Qualitative Study of Patients' and Caregivers' Perceptions and Information Preferences About Hospice

Areej El-Jawahri, MD,^{1,2,*} Lara Traeger, PhD,^{3,*} Jennifer A. Shin, MD,^{2,4} Helen Knight, BA,^{1,3}
Kristina Mirabeau-Beale, MD,^{2,5,6} Joel Fishbein, BA,^{1,3} Harry H. Vandusen, BS,^{1,3} Vicki A. Jackson, MD,^{2,4}
Angelo E. Volandes, MD, MPH,^{2,5,6} and Jennifer S. Temel, MD^{1,2}

Abstract

Objective: The goal of this study is to assess perceptions about hospice among patients with metastatic cancer and their caregivers (i.e., family and/or friends).

Design and Setting: We conducted semi-structured interviews with 16 adult patients with a prognosis ≤ 12 months and 7 of their caregivers. The interviews focused on perceptions, knowledge, and information preferences about hospice. Two raters coded interviews independently ($\kappa > 0.85$). We used a framework approach for data analysis.

Results: Participants showed variable gaps in understanding about hospice, including who would benefit from hospice care and the extent of services provided. They all perceived that hospice involves a psychological transition to accepting imminent death and often referred to hospice from a relatively cognitive distance, using hypothetical scenarios of others for whom hospice would be more relevant. Participants' attitudes about hospice reflected their concerns about suffering, loss of dignity, and death, as well as their perceived understanding of hospice services. These attitudes along with the psychological barriers to projecting a need for hospice and lack of knowledge were all perceived as important barriers to hospice utilization. All participants felt they needed more information about hospice, yet they were mixed regarding the optimal timing of this information.

Conclusions: Study participants had misunderstandings about hospice and perceived end-of-life (EOL) concerns such as fear of suffering, loss of dignity, and death, as well as lack of knowledge as the main barriers to hospice utilization. Interventions are needed to educate patients and their families about hospice and to address their EOL concerns.

Keywords: advanced cancer; barriers to hospice use; end of life; hospice perception

Introduction

CANCER IS EXPECTED to become the most common cause of death within the next decade as the population ages.¹ Thus, it is essential that patients with cancer are educated about their options for care at the end of life (EOL), including the role of hospice services.^{2,3} Hospice provides palliative and supportive care to patients at the EOL through an interdisciplinary team of providers who address the physical, psychological, social, and spiritual needs of patients and their families.⁴ Data have demonstrated that hospice delivers high-quality EOL care to dying patients with excellent patient and

family satisfaction.^{5–9} Longer admissions to hospice are associated with better quality life in patients and lower rates of depression and complicated bereavement in caregivers (i.e., family members and close friends).^{10–12} Recent studies suggest that earlier admissions to hospice may increase caregivers' perceived comfort with EOL care and their loved ones' symptom management.¹³ In addition, caregivers report higher satisfaction with the quality of EOL care for patients who die with hospice involvement.¹⁴

Despite its many benefits, only 30%–40% of people in the United States die while under the care of a hospice program.⁴ Moreover, the median length of stay in hospice is less than

¹Department of Hematology-Oncology, Massachusetts General Hospital, Boston, Massachusetts.

²Harvard Medical School, Boston, Massachusetts.

Departments of ³Psychiatry, ⁴Palliative Care, ⁵Radiation Oncology, and ⁶General Internal Medicine, Massachusetts General Hospital, Boston, Massachusetts.

*These authors contributed equally to this work.

Accepted February 12, 2017.

three weeks, indicating that many patients enroll late during the course of their illness and may not derive the full benefits of having hospice care.^{14,15} Many factors contribute to low rates of enrollment and short lengths of stay in hospice, including (1) poor prognostication and insufficient communication with physicians^{16,17}; (2) patient-caregiver perception of not being ready for hospice¹³; (3) system's barriers, including variable definitions of hospice eligibility and varying interpretation of regulations^{13,18,19}; (4) physicians' overly optimistic beliefs about survival time^{20,21}; and (5) late diagnosis of advanced disease.^{13,22} Indeed, physicians are often reluctant to initiate these conversations and/or discuss hospice very late in the illness course.^{23,24} As a result, patients and caregivers often lack adequate information about hospice, which is also a potential barrier to timely enrollment.^{5,23,25} However, it remains unclear as to what extent patients' and caregivers' perceptions of hospice also contribute to low hospice utilization and late referral patterns.

Several studies have explored factors that may influence hospice decision making for patients with advanced cancer.^{26–31} These studies have highlighted the multidimensional nature of the decision-making process.²⁶ Demographic, clinical, and other patient-related characteristics have all been associated with the decision to enter hospice.^{26,27,29} Importantly, studies have shown that patients' perceptions of their prognosis inform their decision making about their EOL care.²⁰ In fact, hospice patients are more realistic about their disease course and prognosis compared with patients who never receive hospice care.²⁶ Although these studies underscore the complexity of the hospice decision-making process, little is actually known about patients' and caregivers' perceptions of hospice and their perceived barriers to its utilization.³² These perceptions are deeply personal and may require qualitative work to be fully elucidated.³²

In this qualitative study, we examined advanced cancer patients' and their caregivers' knowledge and overall perception of hospice, and their assessments of barriers to hospice enrollment. We also explored patients' and caregivers' preferences for interventions to increase knowledge of hospice services. By examining knowledge gaps and the perceived barriers for hospice utilization from the patients' and caregivers' perspective, we can develop interventions that can both educate patients and their families about their care options and reduce barriers to discussions about hospice with their oncologist.

Methods

Participants

The study included adult (age ≥ 18) English-speaking patients with a diagnosis of metastatic solid malignancy who were receiving their cancer care at the Massachusetts General Hospital Cancer Center. Eligibility criteria also include an (1) estimated prognosis of ≤ 12 months as determined by their primary oncologist; and (2) the capacity to complete a 30-minute interview about hospice. We excluded patients with significant psychiatric or other comorbidities, which the treating oncologist believed impaired their ability to provide informed consent. We also excluded patients who were already referred to hospice. We asked enrolled patients to identify a caregiver (e.g., a relative or a friend who either lived with the patient or had in-person contact with him/her at

least twice per week) and invited this person to participate in the caregiver portion of the study. Patients without a willing or an available caregiver were eligible to participate. This study was approved by the Dana Farber Harvard Cancer Center Institutional Review Board.

Study design and procedures

We recruited participants via referrals from oncologists and palliative care providers during weekly team reviews of patients with scheduled outpatient clinic visits. Oncology and palliative care clinicians were asked to only refer patients who they perceived understood that their illness was incurable. Once a potentially eligible participant was identified, the research assistant introduced the study and obtained written informed consent from the patient (and caregiver if they were willing to participate). We then scheduled a 30-minute telephone visit with consented participants to conduct the interview. We chose 30-minute telephone interviews to increase flexibility for participation and to reduce burden on patients and caregivers. Patients and caregivers were offered either a one-hour parking voucher or a \$10 gift card from Amazon.com or Best Buy as an incentive for their participation.

We conducted semi-structured interviews to (1) explore participants' prior exposure and sources of information about hospice, (2) knowledge about hospice, (3) overall feelings regarding hospice care, (4) perceived barriers to hospice utilization, and (5) preferences for receiving information about hospice. Within each of these topics, we used open-ended questions and encouraged participants to raise points that were important to them. One member of the research team conducted all interviews. We audio-recorded all interviews and transcribed them verbatim. Patients and caregivers were interviewed separately. We also administered a brief demographic questionnaire detailing participants' age, race, ethnicity, education, and income.

Data analyses

We analyzed the qualitative data by using a framework approach, to reduce risk of data misinterpretation.³³ This approach involves a reflexive process of data management and interpretation that allows for shifts back and forth between levels of abstraction while ensuring that results remain rooted in the original data. Analysis was applied systematically across all transcripts and all sections within transcripts. We first reviewed the interview transcripts to identify codes and to develop a coding structure to organize them. Codes were guided by the raw data and interview guide. Transcripts were read and re-read, and flexibility was allowed to test the codes and to amend and clarify the coding structure as the reviews progressed. Use of a template allowed us to document an evidence trail. Phrases were independently coded by two study investigators using NVivo 10. Coders examined discrepant, unexpected, or unclear data with a third study team member until resolution. Kappa coefficients were generated to evaluate coding precision (range: 0 [chance] to 1 [perfect agreement]). The final kappa (>0.85) indicated a high level of agreement. The team collaborated to organize codes into themes and to identify ideas or abstract concepts that were associated with them. Interview transcripts were reviewed throughout this process to ensure that themes reflected the original data and their context. Results were

consistent between patients and caregivers and, therefore, were presented together. Quotes were extracted to highlight specific themes. With a sample size of 16 patients and 7 caregivers, we were able to achieve thematic saturation.

Results

Participants' characteristics

Table 1 depicts patients' and caregivers' demographic and clinical characteristics. We enrolled 16 patients with metastatic cancer and 7 of their caregivers between November 5, 2013 and February 25, 2014. Only one patient refused participation due to time constraints. Participants were primarily white (96%, 22/23), with a median age of 62 (29–86). The majority of patients were men (63%), whereas most caregivers were women (86%). Among the patients included in this study, 38% (6/16) had metastatic gastrointestinal cancers. Most caregivers enrolled in this study were married to the patients (71%, 5/7).

Overarching ideas

Although patients and caregivers showed variable gaps in understanding about hospice, they widely perceived that hospice transition involved a psychological transition to accepting certain imminent death. Thus, patients and caregivers referred to hospice from a cognitive distance, often using downward comparisons to hypothetical others for whom hospice would be more relevant. Fear, nevertheless, featured

prominently in responses, with hospice described as a harbinging, comfort, and/or potential intrusion in the context of difficult EOL experiences. Patients and caregivers, in turn, expressed interest in gaining clarity and reassurance about hospice. Specific themes related to knowledge, attitudes, perceived barriers, and preferences for learning about hospice are described later and summarized in Tables 2 and 3.

Knowledge of hospice

Patients and caregivers primarily defined hospice as a service for patients facing the very EOL—described as “on [their] way out,” “in their last days,” and with “no more hope.” The most common perceived role of hospice was to provide symptom relief ($n=20$), with emphasis on helping patients become “as comfortable as possible.” Other perceived hospice roles included provision of psychosocial or spiritual support for patients and their families (“Lend a good ear for the person to talk”; $n=17$) and patient medical care (e.g., monitor vital signs, titrate medication doses; $n=14$). However, some respondents inaccurately thought that hospice assisted with activities of daily living ($n=6$) or practical issues ($n=5$; e.g., respite care and funeral arrangements). Moreover, a few described hospice as being the most relevant for patients who lack family support ($n=3$; “To know what you have is terminal, and not have any family—I can’t imagine what that’s like.”).

Attitudes about hospice

Respondent attitudes about hospice, whether positive ($n=16$), negative ($n=4$), or unsure ($n=4$), reflected the following factors: concerns about suffering, loss of dignity, and death, as well as their perceived understanding of hospice services.

Concerns about suffering, loss of dignity, and death. Respondents with positive attitudes viewed hospice as a key support in the face of feared outcomes. Hospice was described as a “good safe place” for patients with gaps in family support; a “relief” for family to know that their loved one’s care would be in good hands; and a “comfort” for help to reduce suffering and maintain dignity. In comparison, respondents with negative attitudes focused on hospice as a key harbinger of feared outcomes: “[Hospice] scares me, because it means death.”

Perceived understanding of hospice services. Respondents with positive attitudes reflected on good prior hospice experience (“Everybody was so knowledgeable and nice”), whereas one person with a negative attitude reflected on poor prior experience (“They promise a lot but nothing’s around.”). Conversely, two respondents who had no prior hospice experience felt that a lack of understanding led them to feel neutral (“I don’t know enough...to have feelings [about it]”) or scared (“I hope I can be educated about...what to expect”).

Perceived barriers to hospice utilization

Perceived barriers to hospice utilization were related to knowledge and attitudes, and they highlighted three influencing factors: psychological barriers to projecting a need for

TABLE 1. PARTICIPANTS' CHARACTERISTICS

Variable	Patients (n = 16)	Family caregivers (n = 7)
Gender (%)		
Male	10 (62.5)	1 (14)
Female	6 (37.5)	6 (86)
Median (range)	62 (54–86)	63 (29–70)
White race (%)	15 (94)	7 (100)
Partner status (%)		
Married or with partner	10 (62.5)	5 (71)
Widowed	2 (12.5)	1 (14)
Single, never married	1 (6)	0 (0)
Divorced/separated	3 (19)	1 (14)
Children (%)	14 (88)	5 (71)
Religion (%)		
Catholic	5 (31)	3 (43)
Protestant	2 (13)	3 (43)
Jewish	1 (6)	0 (0)
Other	3 (19)	0 (0)
None	5 (31)	1 (14)
Education (%)		
≤ High school	2 (13)	1 (14)
Some college	5 (31)	2 (29)
College degree	4 (25)	3 (43)
Advanced degree	5 (31)	1 (14)
Type of cancer		N/A
Gastrointestinal	6	
Lung	3	
Genitourinary	2	
Other	5	

N/A, not applicable.

TABLE 2. KNOWLEDGE AND ATTITUDES ABOUT HOSPICE AND PERCEIVED BARRIERS TO HOSPICE UTILIZATION

Overarching ideas

- Patients and their family caregivers showed variable gaps in understanding about hospice but widely perceived that hospice involves a psychological transition to accepting certain imminent death.
- Patients and their family caregivers referred to hospice from a relatively cognitive distance, often using downward comparisons to hypothetical other patients and their families.
- Hospice was perceived as a harbinger, comfort, and/or potential intrusion in the context of difficult EOL experiences.

Major and minor themes

Knowledge about hospice

Patients and their family caregivers perceived that hospice focuses on patients at the very EOL.

"[The purpose of hospice] is to make death as comfortable as possible." (patient)

The perceived role of hospice not only focused on symptom relief but also variously included psychosocial and spiritual support, medical care, and daily living assistance.

"[With hospice] you are just kept comfortable, from what I understand." (family caregiver)

"Hospice is really nothing medical. They just sort of listen to the patient." (patient)

"[Hospice is for] daily living care in terms of personal hygiene, help with meals and help with medical care." (family caregiver)

Attitudes about hospice

Attitudes about hospice reflected two key factors:

1. Concerns about suffering, loss of dignity, and death.
 - "Hospice sounds terrific. I think it is important care for someone who is nearing death and is...just suffering tremendously."* (family caregiver)
 - "[When you need hospice], you have lost all ability to do anything...so I would not be comfortable with that situation."* (patient)
2. Perceived understanding of hospice services.
 - "When my mother passed, [hospice] was very kind. It seems like a decent human thing."* (patient)
 - "The one experience we had with hospice was bad. My brother-in-law died. [Hospice] barely came in to see him."* (family caregiver)
 - "I feel a little bit hesitant about hospice, I guess scared is the right word. I am a bit...standoffish about what I might run into."* (patient)

Perceived barriers to hospice utilization

Barriers were related to knowledge and attitudes, and they highlighted three influencing factors:

1. Psychological barriers impact ability to project a need for hospice.
 - Uncertainty: *"That's hard psychologically to deal with six months ahead, to say ok, I'm really at the end right now."* (patient)
 - Cost of losing hope: *"They're afraid that they're going to miss out on some treatment that is going to keep them alive."* (patient)
 - Avoidance of feared outcomes: *"Maybe there is a false sense of security that everything is okay as long as they stay out of hospice."* (family caregiver)
2. EOL care is a personal or family domain.
 - "I think every family strives to provide the services the patient needs because they feel a sense of abandoning the patient if they dole that off on someone else."* (family caregiver)
 - "All of a sudden...you have six months to live, and you've got these complete strangers in your house who are supposedly going to make you feel better."* (patient)
3. Patients and their families may lack understanding about hospice.
 - "Maybe [barriers are due to]...not understanding what is going to happen. I think it is due to lack of understanding of what hospice is."* (patient)

hospice, perception of EOL care as a personal or family domain, and a lack of understanding about hospice.

Psychological barriers to projecting a need for hospice. These barriers were common ($n=19$) and referenced uncertainty (*"How do you know how long I'm going to live?"*), emotional costs of losing hope (*"...choosing hospice is giving up on treatment"*), and avoidance of feared outcomes (*"It is a scary benchmark to say hey, I am going to die"*). One caregiver noted that family members might avoid contacting hospice *"so they won't put fear into the patient."*

Perception of EOL care as a personal or family domain. Several respondents suggested that patients may prefer to care for themselves or that family may provide

support without the need for hospice ($n=11$). Some respondents voiced specific concerns about hospice staff interfering on patient and family privacy ($n=6$; *"...don't want any outside intrusion into a time that might be terribly personal or difficult."*).

Lack of understanding about hospice. Several respondents noted that people may not utilize hospice because they do not *"understand enough about it,"* are not *"thinking deeply enough about it,"* or don't learn about it *"until the last minute"* ($n=11$).

Preferences for learning about hospice

Given perceived barriers to hospice utilization, respondents largely showed interest in gaining clarity and/or

TABLE 3. PREFERENCES FOR LEARNING ABOUT HOSPICE AMONG PATIENTS AND CAREGIVERS

Overarching idea

- Patients and their family caregivers showed interest in learning about hospice for clarity and reassurance.
- Patients' and their family caregivers' recommendations for learning about hospice showed attention to individual preferences and to timing that would be the most effective and/or the least detrimental to the patient.

Major and minor themes

Areas of interest

Patients and family caregivers primarily wanted to know about hospice logistics.

"Do I see a nurse once a week? Do I see a caregiver only when...my husband calls and says, 'she's made a total mess here and I need somebody to come and help?' I don't know how any of that works." (patient)

Patients and their family caregivers also wanted to know how to qualify for coverage and to find and differentiate between hospice providers.

"What does it take to qualify [for hospice]? Just because the doctor says this patient is a good candidate for hospice, how is it covered [by insurance]?" (family caregiver)

Patients and their family caregivers wanted to understand the extent to which hospice may meet EOL needs.

"How are they easing him into a place where he can be at peace with himself, with dying...where he's not scared and fighting...what [do] they do about that?" (family caregiver)

Preferred methods of learning

Patients and their family caregivers were interested in reviewing information for a gentle introduction, broad picture, or an in-depth look into what hospice is like.

"I like to take [information] home and digest it. And then if I have questions, I would discuss it with my physician. Because when you are hearing information [during a clinic visit]...your mind is like, I can't believe this...and so you are not getting it." (patient)

Patients and their family caregivers also expressed interest in discussing hospice with current providers whom they trusted, often as a follow-up to reviewing information.

"My oncologist is very in tune with [my] feelings and all that. So, I would feel comfortable talking with him [about hospice]." (patient)

Some patients and their family caregivers further proposed learning from current hospice patients or staff or with other families, to gain reassurance, a real-life view, or information that one might not have thought to request.

"I think it would be helpful to...talk with providers that specialize in hospice, visit settings in which hospice is provided. I think it would be reassuring if people could have a visit and an interview or session." (patient)

Preferred timing of learning

Most patients and their family caregivers suggested learning about hospice early on after diagnosis, with a potential brief delay to process the initial shock of diagnosis or a longer delay to present more in-depth information.

"It's good to know...ahead of time. You don't have to decide right then and there, but it gives you time to process everything and think about what you want to do, where you want to be, and know that there are services available, that there are options." (patient)

Some patients and their family caregivers felt that hospice should not be addressed until necessary, so as not to interfere with hope or quality of life.

"In terms of my husband who's fighting desperately for his life, I don't want him to have what would be perceived as any negativity in terms of, 'You're going to die, let's talk about it.'" (family caregiver)

reassurance about hospice. Almost all respondents identified at least one aspect that they wanted to learn more about, with one patient noting that *"once you learn about something and you understand it, you lose your fear."*

Areas of interest. Respondents primarily wanted to know about hospice logistics ($n = 17$), including the range of services, locations of care, members of the hospice team, and frequency/length of home hospice visits. Some also wanted to know how to qualify for insurance coverage for hospice ($n = 7$) and to find and differentiate between hospice providers ($n = 5$). Overall, responses reflected concerns about the extent to which hospice may meet EOL needs—e.g., *"If [the patient] were struggling, would they be more comfortable in the hospital?"*

Preferred methods of learning. Responses reflected that hospice was a sensitive and somewhat mysterious topic to broach. Almost all respondents identified interest in reviewing information about hospice in brochure, video, or Internet format ($n = 22$), for a gentle introduction, a broad

picture, or an in-depth look into what hospice is actually like. Respondents also expressed interest in discussing hospice with current providers whom they trusted ($n = 13$), often as a follow-up to reviewing information. Some respondents further proposed learning from current hospice patients or staff or with other interested families ($n = 10$), to gain reassurance, a real-life view of hospice, or information that one might not have thought to request.

Preferred timing of learning. Perceived optimal timing of learning about hospice reflected attention to what would be the most effective and/or the least detrimental to patients. Most respondents suggested learning about hospice early after diagnosis of *"advanced"* or *"terminal"* disease ($n = 17$), to *"plant the seed," "plan ahead,"* or consider options *"before things get really bad."* Some of these respondents further suggested waiting for time to process the initial shock of diagnosis and to adjust to the treatment plan, or delaying more in-depth information until the patient's health worsens. However, others felt that hospice should not be addressed until *"something imminent"* occurs or there are *"[no] other*

options" (n = 6), with a few specifying that early information would interfere with hope and quality of life: "*If you look too far in the future, it is hard to go from day-to-day.*"

Discussion

Patients with advanced cancer and their caregivers had significant knowledge gaps about hospice, but widely perceived that hospice involves a psychological transition to accepting certain imminent death. Participants' attitudes toward hospice reflected their concerns about suffering, loss of dignity, and death, as well as their perceived understanding of hospice services. All participants desired more information about hospice and perceived lack of knowledge, and psychological barriers to projecting the need for hospice as the main barriers to hospice utilization. Participants preferred to learn about hospice through visual or written media before engaging in a discussion with their oncologists, but they disagreed on the optimal timing to introduce hospice to patients and their families.

This study provides an exploration of patients' and caregivers' perceptions and knowledge about hospice, as well as their perceived barriers to hospice utilization. We found that patients with advanced cancer and their caregivers had significant gaps in their knowledge about hospice, including who would benefit from hospice care and the extent of services provided. In another study of 237 patients and their families referred for a hospice information visit, only a minority reported that they were knowledgeable about hospice before the visit.⁵ These knowledge gaps likely contribute to the mystery of hospice and increase patients' and caregivers' fears about the unknown. By identifying these knowledge gaps, we can develop interventions to educate patients and their families, specifically targeting their needs and misperceptions.

Many participants' attitudes toward hospice were shaped by their EOL concerns as they perceived the hospice transition involving a psychological transition to accepting the dying process. Fear of dying, concerns about suffering, loss of control, and association of hospice with the very last few days of life were important factors exacerbating participants' fear of hospice. Interestingly, we noted that participants actively distanced themselves from the need for hospice and often used hypothetical scenarios of other cancer patients when discussing hospice. These are novel findings and expand our understanding of patients' and caregivers' reluctance to initiate conversations about hospice due to these fears and concerns.²⁴ Moreover, for oncologists to adequately discuss hospice, they must also engage patients and their families in discussions about their EOL concerns.^{25,26} These findings extend the knowledge about the complexity of hospice decision making and underscore the importance of addressing the psychological transition to preparing and accepting imminent death during hospice discussions with patients and their families.^{26-31,34,35} In addition, teaching patients and their families about the role of early hospice use in terms of optimizing quality of life, controlling symptoms, and reducing suffering may help alleviate some level of anxiety about discussing EOL care options.^{13,24}

Notably, all patients and caregivers desired more information about hospice, and most preferred to receive guidance from their oncologists regarding the optimal timing for hospice consideration. Studies have shown that patients who

have EOL discussions with their physicians report less anxiety, and make different EOL decisions.^{20,36} Therefore, discussing hospice openly with patients and their families may similarly decrease their fears and empower them to make more informed decisions regarding their care. Interestingly, hospice discussions that are initiated by a physician are more likely to result in immediate enrollment than discussions initiated by patients, families, or non-physician providers.²⁴ Although patients and their families disagreed on the optimal timing to learn about hospice, they expected to learn from their oncologists about hospice at the most appropriate time in their illness trajectory. Thus, it is the oncologist's responsibility to initiate these discussions in a timely manner to increase informed decision making about early hospice utilization.²⁶

Our study has several important limitations. First, we included a small sample of mostly white participants drawn from a single academic center, and, thus, our findings may not be generalizable to more diverse populations, or patients in other geographic areas. Although generalizability is not the aim of qualitative work, we cannot assume that the same themes would have arisen from a sample in another location or from other ethnic groups not included in this study. Interestingly, this population of mostly white, well-educated patients with advanced cancer is more likely to utilize hospice and view it more favorably.²⁹ However, they had substantial knowledge gaps and significant barriers to hospice utilization, which underscores the potential implications of such barriers to more diverse populations. Second, the caregivers included in this study were mostly married to the patients, and caregivers with different relationships to the patients might offer a different perspective on hospice or barriers to its use. Notably, we selectively recruited patients with advanced cancer who their oncologist perceived had a good understanding of their prognosis. Thus, we are unable to comment on how patients with advanced cancer and poor prognostic awareness perceive hospice.

Future studies should focus on developing interventions that target the knowledge gaps identified in this study and meet the needs of patients and their families to empower them to make informed decisions regarding hospice care. Novel interventions such as video decision aids can be powerful in providing patients and their families with realistic expectations, demystifying hospice, and facilitating discussions regarding difficult topics between patients and their oncologists.³⁷⁻³⁹ Decision support tools can empower and activate patients, providers, and health systems to engage in difficult EOL discussions.³⁸⁻⁴² Our research group is currently developing a hospice video decision aid based on the findings of this study. Future work should also explore effective strategies to promote honest discussions that address patients' EOL concerns, with particular attention to suffering, loss of dignity, and death.¹³

In conclusion, patients with advanced cancer and their caregivers hold significant misperceptions regarding the role of hospice, which patients benefit from hospice care, and the extent of hospice services provided. Patients and their families perceived EOL concerns, fear of death, concerns about suffering and loss dignity, as well as lack of knowledge as the main barriers to hospice utilization. Despite these barriers, all participants desired more information about the role of hospice in providing practical services at the EOL, and the optimal timing to think about hospice care. These findings

suggest that conversations about hospice are intimately linked to addressing patients' and their families' EOL concerns. Interventions that educate patients and their families about hospice may reduce their anxiety and empower them to make informed decisions at the EOL.

Acknowledgments

This work was supported by funds from The American Cancer Society Institutional Research Grant (J.A.S.), The Gordon and Betty Moore Foundation (Dr. Areej El-Jawahri), and K24 CA 181253 (J.S.T.).

Author Disclosure Statement

No competing financial interests exist.

References

- Stewart SL, King JB, Thompson TD, et al.: Cancer mortality surveillance—United States, 1990–2000: MMWR Surveill Summ 2004;53:1–108.
- Earle CC, Landrum MB, Souza JM, et al.: Aggressiveness of cancer care near the end of life: Is it a quality-of-care issue? *J Clin Oncol* 2008;26:3860–3866.
- Parks SM, Winter L: End of life decision-making for cancer patients. *Prim Care* 2009;36:811–823.
- National Hospice and Palliative Care Organization: National Hospice and Palliative Care Organization Facts and Figures: Hospice Care in America. www.nhpco.org/files/public/Statistics_Research/2011_Facts_Figures.pdf. 2011.
- Casarett D, Crowley R, Stevenson C, et al.: Making difficult decisions about hospice enrollment: What do patients and families want to know? *J Am Geriatr Soc* 2005;53:249–254.
- Casarett DJ, Hirschman KB, Crowley R, et al.: Caregivers' satisfaction with hospice care in the last 24 hours of life. *Am J Hosp Palliat Care* 2003;20:205–210.
- Kane RL, Berstein L, Wales J, et al.: Hospice effectiveness in controlling pain. *JAMA* 1985;253:2683–2686.
- Nolen-Hoeksema S, Larson J, Bishop M: Predictors of family members' satisfaction with hospice. *Hosp J* 2000;15:29–48.
- Teno JM, Clarridge BR, Casey V, et al.: Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291:88–93.
- 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.
- Kris AE, Cherlin EJ, Prigerson H, et al.: Length of hospice enrollment and subsequent depression in family caregivers: 13-month follow-up study. *Am J Geriatr Psychiatry* 2006;14:264–269.
- Bradley EH, Prigerson H, Carlson MD, et al.: Depression among surviving caregivers: Does length of hospice enrollment matter? *Am J Psychiatry* 2004;161:2257–2262.
- Waldrop DP, Meeker MA, Kutner JS: Is it the difference a day makes? Bereaved caregivers' perceptions of short hospice enrollment. *J Pain Symptom Manage* 2016;52:187.e181–195.e181.
- Teno JM, Freedman VA, Kasper JD, et al.: Is care for the dying improving in the united states? *J Palliat Med* 2015;18:662–666.
- Teno JM, Gozalo PL, Bynum JP, et al.: Change in end-of-life care for medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 2013;309:470–477.
- Schockett ER, Teno JM, Miller SC, et al.: Late referral to hospice and bereaved family member perception of quality of end-of-life care. *J Pain Symptom Manage* 2005;30:400–407.
- Teno JM, Casarett D, Spence C, et al.: It is “too late” or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. *J Pain Symptom Manage* 2012;43:732–738.
- Emanuel EJ, Ash A, Yu W, et al.: Managed care, hospice use, site of death, and medical expenditures in the last year of life. *Arch Intern Med* 2002;162:1722–1728.
- Christakis NA, Iwashyna TJ: Impact of individual and market factors on the timing of initiation of hospice terminal care. *Med Care* 2000;38:528–541.
- Weeks JC, Cook EF, O'Day SJ, et al.: Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 1998;279:1709–1714.
- Robinson TM, Alexander SC, Hays M, et al.: Patient-oncologist communication in advanced cancer: Predictors of patient perception of prognosis. *Support Care Cancer* 2008;16:1049–1057.
- Teno JM, Shu JE, Casarett D, et al.: Timing of referral to hospice and quality of care: Length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symptom Manage* 2007;34:120–125.
- Cherlin E, Fried T, Prigerson HG, et al.: Communication between physicians and family caregivers about care at the end of life: When do discussions occur and what is said? *J Palliat Med* 2005;8:1176–1185.
- Casarett DJ, Crowley RL, Hirschman KB: How should clinicians describe hospice to patients and families? *J Am Geriatr Soc* 2004;52:1923–1928.
- Casarett DJ, Quill TE: “I'm not ready for hospice”: Strategies for timely and effective hospice discussions. *Annals of internal medicine* 2007;146:443–449.
- Chen H, Haley WE, Robinson BE, et al.: Decisions for hospice care in patients with advanced cancer. *J Am Geriatr Soc* 2003;51:789–797.
- Berry DE, Boughton L, McNamee F: Patient and physician characteristics affecting the choice of home based hospice, acute care inpatient hospice facility, or hospitals as last site of care for patients with cancer of the lung. *Hosp J* 1994;9:21–38.
- Slomka J: The negotiation of death: Clinical decision making at the end of life. *Soc Sci Med* 1992;35:251–259.
- Neubauer BJ, Hamilton CL: Racial differences in attitudes toward hospice care. *Hosp J* 1990;6:37–48.
- Gochman DS, Bonham GS: The social structure of the hospice decision. *Hosp J* 1990;6:15–36.
- Greipp ME: Decisions to utilize hospice—Pilot study results. *Am J Hosp Palliat Care* 1996;13:27–30.
- Campbell ML: “It's not time”: Delayed hospice enrollment. *J Palliat Med* 2014;17:874–875.
- Ritchie J, Lewis J: *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage Publications, 2003.
- Lokker ME, van Zuylen L, Veerbeek L, et al.: Awareness of dying: It needs words. *Support Care Cancer* 2012;20:1227–1233.
- 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.

36. Mack JW, Weeks JC, Wright AA, et al.: End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;28:1203–1208.
37. El-Jawahri A, Mitchell SL, Paasche-Orlow MK, et al.: A randomized controlled trial of a CPR and intubation video decision support tool for hospitalized patients. *J Gen Intern Med* 2015;30:1071–1080.
38. Volandes AE, Paasche-Orlow MK, Mitchell SL, et al.: Randomized controlled trial of a video decision support tool for cardiopulmonary resuscitation decision making in advanced cancer. *J Clin Oncol* 2013;31:380–386.
39. El-Jawahri A, Podgurski LM, Eichler AF, et al.: Use of video to facilitate end-of-life discussions with patients with cancer: A randomized controlled trial. *J Clin Oncol* 2010;28:305–310.
40. Stacey D, Legare F, Col NF, et al.: Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2014;1:CD001431.
41. Elwyn G, Frosch D, Volandes AE, et al.: Investing in deliberation: A definition and classification of decision support interventions for people facing difficult health decisions. *Med Decis Making* 2010;30:701–711.
42. Institute of Medicine: *Dying in America, Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press, 2014.

Address correspondence to:

Areej El-Jawahri, MD

Department of Hematology-Oncology

Bone Marrow Transplant Program

Massachusetts General Hospital

55 Fruit Street, Yawkey 9E

Boston, MA 02114

E-mail: ael-jawahri@partners.org