HHS Public Access

Author manuscript

J Am Geriatr Soc. Author manuscript; available in PMC 2018 January 01.

Published in final edited form as:

J Am Geriatr Soc. 2017 January ; 65(1): 172–178. doi:10.1111/jgs.14497.

A Dyadic Perspective on Engagement in Advance Care Planning

Terri Fried, MD^{1,2}, Maria Zenoni, MS¹, and Lynne Iannone, MS³

¹ Clinical Epidemiology Research Center, VA Connecticut Healthcare System

² Department of Medicine, Yale School of Medicine

³ Program on Aging, Yale School of Medicine

Corresponding author: Terri R. Fried, M.D., CERC 151B, VA Connecticut Healthcare System, 950 Campbell Avenue, West Haven, CT 06516, Tel: (203) 932-5711 x5412, Fax: (203) 937-4932, terri.fried@yale.edu.

Conflict of Interest Checklist

Elements of Financial/Personal Conflicts	TRF		MZ		LI	
	Yes	No	Yes	No	Yes	No
Employment or Affiliation		X		X		X
Grants/Funds		X		X		X
Honoraria		X		X		X
Speaker Forum		X		X		X
Consultant		X		X		X
Stocks		X		X		X
Royalties		X		X		X
Expert Testimony		X		X		X
Board Member		X		X		X
Patents		X		X		X
Personal Relationship		X		X		X

Author Contributions: Study concept and design: Fried. Acquisition of subjects and data: Zenoni, Iannone. Analysis and interpretation of data: Fried, Zenoni, Iannone. Preparation of manuscript: Fried, Zenoni, Iannone

Abstract

Objectives—To understand the perspectives of both patients and the person who would make medical decisions for them if they were unable (surrogates) on their participation in advance care planning (ACP).

Design—Qualitative cross-sectional study.

Setting—Community

Participants—Thirty-one Veterans age 55 years and older and their surrogates.

Measurements—In interviews conducted with both the Veteran and surrogate, they were asked to discuss their participation in four ACP activities: communication about life-sustaining treatment, communication about views on quality of life, completion of a living will, and appointment of a health care proxy. They were asked about barriers to and facilitators of ACP engagement. When they did not agree about engagement, they each provided their perspective on what they believed had or had not occurred.

Results—Many of the same barriers to and facilitators of engagement were discussed by both patients and surrogates. These included difficulty thinking about dying, differences in values, and experiences with others that demonstrated the ability of ACP to decrease burden or avoid conflict. Reasons for disagreements in perceptions about whether communication had occurred included surrogates' need for more detailed information, surrogates' lack of readiness to hear what the patient was saying, and surrogates' reliance on what they know about the patient. For some dyads, participation in the study prompted additional communication, resulting in a better shared understanding of ACP engagement.

Conclusion—Surrogates can both impede and facilitate engagement in ACP, and they can hold different perceptions from patients regarding this engagement. Efforts to promote ACP may be most successful if they assess and address both patients' and surrogates' attitudes and help to facilitate clear communication between them.

Keywords

advance care planning; communication; surrogates

INTRODUCTION

Advance care planning (ACP) is the process by which patients can prepare for how medical decisions will be made in the future at a time of decisional incapacity. ACP, originally conceived as an individual activity, in which the patient documented wishes for future care, is becoming increasingly recognized as a dyadic activity based on clear communication.¹⁻³ One dyad is that of the patient-clinician, with end-of-life discussions within the dyad associated with improved patient and caregiver outcomes,⁴ and a second is that of the patient and surrogate. Surrogate decision makers are frequently called upon to make treatment decisions at the end-of-life, which can be highly stressful^{5,6} and result in adverse psychological outcomes.⁷ Even prior to the end-of-life, surrogates' desire for greater

communication with patients who have advanced illness is associated with increased caregiver burden.⁸

Surrogates' knowledge of patients' preferences and goals can decrease the stress of surrogate decision-making;^{5,6,9} however, a systematic review concluded that surrogates are frequently unaware of these preferences.¹⁰ Participation of patients and their surrogates in ACP has been shown to improve this knowledge.¹¹⁻¹³ While the barriers and facilitators to individuals' engagement in ACP have been characterized,¹⁴⁻¹⁶ much less is known about how patient-surrogate dyads engage in ACP. One prior study demonstrated that, in addition to dyads who agreed that they had not participated in ACP, a sizeable proportion of dyads disagreed about their participation.¹⁷ Such disagreement suggests that dyadic engagement in ACP is a complicated process, with barriers not only to ACP engagement but also to achieving a shared understanding of whether ACP has been completed.

The purpose of this study was to understand participation in ACP as a dyadic process. Using qualitative methods to allow concepts to arise from the data, the study engaged dyads in open-ended interviews. These interviews explored the perspectives of both patients and their surrogates on why they had or had not participated in ACP and, when there was disagreement about participation, the reasons for this disagreement.

METHODS

Participants

Participants were selected from a larger cohort of participants in a quantitative study examining the relationship between participation in ACP and understanding of patients' treatment goals. Potential participants in the larger study were randomly selected from a list of community-living Veterans age 55 years and older receiving primary care within the VA Connecticut Healthcare System with an appointment in the prior twelve months. The list was stratified by gender and ethnicity, which permitted oversampling of women and minorities. Veterans with no exclusion criteria according to chart review for whom permission was granted by their physician for further contact received an opt-out letter and then a telephone call for further screening. Exclusion criteria included: 1) primary language other than English; 2) absence of a potential surrogate; 3) cognitive impairment; 4) active symptoms of mental illness; 5) recent or current severe illness; 6) severely hard of hearing; 7) no telephone and/or address. The Veterans provided contact information for the person they identified as the individual they would want to be their health care surrogate decision maker.

Of 1712 Veterans meeting eligibility criteria, 601 were ineligible by chart review and 26 had physicians who declined to give permission. Of the remaining 1085, 123 were unreachable, and 481 refused the telephone screen. The 442 completed telephone screens revealed an additional 83 ineligible Veterans. Of the 359 eligible Veterans, 6 surrogates refused to do the interview and 3 Veterans became acutely ill, leaving 350 Veterans and their surrogates each completing a separate closed-ended interview assessing their participation in four ACP activities: two communication activities (communication with loved one regarding the use of life-sustaining treatment, communication with loved one regarding valuation of quantity versus quality of life) and two procedural activities (formal appointment of a health care

surrogate decision maker, and completion of a living will). The Veteran was asked about participation on his/her own behalf and the surrogate about participation on behalf of the Veteran. Participants were asked about the acceptability of different health states resulting from treatment of serious illness. Veterans asked about whether they believed the states were acceptable and surrogates asked what they believed the Veteran would say. Participants were also asked about sociodemographic and health status.

From this larger cohort, dyads for the current study were identified using purposive sampling to participate in a second interview (described below). Dyads were selected according to gender, ethnicity, relationship between Veteran and surrogate, such that there were at least 5 dyads representing each category within those characteristics. Dyads were also selected so that there were at least 10 who disagreed about engagement in each ACP activity. The study was approved by the Human Subject Subcommittee of VA Connecticut Healthcare System and the Human Subjects Committee of the Yale School of Medicine.

Data collection

Veterans and their surrogates underwent a dyadic telephone interview conducted with a discussion guide. The Veteran, surrogate, and interviewer were all on the same telephone line, so that they could hear the questions and responses of the others. The interview occurred within one week of the closed-ended interviews. For each ACP activity, the interviewer began with a review of the participants' responses to the closed-ended questions of whether they had engaged in the activity. They were asked whether they still agreed with these responses. Participants who changed their minds were asked what led to the change. The next set of questions was determined by the agreement or disagreement between the members of the dyad regarding engagement in each ACP activity. Participants who agreed they had engaged or agreed they had not engaged were asked about barriers and facilitators to engagement. Participants who disagreed about whether they had engaged were each asked to describe their perception of whether they had engaged, and the other was asked to respond. Interviews were audiotaped and transcribed by an experienced medical transcriptionist.

Data Analysis

Using the constant comparative method and grounded theory, analysis occurred simultaneously with data collection, which allowed the discussion guide to be modified in order to explore concepts arising in earlier interviews in greater depth. Participants were enrolled until theoretical saturation was reached. Transcripts were independently coded into small segments by two of the investigators (TRF and MZ), who jointly created a coding structure and met regularly to compare coding and resolve discrepancies. Once the investigators reached >80% agreement on application of the structure, a single investigator (MZ) coded the remaining interviews, with the two investigators meeting to discuss any new codes as they arose. The investigators then compared codes within and across interviews to identify the larger themes that emerged.

RESULTS

A total of 31 Veteran-surrogate dyads participated in the open-ended interview. Approximately one-third of Veterans were age 55-59 and one-third were age 70 or older. Whereas one-third of Veterans were women, three-quarters of surrogates were women, and approximately one-quarter of both were non-White. The majority (52%) of surrogates was spouses or partners; an additional 29% were children, and the remaining had a variety of other relationships to the Veteran. Additional sociodemographic and health characteristics are presented in Table 1. Disagreement about whether engagement in ACP ranged from 33% for communication about quality of life to 48% for appointment of a healthcare surrogate (Table 1).

Barriers to and facilitators of ACP engagement

Table 2 provides a description of the barriers and facilitators to engagement in ACP along with representative quotations. One of the barriers, believing that ACP was not relevant, was brought up only by a Veteran, and another barrier, having a difference in values, was brought up only by a surrogate. All of the other barriers and facilitators were discussed by both Veteran and surrogate. Some directly involved the interaction of both, such as difficulty in coordinating schedules. Others reflected mutual interests of Veterans and surrogates in ACP, such as the Veteran believing that ACP would help ensure that his/her wishes were followed and surrogate believing that ACP would help him/her honor the Veteran's wishes. The most frequently discussed facilitator of ACP was direct experience with others, either by the Veteran or by the surrogate. These experiences provided illustrations of the benefits of ACP. For example, having been the potential surrogate for her mother led a Veteran to engage in ACP to spare placing burden on her children: "I could see she was not going to be here too long and we would have to say shut the machines off. I didn't want to have to do that. She made a decision for us. I was glad I didn't have to make that decision. I have 2 children and I don't want them to have to make that decision should something happen to me."

Notably, Veterans and their surrogates sometimes made assumptions about barriers held by the other that were not in fact present. For example, one surrogate expressed concern that engaging in ACP was too upsetting for her husband: "Thinking about a living will causes him to be a little bit down every day; I think that word is a little bit depressed." Her husband recognized that this concern resulted in his wife's avoidance of discussion of end-of-life issues: "She doesn't like to discuss those sorts of things because she's afraid that I will get depressed about it." However, when asked to reflect on what he himself thought about engaging in ACP, he responded, "With a living will, once it's completed, I really won't think any more about it, so it's not really an issue to put me into a depression. With the things that have happened in my family in recent years, I feel like it's a good thing to know ahead of time what needs to be done. Once the paperwork is done, I don't think that it will be an issue for me after that."

Disagreement about engagement in ACP

Table 3 presents the reasons for disagreement about engagement in ACP. Despite excluding participants with cognitive impairment, both Veterans and surrogates sometimes failed to

remember engaging in both the procedural and communication ACP activities. In other instances, they had misinformation about procedural aspects. Disagreement about whether communication had occurred also resulted from how discussions were interpreted by each individual in the dyad. When Veterans described the conversations they thought had occurred, but surrogates did not agree, the surrogates most frequently reported that the communication was inadequate because it lacked sufficient detail regarding Veterans' preferences and values. In one dyad, the surrogate acknowledged he had not heard what the Veteran had said because he was not ready to engage in a conversation about end-of-life issues. When surrogates described the conversations they believed had occurred but the Veteran did not agree, most often the surrogates acknowledged that the conversations were general, but they felt they nonetheless knew the Veteran well enough to be sure of their preferences and values. In several instances, the interview revealed that this was the case. However, for one dyad, the surrogate was surprised that the Veteran's preferences were not what the surrogate had assumed.

Engagement in ACP as a result of study participation

In some instances, participants changed their reports of whether they had engaged in ACP as compared to the responses they gave in the closed-ended interviews. This resulted from further conversation between Veterans and surrogates between the two interviews. Participants described being prompted by the study to take action. One Veteran reported, "I never really thought about [talking to my surrogate] until you guys contacted me about it." Both Veterans and surrogates specifically mentioned the questions they had been asked about the acceptability of different health states prompting communication. One surrogate described talking to the Veteran because, "my answers did not agree with hers on some of the things that were mentioned in the questionnaire.... I think we went into it with more detail this time. Whereas before, I kind of had an overview but I did not know specifically what she wanted."

DISCUSSION

Optimal ACP requires engagement of not only patients but also the individual they identify as their surrogate decision maker. This study examined advance care planning as a dyadic activity by conducting joint interviews with both Veterans and their surrogates. These interviews explored the barriers, facilitators, and reasons for disagreement about ACP engagement from the perspectives of each member of the dyad. The findings of the study illustrate the importance of the surrogate in the process of ACP. While several of the barriers and facilitators were specific to the patient, many others either directly involved interactions between patient and surrogate or highlighted the ways in which the surrogate can influence ACP engagement. When disagreement about engagement in the procedural aspects of ACP occurred, there were both circumstances in which the patient had the correct information and circumstances in which the surrogate had the correct information. Reasons for disagreements in perceptions about whether communication had occurred included surrogates' need for more detailed information, surrogates' lack of readiness to hear what the patient was saying, and surrogates' reliance on what they know about the patient. Dyads

participated in separate closed-ended interviews about ACP prior to the open-ended interview, and, for some, this was a prompt to have further ACP discussions.

The findings of this study both confirm and expand our understanding of the factors that encourage and dissuade patients from engaging in ACP. Prior studies have also found that difficulty thinking about death and dying and believing that ACP is irrelevant are barriers to ACP for patients and that the desire to reduce burden on loved ones, have one's wishes followed and avoid unwanted health states are patient facilitators.^{14,15,18} The current study demonstrates that surrogates express similar barriers to and facilitators of engagement in ACP on behalf of the patient. Prior studies have also described concerns from the patient's perspective on the ability to communicate with their loved ones as a barrier to ACP engagement.^{14,15} In the current study, both patients and surrogates expressed concern that the other may not be ready and could even be harmed by engaging in ACP. However, by interviewing pairs of patients and surrogates, the study illustrated that these concerns were sometimes misconceived. The current study also demonstrated that, rather than serving as a catalyst for communication, the patient and surrogate having different values served as an additional barrier. These findings have implications for how clinicians can best help patients and surrogates to complete the different components of ACP, highlighting the need to understand the perspectives of each half of the dyad regarding both his/her own and the other's readiness for engagement. They suggest that efforts to enhance engagement in ACP may be most effective if they assess and address individual barriers for both patients and surrogates as well as relationship barriers. Conversely, surrogates who perceive the benefits of ACP engagement may be enlisted to serve as advocates to encourage the patient. The finding that study participation prompted ACP engagement for some dyads suggests that, for patients and surrogates who are sufficiently prepared, simply involving the surrogate in the assessment of ACP engagement can serve as an intervention. The evidence of the importance of personal experiences with end-of-life decision-making as a motivator for engagement in ACP continues to grow,^{19,20} supporting a strategy of using discussion about these experiences as a starting point for those who have not yet engaged. The current study shows that these experiences can be not only ones had by the patient but also those of the surrogate.

The reasons for disagreement about ACP engagement included factual errors made by both patients and surrogates, resulting from problems with memory, incorrect assumptions, and failure to inform the other. For the components of ACP related to communication, disagreement also arose from differences in interpretation. Surrogates believed that communication had occurred when the patient did not because of what they felt they knew of the patient's values. They believed that communication had not occurred when the patient thought it had because of not being ready to hear what the patient had said and because of what they felt they did not know. The latter surrogates spoke of the need to understand how the patient valued the diminished states of health that could result either from illness or its treatment. For some dyads, having been asked specific questions about these health states in the closed-ended survey preceding the open-ended interview prompted additional communication. A number of observational studies have shown that having this information helps surrogates with the burden of decision-making,^{5,9,21} and an intervention to promote communication between patients and surrogates has been shown to improve surrogate

outcomes.¹¹ The current study further emphasizes that, even for patients who report engagement in the communication aspects of ACP, the quality of this communication may not be sufficient to meet the needs of their surrogates. Clinicians who are engaging their patients in ACP may want to provide them with both specific questions they can use for discussion with their surrogates and strong encouragement to have the conversation.

Because the study examined Veterans who had someone available to be a health care surrogate, its findings do not help to inform the challenges of ACP for individuals who do not have a potential surrogate. While sampling for this study was purposive in order to try to capture a diverse range of experiences, the participation rate in the parent study was modest, suggesting that the dyads in the current study may have been drawn from a population with limited generalizability. As a qualitative study, no conclusions can be made about the frequency of the phenomena presented. Additional quantitative research could both establish the frequency of the barriers and facilitators to ACP engagement elucidated in this study and the strength of association between these factors and actual completion of ACP.

This study of Veterans and their surrogates demonstrates the necessity of assessing engagement in ACP as a dyadic activity. Surrogates can both help and hinder efforts to promote ACP. When perspectives on ACP engagement are not shared, this can be evidence of misunderstanding, mismatched readiness to communicate, or a process of engagement that has failed to meet the needs of both members of the dyad.

ACKNOWLEDGMENTS

Funding Sources: VA HSRD IIR 12-117-2 and the Claude D. Pepper Older Americans Independence Center at Yale University School of Medicine (P30AG21342 National Institute on Aging).

Supported by: VA HSRD IIR 12-117-2 and the Claude D. Pepper Older Americans Independence Center at Yale University School of Medicine (P30AG21342 National Institute on Aging)

Sponsor's Role: The sponsor had no role in the design, methods, subject recruitment, data collections, analysis or preparation of paper.

This material is the result of work supported with resources and the use of facilities at the VA Connecticut Healthcare System. The contents do not represent the views of the U.S. Department of Veterans Affairs or the United States Government

REFERENCES

1. Briggs L. Shifting the focus of advance care planning: using an in-depth interview to build and strengthen relationships. *J Palliat Med.* 2004; 7:341–349. [PubMed: 15130215]
2. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Ann Intern Med.* 2010; 153:256–261. [PubMed: 20713793]
3. Schenker Y, White DB, Arnold RM. What should be the goal of advance care planning? *JAMA Intern Med.* 2014; 174:1093–1094. [PubMed: 24861458]
4. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA.* 2008; 300:1665–1673. [PubMed: 18840840]
5. Vig EK, Starks H, Taylor JS, et al. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med.* 2007; 22:1274–1279. [PubMed: 17619223]

6. Fried TR, O'Leary JR. Using the experiences of bereaved caregivers to inform patient- and caregiver-centered advance care planning. *J Gen Intern Med*. 2008; 23:1602–1607. [PubMed: 18665427]
7. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med*. 2005; 171:987–994. [PubMed: 15665319]
8. Fried TR, Bradley EH, O'Leary JR, et al. Unmet desire for caregiver-patient communication and increased caregiver burden. *J Am Geriatr Soc*. 2005; 53:59–65. [PubMed: 15667377]
9. Tilden VP, Tolle SW, Nelson CA, et al. Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nurs Res*. 2001; 50:105–115. [PubMed: 11302290]
10. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med*. 2006; 166:493–497. [PubMed: 16534034]
11. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010; 340:c1345. [PubMed: 20332506]
12. Kirchhoff KT, Hammes BJ, Kehl KA, et al. Effect of a disease-specific planning intervention on surrogate understanding of patient goals for future medical treatment. *J Am Geriatr Soc*. 2010; 58:1233–1240. [PubMed: 20649686]
13. Inoue M, Moorman SM. Does end-of-life planning help partners become better surrogates? *Gerontol*. 2015; 55:951–60.
14. Schickedanz AD, Schillinger D, Landefeld CS, et al. A clinical framework for improving the advance care planning process: start with patients' self-identified barriers. *J Am Geriatr Soc*. 2009; 57:31–39. [PubMed: 19170789]
15. Fried TR, Bullock K, Iannone L, et al. Understanding advance care planning as a process of health behavior change. *J Am Geriatr Soc*. 2009; 57:1547–1555. [PubMed: 19682120]
16. Johnson KS. What explains racial differences in the use of advance directives and attitudes toward hospice care? Racial differences in beliefs about end-of-life care. *J Am Geriatr Soc*. 2008; 56:1953–1958. [PubMed: 18771455]
17. Fried TR, Redding CA, Robbins ML, et al. Agreement between older persons and their surrogate decision-makers regarding participation in advance care planning. *J Am Geriatr Soc*. 2011; 59:1105–1109. [PubMed: 21649619]
18. Seymour J, Gott M, Bellamy G, et al. Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med*. 2004; 59:57–68. [PubMed: 15087143]
19. Amjad H, Towle V, Fried T. Association of experience with illness and end-of-life care with advance care planning in older adults. *J Am Geriatr Soc*. 2014; 62:1304–1309. [PubMed: 24934237]
20. Carr D, Khodyakov D. End-of-life health care planning among young-old adults: an assessment of psychosocial influences. *J Gerontol B Psychol Sci Soc Sci*. 2007; 62:S135–141. [PubMed: 17379683]
21. Abbott KH, Sago JG, Breen CM, et al. Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med*. 2001; 29:197–201. [PubMed: 11176185]

Table 1

Description of 31 Veteran/surrogate dyads

Characteristic	n	%
Veteran		
Age		
55-59	9	29
60-69	12	39
70+	10	32
Female sex	10	32
Hispanic race	3	10
Ethnicity		
White	23	74
Other	8	26
Education <=12 th grade	8	26
Self-rated health fair/poor	9	29
Surrogate		
Relation to Veteran		
Spouse/partner	15	52
Child	9	29
Other	6	19
Frequency of contact		
Daily	24	77
Weekly	3	10
Monthly	4	13
Age		
<50	6	19
50-59	15	48
60-69	10	33
Female sex	24	77
Hispanic race	4	13
Ethnicity		
White	24	77
Other	7	23
Education <=12 th grade	7	23
Self-rated health fair/poor	3	10
ACP engagement according to initial closed-ended interview		
Communication about quality of life		
Agree yes	13	41
Agree no	8	26
Disagree	10	33
Communication about life-sustaining treatment		

Characteristic	n	%
Veteran		
Agree yes	18	58
Agree no	1	3
Disagree	12	39
Appointment of healthcare surrogate		
Agree yes	5	16
Agree no	11	36
Disagree	15	48
Completion of living will		
Agree yes	6	19
Agree no	13	41
Disagree	12	39

Table 2

Barriers to and facilitators of participation in ACP

Barriers	Quotation(s) Veteran	Quotation(s) Surrogate
Coordinating schedules	<i>It is a logistic problem because of the number of hours that she (surrogate) works. I am usually asleep most nights by the time she gets back home.</i>	
Difference in values		<i>He (Veteran) can say his opinion, but my opinion about that is that being alive is a good quality of life. I don't put the quality of life at different levels.</i>
Difficult to think about dying	<i>It's just a subject that we are both uncomfortable thinking about.</i> <i>I am 70 so I never think about it because I plan on living a long, long time.</i>	<i>She (Veteran) mentioning it just got me all choked up to know that someday she will be gone.</i> <i>You don't want to have to deal with these things and you kind of just want to stick your head in the sand and think everything will just work itself out.</i>
Not relevant	<i>My health does not indicate that I am going to have any problems any time soon.</i>	
Inertia	<i>I have been procrastinating about it.</i>	<i>It is just procrastination.</i>
Facilitators		
Avoiding family conflict	<i>Just in case I could not speak for myself, it would eliminate any arguments that might arise.</i>	<i>Other family members might want something different.</i>
Avoiding unwanted health states	<i>There are conditions that I would not want to live in. Say if my life turned to be in such a dependent vegetative state, I would not want to survive that.</i>	<i>My husband (Veteran) always said, "No, I don't want to be revived if I can't get better ever again," and I said, "Neither would I," and that is how it started.</i>
Having wishes followed	<i>I want to make sure that my wishes are allowed through with when I am unable to do it myself.</i>	<i>Should the situation arise, I would certainly be aware of what she (Veteran) wanted done and how she wanted to be taken care of.</i>
Removing burden of both decision making and caregiving from loved ones	<i>I have a sister who has different religious beliefs than me and I would not want her to be put through the stress of thinking that I had not made my wishes clear.</i> <i>I am not going to be a burden and have someone watch me wither away.</i>	<i>I think we both need to be thinking about it because we only have one child. So, God forbid should anything happen to either one of us. I would not want to leave that burden for her.</i>
Recognition of aging and declining health	<i>[I discussed life support because of] my age and my health. I am a diabetic. I have heart problems. I have a pacemaker and they told me my heart really relies on the pacemaker, so if that should shut down, then that's it.</i>	<i>When I found out that my husband (Veteran) had a touch of COPD, ... that is when I talked to him about what would his decisions be if he could not breathe anymore.</i>
Experience with others	<i>Having gone through the death of my mother and father ... 13 years ago and seeing how my siblings responded differently than I did.</i> <i>I learned from experience just how difficult the decision making process could be.</i>	<i>Most recently my parents passed away in the last 5 years and they were both pretty sick and I know it came up as part of a conversation when we talked about them.</i>
In preparation for a procedure	<i>I did not know what was going to be the outcome, so I just wanted to be prepared in case something went wrong.</i>	<i>She (Veteran) was going in for surgery and she made it very clear what her wishes were if something happened.</i>
Professional guidance	<i>I talked with my primary physician... and she directed me toward the person that I needed to contact, which I did by phone, ... and she walked me through the whole process.</i>	<i>The social worker came in and talked about it.</i>
Strength of relationships	<i>I know that she cares enough about me the same way that I care about her and that made it a lot easier.</i>	<i>We have always had a very open relationship and I have always been able to talk to my Mom (Veteran) and not get overly stimulated by my</i>

Barriers	Quotation(s) Veteran	Quotation(s) Surrogate
		<i>own feelings.</i>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 3

Reasons for disagreement about engagement in ACP

Reason	Quotation(s) Veteran	Quotation(s) Surrogate
Veteran or surrogate does not remember until other describes details	<i>When she (surrogate) said it, I remembered. We went to a military installation and did a will also did the Living Will.</i>	<i>That day we signed a lot of papers. ...there are times when his (Veteran's) short-term recall isn't 100%.</i>
	<i>I agree with him (surrogate). We had a conversation about if anything happened to me.</i>	<i>[The conversation] occurred when my mother died. He (Veteran) doesn't remember because it was a very stressful time.</i>
	<i>I explained what the purpose of it was and he (surrogate) might have been distracted doing something else.</i>	
Veteran or surrogate with misinformation or incorrect assumptions about ACP	<i>Now that I know what you are talking about, I know that it wasn't [a living will.]</i>	<i>I remember that she (Veteran) had filled out a paper on the computer. It has all of her medications and who her contact would be so</i>
	<i>I filled out so many [forms], I just assumed that there was a Health Care Proxy form among all those papers.</i>	<i>I just assumed that since she did that, she did the other.</i>
Veteran has not informed surrogate of engagement	<i>I don't think I told her (surrogate).</i>	
	<i>I just filled [the living will] out and sent it in. One of these days I will get around to telling her (surrogate).</i>	
Surrogate believes conversation has occurred because he/she knows the Veteran		<i>I have been around this guy (Veteran) for 52 years, and I think I understand what he wants in regards to his quality of life.</i>
		<i>It was more of an informal discussion...I know he doesn't want to think about living in that condition.</i>
Surrogate not ready to hear		<i>Well probably back then my thought was that she (Veteran) is probably too young to start thinking about that. We were probably in our mid or lower 50' so probably just not time yet to start thinking and talking about that.</i>
Conversation insufficiently detailed for surrogate		<i>You know he knows that he does not want life support but he doesn't understand the fact that there can be illness that you can still live but will affect the way you live.</i>
		<i>The whole issue of life support, to me anyway, is at what point the person does not want continued life support or even life support to be initiated?...How compromised do you have to be? What chances are there for any level of recovery? All of those things play into it and that we have never discussed</i>