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The Process of Advance Care Planning in HCT Candidates and Proxies: Self-Efficacy, Locus of Control, and Anxiety Levels

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Abstract

The purpose of this study was to examine the relationship between hematopoietic cell transplant candidate and proxy advance care planning (ACP) behavior and attitudes. A total of 49 candidates and 44 proxies completed the Advance Directive Attitudes Survey, Multidimensional Health Locus of Control Scale, Family Decision Making Self-Efficacy Scale, and the State-Trait Anxiety Inventory. In all, 45% of candidates reported completing an advance directive (AD), while only 26% had ADs on file; 80% of candidates discussed ACP wishes with their loved ones and 15% discussed ACP wishes with their medical team. The AD completers were significantly (1) older, (2) more positive about ADs, and (3) were less likely to believe that health events happen by chance. Discrepancies between reported ACP behavior and communication with health care practitioners have implications for end-of-life care.

Keywords

advance care planning; proxy; advance directive; end-of-life care; hematopoietic cell transplant candidates

Introduction

The process of advance care planning (ACP) for end of life is important for all individuals; it is especially relevant for those with a cancer diagnosis. Engagement in such a planning process has implications for patients, immediate loved ones, as well as the health care system at large. Due to medical advancements in cancer care, diagnoses that once were equated with swift death now are associated with prolonged periods of remission or even

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cure. Options to prolong life often are balanced with patient goals and trade-offs in symptom burdens. Even with extraordinary medical advancements, however, rapid changes in bodily functioning and unexpected deterioration in health are common, complicating the end-of-life planning process. Most people will be unable to choose the exact cause or time of death. However, with planning, there is the possibility of creating a hoped for path toward the end.

The ultimate goal of planning for end of life is to prepare patients and loved ones to participate actively with the health care team as situations evolve.¹ The completion of an advance directive (AD) document is one step in an approach that requires ongoing, active communication between patients, proxies, and medical providers. The National Institute of Aging defines ACP as “learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know about your preferences, often by putting them into an advance directive.”² Following the passage of the Patient Self Determination Act, all institutions receiving Medicare and Medicaid funding are required to inform patients of their right to participate actively in their care, including their right to have ADs.³ Potential benefits of AD completion exist for all parties involved in the health care of an individual. Patients with ADs can feel more secure that predesignated life-sustaining measures will be respected; proxies have reduced decision-making and possibly psychological burden; the health care team can plan treatment in a manner that is congruent with the desire of their patient; and both time and costs for undesired life-prolonging care potentially are avoided. In spite of these potential benefits, challenges in their achievement exist.

A number of systemic problems persist within the effort to consider, discuss, and document end-of-life wishes. First, the AD completion rates are low. For example, in an intensive care unit (ICU),⁴ only 15.7% of one sample (N = 1121) had living wills and 47.6% had a designated health care proxy. Similarly only 5.5% of a comprehensive cancer center ICU population were considered do not resuscitate (DNR) on admission⁵ and only 15.2% (N = 362) had DNR orders before discharge. Second, even when patients do elect to complete ADs, these documents alone may not impact the outcomes or quality of end-of-life care received.^{4,6} Their utility may be limited when the health care team is unaware of AD documentation or when there is poor communication related to a patient’s wishes.⁷ Additionally, those who complete these documents typically do so in the absence of a full comprehension of the scope and details of the situation they will be facing and may lack the ability to predict future wishes.⁸ Finally, the relational, family,⁹ social, and cultural¹⁰ systems into which patients are embedded are influential. Numerous variables, often in a complex interplay,¹¹ seem to impact their completion.

ACP is especially relevant for hematopoietic cell transplant (HCT) candidates on account of their preexisting, underlying disease, the nature of the transplant procedure, the risk of potentially fatal complications, and the preparatory time prior to transplant.¹² Although this combination of a high-risk procedure coupled with preprocedure preparation time makes HCT candidates well suited for this research, few studies have been completed with HCT candidates or with their designated decision makers.¹³ Ganti et al found, paradoxically, that those HCT recipients “least likely to have planned for poor outcomes [ie, AD completion]

are the ones most likely to face them”^{13(p5643)} and called for more research pinpointing explanatory factors.

The purpose of this study was to examine the relationship between specific variables and patient and proxy ACP behavior. ACP is a process, not a sole event. As such, a clearer understanding of the influential variables within this dynamic process is needed to guide practice. To gain a deeper understanding of ACP engagement, we specifically chose to explore the following constructs: AD attitudes, decision-making self-efficacy, perceptions of health locus of control, and anxiety levels.

Methods

Participants were introduced to the study in conjunction with the routine, pre-transplant psychosocial assessment between December 15, 2011, and May 25, 2012. Eligibility criteria were (1) 18 years of age or older, (2) English literate, and (3) HCT candidate at Wake Forest Baptist Health or the designated proxy of the candidate. A proxy was defined as the person, designated by the HCT candidate, who was most likely to assist with health care decisions, should the HCT candidate become unable to do so. The HCT candidates were asked to name their currently designated medical decision maker or the person most likely to make medical decisions on their behalf, should they be unable to speak for themselves. Frequently, this designated person had accompanied the HCT candidate to the assessment. In the case of a proxy's absence, the HCT candidate was asked to give written permission to contact the proxy. One member of the dyad could participate without the other as long as the HCT candidate permitted it.

Study introduction and consent were performed by a member of the research team, typically immediately preceding or following the psychosocial assessment within the clinic. If participants could not be consented in the clinic, the study was introduced over the phone and materials were mailed. Those who consented to the study agreed to complete the brief survey packet that included the Advance Directive Attitudes Survey (ADAS); the Family Decision Making Self-Efficacy Scale (FDMSES); the Multidimensional Health Locus of Control (MHLC), Form C; the State-Trait Anxiety Inventory (STAI), Form Y; the distress thermometer; and a sociodemographic form. Results of the distress thermometer are reported elsewhere.¹⁴ Completing the survey packet required approximately 15 to 20 minutes. Researchers also completed a review of participants' electronic medical record for evidence of ADs at hospital discharge. Participants were provided with a US\$10 incentive upon return of the study packet and consent form. This study was approved by the Wake Forest Baptist Medical Center institutional review board.

Instruments

The ADAS—The ADAS consists of 16 items with a 4-point Likert-type response scale (*strongly disagree* to *strongly agree*). It measures the extent to which a respondent perceives ADs as positive or negative. A higher score suggests a more positive attitude. The ADAS has a coefficient α of .74 and acceptable content validity. It was completed by HCT candidates.¹⁵

The MHLC, Form C—The items on the MHLC assess respondents' perceptions of the influences (*Internal HLC* [IHLC], *Powerful Others HLC* [PHLC], and *Chance HLC* [CHLC]) on their health behavior via multidimensional health scales. Form C consists of 18 items with response choices on a 6-point Likert scale (*strongly disagree* to *strongly agree*). Scores can be obtained on three conceptually and empirically different scales. Additionally, for the purpose of measuring the role of God as a locus of control, the 6-item God HLC (GHLC) scale was utilized as well. The MHLC has adequate construct and content validity and internal consistency (α range from .71 to .87). Higher scores indicate stronger perceptions of influence.¹⁶ This was completed by the HCT candidates.

The FDMSES—The FDMSES was designed to measure familial confidence in health care decision-making. It consists of two 13-item scenarios which refer to a conscious or unconscious patient. Proxies were asked to answer items on 5-point Likert-type scales ranging from *cannot do at all* to *certain I can do*. Cronbach's α s are .91 (conscious) to .95 (unconscious). Test-retest reliability rates range from $r = .96$, $P = .002$ (conscious) to $r = .92$, $P = .009$ (unconscious). Higher scores indicate higher decision-making confidence.¹⁷

The STAI, Form Y—The STAI contains 40 items that assess temporary, state anxiety ($n = 20$), and the more enduring, trait anxiety ($n = 20$). Respondents answer items on 4-point Likert-type scales. Higher scores indicate greater anxiety. Trait test-retest coefficients range from .73 to .86, while state test-retest coefficients ranged from .16 to .54 (as expected, given it measures fluctuating mood). Both HCT candidates and proxies completed this instrument.¹⁸

Sociodemographic Form—This included questions about age, race, education, socioeconomic status, religion, number of children, county of residence, length of illness, diagnosis, and AD documentation.

Analyses

Descriptive statistics, including means and standard deviations (SDs) for continuous measures and frequencies and proportions for categorical data, were calculated for all study measures. Nonparametric tests were used to test for associations between the study groups and the continuous measures, while Fisher exact test was used to assess relationships between the study groups and the categorical outcomes. Pearson's correlation coefficient was used to test for associations between continuous measures. Comparisons between dyadic pairs' (HCT candidates and their corresponding proxy) scores were analyzed using paired t tests.

Results

A total of 44 proxies (mean age = 54.3, 66% female, 84% white) and 49 HCT candidates (mean age = 55.9, 33% females, 84% white) participated in the study (Table 1).

The HCT Candidates

Twenty-two HCT (45%) candidates reported having completed any form of AD (ie, which AD documents [ie, legal documents that communicate what type of health care measures you would like if you become seriously ill] do you currently have in place?). In all, 11 (26%) HCT candidates actually had at least one of these AD documents in their medical record at the transplant center. Those who had ADs on file during their transplant had the following group characteristics: 73% male, 91% white, 73% married, and 91% had children. Age was the only sociodemographic variable that differed significantly between AD completers (mean [M] = 63.2; range = 42.6-71.4) and non-completers (M = 56.0; range = 26.3-71.7; $P = .031$). In all, 80% of HCT candidates endorsed discussing wishes regarding life-sustaining treatments with their close loved ones prior to the transplant process; only 15% stated that they had discussed these wishes with their medical team. Attitude scores (Table 2) toward AD completion ranged from 34.7 to 62.0 (M = 52.4, SD = 6.1). The AD completers demonstrated AD attitudes that were significantly more positive (M = 56.6; range = 49.0-62.0) than noncompleters (M = 51.0; range = 34.7-61.0; $P = .006$). Health locus of control scores were internal M = 17.9 (SD = 6.1), chance M = 16.2 (SD = 6.6), powerful others M = 26.7 (SD = 5.1), and God M = 24.7 (SD = 8.1). The AD completers (M = 12.1, SD = 4.7, range = 6.0-19.0) expressed significantly lower chance MHLC scores as compared to the noncompleters (M = 18.5, SD = 6.4, range = 7.0-29.0; $P = .007$). Finally, on the STAI, mean state scores were 33.7 (SD = 10.6, range = 20.0-61.0) and mean trait scores were 32.6 (SD = 8.1, range = 20.0-50.0). For non-AD completers (N = 31), state scores were 31.9 (9.8) and trait scores were 32.9 (8.7). For AD completers (N = 11), state scores were 39.2 (13.3) and trait scores were 31.7 (8.6). State ($P = .12$) and trait ($P = .73$) scores did not differ significantly between groups. No gender differences existed between STAI scores. Significant negative correlations existed between trait STAI scores and powerful others ($r = -.29$; $P = .049$) and God locus of control ($r = -.29$; $P = .047$).

Proxies

Designated proxies included 27 (61%) spouses, 4 (9%) daughters, and various (30%) other family members or social acquaintances (Table 3). Five HCT candidates did not have participating proxies. Proxy decision-making self-efficacy mean scores (*conscious* patients scenario) were 57.8 (SD = 9.5) and (*unconscious*) 58.4 (SD = 9.4). Self-efficacy scores did not differ by spousal status (ie, spouse vs other proxy). In both the scenarios, proxies reported the most difficulty with decisions related to eating if the patient desires to stop (ie, approximately 25% endorsed responses ranging from “certain I cannot do” to “uncertain”) and handling news that their patient’s death is near (conscious scenario; >31% reported “certain I cannot do” to “uncertain”). Proxies endorsed mean state anxiety scores of 39.0 (SD = 12.1, range = 21.0-69.0) and mean trait scores of 36.5 (SD = 11.6, range = 20.0-60.0). Designated proxies endorsed both state and trait anxiety mean scores that were significantly higher (M = +5.6, $P = .012$; and M = +4.5, $P = .014$) than their HCT candidate partners.

Discussion

Completion of ADs and Proxy Designation

A large discrepancy exists between the percentage of HCT candidates who endorsed completing ADs (ie, 45%) and the percentage of patients (ie, 26%) who actually had them on file throughout transplant. This discrepancy may exist because patients neglected to file the documents or because they were mistaken as to the documents that they had completed. Approximately one-quarter of patients actually had ADs on file, a prevalence rate that is lower than other reports within an HCT population¹² (eg, 37%). Similar to the AD completers in the study of Joffe et al (2007), those who had ADs on file were significantly older (M age = 63.2) than noncompleters (56.0). The vast majority (80%) of recipients reported talking with loved ones about their wishes for life-sustaining treatments, but few had documented these wishes formally or reported talking with their medical providers (15%). In spite of existing disease and the transplant complication risk, the majority of participants had not talked about end-of-life wishes with their health care team or documented their wishes formally. In addition to the large role of health care providers in end-of-life care, provider requests can have a significant impact on AD completion.⁹ As such, this apparent lack of communication with providers is startling. Finally, our HCT candidates designated predominantly spouses (61%; females [65%]), followed by daughters [9%]) for proxies. The higher prevalence of women proxies likely is attributable to the higher prevalence of male patients in our study (who designated their female spouses). Some research suggests that female caregivers of advanced cancer patients experience more state anxiety than males.¹⁹ If state anxiety levels differ by sex, the composition of proxy populations may have implications for interventions.

Attitudes of HCT Candidate Toward ADs—Our AD attitude mean score (M = 52.4 [6.1]) was similar to that reported for medical inpatients (M = 50.3 [5.6]) and has been described as “moderately positive.”¹⁵ (p. 206) The AD completers reported significantly more positive AD attitudes than noncompleters, suggesting that the ADAS score is a good indicator of willingness to complete ADs. More than 25% of HCT candidates *agreed* or *strongly agreed* that they were *not sick enough to have an AD*; >27% indicated making [their] end of life treatment wishes clear with an AD would have no impact on [their] family. Many recipients may not be aware of the severity of their conditions or of the potential complications inherent in HCT or believe that the written expression of their health care wishes will not impact their family members significantly. Such findings call into question how informed these candidates are of their medical conditions and the perceived efficacy of ADs.

Locus of Control—Beliefs about the source of influence in health-related events can have strong relevance for health care behaviors. As a group, HCT candidates reported that *powerful others*, such as doctors involved in their care, have the strongest influence over their health status. This finding is interesting when paired with the finding that only 15% reported speaking with their medical team regarding life-sustaining treatments. The perceptions regarding the influence of God in their health condition were only slightly lower than their perceptions regarding *powerful others*. Compared to noncompleters, AD

completers did not differ in terms of perceptions of how much influence they, personally, can exert over their illness. These results may reflect the thought processes of people living with chronic illness for a significant amount of time. However, AD completers were significantly less likely than noncompleters to believe that their health outcomes were the result of chance. In other words, those *less* likely to believe that health events happen because of luck or accidental happenings were those most likely to complete ADs.

Anxiety—Our HCT recipients' state ($M = 33.7$ [10.6]) and trait ($M = 32.6$ [8.1]) scores were lower than anticipated. Comparatively, an alternate pre-treatment autologous transplant population²⁰ reported state $M = 43.8$ (10.2) and trait $M = 38.3$ (8.4). Similarly, our HCT candidates endorsed significantly lower anxiety levels than proxies, suggesting that their designated surrogates' enduring and situational anxiety levels typically exceed those of their patient partners. These relatively higher scores of proxies suggest the need for routine proxy inclusion in screening, psychosocial care, and ACP research. The importance of proxies' medical and moral assumptions in surrogate decision making has been documented.²¹ Although proxies and caregivers are not synonymous, there is considerable role overlap for many proxies. When compared to the anxiety levels of other caregivers of patients with advanced stage cancer¹⁹ (eg, female caregiver state ($M = 53.5$ [10.1]) and trait ($M = 44.5$ [7.8]); male caregiver state ($M = 48.0$ [10.3]) and trait ($M = 41.7$ [7.8]), our proxies' mean anxiety level was lower. It is important to note that our participants typically completed the study questionnaire toward the end of the pre-transplant workup day, after receiving detailed information about what to expect and meeting with a mental health provider, among other activities. The reception of such information and establishment of rapport could have reduced anxiety scores. Although the state anxiety scores of AD completers ($N = 11$; $M = 39.2$ [13.3]) versus noncompleters ($N = 31$; $M = 31.9$ [9.8]) did not differ significantly ($P = .12$), the differences between state scores almost certainly would have reached significance if the sample size had been larger. This finding suggests that AD completers may endorse more state anxiety than their noncompleter counterparts. Finally, the significant negative correlations between trait anxiety and powerful others and God locus of control suggest that those who report less enduring anxiety tend to perceive powerful others and God as having more influence in their health outcomes.

Family Decision Making Self-Efficacy—Proxies endorsed relatively high decision-making confidence in their ability to make end-of-life decisions for their loved ones (*conscious* $M = 57.8$, $SD = 9.5$; *unconscious* $M = 58.4$, $SD = 9.4$). The reported decision-making self-efficacy scores of experienced family decision makers ($M = 61.0$, $SD = 5.7$) versus those without such experience ($M = 56.4$, $SD = 7.8$) serve as a comparison.¹⁷ Although our proxies, on average, reported high decision-making confidence, they may benefit from additional support and information relative to certain perceived difficult aspects of this process, including coping with the news that a loved one's death is near and adjusting to the cessation of eating. Additionally, a select few anticipated great difficulty fulfilling their decision-making role.

In summary, roughly one-quarter of HCT recipients had formal ADs documented in their medical records throughout the transplant process. Those who completed ADs differed

significantly from non-AD completers in that they were older, expressed more positive AD attitudes, and were less likely to believe that health events happen by chance. Although not significant in our relatively small sample size, a larger sample size likely would reveal significantly higher state anxiety reported by AD completers. As a group, HCT recipients expressed relatively positive attitudes toward ADs and comparatively low levels of anxiety. Those who endorsed low trait anxiety levels reported stronger beliefs in the influence of powerful others and God in their health outcomes. Only a small percentage had discussed end-of-life wishes with medical providers, yet they believe these individuals have the most influence in their health outcomes. For their proxy decision makers, HCT recipients designated predominantly spouses, followed by daughters. These proxies endorsed significantly more state and trait anxiety than their paired HCT recipients. They expressed high levels of decision-making self-efficacy in general but identified certain areas of decision making as comparatively more difficult. A minority of proxies anticipated great difficulty with role fulfillment.

There are limitations to this study. First, our sample size was small and relatively homogenous. Second, participants completed the instruments most commonly on the transplant workup day, after completing numerous tests and appointments that determine their eligibility for the procedure. Often, the questionnaires were completed immediately following a meeting with a psychosocial oncology team member. Instrument scores, including anxiety levels, may have been impacted by the events of that rigorous day.

Recommendations for Future Research—Future research is needed in this area to improve quality at the end of life. First, larger, more heterogeneous samples are needed to replicate these findings and to determine whether the results that were below the threshold of significance (eg, the difference in state anxiety scores between completers and noncompleters) in our small sample prove to be significant. Second, additional information on the influence of patients' attitudinal, cognitive, psychological, and sociodemographic variables within ACP will be useful in guiding screening, interventions, and communication within the health care system. Certain investigators²² have suggested the importance of measuring competency as well as contingency (eg, locus of control) measures related to health care behaviors. The role of perceived self-competency in this context may be informative. Third, more information on patient-provider communication about end of life is warranted, given the reported low prevalence of communication about end-of-life wishes with the health care team. And finally, additional information about proxies' decision-making and psychological states is needed. Future investigators could examine role differentiation and overlap between caregivers and proxies as well as dyadic adjustment with their HCT recipients. Including a group of caregivers who are not proxies could help identify role differences in future research. Proxies are crucial players in ACP and their role within this process is not well understood.

In conclusion, end-of-life care planning, including AD completion, is a process, not an event. The ACP research must be designed to measure and reflect the complexities of this dynamic process. Additional information on attitudes and influential variables throughout the ACP engagement process is needed if we are to build and sustain empirically based ACP initiatives capable of impacting health care policy, health care provider dialogue, and

multidisciplinary systems within our health care settings. Such an enhanced understanding of *how* and *why* patients and loved ones engage in the process of end-of-life planning would enable us to improve care and transitions in these most important final days.

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Table 1

Socio-demographic Characteristics of HCT Candidates and Proxies.

Participant characteristic	HCT, N	HCT, %	Proxy, N	Proxy, %
Total	49	53	44	47
Sex				
Female	16	33	29	66
Male	33	67	15	34
Age, mean	55.9		54.3	
Race				
Black	8	16	7	16
White	41	84	37	84
Marital status				
Single	6	13	4	10
Married	29	60	35	83
Separated	2	4	1	2
Divorced	8	17	1	2
Widowed	3	6	1	2
Children				
Yes	40	83	38	88
No	8	17	5	12
Educational level				
1-8 grades	1	2	1	2
9-11 grades	5	10	6	14
High school graduate	15	33	6	14
Some college	14	29	15	36
Junior college degree	1	2	4	10
College degree	5	10	4	10
Some post college work	2	4	–	–
Advanced degree	4	8	6	14
Annual family income				
0-4999	2	5	2	5
5000-9999	1	2	–	–
10 000-19 999	6	14	6	14
20 000-29 999	7	16	4	9
30 000-39 999	7	16	5	12
40 000-49 999	5	12	7	16
50 000-59 999	4	9	6	14
60 000-69 999	2	5	2	5
70 000+	9	21	11	26
Religious affiliation				
Protestant	40	83	35	81
Catholic	3	6	4	9

Participant characteristic	HCT, N	HCT, %	Proxy, N	Proxy, %
Other	4	8	3	7
Spiritual, not religious	1	2	1	2

Abbreviation: HCT, hematopoietic cell transplant.

Table 2The ADAS¹⁵ Question Responses.

	Strongly disagree, %	Disagree, %	Agree, %	Strongly agree, %
ADAS question				
I have choices about the treatments I would receive at the end of my life	2	0	41	57
I would be given choices about the treatment I would receive at the end of my life	0	2	39	59
My doctor would include my concerns in decisions about my treatment at the end of my life	0	2	48	50
If I could not make decisions, my family would be given choices about the treatment I would receive	0	0	43	57
I think my family would want me to have an AD	0	4	43	53
Making my end-of-life treatment wishes clear with an AD would keep my family from disagreeing over what to do if I were very sick and unable to decide for myself	0	6	38	55
Having an AD would make my family feel left out of caring for me	28	52	13	7
Making my end-of-life treatment wishes clear with an AD would help to prevent guilt in my family	4	15	46	35
Making my end-of-life treatment wishes clear with an AD would have no impact on my family	13	60	15	13
Having an AD would prevent costly medical expenses for my family	4	11	60	26
Having an AD would make sure that my family knows my treatment wishes	0	8	40	51
My family wants me to have an AD	4	13	59	24
Having an AD would make sure that I get the treatment at the end of my life that I do want	2	11	26	61
I trust one of my family or friends to make treatment decisions for me if I cannot make them myself	2	2	34	62
It is better to make an AD when you are healthy	4	4	32	60
I am not sick enough to have an AD	37	37	15	11

Abbreviations: AD, advance directive; ADAS, AD Attitudes Survey.

Table 3

Proxy Type.

Proxy type	Number
Spouse	27
Mom	2
Sister	1
Daughter	4
Father	2
Brother	2
Niece	2
Cousin	1
Best friend	1
Partner	2