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Family Caregivers' Characterization of Conversations Following an ACP Event

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Abstract

Background: Advance care planning (ACP) has been shown to benefit patients and families, yet little is known about how an ACP event impacts communication and conversation about end-of-life treatment wishes and the content of such conversations between patients and family caregivers.

Objective: To characterize post-ACP conversations regarding medical wishes between seriously ill patients and their family caregivers.

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Conflict of Interests

Two of the authors (BHL & MJG) have intellectual property and copyright interests for the decision aid used in this study, *Making Your Wishes Known: Planning Your Medical Future* (MYWK), which is available online free of charge. A version of MYWK that can be widely distributed is currently under development in partnership with a private commercial enterprise. All other authors have no conflicts of interest.

Participants: Patients with advanced illness and family caregivers.

Outcome Measured: Post-ACP conversations.

Design: As part of a larger randomized controlled trial, dyads consisting of seriously ill patients and their identified family caregiver engaged in ACP and created an advance directive for the patient. Approximately 4–6 weeks later, semi-structured interviews were conducted with the family caregivers to elucidate the subsequent communications regarding medical wishes. If the dyad did not have any conversations post-ACP, reasons and barriers were explored.

Results: The majority of dyads (131/188, 69.7%) had 2–3 conversations lasting 3–5 minutes each in the weeks immediately following ACP. These conversations most commonly addressed general patient wishes about quality of life and specific medical treatments. The most common reasons for not having conversations were a general discomfort with the topic (13/57, 22.8%) and previously having discussed medical wishes (16/57, 28.1%).

Conclusion: ACP events promote conversation regarding quality of life, general wishes at the end of life, and specific medical wishes. Barriers to conversation following ACP were similar to barriers to ACP in general, suggesting that a more intentional focus on addressing these barriers pre- and post-ACP may be necessary to improve communication.

Keywords

advance care planning; decision aids; end-of-life treatment

Introduction

Advance care planning (ACP) is the process by which individuals determine their goals of care and the medical treatments they would want to receive in the event they lose decision-making capacity. An understanding of the patient's preferences for future medical care is critical for the family member to make decisions that are consistent with the patient's goals of care.¹ The traditional approach to ACP has focused on completion of instructional documents, such as advance directives, and living wills.^{2,3} Decision aids have been developed to support the process of ACP, by prompting patients to consider treatment options and communicate their wishes orally or in writing. Although decision aids for adult ACP are widely available, effectiveness information is lacking in the empirical literature.^{4,5} A number of studies have assessed communication between health care providers and patients and their families during the process of ACP,⁶ but few studies have evaluated whether decision aids are effective in increasing communication between patients and family caregivers.⁷

The purpose of this study is to describe family caregivers' reported experiences with conversations about patients' goals and preferences for end-of-life treatment in the weeks after an ACP event. Specifically, we examined what prompted conversation in the 4–6 weeks following an ACP event, number and duration of conversations, content (topics discussed and topics not discussed), barriers to conversation, and caregivers' reported preparedness to make surrogate medical decisions.

Study Design

This study is part of a randomized controlled trial that included 285 dyads of patients with advanced illness and their family caregivers, enrolled between August 2013 and June 2016 from two tertiary care medical centers in the northeastern region of the US. The objectives of the parent study are to determine whether an online ACP decision aid^{8,9} better prepares family caregivers for surrogate decision making compared to standard ACP (i.e., a simple online advance directive form), and whether ACP was more effective when done together (i.e., patient and caregiver) compared to patients engaging in ACP alone. ACP was delivered to participants in the “Together” group on one computer shared by patient and caregiver. In the “Alone” group, only the patient completed the computer program on ACP while the family member waited in a separate room. A printed advance directive was generated for all patients following the ACP event during study visit 1. The purpose of this qualitative study is to characterize post-ACP event conversations regarding medical wishes between seriously ill patients and their family caregivers. The study was approved by institutional review boards at participating sites. The trial was registered at [ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02429479) (#NCT02429479).

Data Collection

For the purposes of this study, all ACP intervention modes used in the parent study (described above) were considered an “ACP event”. The data examined for this study were collected during the second study visit with caregivers which occurred four to six weeks following the ACP event. Semi-structured interviews with caregivers were conducted (n = 188) to describe communication between patients and caregivers after an ACP event. The research team (JS, JP, JR) formulated the interview questions and developed a well-defined data collection protocol. Key inquiries included frequency and duration of conversations, prompts, topics discussed, and whether conversations impacted caregivers’ preparedness to make surrogate medical decisions consistent with patients’ goals and preferences. Study personnel responsible for conducting the interviews were trained in the protocol. Audio-recorded interviews were reviewed and critiqued by the team early in the data collection period to enhance the quality of the interviews. Minor formatting revisions were made to the interview guide to enhance the clarity of questions for the participants (see Table 1).

Analysis

A team approach was used in analysis. Raw interview data was transcribed and de-identified. All transcripts were reviewed by the interviewer to verify the accuracy of transcription. The qualitative team (JS, JR, JP) read and re-read a subset of ten transcripts to determine initial high-level codes. Iterative analytic sessions by the team produced greater specification in the coding schema. Using agreement in coding as the basis for establishing inter-rater reliability, the coding schema was refined. Ten transcripts were coded (JS and JR), a reliability test was conducted, and discrepancies were resolved. Intra-rater reliability checks were completed by re-coding and checking agreement on every tenth interview to avoid intra-rater drift. This procedure was repeated four times until 40 transcripts were coded. Then, each coder independently coded 30% of the remaining data at which point saturation was reached and no new codes emerged. “Substantial” agreement between coders

was achieved (kappa measure of inter-rater agreement was 0.95). One coder (JR) coded the remaining 148 interviews. All transcripts (N=188) were coded using NVivo, Version 10.

Coded data were then analyzed using techniques of directed content analysis described by Hsieh & Shannon¹⁰ to describe caregivers' conversations with patients following the study ACP event. This analytic approach was used to categorize the family caregivers' reported experiences regarding conversations centered on medical wishes in the weeks after an ACP event. This form of analysis is descriptive; that is, it is not highly interpretive or conceptual, but rather produces a representation of categories of caregivers' post-ACP event conversations.

Trustworthiness of Findings

Study design and procedures were constructed to enhance the credibility of findings. The interview guide was carefully constructed and interviewers were trained and critiqued during initial data collection and periodically across data collection. Triangulation of the data was achieved by using two study sites that were not affiliated and geographically dispersed. Transferability of findings is enhanced by the diversity of the study sites, inclusion of multiple illness contexts, and clear recruitment protocols. To ensure dependability (replicability of research protocol), methodological rigor was established. An audit trail was maintained as the detailed code book was developed and the team's focus did not change course to pursue novel ideas. Confirmability of the findings (that is, the extent to which our findings represent voices of participants) was enhanced by a team analysis approach to develop coding system, regular meetings during initial coding (JS, JR, JP), inter-rater reliability checks and codebook refined until inter-rater reliability exceeded established threshold (kappa \geq 80%).

Results

Interviews averaged 15 minutes in length. The sample characteristics are displayed in Table 2. The majority of the caregivers were females (140/188, 74.5%), and mean age was 56.7 years. Relationship to the patient was mostly spouse (63.3%) followed by parent (18.6%), and the majority lived with the patient (73.8%). Patients were in an advanced stage of a life-limiting illnesses, including: cancer (41.5%), cardiac (28.2%), pulmonary (21.3%), and renal (9.0%). This sample was predominantly white (84.0%) and well-educated; about 70% reported some higher education, college or graduate school degrees. The majority had previously helped someone with medical decision-making (72.9%) and had prior conversations regarding end-of-life wishes (77.1%).

Since completing ACP at the visit occurring about five weeks earlier, 69.7% (131/188) of caregivers reported having had a conversation with the patient about his/her medical wishes. The vast majority of caregivers reported having two or three conversations since the ACP visit, lasting only 3 to 5 minutes each. Of the 131 caregivers who had a conversation, 74.8% (98/131) reported that the conversation(s) helped them understand the patient's medical wishes. Very few caregivers were surprised by the patient's wishes described in the printed advance directive generated during the study visit (<0.5%; 6/131), but in these cases, the

conversation was critical: *“His wishes were a lot different than what I was anticipating, so I was glad to be able to have an open discussion with him.”*

What Prompted the Discussion?

Caregivers often mentioned discussing the advance directive form with the patient after the study ACP event. *“Just when we got home [from the study visit], I wanted to go over what he had put in his advance directive because I wanted to know exactly what his wishes were.”* This review was most often focused on consensus.

We went over the form, and made sure that we were still both in agreement. The bottom line for both of us is fairly simple: If there is an opportunity to survive and have a life, we want to do whatever is medically necessary to make that happen.

Regardless of the form of the ACP intervention (i.e., standard or online program completed alone or together), the ACP event often prompted discussion about the patient’s wishes related to specific medical interventions, such as cardio-pulmonary resuscitation or mechanical ventilation, or a specific medical scenario such as a stroke, organ failure, or being in a persistent vegetative state. Specific treatment discussions and topics appeared to be directly motivated by aspects of the study visit interventions and exercises (e.g., the computer program, questions on the advance directive, etc.). Some caregivers specifically referenced the advance directive creation process which was completed by all dyads. For example, mechanical ventilation was presented as a treatment to be considered across many scenarios and time frames. One caregiver aptly described how the specificity of the scenario often revealed subtle transitions in the wishes for treatment.

What I recall is that she wouldn’t want [the ventilator] longer than a week, and that was kind of surprising. I knew she really didn’t want a ventilator. If there’s a likelihood that you’re gonna get better, then shouldn’t ya? Maybe there’s a little wiggle room there. So, it’s, it really depended on what the scenario was.

However, in other cases, the discussion of the ACP revealed new insights regarding the patient’s wishes that prompted further discussion. *“It surprised me when I read his list... wow, he’s OK with being on life support forever?”* Another caregiver noted:

I was surprised at one or two of the things that she had put on the Advance Directive, like, she put that she didn’t want a feeding tube which surprised me because it just seemed to me like that was a minor, minor intervention. It’s one thing to say, you know, ‘Don’t put me on a ventilator for six months,’ but it’s another thing to say, ‘I don’t want a feeding tube.’

For others, the ACP event heightened awareness of illness progression and alerted caregivers to the need for conversations to clarify wishes. *“Him being so ill, coming in here and you helping us with the advanced directive made us realize that we needed to make everything clear between us. But we’ve been talking about it ever since he got sick.”* The vast majority of caregivers reported that the patient’s medical condition, particularly declining health, was the specific stimulus of conversation. These conversations reflected the significance of the illness trajectory. For example, in the case of depleted treatment options, an abrupt change in prognosis was a powerful stimulus for conversation and action.

They told her yesterday that they can't do surgery. She can't be cured — it's terminal. So we have to get a lot of things going quicker than we had planned, like the Power of Attorney, Living Will. You know, all that stuff needs to kind of get done that we had been dragging our feet on before.

Conversations regarding medical wishes occurred at pivotal points in varied illness trajectories. One caregiver described how an exacerbation of the patient's condition prompted deeper discussion of end-of-life wishes, *"One day I had to bring her into the ER and on the way home, she just started talking about getting the papers notarized and everything ... that's when we started talking about the medical decisions."* Still other conversations reflected the progressive decline of a life-limiting condition, *"We're always discussing [end-of-life wishes] because when you're dealing with cystic fibrosis, you're always discussing medical outcomes, her plans, her wishes. That's just been part of our discussions all along."*

For some caregivers (14.5%; 19/131), the ACP event, coupled with advanced illness, prompted discussion of post-mortem memorialization and burial.

We talk about what should happen when he does pass and what should happen that day. And, what they call the wake and things that he wants and how he wants to be buried, what he wants to wear. We talk about all that and we talk about it quite often.

For others, witnessing illness and death among other family members or friends prompted discussions. One caregiver noted, *"...we just had a death in the family, and we really talked about it yesterday. And we expected it, but it was very sudden. They had nothing planned. They had no cemetery plot."*

Reasons for **Not** Having Discussions

The ACP event did not prompt conversations in all caregiving dyads. In fact, 30.3% (57/188) of caregivers reported either not having a conversation with the patient since the study visit or could not remember. Of those caregivers who did not have a conversation with the patient, 47.4% (27/57) said they *wanted* to have a discussion of the patient's medical wishes, but did not broach the issue and 45.6% (26/57) thought that the *patient* wanted to have a conversation even though none had occurred.

The primary reason cited for not having conversations about medical wishes since the first visit was that previous discussions were perceived to be adequate and further discussion was unnecessary. Sixteen of the 57 (28.1%) caregivers not reporting a conversation attributed the lack of current conversation to past conversations or experience. Some felt adequately prepared before the significant illness episode, *"Even before he got sick, we had Living Wills and Power of Attorney and all that taken care of. We've known each other's wishes for many years."* For others, the influence of the illness trajectory can be seen in the caregivers' responses, *"He and I talked a lot about this during the time his cancer was active, early on."* Another caregiver noted, *"He was very specific with me on what he wanted to begin with. And, as far as I know, that hasn't changed."* Among these caregivers who felt secure with past conversations, there was a reliance on the patient to express any changes in wishes.

She feels confident that her directives are in place, and we don't need to reevaluate ... open this conversation again. She's comfortable with the directives she's put out. And if she changes her mind or something like that, obviously, that would have to be communicated, but that has to come from her.

Several caregivers cited prior caregiving experience as a sufficient background for dealing with potential situations that could arise with the patient. Based on these experiences, they felt no need for conversations about the patient's medical wishes: "*We've been through death of both our parents, we had different things we had to deal with them. Both his parents got dementia. My father had lung cancer and my mother had a stroke.*" A few caregivers even referenced previous conversations held much earlier in their lives: "*We had talked about it back in '92, so I had a general idea. And I will say that since he was diagnosed this time, we really hadn't talked about it again.*"

Besides previous communication, caregivers cited several barriers to conversation. Discomfort was cited by 22.8% (13/57) of those caregivers not reporting conversations following the ACP event. For some, perception of the patient's discomfort thwarted conversation.

Every time we talk about anything medical, when I try to bring anything up about symptoms or explain tests to him or anything, he pretty quickly changes the subject and moves on. I think he likes to avoid the topic and is probably still in a little bit of denial about his health. Or maybe not so much denial as thinking out of sight, out of mind and that kind of thing.

Other caregivers feared upsetting the patient given the patient's frail physical or emotional state.

Here he is...He always took care of me. And now, he can't do that anymore. Even to go into Burger King and order, he used to do that all the time. And he can't do that anymore. He doesn't have the breath to stand there and tell them what we want. And, so to say to him, 'You know, what do you want when you die?' ... I don't think is right now, a good idea.

The patient's burden of illness, with resultant lack of energy, discomfort, or availability to broach the subject was also reported (9/57 = 15.8%).

To be honest, when we left here the last time, he was so exhausted from all of the questions, he didn't even want to go into it. And [he] is very exhausted all the time. He sleeps three-quarters of the day.

Caregivers reported that both patients' and their discomfort with the topics of end-of-life care, dying, and death inhibited conversation. Other caregivers explained the lack of conversation on the choice to focus on the positive, on living with the illness rather than dying from the illness: "*I think both of us emotionally are, well not emotionally, but mentally prepared to handle what we need to do. But it's just not something we dwell on. We're trying to dwell on the positive.*" Balancing the positive with the negatives of the illness experience was described as a delicate balance.

Because we want to kinda put everybody's mind to rest a little bit, rather than continually talking about it every night as dinner conversation. We just want to . . . have some normalcy and not dwell on it constantly.

These caregivers were present-focused, centered on fighting through illness to maximize life: *"I don't want him to get to the point where he's gonna give up. And if he knew that, that there wasn't any hope, he would. So, I want him to keep fighting as long as he can."*

Of those who had not had conversations, 21% (12/57) reported that such discussions would upset the balance between a focus on life versus a focus on death, a balance they sought to maintain. Caregivers wanted to be prepared for end of life surrogate decision making, but at the same time wanted to maintain normalcy, live life fully, maintain hope and not dwell on death.

Topics Not Discussed

Caregivers most often reported wishing they had further conversation about specific questions brought to mind by the hypothetical scenario exercise (vignettes) that was part of the study visit: *"Reading those [study visit] questions...makes me have some further questions that he and I probably will talk about. Reading those vignettes, on some of the scenarios just made me think twice about some of that stuff to talk to him about."*

Some caregivers mentioned wanting to speak more with the patient and medical providers about the patient's prognosis and how to plan accordingly.

We have not talked to the doctors about any kind of long-term prognosis. In other words, the bottom line question that I'd love to ask . . . how long does she have? She doesn't want to have that conversation yet with the doctor. And so, we haven't.

When she's ready, we'll, we'll have that conversation.

Other topics included family dynamics, especially the desire to explore with the patient how to appropriately involve family members in discussions of illness and ACP, as well as what roles these family members should have vis-à-vis surrogate decision-making. Caregivers who did not have conversations with patients about medical wishes cited reasons such as discomfort with the topic of end of life care, the patient's medical condition, desire to preserve normalcy, time constraints, reliance on the patient to initiate conversation, and previous discussion of the patient's wishes. Most of these caregivers said they did want to have such a conversation (66%), and that the patient also wanted to have a conversation (59%).

Caregiver Preparedness to Make Medical Decisions

Regardless of whether or not they had a conversation with the patient about medical wishes, 83% (66/80) of caregivers reported feeling prepared to make medical decisions on behalf of the patient. Caregivers who had conversations reported that these conversations increased their knowledge of the patient's wishes and preparedness to make medical decisions on their behalf, however, 43/74 (58%) did not feel that additional conversations would add to their preparedness to make decisions on behalf of the patient.

Discussion

After an ACP event, patient-caregiver conversations about medical wishes tended to address general patient wishes about quality of life and end-of-life care, post-mortem arrangements, family dynamics, and surrogate decision-making. Caregivers were more likely than patients to start conversations about the patient's medical wishes and reported stimuli for these conversations as being the patient's illness, illness or death of family and friends, and participation in this research study.

Most caregivers (86%) reported feeling prepared to make medical decisions on behalf of the patient, regardless of having had a conversation about medical wishes. 77% reported ACP conversations prior to the study visit, and 73% reported having previously helped someone with medical decision-making. So the high levels of preparedness caregivers reported may have been influenced by their prior experiences. Previous experience matters, however, we did not ask explicitly about previous caregiving, and length of time as a current caregiver was not clear, although quotes support. One caregiver aptly summarized this phenomenon as follows:

We've pretty much in the last nine months talked a lot about medical issues and what if this happens or if that happens? Even before he got sick, we had Living Wills and Power of Attorney and all that taken care of. So, we've known each other's wishes for many years. We've been through death of both our parents. Both his parents got dementia. My father had lung cancer and my mother had a stroke.

Caregivers who did not have post-ACP conversations with patients about medical wishes, and who did not mention previous conversations, cited several reasons why these conversation did not occur, including discomfort with the topic, desire to preserve normalcy, and the patient's medical condition. Strikingly, these reasons echo barriers to ACP itself, articulated in recent literature.¹¹⁻¹⁴ This finding may suggest that engaging in ACP may not be sufficient to lower the barriers to conversation and end of life care planning that ACP is intended to address. One oft-cited benefit of ACP is to reduce unwanted treatments at the end of a patient's life by increasing concordance between the wishes of a patient and the surrogate's knowledge of those wishes.¹⁵ Yet, for some families the persistence of these interpersonal barriers to conversation even after ACP may limit the intended value and benefits of an ACP event. Communication between patients, their family caregivers, and health care practitioners is essential to quality care in serious illness.¹⁶ Although not a focus of this qualitative analysis, we did not detect differences between caregivers' responses in the alone versus together groups, a finding consistent with the published quantitative results of the parent study comparing the two groups.¹⁷ Caregivers often mentioned prior caregiving experiences (most often caring for a parent). Thus, our findings may suggest that future interventions and clinical tools aimed at improving patient-family communication about end-of-life wishes would be most valuable to caregivers who have not had prior experience with caregiving and medical decision-making.

Limitations

There are important limitations to this study. Because we spoke with caregivers to learn about their conversations with patients, we only captured caregivers' perspectives of the post-ACP event. Given that we asked caregivers to recall the content, frequency, and duration of conversations 4–6 weeks after the fact, there is also potential for recall bias. This study may also be subject to self-selection bias, as those who were uncomfortable with discussing end of life care may not have chosen to enroll, a limitation not uncommon among studies that examine end of life communication. Although we sampled from two significantly different study populations in urban and rural areas, our study sample remained predominantly white, but it was diverse in both level of education and disease category. Lastly, we did not account for caregivers' prior experiences with caregiving as a variable that might impact the content and frequency of their communication with patients, which should be further examined in future studies. Despite these potential limitations to the study, the large sample size we garnered from two study sites suggests that these findings may be generalizable to a larger U.S. population.

Conclusion

In the weeks following an ACP event, the majority of patient-family caregiver dyads had a few short conversations, most often about patients' general quality of life issues and medical treatments desired or not desired under specific scenarios. If they did not have a conversation, it was most often due to feeling that a conversation was not needed, usually because they had previously discussed the topic. An important finding suggested by this study is that participating in ACP may not be enough to lessen the impediments to conversation and end of life care planning that ACP is meant to address. To maximize the impact of an ACP event, future research is needed to understand the effect of earlier experiences on end of life caregiving and the influence of the disease trajectory.

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Table 1.

Semi-Structured Interview Guide

Question

Since the first study visit, have you had a conversation with your loved one (the patient) about his or her medical wishes?

If no conversations:

Do you want to have a conversation with your loved one about their medical wishes?
Tell me a little more about that.

Do you think your loved one wants to have a conversation about their medical wishes? What makes you think so?

What do you think is standing in the way of having that talk?

If yes, have had conversations:

Tell me a about that conversation(s)

How many times did you talk about this since the first study visit?

On average, how many minutes do you think the conversation lasted?

Who (usually) started the conversation(s)?

Was there anything specific that prompted the conversation?

Did the conversation help you to understand the patient's medical wishes? If yes, in what way?

What did you and your loved one talk about?

Were there topics that you didn't discuss but wished that you would have?

On a scale of 0–10, where 0 is not at all stressful and 10 is extremely stressful, how stressful were these conversations for you? What led you to pick that number?

All caregivers:

On a scale of 0–10, where 0 is not at all prepared 10 is extremely prepared, how well-prepared do you think you are to make medical decisions for your loved one if needed? What led you to pick that number?

Do you think talking (more) with your loved one about their medical wishes would make you feel more prepared to make a medical decision? If yes, how so?

Table 2.

Demographics of Participants

Characteristics	Family Caregivers (n = 188)
Gender, female N (%)	140 (74.5)
Age, mean \pm SD, years	56.7 \pm 13.1
Race/ethnicity (%)	
Hispanic	9 (4.8)
Black	13 (6.9)
White	158 (84.0)
Other	8 (4.3)
Patient disease category (%)	
Cardiac	53 (28.2)
Pulmonary	40 (21.3)
Cancer	78 (41.5)
Renal	17 (9.0)
Education (%)	
<8th grade	1 (0.5)
Some HS	6 (3.2)
HS or GED	51 (27.1)
Some college or tech	57 (30.3)
College grad	45 (23.9)
Graduate school	28 (14.9)
Previously helped someone with medical decision making	137 (72.9)
Prior ACP conversations	145 (77.1)
Relationship to patient (the patient is my...)	
Spouse/partner	119 (63.3)
Parent	35 (18.6)
Sibling	8 (4.3)
Son/daughter	7 (3.7)
Friend	11 (2.8)
Other relative	3 (5.9)
Lives with patient	138 (73.8)