

Why Don't Patients Enroll in Hospice? Can We Do Anything About It?

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BACKGROUND: United States hospice organizations aim to provide quality, patient-centered end-of-life care to patients in the last 6 months of life, yet some of these organizations observe that some hospice-eligible patients who are referred to hospice do not initially enroll.

OBJECTIVE: Primary objective: To identify reasons that eligible patients do not enroll in hospice (phase 1). Secondary objective: To identify strategies used by hospice providers to address these reasons (phase 2).

DESIGN: Semi-structured interviews analyzed using content analysis.

PARTICIPANTS: In phase 1, we interviewed 30 patients and/or family members of patients who had a hospice admissions visit, but who did not enroll. In phase 2, we interviewed 19 hospice staff and national experts.

APPROACH: In phase 1, we asked participants to describe the patient's illness, the hospice referral, and why they had not enrolled. We performed a content analysis to characterize their reasons for not enrolling in hospice. In phase 2, we enrolled hospice admissions staff and hospice experts. We asked them to describe how they would respond to each reason (from phase 1) during an admissions visit with a potential new hospice patient. We identified key phrases, and summarized their recommendations.

RESULTS: Reasons that patients hadn't enrolled fell into three broad categories: patient/family perceptions (e.g., "not ready"), hospice specific issues (e.g., variable definitions of hospice-eligible patients), and systems issues (e.g., concerns about continuity of care). Hospice staff/experts had encountered each reason, and offered strategies at the individual and organizational level for responding.

CONCLUSIONS: In hopes of increasing hospice enrollment among hospice-eligible patients, non-hospice and hospice clinicians may want to adopt some of the strategies used by hospice staff/experts for talking about hospice with patients/families and may want to familiarize themselves with the differences between hospice

organizations in their area. Hospices may want to reconsider their admission policies and procedures in light of patients' and families' perceptions and concerns.

KEY WORDS: hospice; decision making; terminally ill; terminal care.

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INTRODUCTION

Hospice is considered an optimal model of care for people approaching the end of life because it promotes patient- and family-centered care and aims to maximize patients' quality of life. In the United States, hospice care is a subset of palliative care that is only available to patients with a prognosis of approximately six months or less. Those who elect hospice agree to care focused on quality not quantity of life; thus hospice may not be appropriate for those with the goal of life prolongation. Most hospice care is provided in the home setting. The US government pays for most hospice care under the Hospice Medicare Benefit, paying individual hospices a set amount for each day each patient is enrolled in their organization.

Hospice is an underutilized resource in the US. In 2008, approximately 38.5% of those who died were enrolled in hospice prior to death.¹ Among those who did enroll in hospice, the median hospice length of stay in 2008 was 21 days, and 35% of hospice patients were enrolled for seven days or less.¹

Previous studies have identified many reasons for low rates of use and late referrals to hospice in the US.²⁻¹⁸ Reasons identified include reluctance by patients, families, and/or clinicians to accept that the patient is in a terminal phase of illness, and the requirement that the goals of care are no longer curative.^{10,17,18} Bereaved family members and clinicians have identified that hospice referrals may be delayed because of clinician difficulties with estimating prognosis and inadequate knowledge about the breadth of services provided by hospice.^{7,11-13,18} Additionally, patients' cultural, religious, and/or ethnic backgrounds may impact or even preclude the use of hospice services.¹⁹⁻²⁸ Finally, some clinicians report that they don't discuss hospice with eligible patients until all non-palliative treatments have been exhausted.²⁹

To our knowledge, no study has directly asked patients and their families who had an admissions visit by a hospice organization why they hadn't enrolled. This two-phase study

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addresses this gap in our understanding. In phase 1, we interviewed patients and their loved ones to explore their reasons for not enrolling in hospice. In phase 2, we then presented these results to hospice clinicians and national hospice experts to find out whether they had encountered these reasons, and to understand how they would respond if they encountered the given reason during a hospice admissions visit. The main purpose of this article is to summarize the reasons reported by hospice-eligible patients and their family members. However, we also hope the suggestions by hospice clinicians/experts will be helpful to non-hospice and hospice clinicians when discussing the option of hospice with patients and their families, and to hospice organizations contemplating interventions to increase their rates of enrollment.

METHODS

Phase 1 (Patient and Family Interviews)

Participants. Prior to being admitted to hospice, eligible patients receive a comprehensive visit by hospice staff (a hospice admissions visit) in which their situation, their needs, and the hospice services available to them are reviewed. Patients (and their family members) who had a hospice admission visit, but had not enrolled in hospice afterwards, were eligible for this study. Three participating hospice organizations and hospice coordinators based at two hospitals identified eligible patients (Text Box 1 provides additional information about the hospice organizations/

Text Box 1. - Characteristics of Participating Hospice Organizations/Coordinators

Phase 1

Hospice Organizations/Coordinators Involved with Subject Recruitment

1. *Non profit hospice organization in a large urban area (population 3.3 million), with an average daily census (ADC) approximately 350 during the study
2. *Non profit hospice organization in a large urban area (population 3.3 million) with concurrent home health agency, ADC approximately 60 during the study
3. *Non profit hospice organization in a smaller urban area (population 70,000), ADC approximately 100 during the study
4. Hospice coordinator at Veterans Administration hospital overseeing hospice referrals to organizations in 5 surrounding states
5. Hospice coordinator from an academic county hospital in a large urban area

*Please note that these hospice organizations estimated their rate of non-enrollment to be approximately 10% when the study began.

Phase 2

Hospice clinicians were recruited from 3 hospice organizations – the first and third organization listed above and an additional non-profit hospice organization in a moderate sized city (population 120,000) adjacent to a large urban area, with an ADC of approximately 110 during the study

coordinators). They sent a letter addressed to the patient and their loved ones introducing the study, explaining that the study was independent of both their physician and the hospice organization, and asking those interested in participating to contact the investigators directly. Individual hospice organizations and coordinators had different strategies for sending out recruitment letters, making the period of time between admission visits and study interviews variable. When the study began, the three participating hospice organizations in phase 1 estimated that approximately 10% of patients who had a hospice admission visit did not enroll in hospice after the visit.

When patients and/or family members called us, we answered their questions about the study, and screened for the following eligibility criteria: fluent in spoken English and free from moderate-severe cognitive impairment as measured by the Short Portable Mental Status Questionnaire^{30,31} to ensure that they would be able to provide rich descriptions of why they had not enrolled. Eligible and interested participants selected whether they preferred an in-person or a telephone interview, which was scheduled for a later date.

Data Collection and Analysis. After obtaining written informed consent, one investigator used a semi-structured interview guide to conduct the study interviews (a copy of the interview guide is available upon request from the corresponding author). She asked participants to tell the story of the patient's illness and the initial contact with hospice, and to reflect on the reason(s) for not enrolling. Participants also described hospice in their own words. Patients and family members were interviewed separately. All interviews were audio recorded and transcribed verbatim. All names of people and places were removed during transcription. Data from phase 1 were collected from 2003-2005.

We performed a content analysis to understand why hospice eligible individuals had not enrolled in hospice.^{32,33} First, we drafted a preliminary coding scheme based on the interview guide, and refined it after the initial transcripts were coded and discussed in team meetings. Each transcript was then coded independently by two investigators using Atlas.ti software to facilitate comparison of codes and analysis. When coding differences existed, the investigators discussed their rationale for the coding, reread the transcripts, and, if necessary, involved a third coder in order to reach consensus, and to assure that we comprehensively coded the transcripts. Next, we analyzed the coded text related to the initial contact with hospice, and the reasons why patients did not enroll. We developed a list of reasons for not enrolling in hospice along with representative quotations.

Phase 2 (Hospice Clinician and Leader Interviews)

Participants. Leaders from three hospice organizations (for more information see Text Box 1) sent an email to their staff describing our study and asking for staff interested in discussing the results to contact us. We also contacted the National Hospice and Palliative Care Organization (NHPCO) who convened a group of national hospice experts to discuss the results.

All methods and materials for both phases of this study were approved by the university's Institutional Review Board (IRB) and the IRBs associated with participating hospice organizations.

Data Collection and Analysis. All participants provided written informed consent. One investigator conducted the hospice

staff/expert interviews using a semi-structured interview guide (a copy of the interview guide is available upon request from the corresponding author). All interviews were conducted in-person except for the NHPCO interview, which was conducted by phone.

Participants were shown representative quotations from patients/families about why they didn't enroll from the phase 1 interviews. After reading each quotation, participants were asked whether they had ever encountered each reason in their clinical practice. Next, they were asked how they would respond if they encountered this reason during an admission visit with a potential new hospice patient. They also were asked to identify other reasons why patients don't enroll from their experience. Interviews were audio recorded and transcribed verbatim. Data from phase 2 were collected in 2006.

The principal investigator used Atlas.ti to code responses to three interview questions: one code to capture whether the participant had encountered that response in their clinical practice, another to capture the participant's strategy for responding to that reason, and a third to identify passages in which participants identified additional reasons why patients/families decline hospice. The coded text was analyzed using content analysis.

Trustworthiness. We assured the trustworthiness of the data and analysis of both phases of the study through multiple steps. The coding scheme for the first phase of the study was developed with input from all five investigators who represent different disciplines. Next, each transcript from the first phase was coded independently by two investigators to ensure more comprehensive coding. Next, we verified the results from the first phase by presenting them to hospice staff involved with admitting new patients (a qualitative method analogous to assessing content validity). Finally, we achieved saturation of the data³⁴ in both phases of the study because no new themes/concepts emerged in the final interviews in either study phase.

Table 1. Participant Demographics

	Patient (n=10)	Family (n=20)
Mean age, years (range)	77 (50-89)	61 (26-85)
Gender, % Female	40%	75%
Ethnicity, % White	100%	95%
Marital status, %		
Married	50%	35%
Widowed	50%	50%
Education, n		
High school grad/Some college	3	12
College grad/Grad school	7	8
Religious affiliation, n		
Buddhist	0	5
Catholic	0	2
Jewish	0	1
None	3	3
Protestant	7	9
Relationship to patient, % spouse	—	60%
Mean years known patient (range)		43 (4-64)
Knowledge of hospice, % who identified that hospice care is...		
For terminally ill/dying patients	70%	100%
Provided in home	80%	100%
Focused on comfort/ quality of life	90%	100%

RESULTS

Phase 1—Patient/Family Interviews

In the first phase of the study, we conducted 30 interviews with ten patients and six of their family members (not more than one family member per patient), and 14 family members of other patients (who did not complete interviews because they were too sick or had died). The participants are described in

Table 1. As noted in Table 1, when asked to describe who hospice cares for, where care is provided, and what hospice does, participants provided accurate responses indicating they had a good understanding of these elements of hospice.

Text Box 2 lists reasons why patients didn't enroll in hospice, which fell into three broad categories: patient/family perceptions, hospice specific issues, and systems issues. These categories will be described in more detail below. Illustrative quotations for each category from patients/families are provided in the left column of Text Box 3.

Text Box 2. Patient and family reasons for not enrolling in hospice

Patient/Family Perceptions

- Patient and/or family “not ready” for hospice
 - Misconception that hospice care is for the last hours to days of life
 - Hospice means acknowledging dying
 - Waiting to hear about any other treatment options from doctor(s)
 - Spouse wants help from hospice, patient doesn't
- Wives protective of their caregiving role
- Family concerns about their ability to care for patient at home
- Family not sure what hospice could add to existing care

Hospice Specific

- Definition of the hospice appropriate patient
 - Requiring patients/families to choose between hospice or palliative treatment
- How hospice is presented during the initial visit
 - Focus on what *isn't* provided
 - Expecting patients to acknowledge that they're dying
- Hospice referral confused with a home health referral
- Hospice informational visit confused with a hospice admissions visit

Systems Issues

- Patient concerns about continuity of care after hospice enrollment
 - Concerns of losing their current provider(s) or healthcare system
 - Concerns about the reliability of a new oxygen provider and equipment
- Inadequate hospice benefit from private insurance
- Delay in obtaining physician order for hospice

Text Box 3. Sample patient/family reasons for not enrolling in hospice and hospice providers' strategies for addressing them

Reason for not enrolling in hospice	Sample strategies
<p>Patient and family perspectives</p> <p>1. "Not ready"</p> <p>From a patient's wife, "I just felt he was not ready. When he was on his way out, when he was dying or something, then I'll put him in [hospice]. I didn't want to put him in before." (F12)</p>	<p>Get them to register illness severity</p> <p>"[Ask] What changes have you seen? Then I kind of picture it back to them, mirror it back to them. So, "What would that say to you? What does that mean?"</p> <p>Try it for 3 months</p> <p>"Sign up for three months. You get all the information, support, a hand reaching out in the middle of the night, and somebody who can reach that doctor for you."</p> <p>Emphasize the benefits of hospice</p> <p>"Here are the things that hospice could do, in service of your goals. This can help you stay at home. You've got somebody to call, in the middle of the night. There's somebody with expertise in pain management. If you find hospice isn't the thing for you, you can sign off, at any time. You can always come back to us, if you need to."</p> <p>Explain that patients can be on hospice for > 6 months</p> <p>"We're very bad at knowing how long you have. I've had patients that were on hospice for 18 months or two years ... [I tell them] that they don't have to come off, if they still meet the criteria for hospice. If by chance, they get better, they can be discharged and they can go back on again."</p>
<p>2. Spouse wants help from hospice, patient doesn't</p> <p>From a patient's wife, "I think if they're referred, [hospice] must know that they need it. And maybe it should be more of, we're going to do this, instead of asking the patient, cause that patient maybe doesn't want it, but maybe the wife wants it." (F10)</p>	<p>Reframe it as help for the spouse</p> <p>"We're here just to help your wife and maybe, when we come, we don't see you, but we talk with her and then she's got someone to call at three in the morning when she's worried about something... maybe it'll help her sleep at night."</p>
<p>3. Wives protective of the caregiver role</p> <p>From a patient's wife, "I said, Well, I don't feel that I really need it yet. I said, I'm very comfortable with what I'm doing and am certainly capable of giving the care that he needs." (F5)</p>	<p>Offer support to the patient and spouse</p> <p>"[Some people] are private or feel threatened or feel like [signing up for hospice is] saying, "I'm not doing a good job," [Tell them] "You've done a great job and we're going to be here to support you as things change and new things happen."</p> <p>Emphasize that the patient needs his/her spouse</p> <p>"You don't want to supplant them, so I switch it around and say, "So he's going to need you for a very long time. What do you need to take care of you, so you can be there for that whole length of time?" Then you get to be the wife and not just his care giver. You have time to just be the family and do what matters to the two of you."</p>

	<p>Build the relationship when things are okay “[I explain] you get to know <i>this</i> team, you know <i>this</i> nurse, you know <i>this</i> social worker, [which] makes it easier to get the help you need when things start to go down hill.”</p> <p>Approach it from a different angle “Talk about the financial aspect, [that] this is an entitlement that you have under Medicare to receive these services, your medications, your equipment and all that.”</p> <p>Call us back when... “Depending on what the diagnosis is, we usually know what’s gonna happen. So [we suggest to them], “When they start having this or this or this, you might want to call us back.”</p>
<p>4. Family concerns about their ability to care for patient at home</p> <p>From a patient’s wife, “Within about 48 hours it became pretty evident that that hospice wasn’t a really good option for us because we didn’t have good enough pain management [in the hospital].” (F8)</p>	<p>Talk about fears “it’s really about being afraid. Tell me what you’re most concerned about at home. What I hear him saying is, he really wants to go home. And what I hear you saying is that you’re concerned you’re not gonna be able to give him what you think he needs at home. And so, let’s go through step by step what that might look like.”</p> <p>Reiterate hospice providers’ expertise “I would just reiterate that we’re actually pain specialists, in our community and that the physicians actually look to us, to help them with pain management, even for non-hospice patients.”</p>
<p>Hospice specific</p> <p>5. Defining the hospice eligible patient</p> <p>From a patient, “I thought, “Well, maybe I should do this.”... she didn’t make it clear that you have to make a decision between Hospice or treatment...when I saw the oncologist, I realized that ... that you don’t do both, at the same time, hospice and palliative treatment, that’s outside of Hospice’s purview.” (P16)</p>	<p>Find another hospice “In the olden days, patients were forced to make a choice. And hospices were okay forcing them to make that choice. And they were okay saying, “Well, you’re not on board with us, yet.” That’s how it was rationalized. “She’s not ready, we’re not on board.” And so if that occurred, here, then I would simply say, “This is something that hospice would be responsible for ...”</p>
<p>6. How hospice is presented during the initial visit</p> <p>From a patient, “The first person that talked to us really didn’t explain it [hospice]. He explained it more as restrictive than as beneficial.” (P2)</p>	<p>Re-explain and emphasize what hospice can do “These are people who already feel like they’re losing control. And they’re giving up a lot and why would you come to a service that’s gonna make you give up even more? So, I think you have to do a very straight forward explanation about, “Here’s what they can provide for you and here’s what they can’t provide for you. And here’s how they might meet your needs. And here’s some of the needs they might not be able to address.”</p>

<p>7. Expecting patients to acknowledge they're dying</p> <p>From a patient's daughter, "They says, Well, do you believe you're dying? And he says, No, I do not believe I'm dying, so I don't know why they're sending you here. And they says, Well, if you don't believe you're dying, we don't need to be here. And they got up and walked out the door." (F11)</p>	<p>Avoid the word "hospice"</p> <p>"We don't tell anybody they're dying, [Sometimes families don't want us to] say "Hospice". Probably 20%, want that. [But I] try to get across to the families that, if you don't allow this to be a dying process, then the person who's dying, gets to pretend they're not dying. And you get to pretend they're not dying, so resolution doesn't happen, 'cause everybody's pretending. And you can have some really quality time, if you're not pretending."</p>
<p>8. Concerns about the continuity of care</p> <p>From a patient, "They'll provide oxygen, but with a different supplier and they have no portable equipment and so one of my concerns would be, as soon as I sign up with Hospice, I'm going to be homebound, if I understand their service correctly." (P17)</p>	<p>Be flexible</p> <p>"I've said [to patients who don't want to switch oxygen providers] "There's nothing more scary than the breathing." So we no longer force the change of equipment, before we come on board."</p>
<p>9. Inadequate hospice benefit from private insurance</p> <p>From a patient, "I'm getting closer to needing them, we have very little financial-- or insurance coverage for this, so I'm sure I'll probably use them as little as possible to keep our costs down because my insurance has been very poor throughout this whole thing, and I'm looking at \$75,000 I owe to various people." (P14)</p>	<p>Try to help everyone who's interested</p> <p>"My response to them is that we have a social worker that can help sort through finances because there may be things available that we don't know about. Our policy is that we work with everyone and that we don't not help someone, if they don't have the finances."</p>

Patient/Family Perceptions

Some patients and family members remarked that they didn't enroll because the patient was "not ready" for hospice. For some, this judgment stemmed from a misperception that hospice care was only appropriate in the last hours to days of life. For others, family members spoke of how enrolling in hospice meant acknowledging their loved one was dying. One widow commented, "[Hospice meant] admitting we were dying; we were trying to live."(#F6) Patients and family members also described postponing hospice admission until they had heard from their physicians that no more treatments were available. In two cases, the patients had declined hospice because they were "not ready,"

but their spouses spoke of having wanted the help of hospice. One woman wished the hospice representative had been more inclusive about eliciting her opinion of how her husband was doing, and how well they were managing at home. She did not feel that she had an adequate opportunity to explain that she needed help from hospice, and did not feel comfortable challenging her husband's opinion that he wasn't ready for hospice. Three older wives described the need to protect their caregiving role for their dying spouses. These women expressed a sense that they would be failing in their wifely duty if they allowed others to help care for their husbands.

Two additional reasons for not enrolling in hospice were voiced. Two women expressed concern that their husbands'

conditions were too difficult for them to manage at home even with hospice; both opted for their husbands to remain hospitalized. Conversely, two other family members believed that all their loved one's needs were being met, and did not think that hospice care could add anything to the existing care.

Hospice Specific

Hospices varied in which patients were considered eligible for hospice care within their organizations, and in some cases this variability led to patients not enrolling. For example, patients and family members spoke of declining or postponing hospice services when they were told that they couldn't receive hospice care with concurrent palliative radiation or chemotherapy. One woman stated, *"It was as if I needed to sign up for hospice and not get treatment...[which] wasn't really what I was interested in. I was interested in talking to my oncologist."* (#P16)

How hospice was presented to the patient and/or family during their initial contact with hospice could impact whether or not they enrolled. One patient, who later enrolled in hospice, compared the two hospice admissions visits he'd received and explained how hospice care seemed too restrictive when it was described by the first hospice representative and less restrictive when described by the second representative. A woman described how the hospice admission visit with her stoic father had gone poorly when the hospice representative insisted that he acknowledge that he was dying.

Two additional reasons why patients did not enroll in hospice included confusion between a hospice referral and a home care referral, and confusion between a hospice informational visit and a hospice admissions visit.

Systems Issues

Some patients interviewed had wanted hospice services, but did not enroll because of systems level issues. Patients and family members expressed concerns about continuity of care if they enrolled in hospice, fearing that they would lose contact with their current healthcare providers/systems, even though providers are encouraged to continue to follow their patients receiving hospice care. As one woman remarked, *"[They explained] that the hospice people then would be my interface with my doctor, and instead of going to my doctor, I would go through them. I didn't really like that idea. I would rather go through my doctor myself."* (#P14) Patients who required oxygen were concerned about switching from the oxygen providers they trusted to the one contracted with the hospice organization. One woman who had worked in healthcare was reluctant to enroll in hospice too soon because of her health insurance hospice benefit. Although her symptoms were poorly managed, she did not want to sign up for hospice too early and leave her family with additional debt. Finally, hospice admission for another patient was delayed until an order for hospice care was obtained from the appropriate physician (hospice had been recommended by a clinician peripherally involved in the patient's care).

Phase 2 - Hospice Staff/Expert Interviews

In the second phase of the study, we interviewed 11 hospice staff who had worked for hospices for a mean of 12 years (range 6-20 years), and eight hospice experts. Participants' backgrounds included nine nurses, two physicians, two

persons with PhD's, three persons with master's level training, one social worker, and two lay hospice workers.

Hospice staff and experts had encountered each of the reasons identified in phase 1 of this study in their practice. They provided two additional reasons why patients referred to hospice might decide not to enroll: not wanting strangers in their homes, and funding difficulties for patients who were nursing home residents. In Text Box 4, we present sample statements by patients and family members from phase 1 about why they had not enrolled in hospice, and examples of strategies for addressing them proposed by hospice staff/leaders.

Hospice staff had variable responses to patient/family statements about why they had not enrolled in hospice. In response to a quotation about forgoing hospice because of switching oxygen providers, for example, one clinician provided a philosophical explanation,

"These folks with COPD are married to their [oxygen providers]... 'Cause the same guy comes and sees them once a week and so, giving that up is symbolically asking them to give up so many other things... [They may think] 'You know what? Finally I have a good reason not to take these people. I have good reason not to deal with end of life and I'm gonna make it my oxygen.' You know it's a transitional object, just like chemo." (#H4)

A nurse explained how she responds to this concern, *"I've said, 'Boy, you know, there's nothing more scary than the breathing.'... So we no longer force the change of equipment before we come on board."* (#H1) A nurse from a different hospice organization, however, explained that patients aren't enrolled in her organization if they don't agree to switch oxygen providers. These examples demonstrate the range of policies and approaches that different hospice organizations take to accommodate their patients' prior relationships with other health care providers.

DISCUSSION

The patients and family members in this study reported a variety of reasons for not enrolling in hospice which were not only due to their perceptions about hospice care, but also to inter-hospice variations in policies and practices and systems-level issues. To our knowledge, patients who have had a hospice admissions visit, but have not enrolled in hospice, have not been previously studied. Participants regarded hospice care positively and had a good general understanding of the philosophy of hospice care and the services provided. Some expressed misconceptions, however, such as a belief that hospice care is only appropriate in the last hours to days of life.

Many of the reasons we identified have been previously described in the United States,^{7,10,12,13} but reasons not previously identified in the literature include the protectiveness of some wives toward their caregiving role, the effects of bureaucratic confusions in organizations which provide both home care and hospice services, and the potential effects of hospice admissions policies and initial visits on enrollment.

The hospice staff/leaders we interviewed were familiar with each reason for not enrolling in hospice. They offered two additional patient/family-centered reasons for not enrolling— not wanting strangers in one's home, and difficulties paying for

Text Box 4. – A general approach to talking to patients and families about hospice

1. Help the patient and/or family register the illness severity and trajectory.
 - Ask them to describe the past 6-12 months then ask, “What changes have you seen?” and “What does that say to you?”
2. Identify their needs.
 - Say, “It sounds like you could use some support. What kinds of support would be most helpful to you?”
3. Tailor your description of hospice to the needs they have expressed.
 - Say, “Well, this might be a good fit. So, let me tell you a bit about hospice.”
4. Emphasize what hospice *can* do.
 - Mention that care is delivered in the home, telephone assistance is available to caregivers 24/7, and that hospice pays for most medications and equipment.
5. Explain that patients can receive hospice services for longer than 6 months as long as they continue to meet hospice eligibility criteria.
6. Suggest that they try hospice for 3 months.
 - Mention that they can disenroll at any time, and can still access hospice in the future if they need it.

hospice care in the nursing home. The fact that staff from three hospices and national hospice leaders recognized the reasons voiced by patients and family members suggests that our findings may be generalizable in the United States. Since hospice care is structured differently in other countries, our results would not be expected to be generalizable outside of the United States.

The hospice clinicians provided language that may be useful to both non-hospice clinicians who discuss hospice with their patients and to hospice staff involved in admitting new patients. In Text Box 4, we present a general approach to discussing hospice care with patients and their families which was distilled from strategies described and used by hospice clinicians. If a patient declines hospice admission, his/her clinician may want to inquire about the reason for not enrolling, and then may want to adopt some of the language offered in Text Box 3. However, it should also be noted that hospice care may not be appropriate for all patients, especially those who want to die in the hospital receiving life prolonging care.^{35,36}

Hospice staff provided descriptions of their organizations which illustrate the variability among individual hospice organizations. Hospice organizations define the hospice eligible patient differently. For example, one organization admitted

patients who are receiving some types of palliative radiation and chemotherapy, while another organization did not admit patients who still wanted antibiotics. These differences are important to explore, and they highlight the considerable variability in practice among hospice organizations regarding how they choose to implement the hospice benefit. These differences may be due to different philosophies and financial decisions by individual organizations about their willingness or ability to pay for more expensive treatments such as palliative chemotherapy.

Hospice staff descriptions also highlight the variety of procedures used by hospices for enrolling new patients. For example, some hospice organizations have staff solely designated to admit new patients, while other organizations use any available employees for this task. Of note, the designated hospice admissions staff who participated in this study reported that there was no standard training for this position and that they had learned ways to maximize enrollment from trial and error on the job. To date, there are no published data about the effectiveness of using designated admissions teams and no standard training for those becoming designated hospice admissions staff. Additionally, organizations which provide both hospice and home health services may want to

evaluate their intake procedures to ensure that new referrals are directed to the correct location (hospice or home health).

In order to increase the likelihood of their patients enrolling in hospice, clinicians in areas with more than one hospice organization may want to be familiar with the differences between local hospices. Different hospice organizations, even those within the same city, may have different philosophies about hospice-appropriate patients and employ different procedures when admitting new patients. Knowing the differences between local hospices may help clinicians refer patients who are still seeking some treatments to hospice organizations willing to admit patients receiving those treatments.^{37,38}

This study has limitations. In order to protect confidentiality, potential study participants had to call us if they wanted to enroll. This led to nearly every participant being knowledgeable about hospice and in favor of it; we did not interview people who had not enrolled because of poor knowledge of hospice or a negative attitude towards it. Despite this, participants expressed a range of reasons why they or their loved ones had not enrolled in hospice. Additionally, these reasons were familiar to practicing hospice staff and leaders. Second, participants were predominantly white, which reflects the demographics of the geographic area and hospice population where the study was conducted. Although we reached saturation of the data, we might have heard different themes from participants who were not knowledgeable about hospice, had negative attitudes towards it, were in denial about their clinical conditions, or were from different ethnic, cultural, or religious groups.^{20–23,27} Lastly, participating hospice organizations did not record the number of patients to whom they sent introductory letters; therefore, we do not know what proportion of eligible patients are represented in our study.

In summary, the patients and family members in this study reported different reasons for not enrolling in hospice which were not only due to their perceptions about hospice care, but also were due to inter-hospice variations and systems level issues. When discussing the option of hospice care with patients, clinicians may find it useful to adopt some of the strategies offered and used by hospice staff/experts. If a patient initially declines hospice admission, clinicians may want to find out why and then respond with the proposed strategies. Knowing which local hospice organizations enroll which kinds of patients also may be helpful so that clinicians can refer their patients to the most appropriate hospice organizations in their area. Hospice organizations may want to look critically at their procedures for enrolling new patients including whether referrals are going to the correct location (home health or hospice), which patients they are willing or able to admit, and whether to use a designated hospice admissions team. Future investigations may want to focus on the effects of using some of these strategies on rates of hospice admission, and on the effects of hospice definitions of eligible patients on rates of hospice admission and lengths of stay.

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