

What Questions do Family Caregivers want to Discuss with Health Care Providers in Order to Prepare for the Death of a Loved One? An Ethnographic Study of Caregivers of Patients at End of Life

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ABSTRACT

Objectives: To determine what questions family caregivers want to discuss with health care providers (HCPs) in order to prepare for the death of a loved one.

Methods: Ethnographic interviews and focus groups were used to collect data from current and bereaved caregivers ($n = 33$) of terminally ill patients. Caregivers were asked about: (1) the questions they believe are important to discuss with HCPs in order to prepare for the death, (2) which questions they asked HCPs, and (3) which questions they did not discuss with HCPs. Interviews were audiotaped, transcribed, and analyzed using standard methods.

Results: Caregivers had a wide spectrum of questions that were categorized as medical, practical, psychosocial, or religious/spiritual in nature. Although caregivers felt comfortable asking most questions, many were not discussed with HCPs, particularly questions about what dying “looked like,” medical errors, funeral arrangements, family disagreements, the meaning of illness, and the afterlife. The uncertainty associated with unanswered questions could, in turn, cause distress, even after the death. The primary barriers to asking questions were feeling overwhelmed, “not knowing what to ask,” the perception that HCPs were untrustworthy, and worries about being perceived as “ignorant.”

Conclusions: Family caregivers of patients with terminal illness need more than prognostic information in order to prepare for the death. HCPs should be aware that caregivers may not ask important questions and that unanswered questions may contribute to caregiver distress. Awareness of caregivers’ questions can help HCPs improve the care provided to caregivers by better preparing them for the death of their loved one.

INTRODUCTION

APPROXIMATELY 70% of the 2.4 million deaths a year in the United States result from chronic diseases.¹ Because these conditions often compromise the ability of individuals to function independently, deaths

are typically preceded by family involvement in caregiving.² Not surprisingly, caregivers have numerous questions pertaining to the care of their loved one³ As the illness progresses, caregivers’ often have questions about death and dying.^{4–6} These topics, however, are rarely discussed with health care providers (HCPs).^{7–9}

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For example, in one study of caregivers of patients enrolled in hospice, 40% were never provided with information about life expectancy and 21% were never told that the illness could not be cured.¹⁰ As a result, as many as 20%–25% of bereaved caregivers say they were unprepared for the death.^{11–13}

The objective of this study, therefore, was to determine what questions caregivers believe are important to discuss with HCPs in order to prepare for the death of a loved one.

METHODS

Study design

Ethnographic interviews and focus groups were used for data collection because these methods are well suited for exploratory studies about death and dying.^{14,15}

Sample and recruitment

We chose a purposeful sampling strategy, or one expected to provide in-depth information.¹⁶ We recruited current caregivers to provide insight on the questions relevant to people actively providing care and bereaved caregivers to talk about questions they wish they would have discussed before the death. We oversampled African Americans because we wanted a racially diverse group. Current caregivers were English-speaking adults providing care to a patient with a life expectancy of less than 6 months. Bereaved caregivers were English-speaking adults whose family member was deceased for less than a year. Caregivers were recruited from an inpatient palliative care consult service and a community-based hospice in western Pennsylvania. We recruited from both settings because the consult service also sees patients who are receiving care with life-prolonging intent. Recruiting from both settings allowed us to collect data from caregivers who may have different questions.

Data collection

Focus groups ideally contain six to eight participants.¹⁷ However, cancellations reduced our two groups to only three and five participants. Because caregivers commented on the emotional difficulty of participating in an interview at the hospital where their loved one died, the format was changed to ethnographic interviews held at a location of the caregivers' preference. Some patients had more than one caregiver so one or two caregivers were interviewed at a time.

As is common in ethnographic interviewing, we began with a "grand tour" question: "Think back to when you first realized that your loved one's illness was progressing or was not curable, what questions came to mind?"¹⁸ Caregivers were then asked to discuss: (1) the questions they believe are important to discuss with HCPs in order to prepare for the death of their loved one, (2) which of these questions they asked HCPs, and (3) which questions they did not discuss with HCPs. Interviews were approximately 60 minutes in duration, conducted by an investigator with experience in qualitative methodology, audiotaped, and transcribed. A research assistant took notes during interviews. Data collection and analyses were iterative and conducted until the point of redundancy, or when no new information was forthcoming. Written informed consent was obtained prior to all interviews.

Data analysis

Data analyses was conducted using standard methods.¹⁶ Two investigators (R.S.H. and V.C.C.) read transcripts independently to generate a preliminary list of questions. They met periodically to compare results and resolve inconsistencies. The questions were then reviewed by a multidisciplinary team consisting of individuals with expertise in palliative care, qualitative methods, end-of-life communication, and caregiving, in order to evaluate the importance and wording of each question. The content validity of each question was assessed by asking 10 current family caregivers who had not been interviewed to evaluate (1 = not to 4 = very) the importance and clarity of each question.¹⁹ The interrater agreement (IRA) for importance and clarity was calculated by dividing the number of caregivers who scored a question as a 3 or 4 by 10 (the number of caregivers). The IRA for each question was ≥ 0.80 , indicating excellent agreement among caregivers. Caregivers also thought no questions were missing.

Study procedures were approved by the University of Pittsburgh Institutional Review Board.

RESULTS

Caregivers were predominantly female, adult children, and were providing care to loved ones with cancer or cardiopulmonary disease (Table 1). Their questions were categorized as medical, practical, psychosocial, and religious/spiritual. Table 2 lists the questions in descending order of frequency within each category. The nature and frequency of questions did

TABLE 1. DEMOGRAPHICS CHARACTERISTICS OF CAREGIVERS (N = 33)^a

Caregiving Status—no. (%)	
Bereaved	27 (82)
Current	6 (18)
Gender—no. (%)	
Female	27 (82)
Male	6 (18)
Race—no. (%)	
African American/Black	15 (45)
Caucasian/White	18 (55)
Age—no. (%)	
20–29	1 (3)
30–39	3 (9)
40–49	2 (6)
50–59	14 (42)
60–69	5 (15)
70 and over	4 (12)
Unknown	4 (12)
Education—no. (%)	
Some high school	3 (9)
High school diploma/GED	3 (9)
Some college	10 (30)
College graduate	4 (12)
Graduate degree	5 (15)
Unknown	8 (24)
Relationship to the Patient—no. (%)	
Spouse/fiancé	7 (21)
Child	14 (43)
Other	12 (36)
Primary Patient Illness—no. (%) (23 patients)	
Cancer	10 (44)
Cardiovascular Disease	6 (26)
COPD/pneumonia	2 (9)
Cirrhosis	1 (4)
Dementia	1 (4)
Multiple illness/other	3 (13)

^aPercentages may not equal 100% because of rounding. COPD, chronic obstructive pulmonary disease.

not differ by ethnicity or caregiving status (current versus bereaved).

Questions discussed with HCPs

All caregivers reported asking questions of a medical nature, usually related to treatment or clinical course. Not surprisingly, the most common questions were “How long does my loved one have?” and “What is happening with/to my loved one?”

Family members also asked practical questions about insurance payments, finances, and accessing

medical services. Another common question pertained to the difficulty of getting in touch with physicians.

I was always asking, “How do I get in touch with the doctor?” When you have those high powered neurosurgeons, they don’t always communicate. —bereaved, Caucasian, caregiver wife

Psychosocial questions referred to how best to discuss the patients’ condition with other family members, including children.

Is it ok for the little ones (grandchildren) to see Mom in the condition she was in? —bereaved, Caucasian, caregiver daughter

Questions of a religious/spiritual nature generally referred to asking for clergy.

Questions not discussed with HCPs

Two types of medical questions went unasked. The more common referred to what the dying process “looked like.”

What is this death going to look like? Who knows how ugly it’s going to look when it happens. When seizures occur, is this the end? —current, Caucasian, caregiver son

The other group of questions referred to the caregivers’ perceptions of poor clinical care. Caregivers who were concerned about these issues perceived overall communication as particularly poor. Poor communication, in turn, led caregivers to wonder if HCPs were “hiding something” that may have contributed to their loved ones’ poor outcome. For example,

She was swollen. I said, ‘Mom did you fall? Did someone hit you?’ She had strokes before and her face never swelled . . . I could never get in touch with the doctor . . . and I’m talking to a doctor who doesn’t know her (the patient). When you have negligence and lack of communication and poor care it starts the family on a, such a negative view of you (HCPs) that they (the family) can’t even see the good you (HCPs) do. —bereaved, African American, caregiver daughter

Psychosocial questions were not a problem for most caregivers. Several caregivers, however, wanted advice about how to communicate with fam-

TABLE 2. QUESTIONS FAMILY CAREGIVERS WANT TO DISCUSS WITH HEALTH CARE PROVIDERS IN ORDER TO PREPARE FOR THE DEATH OF A LOVED ONE

<i>Domain</i>	<i>Questions</i>
Medical	What is happening with/to my loved one? How long does my loved one have/Will my loved one recover? What should I expect to happen over the course of the illness? What caused the illness? What are the common side effects of my loved one’s medications? What can I expect when my loved one is dying/What does dying look like? ^a Did the doctors miss something? Could this (illness) have been caught earlier? ^a Will my loved one be in pain/Is my loved one in pain? Can the pain medicine make my loved one’s heart stop or cause him/her to stop breathing? What if my loved one stops eating/Will my loved one starve? Will my loved one need a feeding tube? Will my loved one need IV fluid? What are the risks of the treatment my loved one is receiving? Can my loved one hear me? Will the pain medicines stop working if used too often? Will the pain medicines cause addiction? What do I do if my loved one seems depressed?
Practical	Who can I talk to about insurance/financial concerns? How do I get information about home health services/assisted living/nursing homes? Who can I call if I have questions or need help? How can I get in touch with the doctor? How do I get information about hospice? How do I get information about living wills? How do/When should I make funeral arrangements? ^a
Psychosocial	What do I do if family members disagree about treatment or disagree about what should be done with the patient? ^a Should we discuss death and dying with the patient/family? How can I help the children understand what is happening?
Religious or spiritual	Who can I speak to about religious/spiritual concerns? Why is this happening? Why is God allowing this? ^a Will my loved one go to heaven? ^a Is withholding food and water/withdrawing care allowed? ^a (refer to religious or doctrinal teachings regarding artificial nutrition and withdrawal of terminal care)

^aRefers to questions that caregivers did not ask health care providers.

ily members. In particular, caregivers wanted help when disagreement or conflict was present. The following refers to the tension generated when a family member who was not contributing to the patient’s care placed additional responsibilities on an already burdened caregiver.

When my sister-in-law came she brought her son . . . and she left him here . . . We aren’t on speaking terms anymore. I wish the social worker had said to my husband, “Has there been family conflict because of the illness of your mother?”
 —bereaved, Caucasian, caregiver daughter-in-law

Questions of a religious/spiritual nature could be particularly agonizing, especially those pertaining to the meaning of illness.

I know you aren’t supposed to—we just wonder why, but you’re not supposed to question God. Why is this happening? But, who could answer this question?
 —bereaved, African American, caregiver daughter

Several caregivers noted that it was important that their loved one reconcile with God. The following quote is from a mother who was concerned that her son, who had a history of drug and alcohol abuse, reconcile with God before dying.

I got in touch with his brother. He’s a minister. _____ (patient) never paid much attention to the religious side of anything . . . And I couldn’t believe it because all the rest of us are a religious people . . . His brother talked to _____ (patient) and said make sure that you confess and give your heart to Jesus.
 —bereaved, African American, caregiver mother

BARRIERS TO QUESTION ASKING

The primary barrier to asking questions was caregivers' perceptions of "not knowing what to ask," often because they felt overwhelmed.

When he was in the hospital, they had the social worker, the pulmonologist, and one of the head doctors, and we just talked to so many people. I can't even remember half the stuff that we even talked about. It just was like we were bombarded.
—bereaved, Caucasian, fiancé

As a result, caregivers wanted more guidance from HCPs. In fact, two caregivers recommended that HCPs have a prepared list of questions to give caregivers.

We don't even know enough to know what to ask . . . But why do I have to try to ask all these questions to get an answer. Haven't they (HCPs) done that before to be able to just tell us what to do? If I had all of this on a sheet that I could refer to instead of always having to remember what to say, you know.
—current, Caucasian, caregiver wife

Another barrier included the perception that the HCPs were not trustworthy. For example, one caregiver, a nurse, asked questions of her colleagues rather than of the HCPs caring for her loved one.

I didn't trust the doctor at _____ hospital . . . I have a lot of friends in healthcare because of my job. I talked to them about different things, mainly, medication questions . . . And a lot of it with the nurses, I'd discuss the family issues. They were able to relate to me.
—bereaved, Caucasian, caregiver daughter-in-law

A final impediment was caregivers' concerns that HCPs would perceive them as "ignorant" if they asked questions.

. . . medical terms, to us are foreign. You don't necessarily understand and don't want to show a doctor that you're ignorant, so 9 times out of 10, you say, "Okay, alright, uh huh." Meanwhile I didn't understand a thing you said.
—current, African American, caregiver daughter

Consequences of unanswered questions

The uncertainty associated with "not knowing" could be especially troubling. This quote comes from

a wife who still had unanswered questions five months after the death.

Dr. _____ just disappeared into thin air and I never heard from him again after the day of the operation. It was a completely mystifying experience for the two months (the duration of the patient's hospitalization). I still can't sleep at night just thinking, who missed what? I still have thousands of questions in my mind.
—bereaved, Caucasian, caregiver wife

The following quote comes from a wife who describes, while crying, the overwhelming uncertainty involved with administering medications to her husband who was dying of a brain tumor.

When he can't swallow and take his medicine, what do we do? Can we mix these two drugs (Ativan and Valium) together? Can we give them at the same time or can we stretch them apart? . . . There's really no clear cut rules to follow . . . It's just real confusing . . . Are we giving him too much Valium and that's going to kill him you know, and it will be our fault?
—current, Caucasian, caregiver wife

Conversely, having one's questions answered could bring tremendous relief.

We needed to understand that you can't flush the system with fluid and think it will just bounce back . . . I needed to know that so you don't have the feeling as though you are starving your loved one to death if you don't give them nutrition . . . knowing that (artificial nutrition would not change the outcome) relieved our conscious so much that it was unbelievable.
—bereaved, African American, daughter

DISCUSSION

Family caregivers consistently report that end-of-life communication is often inadequate.^{10,20,21} This deficiency in part reflects the paucity of research about family caregivers' communication needs at end-of-life.²² More specifically, there exists little information about what information caregivers need from HCPs in order to prepare for the death of a loved one.²³ We therefore interviewed family caregivers of persons at end of life in order to characterize the questions they want to discuss. Several findings emerged. First, caregivers had a wide spectrum of questions. The multi-

dimensional nature of the questions is consistent with previous findings that preparing for the death has medical, practical, psychosocial, and religious/spiritual dimensions.^{24,25} We also discovered that some questions were not discussed with HCPs. Questions that were not discussed, in turn, often went unanswered and could contribute to caregivers' distress. To our knowledge, these findings have not been previously reported.

Implications

The breadth of caregivers' questions means that preparing caregivers for the death involves more than providing prognostic information. A multidisciplinary approach is needed. While this should not be surprising, HCPs' biomedical focus may lead them to neglect other areas.²⁶ Other members of the healthcare team can play an integral role. For example, referral to clergy should be offered to those caregivers who want spiritual guidance.²⁷ Social workers can advocate for addressing psychosocial questions.²⁸ This team approach lends itself well to the interdisciplinary nature of palliative care.

Second, preparing caregivers for the death must be individualized. Although all caregivers had questions they wanted to discuss, our list of questions is not meant to imply that all caregivers have all questions or that all questions are relevant at any given time. The only way for HCPs to know which questions are relevant or important to a particular caregiver is to ask.

Third, HCPs often make the erroneous assumption that the absence of questions reflects an unwillingness to discuss end-of-life issues.²⁹ Caregivers may not ask questions because they do not know what or how to ask, they perceive HCPs as unable or unwilling to discuss the questions, they do not want to be perceived as ignorant, or because they prefer the counsel of friends or family. HCPs can facilitate question asking by providing a secure environment where caregivers feel comfortable asking and receiving answers to tough questions. In addition, because caregivers often do not know what to ask, a statement such as "Many caregivers of serious ill patients have questions about _____. Is this something that concerns you?" could open the door to discussion. Offering to include friends and family in discussions would also be an opportunity to clear up misconceptions about palliative care and to facilitate communication among all parties.

Finally, HCPs need to be aware that not attending to unanswered questions may contribute to caregivers' distress, especially if caregivers associate poor communication with mistrust, medical errors, or poor clinical care. The fact that the associated distress may persist for months after the death has important im-

plications for adaptive grieving. It may therefore behoove HCPs not only to ask caregivers if they have any unanswered questions but to directly ask if they have concerns about their loved one's care. This line of inquiry may help allay fears and educate caregivers about the natural history of terminal illness.

Future work

Studies have demonstrated that when caregivers voice questions and perceive that their questions have been answered, satisfaction and quality of life are improved and there are fewer depressive symptoms.^{30,31} Because caregivers who are unprepared for the death may suffer from more psychiatric morbidity, future work should focus on helping caregivers ask questions and explore whether answering these questions results in better mental health.^{13,32}

Also, the questions generated by our participants could be used to develop a question prompt sheet (QPS), or a list of questions that caregivers can refer to when talking to HCPs. QPS are effective in facilitating communication because they give caregivers "permission" to ask questions they may be uncomfortable asking.^{33,34} QPS also take into account the fact that caregivers have different information seeking styles and different needs for information.³⁵ This is important because individualizing information is necessary to avoid the harm that may occur when HCPs discuss topics with caregivers who are unwilling or unable to process the information.³⁶ Finally, it is important to note that information exchange will likely not be sufficient to prepare caregivers for the death. HCPs' interpersonal and communication skills are as, and possibly more important.^{37,38} Because HCPs are often not proficient in these areas, educational programs should be developed to teach the requisite skills.^{39,40}

Limitations

Our results must be placed in context of several limitations. First, our sample consisted predominantly of white and African American caregivers of individuals with cancer or cardiopulmonary disease. The percentage with cancer or cardiopulmonary disease (70%), however, is consistent with the percentage of deaths (66%) due to these illnesses in U.S. adults over age 55.⁴¹ It is possible, however, that caregivers of persons with other illnesses may have different questions. Also, because people of different cultural backgrounds report unique stressors associated with caregiving, it is conceivable that people from different backgrounds may have unique questions.⁴² However, because our results are very consistent with those found in Clay-

ton and colleagues'²⁵ study of caregivers of palliative care patients, we believe our questions are sufficiently broad as to apply to most caregiving situations. Second, our sample was too small to allow us to reliably explore whether certain questions are more relevant to caregivers of different gender, ethnicity, socioeconomic status, etc. Finally, approximately 80% of our sample was bereaved. We do not think this is a major limitation, however, because the questions posed by current and bereaved caregivers did not differ substantially. We also tested the content validity of all questions in a separate sample of current caregivers who thought the questions were valid and important. Nonetheless it is possible that questions that caregivers identify as important or unanswered are influenced by the death of the patient.

SUMMARY

Family caregivers of patients with serious illness need a variety of information in order to care for their loved one. The need for information about death and dying is especially relevant when patients are at end of life. Awareness of caregivers' questions can help HCPs improve the care provided to caregivers by better preparing them for the death of their loved one.

ACKNOWLEDGMENTS

Preparation of this manuscript was supported by grants from the National Institutes of Mental Health (K23 MH074963) and the Cancer and Aging at the University of Pittsburgh program (P20 CA103730).

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