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Advance care planning as a shared endeavor: completion of ACP documents in a multidisciplinary cancer program

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Abstract

Objective—We examined the roles of oncology providers in advance care planning (ACP) delivery in the context of a multidisciplinary cancer program.

Methods—Semi-structured interviews were conducted with 200 women with recurrent and/or metastatic breast or gynecologic cancer. Participants were asked to name providers they deemed important in their cancer care and whether they had discussed and/or completed ACP documentation. Evidence of ACP documentation was obtained from chart reviews.

Results—Fifty percent of participants self-reported completing an advance directive (AD) and 48.5% had named a healthcare power of attorney (HPA), 38.5% had completed both, and 39.0% had completed neither document. Among women who self-reported completion of the documents, only 24.0% and 14.4% of women respectively had documentation of an AD and HPA in their chart. Completion of an AD was associated with number (adjusted odds ratio [AOR] = 1.49) and percentage (AOR = 6.58) of providers with whom the participant had a conversation about end-of-

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Conflict of interest

The authors have declared no conflicts of interest.

life decisions. Participants who named a social worker or nurse practitioner were more likely to report having completed an AD. Participants who named at least one provider in common (e.g., named the same oncologist) were more likely to have comparable behaviors related to naming a HPA ($AOR = 1.13, p = 0.011$) and completion of an AD ($AOR = 1.06, p = 0.114$).

Conclusions—Despite the important role of physicians in facilitating ACP discussions, involvement of other staff was associated with a greater likelihood of completion of ACP documentation. Patients may benefit from opportunities to discuss ACP with multiple members of their cancer care team.

Introduction

The Patient Self-determination Act (PSDA) aimed to empower patient participation in accepting or refusing medical treatment [1]. Evaluation of the PSDA has highlighted the importance of advance care planning (ACP), which is a broad construct that emphasizes the steps required to facilitate patients in guiding their future health care so that it is consistent with their goals when they are no longer capable of making decisions for themselves [2–4]. ACP can take many forms, including discussions about goals for care at the end of life, designation of a healthcare power of attorney (HPA), and completion of an advance directive (AD) or living will[5]. While not all ACP discussions result in power of attorney designations or completion of ACP forms, the presence of such is a marker that these discussions have occurred at least between patients and their family and/or friends.

While there have been a number of challenges identified with the ACP process [6–8], ACP has been shown to improve compliance with the end-of-life (EOL) wishes of patients, enhance patient and family satisfaction with care, and reduce family stress, anxiety, and depression [9,10]. Therefore, it is important to incorporate routine discussions about ACP with cancer patients at various points along the disease trajectory. We focused on women with recurrent and/or metastatic breast or gynecologic cancer. There are minimal standards for when ACP should be discussed with patients living with an advanced disease, including cancer. These include (a) at diagnosis of advanced cancer, (b) before an expected death from cancer, and (c) other sentinel events such as any hospital admission, admission to an intensive care unit, and before mechanical ventilation [2].

Most patients believe that addressing EOL issues is an important part of their cancer care [11,12]. Nevertheless, oncology providers often find it difficult to discuss ACP and EOL issues with patients and assume that patients will be hesitant or even unwilling to have the necessary conversations[13]. In fact, patients report being reluctant and feeling uncomfortable raising the issues themselves [3,14,15] but do want their physicians to initiate the discussions if and when they feel it is necessary [2,3,16].

Advance care planning has been poorly incorporated into many cancer care settings [17,18]. Understanding the structure and influence of patients' social networks may be an important step to address the challenges associated with the ACP process and to develop novel approaches for ACP policies and programs. Social networks have been increasingly used to represent complex structures and relational patterns in a wide variety of disciplines [19,20]. However, there has been limited research applying networks to the understanding of

individual level healthcare decisions. There are a number of ways to conceptualize the role social networks may play in decision-making. The effect of the structure and activation of women's personal networks can be considered such as network size, composition, and frequency of interaction. Alternatively, social networks can be defined more globally, capturing the extent to which women are aware of, and influenced by, the healthcare decisions being made by others such as through shared affiliations with health care providers.

Using a global conceptualization of social networks, we examined whether (a) women who reported having conversations about EOL wishes with their cancer care providers had a higher likelihood of the ACP behaviors of designation of a HPA and completion of an AD than women who did not report such conversations; (b) women who named particular types of providers (e.g., oncologist, surgeon, and non-physician provider) as important in their cancer care were more likely to report designating a HPA and completing an AD; and (c) women who had providers in common (e.g., named the same oncologist) were more likely to have similar ACP behaviors (e.g., named a HPA versus not).

While there are many potential measures of ACP, we focused on ADs or living wills and HPA because these were the focus of the law in place at the time in the state in which the research was conducted and because these two documents provide a procedural mechanism in which EOL plans can be legitimized, recorded, and shared [7]. Under the law, individuals have the right to instruct their physicians to withhold or withdraw life-sustaining procedures in the event of a terminal condition (establish a living will) [<http://webserver.rilin.state.ri.us/statutes/TITLE23/23-4.11/INDEX.HTM>] and to authorize another person to make decisions affecting their healthcare if they become unable to do so (nominate a durable power of attorney for health care) [<http://webserver.rilin.state.ri.us/statutes/TITLE23/23-4.10/INDEX.HTM>]. If individuals wish to name a durable power of attorney for health care, they must use the form in the statute. To establish a living will, they may use the statutory form or may create their own form if it meets the requirements of the law.

Relative to conventional cancer care settings, less is known about the experiences of patients and providers in settings using multidisciplinary integrated care models. This is particularly relevant because these programs are intended to be evidence-based, comprehensive, and patient-centered throughout the cancer care continuum [21,22] and may provide ideal settings for assessing social network approaches for ACP processes. Therefore, we examined experiences with ACP among patients in a multidisciplinary integrated program in women's oncology.

Methods

Patients

Participants were recruited from the Program in Women's Oncology at Women & Infants Hospital of Rhode Island, which employs a multidisciplinary care model. All patients are seen by a social worker at their initial visits, and care is rendered in a team approach, consisting of surgeons, medical oncologists, nurses, nurse practitioners, and specialty

pharmacists. The program also has integrative care available to all patients that includes dietitians, lymphedema and massage specialists, and mind–body practitioners.

Women were eligible if they had an established diagnosis of recurrent or metastatic breast or gynecologic cancer for at least 3 months duration. Only women were included because these were the patients cared for by the Program in Women’s Oncology. Women with recurrent or metastatic cancer were eligible because they were facing decisions about a potentially life-threatening incurable condition and met the minimum standards for when ACP should be discussed.

Eligible patients were identified, recruited, and consented for participation by clinic personnel. After consent was obtained, in-person structured interviews were conducted by trained research staff. Clinical characteristics and evidence of ACP documentation were obtained from chart reviews. This study was approved by the hospital and University Institutional Review Boards.

Measures

Advance care planning—An AD or living will was defined for participants as ‘a set of written instructions in which you state the kind of health care you want or don’t want under certain circumstances’. We asked women if they had completed an AD, and if so, whether the timing of completion of the AD was related to the cancer diagnosis. If the timing was related to the cancer diagnosis, we asked whether it was related to the initial diagnosis or recurrence and whether they had changed the AD since being diagnosed with cancer. Among those for whom the timing was not associated with the cancer diagnosis, we asked for the circumstances prompting completion of the AD and whether the AD had been changed since the cancer diagnosis. A HPA was defined as ‘a document that must be signed by two witnesses or notarized in which you name someone to make decisions about your health care in the event you become incapacitated. The person is sometimes called a health care proxy or health care agent’. Similar to ADs, we asked about naming of, and timing and circumstances for, a HPA. Finally, chart reviews were completed by clinicians blinded to participants’ self-reported data to determine whether there was documentation of an AD and/or HPA in the medical record.

Provider characteristics—We asked women to name up to five healthcare providers that played important roles in their cancer care. This could include providers not affiliated with the oncology program such as primary care providers. Participants were then asked to describe each named provider’s specialty (e.g., oncologist and surgeon) and gender, and whether or not they had ever had a conversation with that provider about their wishes for care at the end of life.

Participant characteristics—Women were asked to self-report their age. From chart reviews, we determined cancer type, stage at initial diagnosis, and number of hospitalizations in the prior year.

Statistical analyses

We first examined whether having a conversation about EOL wishes with a provider was associated with self-reported ACP. We created three variables quantifying the participants' experiences with having conversations about EOL decisions with named providers: (a) the number of providers with whom the participant reported having an EOL conversation, (b) the percentage of providers with whom the participant reported having an EOL conversation, and (c) a dichotomous variable that indicated whether or not the participant reported having an EOL conversation with at least one named provider. We then tested the association between these three variables and completion of an AD and naming of a HPA.

Next, we examined whether participants who named a particular type of provider (e.g., oncologist, surgeon, and nurse practitioner) had significantly higher odds of ACP than those who did not name a particular type of provider. We created indicator variables for each provider type and computed a logistic regression model for each ACP outcome. The models included indicators for provider type, age, cancer type, stage, and hospitalization record.

Finally, we examined whether participants who shared common providers (e.g., named the same oncologist) were more likely to have the same ACP behaviors (e.g., completed an AD). First, two members of the research team formatted and then coded each of the provider names. Second, we determined all the unique pairs of participants (e.g., Participant 1 and Participant 2; Participant 1 and Participant 3). For each of these pairs, we determined whether they had named a common provider as well as had a similar age (within 5 years), stage at diagnosis, hospitalization record, and ACP behaviors. Next, using logistic regression modeling, we computed the odds of a pair of participants having the same ACP behaviors comparing those who shared a common provider to those who did not share a common provider, adjusting for age, stage, and hospitalization record. If the odds ratios were significantly different from 1.0, the probability of similar ACP behaviors was statistically associated with sharing a common provider. Because the pairwise observations were not independent, the standard errors and corresponding traditional statistical tests were not valid. Therefore, to account for the dependence within the observation of the pairs, we performed a Monte Carlo permutation to simulate the distribution of odds ratios under the null hypothesis that sharing a common provider was unrelated to similar ACP behaviors [23]. We repeated the analyses separately for completion of an AD and naming of a HPA.

For all analyses, we restricted the types of providers to oncologists, surgeons, nurse practitioners, oncology nurses, and social workers because these were the most common types of providers named by participants.

Because our primary modeling tool was logistic regression with the probability of the outcomes modeled as a function of individual and social network characteristics, the final sample size was based on our desire to ensure a reasonable denominator size across diverse modes of stratification. The sample size provided us the ability to detect odds ratios of 2.0 or greater as significant assuming two scenarios, stratification on a characteristic relevant for 2/3 and 1/2 of the sample, respectively.

Results

A total of 240 women were identified as eligible and recruited for participation. A total of 210 (87.5%) women consented. Reasons given for refusal included the following: not being interested ($n=15$, 50.0%), being uncomfortable with the topic ($n=5$; 16.7%), feeling too ill to participate ($n=4$, 13.3%), and being too busy ($n=1$, 3.3%). Five women (16.7%) declined to provide a reason for non-participation. A total of 200 women (83.3% of those eligible and 95.2% of those agreeing to participate) were interviewed. Of those not interviewed, eight refused after consent (five reported feeling too ill and three reported being too busy with health issues) and two died prior to the interview.

Demographic and clinical characteristics of the study sample are shown in Table 1. The mean age was 60 years (range = 35–82) years. The majority of participants had been diagnosed with ovarian, breast, or endometrial cancer with initial cancer stages of III or IV. One third of participants had been hospitalized at least once in the year prior to the interview and more than 80% had received two or more lines of treatment.

Half (50.0%) of participants self-reported completing an AD, and 48.5% had named a HPA, 38.5% had completed both, and 39.0% had completed neither document. For the slightly more than half (55.0%) who reported completing the AD, the timing of the completion was not related to their original cancer diagnosis, but was performed as part of life/estate planning (54.0%) and/or prior to a surgery or a hospitalization (40.0%). Of women who completed an AD related to the cancer diagnosis ($n=45$), 73.3% did so at the time of the initial diagnosis. Among all participants with an AD, 12.7% had changed their AD since their index cancer diagnosis.

For 48.5% of those who named a HPA, the timing was not related to the cancer diagnosis. The primary reasons given by these women for naming a HPA were a surgery or hospitalization (59.8%) and/or part of life/estate planning (48.5%). Of women who named a HPA related to their cancer diagnosis ($n=47$), 78.7% did so at the time of the initial diagnosis. Among all participants who named a HPA, 6% had changed their HPA since their cancer diagnosis.

Despite these results, review of the medical charts showed that of women who self-reported completion of ACP documents, a documented AD and HPA was available for 24.0% and 14.4% of all women, respectively.

There were 122 unique providers named by participants as important in their cancer care. The majority (75.5%) of participants did not report EOL conversations with any of the named providers. The adjusted odds ratios for completion of an AD and naming a HPA for each variable related to EOL conversations are presented in Table 2. Completion of an AD was positively associated with the number and percentage of providers with whom the participant had a conversation about EOL decisions, as well as having had an EOL conversation with at least one provider. However, none of these variables was associated with naming a HPA.

The relationship between provider type and ACP behaviors are presented in Table 3. Participants who named social workers or nurse practitioners as important to their care were significantly more likely to report having completed an AD than participants who did not name those providers. There was no association between provider type and naming a HPA.

Participants who had at least one named provider in common had significantly higher odds of comparable behaviors related to naming a HPA ($AOR = 1.13, p = 0.011$) and higher, although not significant, odds of comparable behaviors related to completion of an AD ($AOR = 1.06, p = 0.114$).

Discussion

In a multidisciplinary program in women's oncology, approximately 50% of women with recurrent or metastatic breast or gynecologic cancer reported having an AD and/or HPA. However, among women who self-reported completion of the documents, ADs and HPAs were recorded in the charts for only 24% and 14% of women, respectively. This is within the low-range to mid-range of what has been previously reported regarding patient-reported AD completion and clinician-documented ACP information described in other studies of patients with advanced cancer [13,24–26].

To our knowledge, this is the first study to use a social network approach to understand the roles of oncology providers in ACP processes. We found that having more than one provider involved in a patient's care was positively associated with completion of an AD. In addition, women who shared at least one healthcare provider in common had a higher likelihood of similar ACP behaviors compared with women who did not share any providers in common. Not surprising, we also documented that women who reported EOL conversations with more providers had a higher likelihood of having an AD, after adjusting for possible confounders. These results suggest that patients of some providers are more likely to have considered ACP because these providers are more likely to engage their patients in EOL discussions. Alternatively, women with a tendency towards similar ACP decisions may be more likely to choose the same provider. Regardless, these data provide evidence that social network theory [19,20] may apply in this scenario and that patients may benefit from opportunities to discuss ACP with multiple members of their cancer care team.

Our data also suggest that the involvement of non-physician providers may have a positive relationship with ACP. Women who named a nurse practitioner or social worker as important in their cancer care were more likely to have an AD than women who did not name those kinds of providers after adjusting for age, stage of disease, severity of illness, and other types of providers named. Although we do not have data to explain these findings, social workers and nurse practitioners may have more training in, be more comfortable with, and/or have more time for ACP discussions than other types of providers. Women who were more inclined to complete an AD may also have sought out the care and advice of non-physician providers perhaps because they had questions or concerns that were unaddressed by their physicians. These findings support the recommendations by You *et al.* [27] for the development of novel models to optimize inter-professional team members' roles in facilitating communication and decision-making about goals of care.

Our study has limitations that must be acknowledged. First, we had no way to confirm the validity of the self-reported or chart-documented ACP behaviors. While some women may have incorrectly self-reported their ACP behaviors, qualitative information suggests that it is more likely that ACP discussions, if conducted, were not consistently documented in the medical records. Furthermore, for 54% of women who completed an AD and 49% of those who named a HPA, ACP was performed as part of life/estate planning, and as a result, the documents may only be in attorney's offices, particularly if women were not asked to provide copies by any medical personnel. Our data are also consistent with Morrison *et al.* who found that among the medical charts of patients who had completed a living will prior to being hospitalized, only 26% of the charts accurately recorded information about the AD and only 16% of the charts contained the form. [28] This highlights that programs and policies focused on enhancing and documenting the ACP process for cancer patients will likely be as beneficial to multidisciplinary cancer programs as to conventional programs [5] and may be facilitated with increased use of electronic health records and routine incorporation of ACP into clinical settings including regular inquiry as to whether such documents exist[7]. Second, we included women from only one multidisciplinary cancer program. Third, because women were not randomly assigned to providers, we cannot make any statements about causality. Fourth, participants were only asked to name up to five providers who were important in their cancer care. We may have observed stronger relationships if each participant was permitted to name more than five providers. Fifth, because all the non-physician providers included in the analyses were women, we were not able to test the relationship of provider gender on the ACP outcomes. Finally, we did not ask women in our study when they preferred to have conversations about EOL care. However, other studies indicate that cancer patients vary in their willingness to engage in, and preferred timing of, decisions about EOL issues [29–32]. Therefore, despite its importance, clinicians must acknowledge that some patients may reject the offer of this discussion at one or more stages of the cancer continuum[3]. Although we do not have data to provide confirmation, rejection of clinician offers to discuss EOL wishes may partially explain why a proportion of women in our study had not completed an AD or named a HPA.

Despite these limitations, our data support those of other studies that have called for programs to facilitate the training of, and implementation by, providers for EOL discussions with their patients [3,5] and completion of ACP documents. Inclusion of non-physician providers may be especially important. In addition, involvement of multiple provider types may facilitate ACP discussions given that the number of providers named was associated with increased rates of ACP completion, rather than the involvement of any one particular physician specialty. Alternatively, it may simply be important for at least one clinician to raise the topic of ACP at multiple points during a patient's disease trajectory. Promising resources to aide in communication about ACP include programs such as the Physician Orders for Life-sustaining Treatment [33,34], Five wishes (www.agingwithdignity.org), and Caring conversations [35]. In addition, web-based interventions [36,37], video educational media [38,39], and multi-media computer-based decisions aids [40] may offer opportunities to facilitate patients' ACP. These types of resources along with clinical care protocols for consistent and routine conversations about ACP [7] can assure these planning

conversations are occurring and assist patients in identifying and articulating their goals and preferences in ways that help guide decision-making for surrogates and clinicians.

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What is already known about this topic?

Most patients believe that addressing EOL issues is an important part of their cancer care. However, oncology providers often find it difficult to discuss ACP and EOL issues with patients, and ACP has been poorly incorporated into many conventional cancer care settings.

What this paper adds?

Among women being cared for by a multidisciplinary program in women's oncology who self-reported ACP, documentation of ADs and/or HPA was recorded in the medical charts for only 24% and 14.4% of women, respectively. Having more than one health care provider involved in a patient's care had a positive association with self-reported completion of an AD. Women who named a nurse practitioner or social worker as important in their cancer care were more likely to self-report having an AD than women who did not name those kinds of providers. These findings support a potential role for members of a patient's cancer care team beyond the oncologist in ACP. As such, there is need for programs to facilitate the training of, and implementation by, providers for EOL discussions with patients.

Table 1

Demographic and clinical characteristics of study sample

Variable	<i>n</i>	%
Age (range: 35–82 years)	Mean = 60.1	SD = 10.5
Hispanic ethnicity		
No	193	96.5
Yes	6	3.0
Don't know/did not answer	1	0.5
Race		
White	181	90.5
Not-White	19	9.5
Education		
High school or less	64	32.0
Some college/technical training or certification	57	28.5
College degree or higher	79	39.5
Employment		
Working full or part-time	44	22.0
Unemployed	70	35.0
Retired	85	42.5
Don't know/did not answer	1	0.5
Financial situation		
Not enough to pay some bills	26	13.0
Enough to pay bills, but have had to cut back	42	21.0
Enough to pay bills without cutting back but no extras	48	24.0
Enough money for extras	81	40.5
Don't know/Did not answer	3	1.5
Cancer type		
Breast	56	28.0
Cervical	12	6.0
Endometrial	36	18.0
Ovarian	82	41.0
Endometrial and ovarian	1	0.5
Other	13	6.5
Initial cancer stage		
I or II	69	34.5
III or IV	127	63.5
Missing	4	2.0
Number of hospitalizations in past year		
0	135	67.5
1	41	20.5
2 or more	24	12.0
Number of lines of treatment		

Variable	<i>n</i>	%
1	29	14.5
2	85	42.5
3	86	43.0

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Table 2

Relationship between measures of end-of-life conversations with providers and advance care planning behaviors

	<u>Completion of an advance directive</u>		<u>Naming of a healthcare power of attorney</u>	
	AOR*	95% CI	AOR*	95% CI
<i>Model 1:</i> Number of providers with whom participant has had a conversation about end-of-life decisions	1.49	(1.06, 2.11)	1.01	(0.74, 1.39)
<i>Model 2:</i> Percentage of providers with whom participant has had a conversation about end-of-life decisions	6.58	(1.70, 25.51)	1.78	(0.55, 2.12)
<i>Model 3:</i> Conversation about end-of-life decisions with at least one provider				
Yes	3.26	(1.56, 6.83)	1.08	(0.55, 2.12)
No	Reference			

* Models include participant age, cancer stage, cancer type, and hospitalization record

AOR, adjusted odds ratio; CI, confidence interval.

Table 3

Relationship between provider type and advance care planning behaviors

	<u>Completion of an advance directive</u>		<u>Naming of a healthcare power of attorney</u>	
	AOR	95% CI	AOR	95% CI
Provider Type				
Oncologist				
1 named	2.15	(0.80, 5.77)	1.16	(0.45, 2.99)
0 named	Reference		Reference	
Surgeon				
1 named	0.75	(0.37, 1.51)	0.53	(0.26, 1.05)
0 named	Reference		Reference	
Nurse practitioner				
1 named	2.32	(1.01, 5.38)	1.08	(0.50, 2.34)
0 named	Reference		Reference	
Oncology nurse				
1 named	0.90	(0.48, 1.70)	0.86	(0.46, 1.59)
0 named	Reference		Reference	
Social worker				
1 named	2.72	(1.01, 7.40)	1.68	(0.65, 4.30)
0 named	Reference		Reference	
Participant characteristics				
Age (in Years)	1.07	(1.04, 1.11)	1.04	(1.01, 1.08)
Cancer stage				
I/II	0.85	(0.44, 1.63)	1.17	(0.62, 2.20)
III/IV	Reference		Reference	
Cancer type				
Gynecologic	1.72	(0.82, 3.59)	0.71	(0.37, 1.38)
Breast	Reference		Reference	
Hospitalizations in past year				
0	0.94	(0.47, 1.85)	2.08	(1.02, 4.24)
1	Reference		Reference	

AOR, adjusted odds ratio; CI, confidence interval.