

# Dances With Denial: Have Medical Oncology Outpatients Conveyed Their End-of-Life Wishes and Do They Want To?

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## Abstract

**Objectives:** This study surveyed a sample of medical oncology outpatients to determine (1) the proportion who have already discussed and documented their end-of-life (EOL) wishes; (2) when and with whom they would prefer to convey their EOL wishes; (3) the EOL issues they would want to discuss; and (4) the association between perceived cancer status and advance care planning (ACP) participation. **Methods:** Adult medical oncology outpatients were approached in the waiting room of an Australian tertiary treatment center. Consenting participants completed a pen-and-paper survey assessing participation in ACP, preferences for conveying EOL wishes, timing of EOL discussions, and EOL issues they want to be asked about. **Results:** A total of 203 patients returned the survey (47% of eligible). EOL discussions occurred more frequently with support persons (47%) than with doctors (7%). Only 14% had recorded their wishes, and 45% had appointed an enduring guardian. Those who perceived their cancer as incurable were more likely to have participated in ACP. If facing EOL, patients indicated that they would want family involved in discussions (85%), to be able to write down EOL wishes (82%), and to appoint enduring guardians (91%). Many (45%) preferred the first discussion to happen when their disease became incurable. Slightly less than one-third thought discussions regarding EOL should be patient-initiated. Most agreed doctors should ask about preferred decision-making involvement (92%), how important it is that pain is managed well (95%), and how important it is to remain conscious (82%). Fewer (55%) wanted to be asked about the importance of care extending life. **Conclusions:** Many patients would like to have discussions regarding EOL care with their doctor and involve their support persons in this process. Only a small percentage of respondents had discussed EOL care with their doctors, recorded their wishes, or appointed an enduring guardian. The first step requires clinicians to ask whether an individual patient wishes to discuss EOL issues, in what format, and at what level of detail.

*J Natl Compr Canc Netw* 2018;16(5):498–505  
doi: 10.6004/jnccn.2017.7054

The last year of life is one of the most resource-intensive stages of cancer care,<sup>1</sup> and one in which people face difficult care decisions.<sup>2</sup> Inaccurate perceptions about prognosis or treatments can impair decision-making processes.<sup>3,4</sup> Previous studies have indicated that patients with cancer are receiving increasingly aggressive

care at the end of life (EOL), including receipt of chemotherapy in the last month of life, late referrals to hospice, and frequent emergency department (ED) visits, hospitalizations, and intensive care unit admissions.<sup>5–8</sup> Such care may produce poorer outcomes,<sup>9</sup> particularly when care is in direct contrast to patient wishes. For in-

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Submitted September 17, 2017; accepted for publication October 30, 2017.

The authors have disclosed that they have no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors.

The authors received research support from Lucy Boyd, Judy Hollingworth, and Natalie Dodd; infrastructure support from University of Newcastle and HMRI; and funding from the National Health and Medical Research Council and The Cancer Council NSW.

**Author contributions:** *Study concept and design:* Waller, Sanson-Fisher, Zdenkowski, Pearce, Douglas. *Recruitment:* Zdenkowski, Douglas. *Data acquisition:* Waller, Walsh. *Data analysis and interpretation:* Evans. *Manuscript preparation and final approval:* All authors.

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stance, many patients wish to die at home, yet many die in hospital,<sup>10,11</sup> which can lead to higher rates of unwanted aggressive treatment and poor symptom management.

For patients to get the care they want at EOL, their wishes must be known to those involved in care decision-making and delivery.<sup>12,13</sup> Advance care planning (ACP) is a process whereby individuals consider, discuss, and document their values, wishes, and preferences about future medical care in case they later experience loss of capacity.<sup>12,14</sup> ACP requires explicit discussions about the inevitability of death, prognosis, and the likely trajectory of illness. People can legally appoint substitute decision-makers (referred to as enduring guardians throughout) and record wishes in written documents, such as an advance care directive or care plan.<sup>15</sup> Completed appropriately, ACP has been shown to reduce stress, anxiety, and depression.<sup>12</sup> It has also been associated with less unwanted aggressive medical care and lower healthcare costs.<sup>9,16</sup>

Despite these potential benefits, those involved in the care of patients with cancer report difficulties in knowing when, how, and with whom to initiate these conversations.<sup>17,18</sup> The reported proportion of patients with advanced cancer who engage in EOL discussions varies, with some reporting <40%<sup>9,19</sup> and others as high as 73%.<sup>20,21</sup> Most of these conversations begin in the final weeks of life, in the context of hospital admissions or ED visits.<sup>20</sup> Furthermore, documentation of a person's EOL wishes is often limited.<sup>20</sup> The extent to which this corresponds with patient preferences remains unclear. Of the 40 published studies in a recent systematic review exploring ACP in oncology populations,<sup>17</sup> most were conducted in the United States and relied primarily on qualitative data. Only 5 of 14 studies examined outpatient preferences quantitatively, with limited information about the determinants of ACP participation,<sup>17</sup> the manner in which patients wanted EOL wishes conveyed, or the content of discussions, emphasizing the need for methodologically rigorous research examining the patient perspective about this range of issues.

This study aimed to determine in a sample of medical oncology outpatients: (1) the proportion who have already discussed and documented EOL wishes; (2) when and with whom patients would prefer to convey their EOL wishes; (3) the EOL issues patients would want to be asked about; and (4)

the association between perceived cancer status and participation in ACP.

## Methods

### Sample and Procedure

A description of the study sample and procedures was published previously.<sup>22,23</sup> Briefly, clinic staff identified eligible participants, which included adult medical oncology outpatients attending their second or subsequent appointment at a tertiary treatment center, who were able to read and understand English, and who were judged as being physically and cognitively able to participate. Patients who indicated to clinic staff that they would be willing to talk to a trained research assistant were approached for consent to complete a pen-and-paper survey. Given the potentially sensitive nature of the items, oncologists asked consenting patients to complete the survey at home and return it directly to the research team in a reply paid envelope. Nonresponders received a reminder letter 2 weeks later.

### Outcome Measures

The items described here are drawn from a larger set of survey items, some of which are reported elsewhere because they address different themes.<sup>22,23</sup> The survey instrument included the following definitions of ACP and EOL care: "ACP provides an opportunity for people to think, discuss, and plan for the medical treatment they would prefer if they became too ill in the future to express their wishes. Everyone should consider ACP, regardless of their age or health. But it is particularly important for people who have ongoing health problems. These questions ask for your views and experiences in talking and making decisions about your future medical care, including EOL care. EOL care refers to care that helps people with advanced, incurable illness to live as well as possible until they die."

**Self-Reported Participation in ACP:** Patients were asked to respond either yes/no to whether they had ever: discussed the type of EOL care they would want to receive with their doctor and/or support person; written down their wishes for EOL care (eg, in an advance care directive or advance care plan); and appointed an enduring guardian (ie, someone legally appointed to make medical decisions on their behalf if they are unable to make decisions themselves).

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**Timing of First EOL Discussion:** Participants were asked to respond to the statement, “When would it be best to have the first conversation with your doctor about EOL care,” with one of the following responses: “When you are first diagnosed,” “When your cancer becomes incurable,” “When you decide to raise the matter,” “When your doctor decides to raise it,” and “Would not want to discuss at all.”

**Preferences for Conveying EOL Wishes:** Under a question that asked, “What you would want if you were facing the end of your life,” participants were asked to respond on a 5-point Likert scale (1 = strongly disagree; 5 = strongly agree) to each of the statements, “I would want to be able to: (1) have my family/friends present when discussing my EOL options; (2) write down my wishes for EOL care; and (3) appoint someone to make decisions on my behalf if I were unable to make decisions myself.”

Participants were also asked to choose a response to the question, “If you became physically or mentally unable to make decisions on your own, would you prefer your EOL care to be decided by: (1) a plan you had made before you got too sick to make decisions; (2) your doctor with your family/friends, based on their views of what was best; or (3) only your doctor, based on their view of what was best for you.”

### What Topics Did Patients Want to Be Asked About?

Again under a heading, “What you would want if you were facing the end of your life,” participants were asked to respond on a 5-point Likert scale to each of the statements, “I would want my healthcare team to ask me: (1) how involved I want to be in decisions about my EOL care; (2) how important it is that my pain is managed well at EOL; (3) how important it is I remain conscious and able to talk with my loved ones; and (4) how important it is that my care extends my life for as long as possible.”

### Associate Variables

All independent variables were obtained from patient self-report, except for patient’s current cancer status (palliative vs curative), which was obtained from their medical records. Sociodemographic items included sex, age, and country of birth. Clinical items included the patient’s self-reported cancer type and perceived cancer status, and personal estimation of life expectancy. Perceived cancer status was based

on responses to the question, “Where are you in your cancer journey?” The response options were “I am receiving treatment to try and cure my cancer,” “I have completed treatment to cure my cancer and am now in follow-up,” “I have been told my cancer cannot be cured and I am receiving anticancer treatment,” and “I have been told my cancer cannot be cured, and am not currently receiving anticancer treatment.” For analysis, the first 2 and last 2 response categories were collapsed to give 2 categories: “curable” and “incurable,” respectively. The question, “What is your estimation of your life expectancy,” provided 6 response options: “Less than 6 months,” “6 months to 1 year,” “1–2 years,” “More than 2 years,” “Don’t know, but I would like this information,” and “Don’t know and I do not want this information.” For analysis, the first 3 of these categories were collapsed to form one category (“Less than 2 years”).

### Ethics Approval

The study was approved by the University of Newcastle Human Research Ethics Committee (H-2014-0411) and the ethics committee of the participating health service (14/11/19/4.04).

### Statistical Analysis

Statistical analyses were programmed using SAS 9.4 (SAS Institute). Exploratory chi-square or Fisher exact tests for independence were performed for survey items with cancer status (ie, curable vs incurable). Due to the large number of tests performed, a more stringent chi-square *P* value threshold of <.01 was used to indicate statistical significance; Bonferroni adjustment was deemed overly conservative for exploratory purposes.<sup>1</sup> A composite ACP score was then created by summing the number of “yes” responses for 4 ACP items (discussion with doctor, discussion with support person, written EOL wishes, and appointed enduring guardian). Scores ranged from 0 (none) to 4 (all). Missing values assumed a value of 0. Ordinal logistic regression of this outcome on cancer status was performed. Crude and adjusted odds ratios (ORs), Wald 95% CIs, and *P* values are presented. The relationship was adjusted for patient age, sex, and country of birth. Because the main interest was in the perceived cancer status variable, we do not present ORs for the confounding variables (data were insufficient for us to assess whether these were truly predictors). The propor-

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tional odds assumption was assessed using the score test. Available-case analysis was conducted. A sample size of 203 allowed estimation of population proportions within a 7% margin of error.

## Results

### Sample

Of the 436 eligible patients approached for consent, 366 consented to participate (83% of eligible) and 203 (55% of consenters) returned a survey. Mean participant age was 65 years, 59% were female, and 34% had a diagnosis of breast cancer. One-third reported being told their cancer could not be cured; 53% reported they did not know their life expectancy, and of these, approximately half reported that they wanted this information (Table 1).

### Have Patients Participated in ACP?

Fewer than half of the patients had already discussed with their support person the type of care they would want to receive (46.8%), and only 7.4% had discussed this with their doctor. Few patients indicated that they had completed an advanced care directive

or ACP (13.8%), whereas 45.3% had appointed an enduring guardian (Table 2). One-third (35%) had not participated in any component of ACP, and only 3% had participated in all 4 components.

### When Would Patients Prefer EOL Discussions to Occur?

Regarding when patients would prefer to have their first discussion about EOL care, 45.3% responded when their cancer became incurable. Almost a third (29.5%) preferred for it to occur when they decided to raise the topic themselves, whereas 13.3% preferred for it to occur when the doctor decided. Only 6.9% felt it should happen at initial diagnosis (Table 2).

### With Whom Do Patients Want to Convey EOL Wishes?

Most participants wanted to be able to have their family present when discussing EOL care options (84.7%); write down their wishes in an advance care directive or care plan (81.8%); and to appoint an enduring guardian (90.6%). If unable to make decisions themselves, patients indicated a preference for their care to be decided by their doctor in consultation with their family (47.3%) or by a care plan they had completed themselves (43.8%). Very few patients wanted their doctor to make decisions about their EOL care without consultation (4%) (Table 2).

### What EOL Issues Do Patients Want to Be Asked About?

If facing the end of their life, almost all patients would want their doctor to ask them how involved they would like to be in EOL decisions (92.1%), how important it is their pain is managed well (95%), and that they remain conscious and able to talk with loved ones (81.7%). Fewer patients wanted to be asked by their doctor how important it is that their care extends their life (55.2%) (Table 2).

### Exploratory Analyses: Curable Versus Incurable

**Chi Square Analysis:** Statistically significant differences were reported for the item, “When would it be best to have the first conversation with your doctor about EOL care?” Patient-perceived curable patients (54.4%; n=68) preferred the first conversation with their doctor to occur when their cancer was deemed incurable, whereas the predominant response for

**Table 1. Patient Sociodemographic and Clinical Characteristics (N= 203)**

	Sample n (%)
Sex	
Male	84 (41%)
Female	119 (59%)
Mean age (SD), y	65 (11.5)
Australian born	
Yes	173 (85%)
No	25 (12%)
Missing	5 (2.5%)
Cancer type	
Breast	69 (34%)
Colorectal	35 (17%)
Prostate	21 (10%)
Lung	21 (10%)
Other	55 (27%)
Missing	2 (1%)
Self-reported cancer status	
Curable	125 (61.6%)
Incurable	72 (35.4%)
Missing	6 (3.0%)
Life expectancy	
≤2 years	21 (10.3%)
>2 years	69 (34%)
Unsure, wanted to know	52 (25.6%)
Unsure, did not want to know	56 (27.6%)
Missing	5 (2.5%)

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Table 2. Participation and Preferences Regarding EOL Discussions

	Total n (%)	Curable n (%)	Incurable n (%)	P Value
<b>Total</b>	203	125	72	
<b>I would want to be:</b>				
Asked how important it is that my pain is managed well at the EOL				.4436
Disagree	2 (1.0%)	1 (0.8%)	1 (1.4%)	
Unsure	5 (2.5%)	2 (1.6%)	3 (4.2%)	
Agree	193 (95%)	120 (96%)	67 (93%)	
Missing	3 (1.5%)	2 (1.6%)	1 (1.4%)	
Asked how important it is I remain conscious and able to talk with my loved ones.				.1606
Disagree	6 (3.0%)	4 (3.2%)	2 (2.8%)	
Unsure	28 (13.8%)	13 (10.4%)	15 (20.8%)	
Agree	166 (81.7%)	105 (84%)	55 (76.4%)	
Missing	3 (1.5%)	3 (2.4%)	0	
Asked how important it is that my care extends my life for as long as possible				.1945
Disagree	40 (19.7%)	27 (21.6%)	11 (15.3%)	
Unsure	49 (24.1%)	25 (20%)	22 (30.5%)	
Agree	112 (55.2%)	72 (57.6%)	38 (52.8%)	
Missing	2 (1.0%)	1 (0.8%)	1 (1.4%)	
Asked how involved I want to be in decisions about my EOL care				.0049*
Disagree	4 (2.0%)	3 (2.4%)	0	
Unsure	11 (5.4%)	2 (1.6%)	8 (11.1%)	
Agree	187 (92.1%)	119 (95.2%)	64 (88.9%)	
Missing	1 (0.5%)	1 (0.8%)	0	
Family/Friends present when discussing my EOL care options				.0273
Disagree	14 (6.9%)	10 (8.0%)	1 (1.4%)	
Unsure	13 (6.4%)	5 (4.0%)	8 (11.1%)	
Agree	172 (84.7%)	107 (85.6%)	62 (86.1%)	
Missing	4 (2.0%)	3 (0.8%)	1 (1.4%)	
Able to appoint someone to make decisions on my behalf if I was unable to make decisions myself				.3528
Disagree	7 (3.4%)	5 (4.0%)	1 (1.4%)	
Unsure	9 (4.5%)	4 (3.2%)	5 (6.9%)	
Agree	184 (90.6%)	114 (91.2%)	65 (90.3%)	
Missing	3 (1.5%)	2 (1.6%)	1 (1.4%)	
Able to write down my wishes for EOL care				.8817
Disagree	12 (5.9%)	7 (5.6%)	5 (6.9%)	
Unsure	21 (10.3%)	12 (9.6%)	8 (11.1%)	
Agree	166 (81.8%)	103 (82.4%)	58 (80.6%)	
Missing	4 (2.0%)	3 (2.4%)	1 (1.4%)	
If you became unable to make decisions on your own, would you prefer EOL care be decided by				.3996
Care plan you made in advance	89 (43.8%)	57 (45.6%)	30 (41.7%)	
Doctor in consultation with family	96 (47.3%)	57 (45.6%)	37 (51.4%)	
Doctor only	8 (4.0%)	6 (4.8%)	1 (1.4%)	
Missing	10 (4.9%)	5 (4.0%)	4 (5.5%)	
When would it be best to have the first conversation with your doctor about EOL care?				.0099
When you are first diagnosed	14 (6.9%)	7 (5.6%)	7 (9.7%)	
When your cancer becomes incurable	92 (45.3%)	68 (54.4%)	21 (29.2%)	
When you decide to raise the matter	60 (29.5%)	28 (22.4%)	29 (40.2%)	
When your doctor decides to raise it	27 (13.3%)	15 (12%)	12 (16.7%)	
Would not want to discuss at all	6 (3.0%)	4 (3.2%)	2 (2.8%)	
Missing	4 (2.0%)	3 (2.4%)	1 (1.4%)	
<b>I have already:</b>				
Discussed the type of EOL care I would like to receive with my doctor				<.0001
Yes	15 (7.4%)	2 (1.6%)	13 (18.1%)	
No	172 (84.7%)	114 (91.2%)	52 (72.2%)	
Missing	16 (7.9%)	9 (7.2%)	7 (9.7%)	
Discussed the type of EOL care I would like to receive with my SP				.0062
Yes	95 (46.8%)	49 (39.2%)	43 (59.7%)	
No	104 (51.2%)	73 (58.4%)	28 (38.9%)	
Missing	4 (2.0%)	3 (2.4%)	1 (1.4%)	
Written down my wishes for EOL care in ACD or care plan				.2049
Yes	28 (13.8%)	14 (11.2%)	13 (18.1%)	
No	165 (81.3%)	104 (83.2%)	57 (79.1%)	
Missing	10 (4.9%)	7 (5.6%)	2 (2.8%)	
Appointed an enduring guardian				.1005
Yes	92 (46%)	50 (40%)	38 (53%)	
No	109 (53.7%)	73 (58.4%)	34 (47%)	
Missing	2 (1.0%)	2 (1.6%)	0	

Abbreviations: ACD, advance care directive; EOL, end of life; SP, support person.

incurable patients (40.3%; n=29) was when they decide to raise the matter (Table 2). Statistically significant differences were also reported for the item, “I would want to be asked how involved I want to be in decisions about my EOL care”; a higher percentage of incurable than curable patients were unsure (11% vs 1.6%, respectively;  $P<.05$ ). No other statistically significant differences were found between these 2 groups.

**Ordinal Regression on ACP Composite Score:** The odds of participating in ACP were greater for incurable patients (OR, 2.6; 95% CI, 1.48–4.67).

## Discussion

It is encouraging that many patients had discussed EOL with a support person and/or had nominated an enduring guardian. However, the proportion who had discussed EOL care with their doctor or had written down their wishes was negligible, even among those who perceived their disease was incurable. Some patients and families may be reluctant to be fully informed or involved in decisions about EOL at all.<sup>24</sup> When discussions are initiated in these circumstances, patients and families may experience increased emotional distress.<sup>25</sup> However, when a desired discussion does not happen or if it is conducted poorly, patients/families may overestimate prognosis or misunderstand the goals of treatment.<sup>26</sup> The absence of discussions with doctors is particularly concerning. Without their involvement in discussions, the patient and support person may not clearly understand the intent of treatment.<sup>27,28</sup> Relying on the views of support persons or clinicians may not always result in decisions that accord with patient views. Greater clarity is needed regarding the extent to which the low discussion rates reflect patient preferences (eg, doctor raised topic but patient reluctant to discuss); low recall by patients about EOL discussions; or provider- or other system-related barriers (eg, lack of provider skills, fear of depriving patient of hope).

Clinicians infrequently elicit patients' preferred involvement in decision-making and their preferences for involving support persons in cancer care.<sup>29</sup> Most respondents in this study reported that if they were facing EOL, they would want their support person present when EOL options are discussed, to be able to appoint an enduring guardian, and to record

their EOL wishes. Involving support persons when desired by patients can relieve stress and provide comfort at EOL.<sup>17</sup> Ensuring support person involvement would seem particularly important for patients who indicate a preference for a shared approach to EOL decision-making (ie, doctor deciding in consultation with the family). Patients' and families' distress must also be managed when deciding on goals of care.<sup>30</sup> Opportunities to document the content of EOL discussions should be offered, given that half of respondents wanted EOL care to be decided by an ACP they had made. Documenting discussions may also address patient concerns about upsetting or placing undue burden on enduring guardians.<sup>18</sup> Although some patient preferences may be sufficiently stable that they may be used to inform decisions at a later time,<sup>31</sup> clarifying these preferences at a time when choices become more clinically relevant is recommended.<sup>26</sup>

Approximately half of the patients in this study reported that the first discussion about EOL care should occur when disease became incurable (45.3%). This requires that patients have an accurate perception of curability of disease. Consistent with findings from previous studies,<sup>32–34</sup> a quarter of the patients surveyed herein reported that they were not getting the information they wanted about their life expectancy. Most patients prefer their doctor to ask them before discussing the impact that cancer might have on their life expectancy. Communication skills training can improve confidence, skills, and knowledge among clinicians in approaching these conversations.<sup>35</sup> Other strategies, such as audio recording consultations and providing oncologists with tailored feedback, have positively influenced patient trust and oncologist responsiveness to patient concerns.<sup>36</sup>

Not all patients agreed that incurable disease should trigger EOL conversations; almost one-third indicated that they would want to decide when to initiate EOL discussions. A small minority wanted their doctor to decide when to raise the issue or for the discussion to occur at initial diagnosis. Clinicians are therefore faced with trading off the potential benefits of an EOL discussion against respecting indications from their patients that they are not ready. Patient control over when EOL discussions occur was particularly favored by those who perceived their cancer was incurable. However, not all patients have the knowledge or skills to do so. Some

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may feel apprehensive about raising the topic themselves or perceive that the doctor does not have time for a discussion.<sup>37</sup> Increasing patient knowledge and skills may be achieved through interventions such as Web-based programs and decision aids. When made available to patients, these programs have increased documentation of EOL preferences by 25% to 30%.<sup>38</sup> Clinicians must also be willing and able to respond to issues raised, highlighting the importance of interventions that target both patients and providers. For instance, skills-based training and tailored previsit educational coaching interventions have been effective in improving EOL communication.<sup>39</sup>

Some respondents expressed negative or ambivalent attitudes toward the sort of patient-centered treatment-limitation decisions that are implicit in EOL care planning. Although most respondents in this study reported that they would want to be asked by clinicians about the importance of being able to remain conscious and about pain management, fewer patients indicated that they would want to be asked about the importance of care extending life. Clinicians should therefore anticipate that people will want to talk about the potential impact their EOL choices will have on quality and, perhaps to a lesser extent, quantity of life. The assumption that people would wish to extend their life irrespective of the consequences<sup>40</sup> does not always hold true.

### Strengths and Limitations

Although this study provides novel data about preferences and experiences in EOL discussions and ACP among a large group of Australian medical oncology outpatients, it has a number of limitations. Patients taking surveys home to complete and/or the nature of the topic may have contributed to low response rates. However, these rates are similar to previous studies in this field. Our results are from a single-institution sample, which may not be representative

of results from other institutions. The cross-sectional nature of the data is also a limitation, given the potentially dynamic nature of decision-making about preferences and the influences of deterioration in physical functioning, diminished family resources, or available healthcare system factors on preferences. Choices about a hypothetical situation (ie, “if you were facing the end of your life”) do not necessarily translate to a real situation faced in the future. Replicating the survey with patients at a point late in the illness trajectory would help determine whether preferences differ in these circumstances, but such a survey faces ethical challenges in confronting patients with issues they may not wish to consider. Replicating the survey with culturally and linguistically diverse groups is also an important next step.

### Conclusions

There is increasing evidence that conducting early EOL discussions with patients improves outcomes and quality of care. However, there is variability among patients about when and with whom they would want to convey their EOL wishes. The first step in approaching this process requires that clinicians ask whether an individual patient wishes to discuss EOL issues, in what format, and at what level of detail. Adequate time for discussions and appropriate supportive care staff/resources are also needed to ensure that concerns are addressed effectively. Further work is needed to examine the potential benefits of complex interventions that target multiple stakeholders (eg, patients, support persons, healthcare providers) in enhancing ACP in oncology.

### Acknowledgments

The authors wish to thank the hospital staff, patients, and families for their contribution to this research.

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