participant described dealing with the uncertainty involved with spirituality, death, and the patient's belief in an afterlife:

I said, “For the first time in your life will you please tell me... answer the question.” So he said, “Yeah, I'm afraid.” I said, “Of what? Are you afraid of dying?” He said no, but I don't believe that either anymore. He said, “I've got to do everything I can to save my soul.” So I said that do you think that stopping your medications is not going to save your soul? He said yes.

Although several participants discussed their spiritual beliefs as a means of comfort and reassurance, others approached them with uncertainty and fear for what may exist after death. This spiritual concern, while expressed only a couple of times, remained an important emotion for the caregivers who experienced it.

Discussion

This study explored how a patient's pain may lead to distress and suffering for the caregiver. The first research question explored the varying types of concerns that were identified as problematic by hospice caregivers. The overwhelming majority of caregiver concerns were psychological, which confirms the dearth of research on caregiver burden and also suggests that care for these “second order patients” should begin with interventions that target these psychological needs. This category accounted for almost half of all caregiver concerns and identifies an important need for the care of hospice caregivers.

The second most prevalent concern was the patient's physical pain. Just as hospice nurses primarily focus on patient pain management (20), caregivers also were preoccupied with this role. Prioritizing patient care over self-care is a consistent theme among caregivers, and physical quality of life for caregivers has been found to be lowest near hospice admission (21). In this study, only three of 125 caregiver references included talked about their own physical pain, indicating that the reciprocal nature of physical pain between patient and caregiver is characterized by the relationship between the patient's physical pain and its psychological impact on the caregiver. Although the caregiver's own physical concern may be due to tasks related to the caregiving role, it was not discussed as a problem that emerged between patient and caregiver.

Almost equal to physical concerns, caregivers discussed the lack of social support when the demands for time and resources were high. Caregivers in this study addressed issues previously identified in other research, specifically that logistics, lack of financial skills/support and other restrictions related to transportation needs inhibit caregiver resources (22). Finally, spiritual concern was rarely identified as a problematic aspect of caregiving and suggests that these concerns are only shared when caregivers are prompted.

Interestingly, one-third of the discussions in the data set did not identify problems related to any one of the four concerns, which are based on total pain types. This finding suggests that hospice agencies may be meeting the needs of caregivers. Several caregivers described their caregiving duties as well-managed and under control, causing little or no distress for the caregivers. Moreover, when asked to identify if and how their caregiving roles challenged them, some caregivers described every element of their duties as expected, and, therefore, not significantly painful or stressful.

The second research question focused on concerns within the caregiving experience. Psychological concern highlighted the caregiver's reciprocal role in the dying process, illustrating that the magnitude and scope of their role includes relational maintenance. Most evident was the approach and perspective of the emotional work of caregiving, which caregivers felt exacerbated psychological well-being. Emotional exhaustion influences the caregiver's ability to speak openly with the patient about illness and death (6) and caregivers shared that relational maintenance was yet another task to complete. One of the goals of hospice care is to afford patients and families more time to communicate with loved ones, yet findings in this study suggest that overwhelmed caregivers do not always capitalize on these opportunities. Rather, the performance of caregiving takes the place of open communication when open communication should be affording time for the caregiving role. More research is needed to understand the perceived barriers between patients and caregivers that inhibit relational maintenance strategies during hospice care.

Not surprisingly, physical concerns were central to the caregiver's role in providing patient pain management. The need for education regarding patient pain management was reinforced by caregivers in this study (19). The need for understanding the dying process highlights the reciprocal nature of suffering that takes place between patients and caregivers (23). Patients are often more concerned about the suffering of their family members than their own suffering (7). Suffering can emerge for family caregivers when they experience a loss of control, such as when they are not confident that they are managing pain properly, in forecasting the sense of loss when their loved one passes, and in recognizing their own mortality as they bear witness to their loved one's declining health (23). Findings from this study reveal the caregiver's perplexing situation of providing medication while simultaneously observing the body fail. The reciprocity of this role requires education to understand what is normal and natural versus what is controllable.

Finally, limited resources and lack of support prompt caregiver realization about the quandary of the caregiving role; that is, they recognize that the provision of hospice care to their loved one is both the problem and solution. Some caregivers react to their feelings of loneliness and knowledge of impending death by self-alienation or pulling away from loved ones (24). For many caregivers, ignoring the problem was the solution.

Limitations

This study represents only one hospice program with an urban population and an almost exclusively Caucasian sample. These limitations are currently being addressed by the larger randomized trial, which will accrue an expanded and more diverse subject pool. Thus, no generalizations can be made about hospice caregiver's experiences in general, but the study does lend insight to opportunities for further research.

Implications

Despite limitations, the study extends prior research on caregiver burden and quality of life to reveal the needs of caregivers in relation to their patients. Overall, these findings bolster

prior arguments that caregivers are “second order patients” who require care (7,17,25). This study points to specific aspects of care that would benefit hospice caregivers.

First, caregivers’ psychological concerns demonstrate the need for emotional care to occur between patients and caregivers. Providing emotional care and support to caregivers can help them make best use of the time left with patients. Data in this study show that caregivers receive requests from patients for open communication, suggesting that patients want to sustain quality relationships with their caregivers, yet caregivers reported that they are not always able to reciprocate because of caregiving demands. Hospice staff should encourage emotional care for patients by helping caregivers address relationship issues, particularly because they may impact their role in providing pain management.

Second, caregivers need patient pain management education (19). Caregivers are an extension of patient care, often providing hospice staff with patient pain measurements. However, research has shown that caregivers overestimate pain symptom intensity and cannot reliably provide patient symptom intensity (26). Moreover, caregivers’ inappropriate knowledge and fears about pain management are often worse than patients (27). While issues of adequate pain management for the patient are the focus of the hospice team, there also is a need to recognize the impact of patient suffering on caregivers. This study notes the duality of the caregiver’s position as caretaker while at the same time watching their loved one’s body decline. The hospice team can use this opportunity to educate caregivers about differences in patient status caused by natural disease progression and the side effects of pain medication (19). Increased understanding about pain medication practices and the dying process can reduce anxiety associated with the caregiver’s role in providing pain management.

Finally, the lack of spiritual concerns in this study was, in large part, because of the absence of spiritual concerns on the checklist. Caregivers might not have discussed these concerns because the interventionist did not ask about them. This finding highlights the unique role that chaplaincy plays in hospice care and reinforces the interdisciplinary team-based approach used in hospice. Overall, this study bolsters hospice ideology regarding the physical, psychological, social, and spiritual dimensions of dying and the subsequent need for an interdisciplinary team to provide care for patients. Findings presented here point to the immediate need for hospice staff to focus on caregivers in order to provide quality care and help to patients.

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Appendix

Problem/Concern Checklist

- Concern about Pain
- Concern about Shortness of Breath
- Concern about Constipation
- Communication with Patient
- Communication with Health Care Providers
- Concern about Mental Confusion
- Concern about Seizures
- Need for Respite Care or extra help
- Help during Final Weeks
- Concern what to do before and after Death
- Grief
- Financial concerns
- Anxiety
- Fatigue
- Depression
- Other _____

Table 1

Summary Demographic Variables for Patients and Caregivers

Variable	Caregiver	Patient
Diagnosis	Not applicable	
Cancer		13% (4)
No Cancer		87 % (26)
Mean Age	62 years (range 45–83)	84 years (range 51–104)
Sex		
Female	77 % (23)	57% (17)
Male	23% (7)	43% (13)
Marital Status		
Never married	7% (2)	0
Widowed	3% (1)	57% (17)
Divorced	13% (4)	3% (1)
Married	77% (23)	40% (12)
Race		
White/Caucasian	97% (29)	97% (29)
Black/African American	3% (1)	3% (1)
Education		Not captured
Less than high school	3% (1)	
High school	10% (3)	
Some college	13% (4)	
2-year college degree	20% (6)	
4-year college degree	37% (11)	
Master's degree	17% (5)	
Relationship to patient		
Spouse/partner	30% (9)	
Adult child	43% (13)	
Sibling	3% (1)	
Other	7% (2)	
Unknown	17% (5)	
Resides with patient		
Yes	40% (12)	
No	43% (13)	
Unknown	17% (5)	

Table 2

Themes by Concern Type

Concern	n (%)	Themes	Examples
Psychological	61 (49%)	Heaviness of caregiving	"This has been the most stressful, and the most painful... dealing with her and everything related to her that I've had to deal with, than anything I've ever encountered."
		Desire for the end	"I think if she passed away this week, I think I would kind of say, ok, it was time. I think. Or I would say, oh my gosh, I wasted all this time wishing it was over, and now it is, and I want it back. So it makes you crazy."
		Accepting hospice care	"My mother, I would say the critical thing was whether to put her into hospice or not, because there you're really sort of deciding that there's certain cares you're not going to have done. So... that's hard to rationalize that one."
		Fear of the future	"The question's going to be, when [patient] actually dies, what is the impact going to be on the boys? And how are they going to handle it? And how do I respond to how they handle it? And I don't know. I don't know."
Physical	35 (28%)	Apprehension regarding pain management	"We had another morphine bottle... and I didn't want to give her too much or too little."
		Difficulty observing patient suffering	"I worry about him being in pain. I don't know... that he's capable or that he will really voice how he feels."
Social	27 (22%)	Demands on time and resources	"It's hard to be out and about because I feel like I have to hurry back home. So my focus is all to get back here."
		Lack of support	"I haven't talked to someone in the family or my friends because they're not in the same situation like I am in caring for my mother. "
Spiritual	2(1%)	Existential uncertainty	"That's when he was so angry and not knowing what to do so he wanted to see the priest. So the doctor called and talked to him... But I think you need to talk to your priest first because that's what you want to do."