Using the Experiences of Bereaved Caregivers to Inform Patient- and Caregiver-centered Advance Care Planning

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BACKGROUND: Traditional approaches to advance care planning (ACP) have many limitations; new approaches are being developed with the goal of improving end-of-life care.

OBJECTIVE: To understand how the end-of-life care experiences of older patients and their caregivers can inform the development of new approaches to ACP.

DESIGN: Qualitative cross-sectional study.

PARTICIPANTS: Caregivers of community-dwelling persons age ≥ 60 years who died with advanced cancer, chronic obstructive pulmonary disease, or heart failure during follow-up in a longitudinal study.

APPROACH: In-depth interviews were conducted 6 months after the patient's death with 64 caregivers. Interviews began with open-ended questions to encourage the caregiver to tell the story of the patient's experiences at the end of life. Additional questions asked about how decisions were made, patient-caregiver, patient-clinician, and caregiver-clinician communication.

MAIN RESULTS: Although the experiences recounted by caregivers were highly individual, several common themes emerged from the interviews. These included the following: 1) the lack of availability of treatment options for certain patients, prompting patients and caregivers to consider broader end-of-life issues, 2) changes in preferences at the very end of an illness, 3) variability in patient and caregiver desire for and readiness to hear information about the patient's illness, and 4) difficulties with patient-caregiver communication.

DISCUSSION: The experiences of older patients at the end of life and their caregivers support a form of ACP that includes a broader set of issues than treatment decision-making alone, recognizes the dynamic nature of preferences, and focuses on addressing barriers to patient-caregiver communication.

KEY WORDS: end-of-life care; caregivers; advance care planning.

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INTRODUCTION

Advance care planning has traditionally been conceptualized as the process by which persons can indicate the type of treatment they would want to receive in the future if they were no longer able to participate in the decision-making process. This process has focused on the consideration of specific treatment interventions and the completion of forms, such as the living will or other instructional documents.¹ Many concerns have been raised about this conceptualization of ACP, including patients' inability to predict their future treatment preferences,² the difficulty in anticipating all of the situations a patient may face,¹ and the failure of this process to consider additional aspects of end-of-life care that are important to patients, such as decreasing the burden on loved ones.^{3, 4} In addition, there has been a lack of consideration of caregivers, who are frequently called upon to make treatment decisions on behalf of patients without knowing their preferences.³ These concerns have led to a newer conceptualization of advance care planning as an act of communication between patients and caregivers that goes beyond consideration of specific treatment interventions.⁵

There has been little formal study of how these conceptualizations of advance care planning relate to the actual experiences of patients and caregivers at the end of life. Qualitative and quantitative studies of seriously ill patients and caregivers, as well as bereaved caregivers, have been critical to identifying patient- and caregiver-centered definitions of quality end-of-life care.⁶⁻⁸ The complex nature of the experiences of patients at the end of life and their caregivers supports the need for qualitative studies providing an in-depth analysis of these experiences.⁹ We sought to expand upon these studies by examining the experiences of patients and caregivers, focusing on communication and decision-making about treatment at the end of life, as related by the caregiver, in order to improve our understanding of how they might best plan for end-of-life care.

METHODS

Participants

Eligible participants were the caregivers of community-dwelling patients who were age 60 years or older who died with advanced cancer, chronic obstructive pulmonary disease,

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(COPD), or heart failure (HF)^{10, 11} during follow-up in a longitudinal study of treatment preferences. Identification, enrollment, and follow-up of the patient cohort have been previously described.¹² At the time of enrollment, patients were asked to identify the person who helped them the most with daily activities as their primary caregiver. Of the 125 patients who died, 104 had a caregiver who had agreed to participate and was enrolled in the study. Of these, 96 (92%) completed either a face-to-face ($n=64$) or telephone interview ($n=32$) following the death of the patient. Among the remaining eight, two caregivers had died, three had moved away from the area, and three refused. The 64 caregivers completing face-to-face interviews are the subject of the current analysis because only these interviews were audiotaped. Caregivers completing face-to-face interviews did not differ from those completing telephone interviews in age, education, gender, ethnicity, diagnosis of the patient, or relationship to the patient.

Data Collection

Interviews were conducted 6 months after the patient's death in the caregiver's home by one of the two research nurses who had established a relationship with the caregiver during the longitudinal study. Interviews were semi-structured, utilizing a discussion guide. The interviews began with the open-ended question, "Can you tell me what happened after the last time we talked" in order to encourage the caregiver to tell the story of the patient's experiences at the end of life. The guide included questions about how decisions were made; patient-caregiver, patient-clinician, and caregiver-clinician communication; patient and caregiver concerns, such as the presence of symptoms, the ability of the caregiver to care for the patient, and whether the patient received the care he/she wanted; and factors that helped patients and caregivers with these concerns, such as additional formal and informal supports. Interviews lasted approximately 60 minutes. The research nurse audiotaped the interviews, and the tapes were transcribed by an experienced medical transcriptionist.

Descriptive patient and caregiver data were obtained by self-report from the patient and the caregiver, and were taken from the last quantitative interviews conducted prior to the patient's death. In the parent study, patients and caregivers participated in face-to-face in-home interviews at least every 4 months and more frequently as the patient's status declined, for up to 2 years. Data taken from the caregiver interview consisted of sociodemographic variables including age, gender, race; caregiver's understanding of the patient's life expectancy; and relationship of the caregiver to the patient. Data taken from the patient interview included patients' understanding of their own life expectancy and whether they had completed traditional advance directives. In addition, patients' treatment preferences at the time of this interview were recorded, in order to facilitate comparison between these preferences and the actual decisions made by patients and caregivers. The patient interviews occurred a median of 94 [interquartile range 52, 125] days and the caregiver interviews 33 [interquartile range 14, 84] days prior to the patient's death.

Analysis

The transcripts were analyzed with multiple close readings by the two investigators, a geriatrician and a data analyst, each of

whom had formal training in qualitative methods and who worked together on acquisition and analysis of quantitative data in the longitudinal study.¹²⁻¹⁴ Analysis was conducted using the constant comparative method.¹⁵ In this method, discrete sections of text representing a given idea are coded. Related codes are organized into concepts. These concepts are then compared both within and across interviews. Analysis of the dimensionality of the concepts and their relationships to one another leads to the development of theories, presented in this study as the major themes.

Initially, small segments of five transcripts were coded by the investigators independently. The investigators then met to review these codes in each interview. When disagreement existed about the presence, scope, or definition of a code, consensus was reached through discussion. This initial coding structure was used to analyze the subsequent interviews by each of the two investigators. The investigators met regularly to compare coding and resolve differences in the application of a code. As the investigators identified new ideas that were not captured by the existing coding structure, they met to reach consensus about the scope and definition of new codes. These codes were then added to the coding structure, and the structure was reviewed to determine relationships among codes in order to organize codes into broader themes. Once the final coding structure was determined, a third investigator independently coded the transcripts, and differences in coding were resolved through further discussion.

Coding was performed using NVivo 2.0 (QSR International). The software was utilized once an initial coding structure was developed in order to refine the coding structure, apply codes to text, identify recurrent concepts, and examine the relationship among themes within and among interviews and between concepts and basic patient characteristics, such as the patient's primary diagnosis.

RESULTS

Description of Caregivers and Patients

Descriptive characteristics of the caregivers and the patients for whom they cared are provided in Table 1.

Themes Related to Advance Care Planning

The experiences related by the caregivers were highly individual and were shaped by interactions among many factors, including the patient's diagnosis, symptom burden, and care needs; the caregiver's social supports; caregiver and patient religious views; and the quality of interactions with care providers, including physicians, nurses, and social workers. Nonetheless, several common themes emerged that were related to advance care planning. These themes challenged traditional notions of advance care planning. These themes included: 1) the availability of treatment options and effects on decision-making, 2) changes in and variability of preferences at the very end of an illness, 3) variability in patient and caregiver desire for prognostic information, and 4) the importance of patient-caregiver communication. In each of the following sections, we contrast the traditional conception of or concern regarding advance care planning with the theme suggested by the interviews.

Table 1. Description of 64 caregivers and the 64 patients for whom they cared

Caregivers	
Age (yrs $\pm$ SD)	61 $\pm$ 13
Female (%)	89
White (%)	95
Relationship to patient (%)	
Spouse	52
Child	24
Other	24
Perceived patient's life expectancy < 6 months (%)*	30
Patients	
Age (yrs $\pm$ SD)	74 $\pm$ 7
Female (%)	39
White (%)	92
Diagnosis (%)	
Cancer	52
Chronic obstructive pulmonary disease	27
Heart failure	21
Perceived life expectancy < 6 months (%)*	10
Advance care planning (%)*	
Living will	67
Health care proxy	60

* Obtained at final interview performed prior to the patient's death

Availability of Treatment Options and Effects on Decision-making

Advance care planning traditionally focuses on patients' preferences for specific treatment interventions. We found that the need to make intervention-based treatment decisions arose for patients with HF and COPD but did not arise among the subgroup of patients with cancer. Cancer patients reached a point in their illness when it was accepted that there were no longer any treatment options available to try to meet a goal for controlling the cancer or prolonging the patient's life. For these patients, the emphasis shifted to a consideration of other goals and decisions, such as their preferences for site of care and their end-of-life concerns:

Dr. ____ said, 'OK, that's it, nothing else is working. This is all I have to offer you.' So we sat here one day and I said, 'OK, now we just have to basically decide. There is nothing else to do to save or even prolong you[r] life, so we just have to decide what your end-of-life issues are and where you want to die.'

Dr. ____ had come in, and he came around and he said that he really wasn't going to get any better. I knew that, but I think he had to hear that, and he asked us to decide what we wanted to do. If he wanted to go home with hospice or just what to do.

In contrast to these caregivers, many of the caregivers of patients with COPD and HF recounted the need to make specific treatment decisions about both starting and stopping potentially life-sustaining treatment:

She asked me about resuscitating [my husband], and I said, "No, no don't do that," it just came out of me. And I broke down because I couldn't believe that it came out of me like that.

He was breathing from the machine, and I told the doctor, "You have to take off the machine ... because there was no hope."

[The emergency room doctor] came out saying, "Do you want us to resuscitate her? If she doesn't stop with the seizures, do you want us to let her go?" I was shocked because I didn't know I had to come up with the answer right then.

Changes in and Variability of Preferences at the Very End of Illness

A growing concern about the utility of advance care planning is whether patients can accurately predict their future treatment preferences.^{2, 16, 17} This concern is based on the findings that patients with declining health have been shown, when asked about hypothetical future situations, to become more accepting of life-sustaining treatment.¹⁸ Such findings support the notion that, as patients adapt to their declining health, they become more willing to undergo interventions to maintain that health state and/or to accept further diminishing states of health. None of the caregivers, however, in this study, described patients making a decision to undergo therapy that they had previously decided to forgo. Instead, there were several stories of patients facing the need for intervention who were able to participate in the decision-making process and decided to forgo therapy. Each of these patients had, in their last interview prior to death, indicated a willingness to undergo invasive therapy even if the likelihood of survival was low:

The hospital was telling my mother that they wanted to intubate her, and they said that if they didn't intubate her, she would die. They needed to intubate her to get her strength back and her lungs clear, and my mother wouldn't have it. She said, "I'm not going through that." I said, "Do you understand that you're going to die?" and she said, "I'm ready to die."

That was in the ER; he was never admitted. By then the family arrived ...and he said to the assembled family that he wanted to go home to die, and we kept asking him, "Are you sure that's what you want?" and he kept saying yes, that's what he wanted.

Other descriptions of decisions to forgo therapy, regardless of patients' prior wishes, involved a description of the patients' being "too tired" to "fight" their illness:

All he kept saying to me was that he was tired, tired, tired, and he wanted to go.

I think she was tired. You know it was just a long grind, and she was just very tired, saying "I just don't want to do this any more."

There were also several stories of patients who maintained a desire for aggressive therapy, regardless of whether any such interventions were offered to them:

It was like he was fighting until the very, very end. He would have continued with treatment to the very end.

And that's when [the doctor] discussed having the open-heart surgery.... [He said] she had a 50/50 chance of coming off the table. [Interviewer: And what was her response to that?] "I'll take the 50/50 chance."

Variability in Patient and Caregiver Desire for Prognostic Information

Although there is debate regarding the provision of prognostic information to patients and their families, the argument is frequently made that patients need more prognostic information in part because this information is critical to advance care planning.¹⁹ The stories told by the caregivers in this study suggest that there is tremendous variability in the amount of prognostic information that patients and caregivers are ready, willing, and able to hear:

I mean she had it for 4 years, and every doctor from the onset had told her this is not curable. The most we were looking at, after he got all the results back, he said two to five years, but my mother never heard that. She would come back from the doctors saying, "They are going to cure me, they will cure me."

And she'd say, "Yep, I'm going to ask him today." [Interviewer: "and the question is?"] How long do I have to live? And I'd tell her, "You don't need to ask him that if you don't want to go there," and she'd say, "No, I want to ask him." So we'd go for the appointment... and I'd say, "Well?" and she'd say, "I want to but another part of me doesn't want to." She would never do it - she would never come out and ask - not until that very last time that we saw him.

If they told me I don't know if it would have done any good because sometimes I had information overload. It would like bounce off and I just couldn't absorb it. So, [the social worker] said to me that if I wanted to, I could ask the doctor how long she thought he had to live, but I didn't want to know that.

Other caregivers were pleased with the prognostic information they and their loved ones received:

The doctor came out and she said, "Mrs. M., your husband is dying." The way she said it, it was so nice. I mean the way she came out with it, she was so comforting and so compassionate.

[His doctor] would explain what was going on. [My husband] knew everything that was happening to him. He wanted to know.

Caregivers also spoke of their appreciation for clinicians who took the time to find out how much information they wanted to have:

Both nurses that I dealt with asked me, "How much do you really want to know?" and I said, "I want to know everything." ...it was nice to know that if I didn't want to know something, I could say, "You know what, just tell me a little bit." I felt like I had that option

Importance of Patient-Caregiver Communication

Traditional conceptualizations of advance care planning focus on the process by which the patient can make his/her wishes known regarding future healthcare. There is no explicit consideration given to the caregiver in this process. Newer conceptualizations have highlighted the importance of patient-caregiver communication, noting that caregivers need to understand patients' preferences and values in order to be effective surrogate decision-makers.⁵ The caregivers in this study highlighted the barriers to patient-caregiver communication, including patients' and caregivers' differing hopes and fears about the patient's illness and concerns that the other person did not know and would not be able to accept the severity of the illness.

[Interviewer: "He would say that he did not want to live this way?"] Right, and of course I'd get annoyed at him. I'd say, "What are you talking about?" I kept trying to tell him he was going to be OK.... See, what I didn't know was that he was praying to die, and I was praying that he would get better.

But what I didn't know until after he had died - two weeks before he died, he called my sister in Long Island and told her he wasn't going to be around much longer. He knew he was going but he didn't want to tell me because I'd get mad at him.... I just wanted him to fight, and he just wanted to tell her what he felt for me.

Some patients and caregivers went to great lengths to avoid communication:

The social worker from Hospice came to talk to me, and I found out after he died that he already knew he was dying, but he did not want to tell me, and I did not want him to know that I knew he was dying, so I told them not to say anything. So, between the two of us, we were trying to keep each other from knowing that he was dying.

The caregivers' stories also illustrated the adverse consequences to both patients and caregivers from failing to communicate. One participant was the caregiver for a patient who had reported during his final interview that his preferred site of death was inpatient hospice. This caregiver was unaware of this preference, stating:

Well, there are only two things that stay in my mind constantly. The day we had to make the decision about hospice, that was the toughest day of my life. My son and I sat there, and we cried together.

Conversely, open communication was seen as having many benefits, including preventing dissension among different family members and providing closure:

I knew that she always did not want to have a respirator, but, because my sisters lived far away, she wanted them to know.... So she left the burden off of me a little bit, saying, "This is what I want." And I felt good about that because the last couple days of her life it was so hard for me to communicate with them

knowing that this is what Mom wants and we have to give her wishes.

I was sitting by her side, and she said, "D., you've been good to me and I love you," and that was the last word she spoke to me. That was a gift.

DISCUSSION

The experiences of bereaved caregivers for older patients with cancer, COPD, and HF in this qualitative study were highly individual and depended upon the interactions among a wide variety of factors. Despite the individual nature of these experiences, several themes related to decision-making and communication at the end of life emerged. These themes help to inform a patient- and caregiver-centered approach of advance care planning that best meets the needs of patients and their caregivers facing difficult decisions at the end of life.

The finding that some patients with cancer reached a point in their illness where there were no further treatment options available to achieve the goal of prolonging life helps to explain previous quantitative findings in this cohort.²⁰ Prior quantitative investigation has shown that older patients with advanced cancer are more likely to receive a palliative approach to care despite a greater willingness to undergo intensive interventions than are older patients with COPD or HF.²⁰ The current results suggest that this mismatch between patients' preferences and care is not a result of a disregard of these preferences. Rather, clinicians recognized the point in the patient's illness at which life prolongation was no longer a reasonable treatment goal and helped patients and caregivers to understand this. The findings illustrate that, for such patients, other issues, such as site of care, become the focus of decision-making. The findings also highlight the burden on caregivers when they must make a decision about site of care that conflicts with what they believe to be the patient's preferences. Taken together, these results highlight the need for advance care planning to go beyond a consideration of treatment options and include future sites of care. In such planning, patients and caregivers could decide together about if and when it might be appropriate for the patient, who may want to receive care at home for as long as possible, to be transferred to another site of care. However, the need expressed by caregivers for patients with COPD and HF to make decisions regarding potentially life-prolonging therapies highlights the importance of including treatment goals as part of advance care planning for patients whose diseases have an unpredictable course.²¹

The finding that some patients became less willing to undergo intensive therapies when faced with an exacerbation of their illness adds to the complexity of our understanding of how patients' treatment preference change over time. Prior studies have documented that patients' preferences can change in response to changes in their state of health.^{13, 18, 22} The current study demonstrates how these changes can affect decision-making at the end-of-life. The stories of patients who made decisions to forgo therapy illustrates that advance planning should account for the possibility of changes in preferences and goals that may occur acutely. For patients who are pursuing therapy with a goal of life-prolongation, this planning would

consist of formulating an alternative approach to care to accommodate those who reach a point in their illness when they no longer have the energy or desire to "fight."

The themes related to communication and information needs illustrate the central role of these issues in advance care planning. The variability in desire for information about disease and prognosis, along with the ambivalence of some patients and caregivers, is consistent with prior quantitative research.²³⁻²⁵ Caregivers' observations about their lack of readiness to hear certain information may help to account, at least in part, for prior findings of discrepancies in perceived communication between physicians and patients or caregivers.²⁴ The strongly expressed desire of certain caregivers and patients not to receive prognostic information highlights the challenge of doing advance care planning among those who are not ready to accept a patient's terminal diagnosis, and it supports the conception of advance care planning as a behavior for which patients and caregivers can be in different stages of change.²⁶ Caregivers' recollections of missed opportunities for communication with their loved ones provide strong support for an approach to advance care planning that focuses on overcoming barriers to patient-caregiver communication. Addressing these barriers to communication might not only improve caregivers' knowledge of patients' preferences and goals, but might also address other factors important to good end-of-life care, including helping to provide a sense of completion⁸ and reducing caregiver burden.²⁷

Because this was a qualitative investigation, the results of this study cannot be used to draw conclusions regarding the frequency of the experiences described in the results. The qualitative approach instead allowed caregivers to elaborate on their experiences, which helps to provide a more in-depth analysis of their concerns and needs. It is important to note that caregivers are not always accurate reporters of the patient's end-of-life experiences.^{28, 29} The interview attempted to minimize inaccurate reporting by asking caregivers to focus on their own direct experiences and their observations of their loved ones.

The experiences related by caregivers about older patients' end-of-life care illustrate the highly individual nature of patients' and caregivers' preferences and needs regarding information, communication, and treatment. The commonalities across these experiences support a process of advance care planning based on the facilitation of communication between patients and their caregivers, recognizing the potential for changes in preferences and goals, and reaching beyond the consideration of treatment decision-making alone.

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