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# Effect of Advance Care Planning on Surrogate Decision Makers' Preparedness for Decision Making: Results of a Mixed-Methods Randomized Controlled Trial

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**Abstract**

***Background:*** Advance care planning (ACP) is intended to help patients and their spokespersons prepare for end-of-life decision making, yet little is known about what factors influence the extent to which spokespersons feel prepared for that role.
***Objective:*** To examine spokespersons' perceived preparedness for surrogate decision making after engaging in ACP.
***Design:*** Mixed methods experimental design with qualitative thematic analysis and data transformation (creating categorical data from rich qualitative data) of interviews collected during a randomized controlled trial (2012–2017).
***Setting/Participants:*** Two tertiary care medical centers (Hershey, PA and Boston, MA). Of 285 dyads (patients with advanced illness and their spokespersons) enrolled in the trial, 200 spokesperson interviews were purposively sampled and 198 included in the analyses.
***Main Outcomes and Measures:*** Interviews with spokespersons (four weeks post-intervention) explored spokespersons' perceived preparedness for surrogate decision making, occurrence of ACP conversations, and spokespersons' intentions regarding future surrogate decisions. Data transformation was used to categorize participants' responses into three categories: *Very Prepared*, *Very Unprepared*, or *In Between Prepared and Unprepared*. Themes and categories were compared across arms.
***Results:*** About 72.72% of spokespersons (144/198) reported being *Very Prepared* and 27.28% (54/198) reported being *Very Unprepared* or *In Between* with no differences in preparedness across study arms. Occurrence of post-intervention ACP conversations did not influence perceived preparedness; however, spokespersons who used an ACP decision aid reported more conversations. Four themes emerged to explain spokespersons' perceived preparedness: (1) perceptions about ACP; (2) level of comfort with uncertainty; (3) relational issues; and (4) personal characteristics. Regarding future intentions, it emerged that spokespersons believed their knowledge of patient wishes, as well as other personal, relational, situational, and emotional factors would influence their surrogate decisions.
***Conclusions:*** Factors extrinsic to specific ACP interventions influence how prepared spokespersons feel to act as spokespersons. Understanding these factors is important for understanding how to improve concordance between patients' stated end-of-life wishes and surrogate decisions.
**Trial Registration:** NCT02429479

**Keywords:** advance care planning; advanced illness; data transformation; mixed methods; randomized controlled trial; surrogate decision making

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## Introduction

FAMILY MEMBERS of chronically ill loved ones encounter complex and multifaceted challenges as they assume a caregiving role.[1–3] These challenges often result in significant caregiver burden that affects multiple domains of health and well-being.[4–7] One particularly challenging responsibility for many family caregivers involves serving as a surrogate decision-maker (hereafter referred to as a spokesperson) should their loved ones lose capacity to make their own medical decisions. Up to 47% of older adults require some level of surrogate decision making during an acute hospitalization before death; nearly a quarter require surrogates to make *all* decisions while hospitalized; and up to 70% of patients require surrogates to make medical decisions at the end of life.[6]

Having to make surrogate decisions is stressful, with up to 34% of spokespersons experiencing some form of psychological morbidity after making end-of-life decisions,[8,9] and up to 30% suffering from post-traumatic distress disorder.[6,7] Family dynamics, communication, stress, and the clinician–spokesperson relationship can influence spokespersons' experiences with surrogate decision making.[4,9–13] Advance care planning (ACP) has been associated with decreased decisional conflict; improved self-rated health, mental health, physical function; and bereavement outcomes for spokespersons.[14–19] However, it is unknown whether engagement in ACP affects spokespersons' sense of preparedness. Thus, our objective was to explore how spokespersons' perceived their preparedness for surrogate decision making after an ACP intervention, and what impact ACP had on their intended surrogate decisions. To accomplish this goal, we analyzed interview data with surrogates that were collected as part of a large, randomized controlled trial (RCT) of ACP. These interviews were investigated using thematic analysis and data transformation, and comparisons were made across arms of the parent trial.

## Methods

### Study design, participants, and setting from the parent study

Interview data were collected during a four-armed RCT conducted from 2012 to 2017 comparing two online ACP interventions (*Standard ACP* vs. a comprehensive ACP *Decision Aid* called ''Making Your Wishes Known'') that were completed either by the patient alone, or by the patient and spokesperson dyad together. Details and quantitative findings from the parent trial have been published previously.[20] Participants were enrolled as dyads, consisting of patients with advanced illness and their designated spokesperson. Participants were recruited from two tertiary care centers: the Hershey, Pennsylvania site served as the primary center for study recruitment ($n = 150$), whereas the Boston, Massachusetts site was included to increase minority enrollment ($n = 50$). Detailed inclusion criterion from the parent study are given in Supplementary Method S1. Supplementary Figure S1 provides the consort diagram from the parent study.

The parent trial involved three study visits. Qualitative interviews were embedded within the study protocol to promote deeper understanding of the factors contributing to the study's quantitative outcomes of interest.[21]

At the first visit, patients and spokespersons completed baseline questionnaires. Spokespersons completed a baseline assessment of their perceived preparedness for serving as a spokesperson (self-efficacy) using a modified version of Nolan's validated self-efficacy questionnaire.[22] Dyads were then randomized to one of four interventional arms: (1) *Standard* ACP completed by the patient alone; (2) *Standard* ACP completed together by the patient and their spokesperson; (3) comprehensive ACP *Decision Aid* completed by the patient alone; and (4) comprehensive ACP *Decision Aid* completed by the patient and their spokesperson together. The intervention was completed at the first study visit.

During the second visit, which occurred four weeks later and included spokespersons but not patients, qualitative, semi-structured interviews were used to characterize the frequency and depth of communication between patients and spokespersons since the initial intervention, and to explore how prepared spokespersons felt to carry out surrogate decision making (see Supplementary Method S2 for interview guide). These interviews were analyzed using a mixed methods approach that involved both thematic analysis and data transformation to analyze 200 of the 285 interviews (chosen using purposive sampling, see hereunder).

The third study visit occurred after a surrogate decision was made, but we do not report those findings here as data collection and analysis is ongoing. The Penn State Hershey Institutional Review Board approved this study.

### Description of interventions

One of two types of ACP were provided: (1) *Standard ACP* involved reviewing educational materials developed by the American Hospital Association and completing an online advance directive that included a living will form and the opportunity to designate a spokesperson. (2) *Comprehensive ACP* involved use of the decision aid *Making Your Wishes Known*, a computer-based educational program designed to facilitate ACP discussions between patients and their medical team. The *Decision Aid* has been described and validated in previous studies[23–26] and consists of six sections that take approximately one to two hours to complete. Sections 1 to 4 consist of an introductory overview of the program, a review of surrogate decision making and an opportunity to choose a primary and alternate spokesperson, an exploration of participants' values and goals for end-of-life medical care, and an explanation of health conditions that could result in the loss of decision making capacity and the need for medical decision making. The final sections incorporate participants' selections into an advance directive document that can be printed and shared with others.

### Purposive sampling

We used stratified purposive criterion sampling[27] within each of the four arms to select transcripts for the secondary analysis using the following strata: spokesperson gender, site of recruitment, disease entity, relationship of the spokesperson to the patient, and whether the participants had an advance directive before study participation (see Supplementary Method S3 for randomization). This purposive sampling approach conferred diverse representation of experiences across gender, disease entity, or spokesperson relationship. Of the 285 dyads, 200 were purposively sampled. A large sample size was required for this analysis to conduct robust statistical

comparisons between arms using the transformed qualitative data (described in the following section). After sampling, the research team was blinded to arm assignment. On rare occasions (estimated <5), inadvertent unblinding occurred as participants revealed arm assignment within the transcript itself.

### *Thematic analysis and data transformation*

An interdisciplinary team of clinicians and researchers examined the data using thematic analysis to identify the most important concepts. First, four transcripts were reviewed to create a preliminary codebook consisting of broad categories and individual codes. The team then applied the constant comparative method to code four additional transcripts. Coding discrepancies were discussed and the codebook was refined. Finally, four analysts were trained by experienced qualitative investigators to code 12 additional transcripts and to further refine and finalize the codebook before using it for the remainder of the data. The codebook (which included detailed definitions and examples, Supplementary Table S1) was finalized after review of 20 transcripts (when data saturation had been reached). A round-robin coding format was then used to code the 180 remaining transcripts (two analysts per transcript) using NVivo (Version 11) software. Transcripts were initially analyzed in batches of 10 to 20, and subsequently reviewed by a third analyst to maintain fidelity to the codebook and to confirm inter-rater reliability. Discrepant codes were flagged and discussed at monthly group meetings. To extract themes, codes and categories were systematically reviewed to identify patterns within the data to generate themes.

Standard data transformation procedures were also used to transform qualitative categories that emerged during coding.[28] Each spokesperson was coded into one of three categories to summarize the spokesperson's perceived level of preparedness to serve as a surrogate decision-maker: (1) *Very Prepared*; (2) *Very Unprepared*; and (3) *In Between Prepared and Unprepared*. Categories were assigned by each independent analyst and then reviewed by the third analyst (as described previously) and reconciled (if necessary).

### *Statistical analysis*

All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC), and all variables were summarized before analysis. Ordinal logistic regression was used to look for an association between the study group and the spokespersons' perceived preparedness for surrogate decision making as the outcome variable, whereas binomial logistic regression was used to examine the association between study group and the occurrence of ACP conversations. Odds ratios were used to quantify the direction and magnitude of any significant associations and differences in odds of the outcome variables between study groups.

## Results

### *Spokesperson perceived preparedness for surrogate decision making*

Patient and spokesperson demographics and baseline self-efficacy results are given in Table 1. Thematic analysis and data transformation of transcripts of spokespersons revealed that most spokespersons reported feeling *Very Prepared* for surrogate decision making (72.72%, $n=144$), few felt *Very Unprepared* (3.03%; $n=6$), and that a significant minority felt *In Between Prepared and Unprepared* (24.24%; $n=48$). Whether or not spokespersons reported having ACP conversations with their loved ones in the four weeks after the intervention did not substantially change the distribution of spokespersons in each preparedness category (Table 2); however, several interesting themes and subthemes emerged with regard to spokespersons' sense of preparedness (Table 3). A concept was assigned to the level of a theme or subtheme only if it was highly prevalent within each preparedness category.

**Theme 1: Spokespersons' perceived preparedness is influenced by their experiences during ACP conversations.** Although most participants reported that ACP conversations with their loved ones were ''helpful,'' different subthemes emerged depending on spokespersons' perceived level of preparedness. Specifically, spokespersons who reported feeling *Very Prepared* commonly described ACP conversations as improving their overall knowledge, clarity, and/or understanding of the patient's wishes insofar as the discussions reinforced or clarified what they already knew (Table 3, subtheme 1A.i). These *Very Prepared* spokespersons seldom experienced ACP discussions as upsetting or uncomfortable, but instead often appreciated the conversations for revealing a change in the patients' end-of-life care preferences that the spokesperson had not known about. Some *Very Prepared* spokespersons reported that no ACP conversations occurred after the initial study visit and that they (the spokesperson) already knew their loved one's wishes (Table 3, subtheme 1B.i).

By contrast, spokespersons who reported feeling *Very Unprepared* or *In Between Prepared and Unprepared* reported not just uncertainty about the patient's wishes, but surprise or confusion when conversations revealed that a change in their loved one's wishes had taken place (Table 3, subtheme 1A.ii). Spokespersons who felt *In Between Prepared and Unprepared* or *Very Unprepared* often reported that ACP conversations revealed potential points of conflict, including that their loved ones did not fully comprehend their condition or circumstances (Table 3, subtheme 1B.ii). These spokespersons described how conversations about specific details/aspects of their loved one's wishes (e.g., under what types of circumstances their loved one would be willing to accept specific interventions) left them feeling less prepared, confused, or at times conflicted because they did not agree with their loved one's stated preferences. For many in the *In Between* group, such surprise left them feeling less prepared than before ACP or their subsequent discussions. For many spokespersons, ACP had revealed that their loved one's wishes had changed or were different from what spokespersons had believed them to be (Table 3, subthemes 1C.i and 1C.ii). Comfort with ACP conversations was described in *Very Prepared* spokespersons, whereas participants in the *In Between* or *Very Unprepared* described distress, discomfort, or other negative emotions related to ACP conversations (Table 3, subthemes 1D.i and 1D.ii).

**Theme 2: Spokespersons' perceived preparedness is shaped by their comfort with uncertainty.** Spokespersons expressed varying degrees of comfort with the uncertainty of not knowing when surrogate decision making would be

Table 1. Purposive Sample Characteristics Overall and by Arm from Qualitative Analysis

| | *Total from purposively sampled participants,* n *(col. %)* | *Standard ACP alone,* n *(row %)* | *Standard ACP together,* n *(row %)* | *Decision aid alone,* n *(row %)* | *Decision aid together,* n *(row %)* |
|---|---|---|---|---|---|
| Full sample ($n=285$), *n* | N/A | 65 (22.81) | 70 (24.56) | 61 (21.40) | 71 (24.91) |
| Purposively sampled, *n* | 198 | 49 (24.75) | 51[a] (25.76) | 49 (24.75) | 49 (24.75) |
| Purposively sampled variables (sampled to be equal across arms to the extent possible) | | | | | |
| Location | | | | | |
| Hershey, PA | 137 (69.19) | 33 (24.09) | 34 (24.82) | 37 (27.01) | 33 (24.09) |
| Boston, MA | 61 (30.81) | 16 (26.23) | 17 (27.87) | 12 (19.67) | 16 (26.23) |
| Spokesperson gender | | | | | |
| Male Spokesperson | 63 (31.82) | 17 (26.98) | 17 (26.98) | 11 (17.46) | 18 (28.57) |
| Female Spokesperson | 135 (68.18) | 32 (23.70) | 34 (25.19) | 38 (28.15) | 31 (22.96) |
| Disease entity | | | | | |
| Cardiac | 50 (25.25) | 12 (24.00) | 13 (26.00) | 13 (26.00) | 12 (24.00) |
| Pulmonary | 50 (25.25) | 13 (26.00) | 13 (26.00) | 12 (24.00) | 12 (24.00) |
| Cancer | 53 (26.77) | 13 (24.53) | 14 (26.42) | 13 (24.53) | 13 (24.53) |
| Renal | 45 (22.73) | 11 (24.44) | 11 (24.44) | 11 (24.44) | 12 (26.67) |
| Relationship of spokesperson to patient | | | | | |
| Spouse | 86 (43.43) | 20 (23.26) | 16 (18.60) | 29 (33.72) | 21 (24.42) |
| Parent | 61 (30.81) | 15 (24.59) | 17 (27.87) | 10 (16.39) | 19 (31.13) |
| Sibling | 9 (4.55) | 1 (11.11) | 5 (55.56) | 2 (22.22) | 1 (11.11) |
| Children | 11 (5.56) | 5 (45.45) | 2 (18.18) | 2 (18.18) | 2 (18.18) |
| Other Relative | 7 (3.54) | 2 (28.57) | 4 (57.14) | 0 (0.00) | 1 (14.29) |
| Friend | 17 (8.59) | 5 (29.41) | 5 (29.41) | 5 (29.41) | 2 (11.76) |
| Other | 7 (3.54) | 1 (14.29) | 2 (28.57) | 1 (14.29) | 3 (42.86) |
| Prior AD status | | | | | |
| Patient has prior AD | 107 (54.04) | 23 (21.50) | 23 (21.50) | 25 (23.36) | 35 (32.71) |
| Family has prior AD | 75 (37.88) | 20 (26.67) | 11 (14.67) | 21 (28.00) | 23 (30.67) |
| Other characteristics | | | | | |
| Age | | | | | |
| Patient's age, mean years | 64.17 | 62.90 | 64.96 | 66.55 | 62.24 |
| Spokesperson's age, mean years | 55.09 | 56.47 | 54.73 | 57.47 | 51.71 |
| Patient gender | | | | | |
| Male patient | 79 (39.90) | 16 (20.25) | 16 (20.25) | 27 (34.18) | 20 (25.32) |
| Female patient | 119 (60.10) | 33 (27.73) | 35 (29.41) | 22 (18.49) | 29 (24.37) |
| Highest education | | | | | |
| High school or less | 56 (28.28) | 12 (6.06) | 12 (6.06) | 17 (8.59) | 15 (7.58) |
| Some college | 62 (31.31) | 13 (6.57) | 19 (9.60) | 12 (6.06) | 18 (9.09) |
| College graduate | 80 (40.40) | 24 (12.12) | 20 (10.10) | 20 (10.10) | 16 (8.08) |
| Race[b] and ethnicity | | | | | |
| Patient, white | 122 (62.56) | 29 (23.77) | 33 (27.05) | 30 (24.59) | 30 (24.59) |
| Patient, other | 73 (37.44) | 18 (24.66) | 17 (23.29) | 19 (26.03) | 19 (26.03) |
| Spokesperson, white | 134 (68.02) | 32 (23.88) | 35 (26.12) | 36 (26.87) | 31 (23.13) |
| Spokesperson, other | 63 (31.98) | 16 (25.40) | 16 (25.40) | 13 (20.63) | 18 (28.57) |
| Patient, Hispanic/Latino | 11 (5.88) | 5 (45.45) | 3 (27.27) | 1 (9.09) | 2 (18.18) |
| Spokesperson, Hispanic/Latino | 12 (6.32) | 7 (58.33) | 2 (16.67) | 1 (8.33) | 2 (16.67) |
| Baseline self-efficacy score | | | | | |
| Spokesperson, mean score of 100 (SD) | 90.28 (10.37) | 91.37 (11.47) | 89.28 (9.66) | 90.07 (11.27) | 90.43 (9.15) |

[a]Race category ''Other'' includes individuals self-identifying as American Indian/Alaska Native, Asian, Native Hawaiian or Other Pacific Islander, and/or Other.

ACP, advance care planning; AD, advance directive.

required. Spokespersons' comfort level had a clear relationship with their perceived level of preparedness. *Very Prepared* spokespersons described uncertainty as inevitable and seemed to accept that it was inherent to the process of surrogate decision making (Table 3, subtheme 2A.i). Those in the *In Between* and *Very Unprepared* groups expressed considerably more concern about uncertainty, particularly as it related to wanting more details and situational information regarding patients' end-of-life wishes (Table 3, subtheme 2A.ii).

**Theme 3: Spokespersons' relationships with their seriously ill loved one, their other family members, and/or the medical team influence their perceived preparedness.** Trust and mutual support emerged as being related to preparedness in several ways. First, among *Very Prepared* spokespersons, expressing a sense of duty to their loved one was related to having been entrusted to make end-of-life decisions, which they said made them feel they ''had to be'' prepared to make decisions (Table 3, subtheme 3A.i).

Table 2. Relationships between Perceived Preparedness and Whether Dyads Had Advance Care Planning Conversations Four Weeks after Advance Care Planning Intervention ($N$= 198)

| | *Feels very prepared,* n *(column %)* | *Feels very unprepared OR feels in between prepared and unprepared,* n *(column %)* | *Total,* N *(column %)* |
|---|---|---|---|
| Had ACP conversation | 108 (75.00) | 39 (72.22) | 147 (74.24) |
| Did not have ACP conversation | 35 (24.31) | 15 (27.78) | 50 (25.25) |
| Unclear if had ACP conversation | 1 (0.69) | N/A | 1 (0.51) |
| Total, *N* (row %) | 144 (72.72) | 54 (27.27) | 198 (100.00) |

Strong relationships with family and clinicians also emerged as contributing to a spokesperson's sense of being *Very Prepared*—with spokespersons noting that support from these relationships would likely help them better understand end-of-life scenarios, as well as guide their surrogate decisions (Table 3, subtheme 3B.i).

By contrast, spokespersons who anticipated conflict when difficult end-of-life decisions would need to be made noted mistrust of clinicians or family members, and reported feeling *Very Unprepared* or *In Between Prepared and Unprepared* to make end-of-life decisions (Table 3, subtheme 3B.ii).

**Theme 4: Spokespersons' perceived preparedness is shaped by personal characteristics (e.g., self-described personal tendencies) and/or personal experiences with surrogate decision making.** When asked to describe reasons they felt more or less prepared to make end-of-life care decisions for their loved ones, spokespersons often pointed to personal characteristics or past experiences (Table 3, subthemes 4A and 4B). This included both personal tendencies such as being bold (vs. timid) or decisive (vs. indecisive), as well as the tone or outcome of prior decision making experiences.

### *Spokespersons intended process for surrogate decision making*

Thematic analysis of the interviews revealed that spokespersons had a variety of ideas regarding how to go about making decisions for their loved ones should the need arise. In order of most to least common, these themes are as follows (see Table 4 for exemplar quotations for each theme).

**Theme 1: Spokespersons intend to draw upon existing knowledge of patient wishes.** Spokespersons most commonly described wanting to respect their loved one's autonomy, and they intended to do so by making surrogate decisions that relied on their knowledge of their loved one's wishes. Spokespersons who reported having a strong understanding of their loved one's wishes expressed that such knowledge was both empowering and comforting.

**Theme 2: Spokespersons intend to involve family, friends, and/or medical staff to aid in the decision making process.** Most spokespersons reported they would involve others in the surrogate decision making process, and that doing so would provide reassurance and comfort, and lessen their own sense of burden. That said, some spokespersons regarded others' involvement with apprehension, notably because they anticipated conflict between their loved one's stated wishes and either the family members' or medical staff's preferences. Despite this, however, these spokespersons often felt obligated to involve other family members in the surrogate decision making process.

**Theme 3: Spokespersons intend to incorporate personal judgments based on their history and/or relationship with their loved one.** Although acknowledging the uncertainty regarding how their loved one's end-of-life care would unfold, many spokespersons discussed how they would draw upon their knowledge of that person's beliefs and values, and how their loved one lived their life, to discern what should or should not be done in a given situation.

**Theme 4: Spokespersons intend to use guidance from religious or faith-based beliefs and teachings.** Many spokespersons noted the importance of faith-based beliefs for making end-of-life decisions, noting that these beliefs would likely influence their surrogate decision making process.

**Theme 5: Emotions can overpower rational decision making.** This theme was woven throughout the above four themes in that as spokespersons discussed their decision making processes; many noted that they anticipated that their own emotions would inevitably play a major role in their surrogate decision making, possibly to the point that such emotions might overpower efforts to engage in rational or logical thinking. Of interest, however, spokespersons who reported prior experience with ACP expressed considerably more confidence that they would be able to set aside their emotions to carry out the tasks and make the decisions that would be needed.

### *Arm comparisons*

Table 5 provides the RCT arm comparison results using the transformed data. Comparisons of transformed data by study arm revealed no significant differences in perceived preparedness based on either the type of ACP intervention, or whether ACP was completed alone or together. However, those who used the *Decision Aid* were more likely to have engaged in ACP conversations after the initial study visit than those who completed *Standard ACP*.

## Discussion

The results of this study show that while the vast majority of spokespersons perceived themselves to be *Very Prepared*, such self-perceptions were not related to the type of ACP

Table 3. Qualitative Themes, Subthemes, and Quotations Related to Perceived Preparedness Organized by Transformed Category

| | *Very prepared* | | *In between or very unprepared* | |
|---|---|---|---|---|
| *Theme* | *Subtheme* | *Quote* | *Subtheme* | *Quote* |
| 1. Spokespersons' perceived preparedness is influenced by their experiences during ACP conversations | 1A.i. Conversations increased knowledge or confidence because it reinforced what they already knew or clarified specific elements they were not sure of previously | "Absolutely, [the conversations] helped, because there were some things that I just never even thought to ask myself. And it makes me more comfortable to know the type of things I may be faced with." "[The conversations helped] because they clarified some fine points even though we've had these discussions before" | 1A.ii. Conversations introduced uncertainty or confusion ("surprise") | "[The conversations] made me realize how unprepared I was and how I need to be a little more mindful of this because I realize she does have health conditions that could lead to some of these things. So, I just need to continue daily to try and wrap my mind around it and I don't know in the situation what I am going to do." "I was surprised at one or two of the things that she had put on the advance directive, like that she didn't want a feeding tube. Which surprised me because it just seemed like that was a 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.' So that surprised me, I'll be quite honest it did. And we have to kinda go through that in a lot more detail" |
| | 1B.i. Conversations not necessary because knows patient well | "I think because I've always been [very prepared]. I've been in this role with [loved one] from the beginning" | 1B.ii. Conversations led to concern for conflict or that loved one does not fully understand their condition or circumstances | "…some of the answers kind of disturbed me a little bit. And he said, 'what do you mean?' and I said, 'well I mean I just don't understand why you would want [to be] revived in all these circumstances where your quality of life would be terrible or you'd be in a lot of pain…I feel like it sort of puts me in a kind of bad place because I don't know that in these scenarios, if he gets to that point, that I would want to agree with his wishes…I was really very surprised and upset by his answers…I think it helped me realize his lack of reality. Like I really didn't think he was very grounded, and I think he's even less grounded than I thought" |
| | 1C.i. Conversations revealed change in patient wishes | "She used to say she did not want resuscitation, but she has changed her mind. And she said she didn't want a feeding tube, colostomy bag…but she has changed her mind… the reasoning is she wants to live" | 1C.ii. Conversations revealed a disconnect between loved one's wishes and spokespersons' understanding of wishes | "I always assumed he wanted dialysis, but when we [completed the ACP intervention] I gathered that he either changed his mind about dialysis, maybe because he has cancer. I am a little unsure [now]" |

(*continued*)

Table 3. (Continued)

| Theme | *Very prepared* | | *In between or very unprepared* | |
|---|---|---|---|---|
| | *Subtheme* | *Quote* | *Subtheme* | *Quote* |
| | 1D.i. Conversations not upsetting or uncomfortable | "I'm very comfortable with the kind of conversations that we need to have" | 1D.ii. Conversations are upsetting or uncomfortable | "If I think about it, I'm going to get stressed out. I won't be able to work…I got responsibilities, I got a house, I got girls and I got a wife I got to take care of" |
| 2. Spokespersons' perceived preparedness is shaped by their comfort with uncertainty | 2A.i. Comfort with not knowing all specifics or nuances of potential end-of-life scenarios and how they may impact patient's preferences | "There's probably wild card scenarios I'm not prepared for, but I think common sense and knowing her directives or wishes, I could probably figure out what she wants. But I mean, I would never say I'm totally prepared because [laughing] I don't think you could be totally prepared for everything." "I think I have a fairly good understanding. I mean I think you can never be fully prepared because life throws all kinds of curveballs at you" | 2A.ii. Discomfort with uncertainty; preference for knowing situational specifics | "It's not as black and white … I don't want this or I don't want that…I would have to ask the doctor more when I'm making that decision…I'd have to get a little clearer in my mind to be able to [make decisions] according to [patient's] wishes" |
| 3. Spokespersons' relationships with their seriously ill loved one, their other family members, and/or the medical team influence their perceived preparedness | 3A.i. Being entrusted to assure loved ones' wishes are carried out contributes to feeling prepared (i.e., sense of duty) | "I'll stand up to anybody and say, 'No, this is what she wants.' She's the important one here." "I want to do what it is that she wants…if I could be a vessel to make that happen…that's where I am." "I just have to, so to speak, tie my shoelaces, tighten my belt, and do what I have to do as a father and a husband for my kids and wife" | 3A.ii. Mistrust of medical team or anticipating conflict with medical team or conflicting information from medical team | "Sometimes the doctors don't respect you, either, when your family seems to me like they should have the most say. You come in with your papers. Is it [the Advance Directive] going to hold up? That's my concern." "[After patient's last admission] now I know that it doesn't really matter what you know about your husband's choices…if the information conflicts. You don't know what you're working with. So while I could say in this situation, he would want this, one physician is saying, "oh this is all gonna get better," and another is saying, "don't know anything put him right in hospice." What are you supposed to do? So a little real life experience made me decrease my confidence in the ability to carry out his wishes" |
| | 3B.i. Supportive family members will relieve some of the burden | "Ultimately the decision isn't just up to me. There will be input from others in his family" | 3B.ii. Anticipating conflict among family | "It would be a fight between her family trying to hold on and me saying, 'well, that's not exactly what she wanted'" |

(*continued*)

Table 3. (Continued)

| | *Very prepared* | | *In between or very unprepared* | |
|---|---|---|---|---|
| *Theme* | *Subtheme* | *Quote* | *Subtheme* | *Quote* |
| 4. Spokespersons' perceived preparedness is shaped by personal characteristics (e.g., personal tendencies) and/or personal experiences with surrogate decision making | 4A.i. Personal tendencies influence perceived ability to make surrogate decisions | "I've had no problem at all making decisions for [loved one]. If she was at the point where she couldn't really understand or was unconscious I'm bold enough" | 4A.ii. Personal tendencies influence attitude toward need for ACP conversations | "I'm non-confrontational. I don't really deal with things that I can't affect or change. I just kind of brush them off and don't think about them, and I'm really more of an optimistic person so she's got kidney failure and I'm like, 'well you know, it'll be alright'' |
| | 4B.i. Past experiences increased their confidence for surrogate decision making | "I had that experience…[my girlfriend] had cancer. She and I talked real clear…she didn't want to suffer through cancer treatment again and it had metastasized anyhow. It was a good experience for me. I saw it play out, so I see it can work" | 4B.ii. Past experiences or experiences of others increased their awareness of how difficult surrogate decision making is | "I think I faced the issues previously with other family members and observed friends [facing these issues] and it's not an easy one, so although I thought about it and I do think I know his wishes I would hope that I could do what he would want" |

Quotes have been minimally edited for brevity or clarity.

Table 4. Themes Related to Spokespersons' Intended Process for Future Surrogate Decision Making

| *Theme* | *Quote* |
|---|---|
| 1. Spokespersons intend to draw upon existing knowledge of patient wishes | ''I have everything that he wants on paper, so in that situation, I can, in theory, remove myself from the emotional side of it and just say…this is what he would have wanted, and just do that'' |
| | ''[The ACP conversations] made me feel like I could defend choices to other members of the family, particularly his daughters who are always the hardest ones'' |
| 2. Spokespersons intend to involve family, friends, and/or medical staff to aid in the decision making process | ''Before the study, I basically already knew what she wants so it pretty much just helped me understand that I don't have to know by myself what she wants. Like the doctor is also included and can help me understand, OK, based on what she wants, whatever goes down, if he says, ''this is what it is,'' then we can kind of know what she wants then'' |
| 3. Spokespersons intend to incorporate personal judgments based on their history and/or relationship with their loved one | ''Because, the way I feel about her and, and as much as we been together…I know what's best for her. And I wouldn't want her to suffer, and I'd want her to be as comfortable as possible, without pain and not suffer.'' |
| | ''Well [if my wife] had to go on a machine, she wouldn't want to. But for me, I would try anything to prolong her life. I wouldn't just want to see her deteriorate, not wanting to do it, not wanting to get the help she actually needs every time''' |
| 4. Spokespersons intend to use guidance from religious or faith-based beliefs and teachings | ''We still have to keep in mind the Catholic teaching of keeping the person comfortable and not doing anything that would terminate their life more quickly'' |
| 5. Emotions can overpower rational decision making | ''I think that it's hard because I feel like any kind of medical decisions are intensely personal and not always logical. The decision that you have to make is sometimes a combination of emotional and logical'' |

Table 5. Arm Comparisons Using Transformed Qualitative Data

*Comparisons using 2×2 factorial design*

| | *Standard ACP alone* (n=*49*), n *(%)* | *Standard ACP together* (n=*51*), n *(%)* | *Decision aid alone* (n=*49*), n *(%)* | *Decision aid together* (n=*49*), n *(%)* | *Total,* N *(%)* | p |
|---|---|---|---|---|---|---|
| Very prepared | 35 (71.40) | 38 (74.50) | 32 (65.30) | 39 (79.60) | 144 (72.70) | 0.210 |
| In between | 12 (24.50) | 12 (23.50) | 17 (34.70) | 7 (14.30) | 48 (24.20) | |
| Very unprepared | 2 (4.10) | 1 (2.00) | 0 (0.00) | 3 (6.10) | 6 (3.00) | |
| Had ACP conversations | 29 (59.20) | 36 (72.00) | 40 (81.60) | 42 (85.70) | 147 (74.60) | 0.013[a] |
| Did not have ACP conversations | 20 (40.80) | 14 (28.00) | 9 (18.40) | 7 (14.30) | 50 (25.40) | |

*Comparisons by ACP interventional type*

| | *Standard ACP* (n=*100*), n *(%)* | *Decision aid* (n=*98*), n *(%)* | *Total*, N | p |
|---|---|---|---|---|
| Very prepared | 73 (73.00) | 71 (72.50) | 144 (72.70) | >0.99 |
| In between | 24.0 (24.00) | 24 (24.50) | 48 (24.20) | |
| Very unprepared | 3 (3.00) | 3 (3.10) | 6 (3.00) | |
| Had ACP conversations | 65 (65.70) | 82 (83.70) | 147 (74.60) | 0.004[a] |
| Did not have ACP conversations | 34 (34.30) | 16 (16.30) | 50 (23.40) | |

*Comparisons by completion of ACP alone vs. together*

| | *Alone* (n=*98*), n *(%)* | *Together* (n=*99*), n *(%)* | *Total,* N *(%)* | p |
|---|---|---|---|---|
| Very prepared | 67 (68.40) | 77 (77.00) | 144 (72.70) | 0.174 |
| In between | 29 (29.60) | 19 (19.00) | 48 (24.2) | |
| Very unprepared | 2 (2.00) | 4 (4.00) | 6 (3.0) | |
| Had ACP conversations | 69 (70.40) | 78 (78.80) | 82 (83.7) | 0.177 |
| Did not have ACP conversations | 29 (29.60) | 21 (21.20) | 16 (16.3) | |

[a]Statistical significance level, $p < 0.05$.

intervention, whether the ACP was completed together or by the patient alone, or whether ACP conversations occurred after ACP. This is surprising because the central goals of ACP are to promote understanding and communication, with the expectation that better and more informed communication would result in better prepared spokespersons. Contrary to our initial hypothesis, detailed multimedia education about ACP and decision making did not increase spokespersons' sense of preparedness, nor did having spokespersons engage in ACP with their loved ones. Rather, this analysis revealed that perceived preparedness may have more to do with spokespersons' comfort with uncertainty, previous experiences, personal tendencies, and the existence of trusting, supportive relationships with loved ones and clinicians.

We also found that participants in the *Decision Aid* group were more likely to engage in subsequent ACP conversations than those who completed Standard ACP, whereas those who completed ACP alone were no more likely to engage in conversations than those who completed ACP together. That the *Decision Aid* was associated with increased ACP conversations is an encouraging finding; yet the lack of effect of ACP conversations on improving spokespersons' perceived preparedness warrants investigation into how ACP conversations lead to changes in preparedness.

Our findings have implications for how to design and implement ACP interventions. Specifically, they remind us that even a validated ACP intervention such as *Making Your Wishes Known*, which has been shown to be effective with patients and clinicians,[23–26] may fall short as a tool for addressing the needs of family caregivers who serve as spokespersons. The results reinforce the importance of integrating family members' views into the development of ACP interventions, and suggest that the ACP process may benefit from helping spokespersons better understand their role. This can be accomplished, in part, by having family members call upon their past experiences with loved ones when making surrogate decisions, identifying people and relationships that can provide support, and leveraging other members of the care team such as social workers, chaplains, or psychologists to manage clinician and/or family conflict associated with surrogate decision making. In addition, given the role that religious and faith-based beliefs play in guiding spokespersons through their surrogate decision making, finding meaningful ways to incorporate and leverage existing and trusted social/spiritual networks may help to extend ACP interventions into a community setting. In fact, there is strong evidence that using a community-based delivery model that includes places of worship is an effective means for engaging individuals, including underserved minority populations, in ACP.[29]

Furthermore, our data suggest that personal tendencies can affect the ACP process and it is plausible that these tendencies may be related to ACP effectiveness. Although we were limited in our ability to further explore the personal tendencies that spokespersons often referred to in interviews and whether they may represent personality traits, cognitive sets, or other self-perceived attributes, future research should consider investigating the role of such concepts in end-of-life surrogate decision making and incorporating such assessments into ACP intervention trials.[30] Moreover, our findings related to uncertainty suggest that spokespersons may have varying levels of tolerance for uncertainty that may affect their ability to feel prepared for surrogate decision making. Psychological research on the concept of intolerance of uncertainty has demonstrated its relationship with personality traits.[31–33] Although some evidence suggests certain aspects of personality, such as high levels of neuroticism, conscientiousness, and openness, are associated with engagement in ACP,[34,35] less is known about how these traits may impact the efficacy of ACP interventions for spokespersons. It is possible that uncertainty around the specific end-of-life circumstances under which decisions will need to be made could affect feelings of preparedness and negate some or all impact of an ACP intervention intended to increase preparedness.

Few studies have examined how spokespersons intend to make surrogate decisions after ACP interventions. We found that whereas most spokespersons indicated an intent to draw upon their knowledge of patient's preferences to respect their loved one's wishes, other factors clearly influenced how spokespersons intended to make surrogate decisions. By acknowledging the role of personal judgments and opinions, emotions, involvement of others, and religious beliefs, future ACP interventions might help spokespersons feel (and be) better prepared to make surrogate decisions. It is important to note that, although many spokespersons stated that they intended to set their emotions aside and use the knowledge of their loved ones wishes to make surrogate decisions, much of the current literature on the role of emotion in decision making suggests that emotions play a large role in decision making.[36,37] The role of emotions in surrogate decision making is being further explored as data are being collected during the third study visit (which takes place after a spokesperson has made a decision). Some literature also suggests that having clear goals or intentions for how decisions will be made could help prepare caregivers to serve as spokespersons.[38] If true, examining the intentions of spokespersons and helping them to set goals for their decisions may increase self-efficacy for future surrogate decision making.

Like all studies, this study has a number of limitations. First, the interviews were conducted four weeks after an ACP intervention, but before an actual decision was made. Thus, spokespersons responses are based on their self-assessed level of preparedness, not their actual level of preparedness after having made a surrogate decision. In ongoing work, we are continuing to follow spokespersons until actual decision making occurs, and those data will be presented when that aspect of the project has been completed. Second, because our data involve self-report, they are subject to social desirability and recall biases. Third, because the focus of the parent trial was on spokespersons' experiences, we did not assess patients' perceptions of ACP, illness understanding, or preparedness. Fourth, as a secondary analysis, the trial was not designed to determine causality with regard to the current findings, so readers should use caution about drawing conclusions regarding the relationships that we describe. Finally, although this analysis focused on differences in preparedness related to interventional arm assignment, there are several other variables that may influence spokespersons preparedness including gender, prior experiences with ACP, rural versus urban status, relationship between spokesperson and patient, disease entity, and others.

Despite these limitations, the study has important strengths. It is a large longitudinal study using qualitative methods. This allowed for a rich, contextual understanding of

spokespersons' sense of preparedness, and by means of data transformation we were able to examine differences among arms. To our knowledge, this approach is novel in the field of ACP, and could be of value in other research trials that seek to include a nuanced contextualization that can be compared across study arms. Our study's novel methodology, data transformation, allowed for a thematic analysis and statistical comparison of spokespersons with varying perceptions of their preparedness for surrogate decision making. In addition, the majority of literature examining effects of ACP focuses on patient outcomes, with the few studies that do focus on spokespersons examining postmortem outcomes such as their satisfaction with end-of-life care.[39] As a result, our study provides important insight into how ACP may be used to prevent the negative sequelae that can follow surrogate decision making and to improve patient end-of-life outcomes.

In addition, we analyzed large amounts of qualitative data (198 participants) from multiple sites, and doing so enhances generalizability of our findings.

In conclusion, if future ACP interventions are to better prepare spokespersons for surrogate decision making, such interventions should incorporate factors such as surrogate comfort with uncertainty, personal tendencies, and relational issues, as these factors are relevant to the ACP planning process.

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Two authors, B.H.L. and M.G., are the co-creators of the decision aid, *Making Your Wishes Known,* which was developed for research purposes and continues to be available free of charge. A commercial version of this decision aid called *My Living Voice* is owned by Vital Decisions, and Drs. Green and Levi have financial interest in its success through a consulting arrangement with Vital Decisions. Any research involving *Making Your Wishes Known* or *My Living Voice* is carefully monitored by Penn State's Institutional Review Board and Conflict of Interest Review Committee.

### Supplementary Material

Supplementary Method S1
Supplementary Method S2
Supplementary Method S3
Supplementary Figure S1
Supplementary Table S1

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