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## Communication between Physicians and Family Caregivers about Care at the End of Life: When Do Discussions Occur and What Is Said?

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### Abstract

*Background:* Few studies have examined physician-family caregiver communication at the end of life, despite the important role families have in end-of-life care decisions. We examined family caregiver reports of physician communication about incurable illness, life expectancy, and hospice; the timing of these discussions; and subsequent family understanding of these issues.

*Design:* Mixed methods study using a closed-ended survey of 206 family caregivers and open-ended, in-depth interviews with 12 additional family caregivers.

*Setting/Subjects:* Two hundred eighteen primary family caregivers of patients with cancer enrolled with hospice between October 1999 and June 2002

*Measurements:* Family caregiver reports provided at the time of hospice enrollment of physician discussions of incurable illness, life expectancy, and hospice.

*Results:* Many family caregivers reported that a physician never told them the patient's illness could not be cured (20.8%), never provided life expectancy (40% of those reportedly told illness was incurable), and never discussed using hospice (32.2%). Caregivers reported the first discussion of the illness being incurable and of hospice as a possibility occurred within 1 month of the patient's death in many cases (23.5% and 41.1%, respectively). In open-ended interviews, however, family caregivers expressed ambivalence about what they wanted to know, and their difficulty comprehending and accepting "bad news" was apparent in both qualitative and quantitative data.

*Conclusion:* Our findings suggest that ineffective communication about end-of-life issues likely results from both physician's lack of discussion and family caregiver's difficulty hearing the news. Future studies should examine strategies for optimal physician-family caregiver communication

about incurable illness, so that families and patients can begin the physical, emotional, and spiritual work that can lead to acceptance of the irreversible condition.

## INTRODUCTION

COMMUNICATION IS A KEY ELEMENT of high-quality care in end-of-life care.<sup>1-5</sup> Several studies have examined what matters to patients and families at the end of life, and having a clear understanding of the patient's illness and treatment options are frequently mentioned as being important.<sup>6-8</sup> Despite widespread acceptance that communication among patients, families, and clinicians is an important component of high quality care, empirical data suggest that communication about end-of-life care is often limited in frequency and scope.<sup>1,9-13</sup>

The scope and timing of communication about end-of-life issues between primary family caregivers and the patient's clinicians are particularly important. Family members often play central roles in end-of-life treatment decisions,<sup>14-18</sup> and they depend on clinicians for an understanding of prognosis and alternative approaches to care including hospice. Nevertheless, few studies have examined how and when key elements of communication between family caregivers and physicians take place in the months prior to death. Three recent studies on this topic<sup>9,16,17</sup> reveal substantial limitations in family caregiver and physician communication at the end of life including infrequent discussion of hospice by physicians,<sup>16</sup> inadequacy in physician understanding of patient preferences and shared decision making,<sup>17</sup> and poor agreement on whether prognosis information was discussed among patient, family members, and physicians.<sup>9</sup> Although these studies are valuable, the first<sup>16</sup> focuses only on hospice discussions rather than other areas of communication that may be important and does not examine the timing of such discussions relative to hospice enrollment or death; the second<sup>17</sup> focuses on patient experiences, rather than family caregiver experiences, and the third<sup>9</sup> examines family caregivers of seriously ill patients who were not yet in the final phases of life, so the findings may underestimate the frequency and scope of discussions that take place closer to the time of death.

To understand physician-family caregiver communication at the end of life better, we sought to describe patterns of communication regarding three key elements: (1) communication that the patient's illness could not be cured, (2) communication of life expectancy, and (3) communication about the possibility of using hospice. We focused on primary family caregivers of adult patients with cancer who received hospice prior to their death. We studied patients with cancer because the increased prognostication accuracy for this illness<sup>19,20</sup> makes effective communication about incurable illness, life expectancy, and hospice more feasible.

## METHODS

### Study design and sample

We used mixed methods<sup>21</sup> to examine communication between physicians and primary family caregivers about incurable illness, life expectancy, and hospice. We used a concurrent nested design,<sup>21,22</sup> which entailed simultaneous collection of quantitative and qualitative data. The mixed-methods design is useful because it enhances both the quantitative and qualitative approaches by allowing a deeper understanding of complex phenomena, such as communication about incurable illness, life expectancy, and treatment options. The present study was part of a larger prospective, longitudinal study<sup>23</sup> examining caregiver wellness using data from interviews with primary family caregivers at the time of the patient's enrollment with hospice and again at 6 and 13 months after the patient's death.

The quantitative portion of the present mixed-methods study used data from structured interviews with 206 primary family caregivers of patients with incurable cancer consecutively

enrolled in the largest hospice facility in the state of Connecticut between October 1999 and September 2001. Primary family caregivers were identified by the primary hospice nurse as the person most involved with the patient's health care. We attempted to conduct these interviews at the time of hospice enrollment before the patient's death; however, that was not possible for all caregivers, and 130 of the 206 caregivers were interviewed in the month after the death. A total of 391 caregivers were initially approached during the enrollment period by a hospice staff research liaison. Out of the 391 approached, 100 caregivers requested not to be contacted for the study, 28 could not be contacted because of missing or inaccurate telephone or address information, 6 of the caregivers were either too ill or cognitively impaired to participate as determined by the interviewer, and 51 of the caregivers were contacted but refused to participate. The 206 caregivers represented 78% of those contacted (206/263) and 53% of the original 391 caregivers originally sampled. There were no significant differences ( $p > 0.10$ ) between caregiver participants and those who could not be contacted or did not participate in terms of gender, kinship relationship to the patient, or the number of days enrolled with hospice.

The qualitative portion of the present mixed-methods study included in-depth interviews with primary family caregivers whose loved ones were enrolled with hospice during November 2000 to June 2002. We used purposive sampling as is common in qualitative research<sup>24,25</sup> yielding a sample that reflected diverse demographic characteristics of the caregivers (e.g., gender, age, marital status and relationship to the patient). We continued interviewing until we reached theoretical saturation on the primary topic of interest: communication preceding hospice enrollment. This occurred after 12 completed in-depth interviews. All research procedures were approved by the Institutional Review Board at the Yale School of Medicine and the participating hospital, where the study was conducted.

### Data collection and measurement

In the quantitative part of the study, we sought to understand the prevalence and timing of physician-family caregiver communication regarding key aspects of end-of-life care, including the incurable nature of the illness, life expectancy, and hospice as a treatment alternative. The structured questionnaire with the primary caregiver was administered in person at or near the time of hospice enrollment by a social worker with extensive experience in end-of-life care research and practice. The 6 survey questions used for this analysis were: (1) When did the doctor first tell you that the patient's illness could not be cured? (2) When did you first think that the patient's illness could not be cured? (3) When the doctor first told you the illness could not be cured, how long did the doctor tell you the patient had to live? (4) At that time, how long did you think the patient had to live? (5) When did a doctor first talk to you about the possibility of using hospice? (6) When did you first think that the patient needed hospice?

In the qualitative portion of the study, we used in-depth interviews to understand caregivers' experiences in the month preceding hospice enrollment with a focus on the nature of the communication concerning end-of-life choices and how the decision to enroll with hospice was made. As is standard in qualitative interviewing,<sup>24-26</sup> we used a discussion guide beginning with the grand tour question,<sup>26</sup> "Tell me about your experiences with the patient's illness during last 6 months or so as he/she transitioned into hospice care." Open-ended probes were used to expand on views and experiences of respondents, and caregivers were encouraged to provide added detail and vignettes that illustrated their points. We were particularly interested in patterns of family caregiver-physician communication and its influence on end-of-life treatment choices. All in-depth interviews were audiotaped and transcribed by an independent, professional transcriptionist.

## Data analysis

In the analysis of the quantitative survey data, we used standard frequency analyses to summarize the prevalence and timing of reported family caregiver-physician communication regarding the incurable nature of the illness and possibility of using hospice. We used a *t* test to determine the association between the physician reportedly telling the family caregiver that the patient's illness could not be cured and the patient's length of stay with hospice, including home and inpatient hospice days. We also compared the reported timing of physicians' communication and the timing of caregivers' understanding of the information reportedly communicated. Finally, with frequency analyses, we compared physicians' and caregivers' prognostications about the patient's life expectancy.

In the analysis of the qualitative data from the in-depth interviews, we used the constant comparative method of analysis.<sup>25,27</sup> Three investigators (E.B., D.S.G., E.C.) performed line-by-line coding of each transcript, first independently and then in joint sessions to discuss the coding and develop a coding structure.<sup>27,28</sup> The coding structure was expanded and revised as additional transcripts were coded, and a final code structure was developed through this process. The final code structure was then reapplied to each transcript independently by the researchers followed by a joint session to discuss differences, which were resolved through negotiated consensus. We report key themes and illustrative quotes related to communication. The computer software program QSR NUD-IST 4.0 (Sage Publication Software, Thousand Oaks, CA) was used to assist with the coding and analysis for common themes.

## RESULTS

### Characteristics of the study samples

In the quantitative study sample ( $n = 206$ ), three-quarters of the participants were female, and the mean age was 57 years (Table 1). Approximately half (51.4%) of the family caregivers were children of the patients; 30.6% of respondents were patients' spouses. Of the 206 respondents, 23 did not answer the communication questions. These nonrespondents were not significantly different ( $p > 0.10$ ) from the remaining respondents ( $n = 183$ ) in terms of gender, age, or kinship relationship with the patient. The qualitative study sample ( $n = 12$ ) was similar in sociodemographic characteristics, with two thirds of the primary family caregivers being female; about half were children of the patient, and the mean age was 48.6 years.

### Prevalence of physician-family caregiver communication

In a notable proportion of cases, family caregivers reported that a physician never told them that the patient's illness was incurable or that hospice was a possibility. Nearly 20% ( $n = 38/183$  or 20.8%) of the family caregivers reported that they had not been told by a physician that the patient's illness could not be cured, while approximately 80% ( $n = 145/183$  or 79.2%) reported they were told. Hospice length of stay (including home and inpatient hospice days) was significantly shorter for the group reporting they were not told that the illness was incurable (17.8 days versus 34.6 days,  $p = 0.008$ ). Of the approximate 80% ( $n = 145/183$ ) who reported being told the illness could not be cured, about 60% ( $n = 86/145$  or 59.3%) reported that the physician also told them how long the patient had to live at that time, while approximately 40% ( $n = 59/145$  or 40.7%) report the physician never estimated life expectancy. In approximately one third of all family members ( $n = 59/183$  or 32.2%), the caregiver reported that a physician had never discussed hospice as a possibility with the caregiver, while in the remainder of the cases ( $n = 124/183$  or 67.8%), caregivers reported that the physician did discuss hospice as a possibility with them.

### Timing of physician-family caregiver communication

Many family caregivers who reported having such discussions with a physician reported that the communication about the illness being incurable and possible use of hospice occurred quite late in the course of the illness (Figs. 1 and 2). Approximately one quarter ( $n = 34/145$  or 23.5%) of the family caregivers who reported that a physician had told them the patient's illness could not be cured said that they were told less than 1 month prior to the patient's death. Some of these 34 caregivers ( $n = 18$ ) reported being told less than 2 weeks before the patient's death. The remaining family caregivers reported being told 1-6 months before the patient's death ( $n = 64/145$  or 44.1%) or more than 6 months before the patient's death ( $n = 47/145$  or 32.4%) (Fig. 1). A substantial proportion of family caregivers ( $n = 51/124$  or 41.1%) who reported that the physician had discussed the possibility of using hospice did so for the first time in the month preceding the patient's death. Many of these caregivers ( $n = 34$ ) reported being told about hospice by the physician less than 2 weeks before the patient's death. The remaining caregivers reported that the physician first discussed hospice 1-6 months before the patient's death ( $n = 62/124$  or 50.0%) or more than 6 months before the patient's death ( $n = 11/124$  or 8.9%) (Fig. 2).

### Physician-family caregiver communication and subsequent caregiver understanding

Most family caregivers indicated that communication from the physician was pivotal in their own understanding of the patient's condition (Fig. 3) and of hospice as a treatment alternative (Fig. 4). In the majority of the cases, the family caregiver reported that he/she did not know the illness was incurable until the physician told him/her ( $n = 98/145$  or 67.6%) or until days after the first physician discussion of the illness being incurable ( $n = 12/145$  or 8.3%). A minority of caregivers reported that they already knew the illness was incurable ( $n = 35/145$  or 24.1%) before the physician discussed this with them (Fig. 3). Similarly, in the majority of cases, the family caregiver reported he/she did not think the patient needed hospice until the physician first discussed the possibility of hospice ( $n = 56/124$  or 45.2%) or days after that first physician discussed the possibility of hospice ( $n = 49/124$  or 39.5%). A minority of caregivers ( $n = 19/124$  or 15.3%) reported that they thought the patient needed hospice before the physician discussed it.

### Physician-family caregiver concordance of prognostications about life expectancy

Many family caregivers did not share the same view as the physician on how long the patient had to live. Only about one quarter ( $n = 21/86$  or 24.4%) of the 86 family caregivers who reported that the physician told them how long the patient had to live thought the patient's prognosis was the same as what the physician had told them. Some family caregivers thought the patient would live longer than the physician prognosticated ( $n = 15/86$  or 17.4%), and others thought the patient would not live as long as the physician prognosticated ( $n = 18/86$  or 20.9%). More than one third of family caregivers ( $n = 35/86$  or 40.7%) would not estimate how long the patient had to live, even after hearing the physician's prognostication.

### The caregiver's experience: communication prior to hospice enrollment

The overarching theme that emerged from the in-depth, open-ended interviews with family caregivers was variability concerning communication about these sensitive topics. Every caregiver described physician communication about the seriousness of patient's illness, life expectancy, and treatment alternatives as an important aspect of their experience caring for the patient. However, their views were diverse. Several family caregivers articulated the desire to have known sooner that the patient's illness was incurable. In fact, some caregivers described being suspicious that physicians knew more than they communicated, withholding potentially useful information from the caregiver. On the other hand, some caregivers were thankful that

the physician did not discuss these topics with them. Still others were ambivalent about whether they had wanted to know more or not and how and when physicians should discuss these issues.

The following quotations from two caregivers reflect the more common desire of wishing they had been told more by the physician and believing that they might have made different decisions had they known more:

Well, none of us would have made the decisions we did [to continue treatment] if we had known the truth about her illness. I just don't know if the doctors knew, but they must have. Why wouldn't they tell us? You have got to wonder why they put her through all that—I mean the chemo and especially the radiology and all those burns. She was in pain and had burns everywhere from the radiation. It was awful. She wouldn't have gone through it if she had known what they knew, but they told us it was curable; so what are you going to do?

I don't think the decisions were in our control at all. We were not the empowered ones in this because we did not know. How can you know? I mean, we are not the experts in medical things. Should we be? We didn't really have any decisions to make because we didn't know anything. And they told us that her disease was curable. They even said the cancer was gone. That still has me wondering even now. What did they know?

In contrast, one caregiver expressed not wanting to know more about the patient's illness and life expectancy, as illustrated by this quotation:

No, to tell you the truth, I'm very happy that the doctor never made mention of her prognosis. I'm sure the doctor knew because when she [patient] said "How much time have I got," he said, "Well, what do you think?" He left it up to her. He didn't say X amount of time because I think, probably, it would have made her more distraught, and maybe worry more.

Finally, some caregivers were ambivalent about how the communication should have taken place and whether they wanted to know more or not. As stated by one caregiver:

I think maybe the doctor needs to be hopeful, but also plant a seed that [she could be dying]. For instance, he could say, "We have another drug we can try. I don't know if it will work or not." But that is not what he did. He didn't say, "I don't know if it will work." Instead, he said, "I haven't given up hope on you yet." Maybe, there is another way to say it. I don't know. Maybe you don't want to hear the news anyways. I don't know.

## DISCUSSION

Our findings indicate that there is substantial variation in the communication that occurs between physician and family caregivers of patients who die with hospice about key aspects of care at the end of life. We find that in a notable minority of cases primary family caregivers report that they have not been told by a physician that the patient's illness cannot be cured, and even larger proportions never discuss hospice with the patients' physicians. Although this finding is consistent with previous research,<sup>1,16,29,30</sup> we additionally find that those who are told that the patient's illness is not curable are often told very late in the course of the patient's illness. In a number of cases, communication about the illness being incurable and the possibility of hospice as an alternative is reported to occur only in the last month or even week of the patient's life. The reported apparent delay in such discussions may be preventable, especially in the case of cancer for which prognostication is more accurate.<sup>12,19,31</sup> Reducing delays in communication regarding the patient's illness may provide more opportunities for patients and families to say goodbye, complete personal and financial arrangements, and plan for the last phase of the patient's life. Data suggest that patients and families value being able

to prepare for death<sup>5-7,32</sup> and timely, effective communication about the irreversible and progressive illness can promote such preparation.

In addition, we find that the family caregivers' own understanding of the patient's condition and the possible treatment alternatives is strongly influenced by discussions they report having with the physician. In the vast majority of cases, family caregivers report that they did not know the patient's illness was incurable or that hospice might be appropriate until a physician raised it with them, and patients whose family caregiver reported discussions of the patient's incurable illness had significantly longer hospice length of stays prior to death. The importance of physician-family caregiver discussions of the patient's terminal status was shown a decade ago to be associated with hospice use<sup>13</sup>; the current study suggests that such discussions may also be important to earlier hospice enrollment in the course of the illness. Recent research has shown significant benefits of earlier hospice enrollment for both patients and family caregivers,<sup>23,33</sup> and earlier communication about hospice as an option might promote its more timely consideration and use.

Our findings concerning the discussion and understanding of life expectancy paint a somewhat more complex picture. While only a minority of family caregivers did not believe the patient's illness was incurable after a physician told them, a larger proportion of caregivers did not accept the prognosticated life expectancy provided by the physician. In fact, only a quarter of family caregivers reported that they agreed with the physician when he/she provided an estimated life expectancy. Many were either more optimistic or more pessimistic than the physician, but more importantly, nearly 40% still indicated that they did not know and would not estimate the patient's life expectancy, even after a physician reportedly provided such information. Prior work has indicated that prognosis is often not discussed<sup>9,10,12</sup> or discussed only indirectly.<sup>10,11,31</sup> Our finding is consistent with this previous literature but also suggests that, even when physicians discuss prognosis, family caregivers may not agree or accept to what has been said. Therefore, family caregivers' limited understanding of prognosis likely results from a combination of physician and caregiver communication factors, not from poor physician communication alone. Future research is needed to understand why family caregivers may not accept the prognostic information provided to them by physicians, such as lack of trust in the physician, lack of demonstrated reliability of these predictions, denial, a sense that time of death is divinely determined, or some combination of these.

The complexity of communicating effectively and appropriately about end-of-life issues is highlighted by the voices of several caregivers who reflect the ambivalence they felt about knowing the truth and the related ambiguity likely felt by physicians in deciding how and when to communicate such sensitive and potentially unreliable information. Although most caregivers reported wanting to know about the patient's condition and alternatives earlier in the course of the patient's illness, several did not want to know more, and others remained conflicted about what they wanted to know and when. Faced with this variation in family caregiver desires and needs for communication, the challenge may be not in teaching physicians to communicate more with patients and families, but in assessing which patients and families desire and would benefit from such communication. Despite the principles of autonomy and informed decision-making, uniform approaches to communication in this area are unlikely to be successful or appropriate, given the diversity of preferences and views of patients and their families.

Our findings should be interpreted in light of our study limitations. Caregiver reports of physician communication and its timing are subjective and may be biased. Previous studies have found that caregiver and physician reports about communication at the end of life differ, and agreement on communication is limited.<sup>9</sup> Furthermore, we did not examine communication between the patient and physician. Nevertheless, given that the primary family

caregiver is often a strong influence on treatment choices,<sup>13,14,34</sup> the caregiver's perception of what is communicated remains an important factor that may influence end-of-life outcomes. In addition, our sample focuses on caregivers of hospice users, who may report greater communication than caregivers of patients do not receive hospice; therefore, our findings may underestimate the deficiencies in end-of-life communication in a more general population of dying patients and their families. We interviewed caregivers at one point in time, potentially limiting our ability to measure changes in their perceptions over time. Reported communication did not differ significantly between caregivers interviewed before and caregivers interviewed after the patient's death. Our response rate was similar to studies of this nature and our nonresponding caregivers did not differ in gender or kinship with the patient; however, they may have differed in unmeasured ways from the participants. The direction of this potential bias cannot be predicted. Finally, our study was conducted in a single state with a relatively modest sample of caregivers; however, our objectives were descriptive in nature, and this exploratory study provides new insights about the timing, scope, and acceptance of physician communication with family caregivers about care at the end of life. Future efforts should include more geographically, culturally, and racially/ethnically diverse groups to further understand the complexity of communication about end-of-life issues.

Although communication is a critical element of high quality end-of-life care,<sup>1-5</sup> many family caregivers report limited and delayed communication about the incurable illness, life expectancy, and hospice as a treatment alternative. Our findings suggest that approaches to communication, which is central to the care itself, will be most effective if tailored to fit the circumstances and preferences of patients and families. Physicians' discussions of these topics do influence family caregivers, who often become aware of the gravity of the patient's situation for the first time during discussion with a physician, but who also may require time to accept the implications of the new information. Disparities between what physicians think they are communicating and what caregivers hear communicated are important to understand in light of our findings. Future studies should examine strategies for optimal physician-family caregiver communication about incurable and progressive illness, so that families and patients can begin the physical, emotional, and spiritual work that can lead to acceptance of the irreversible condition.

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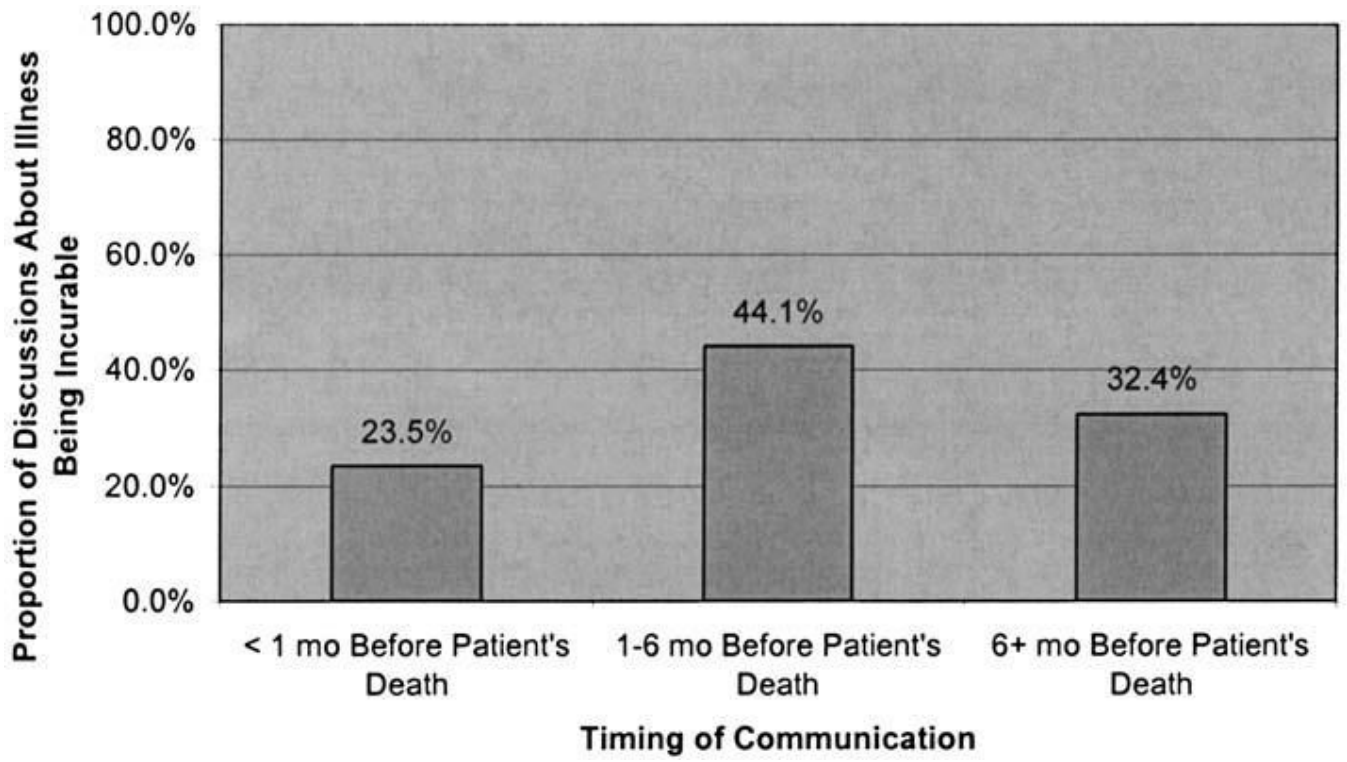
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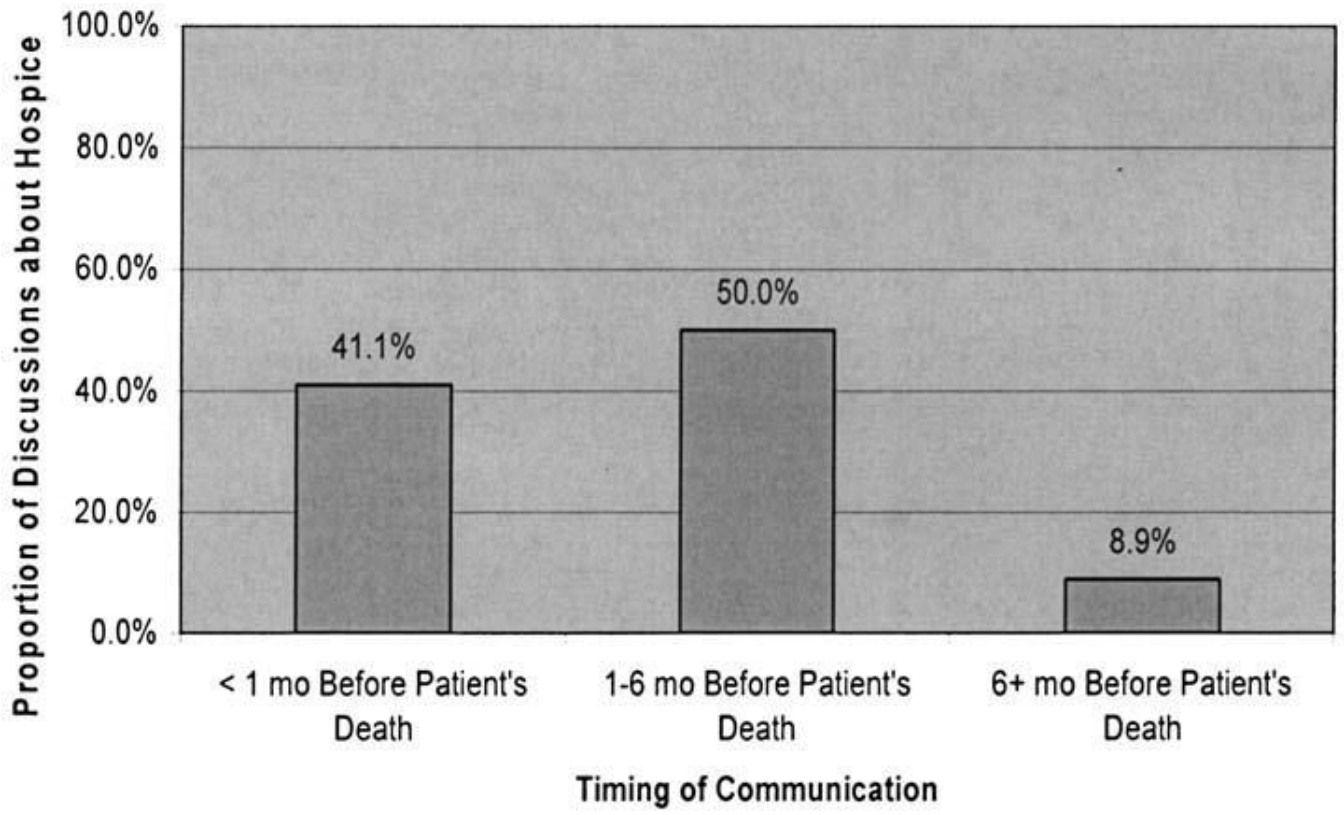


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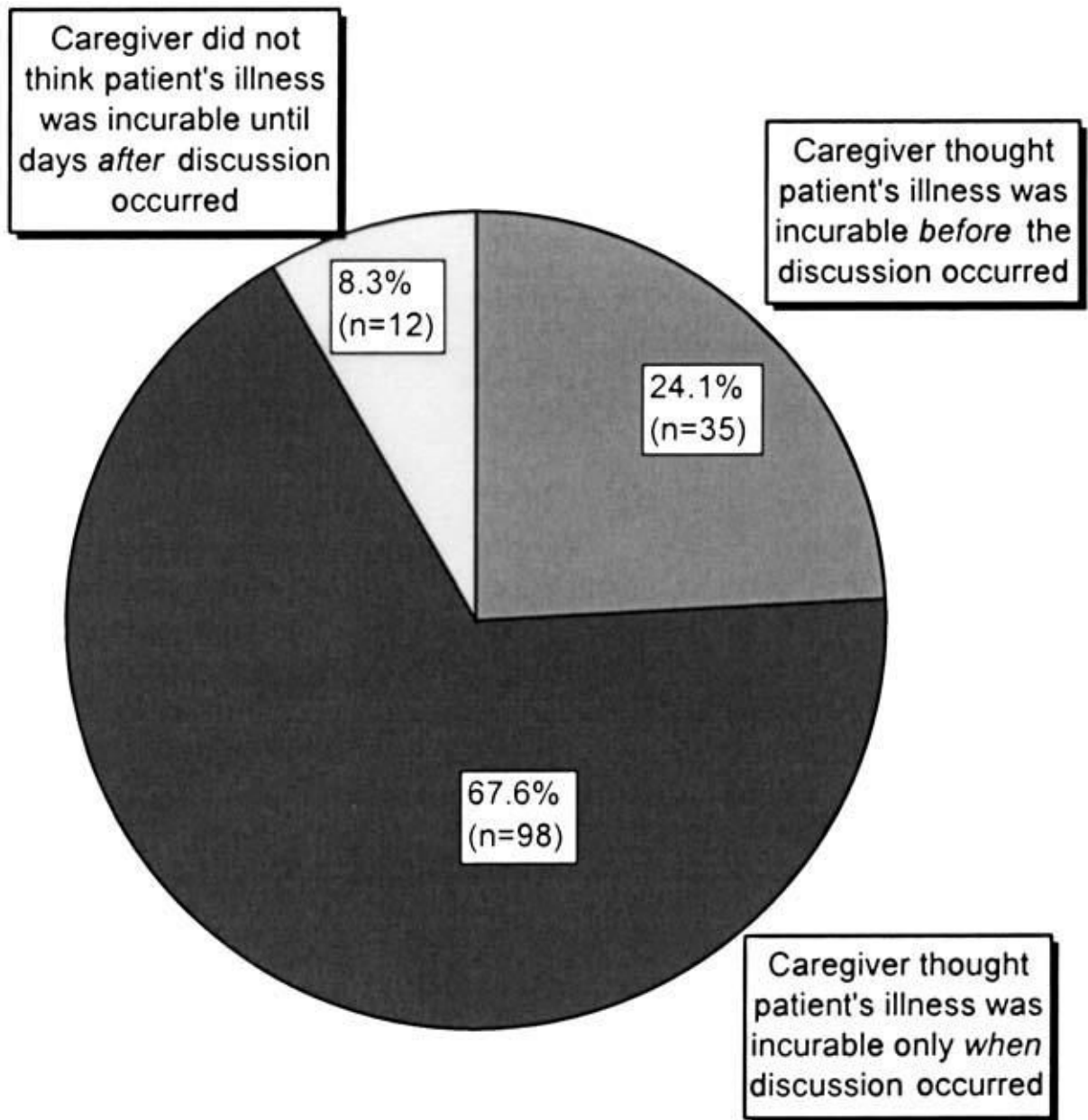
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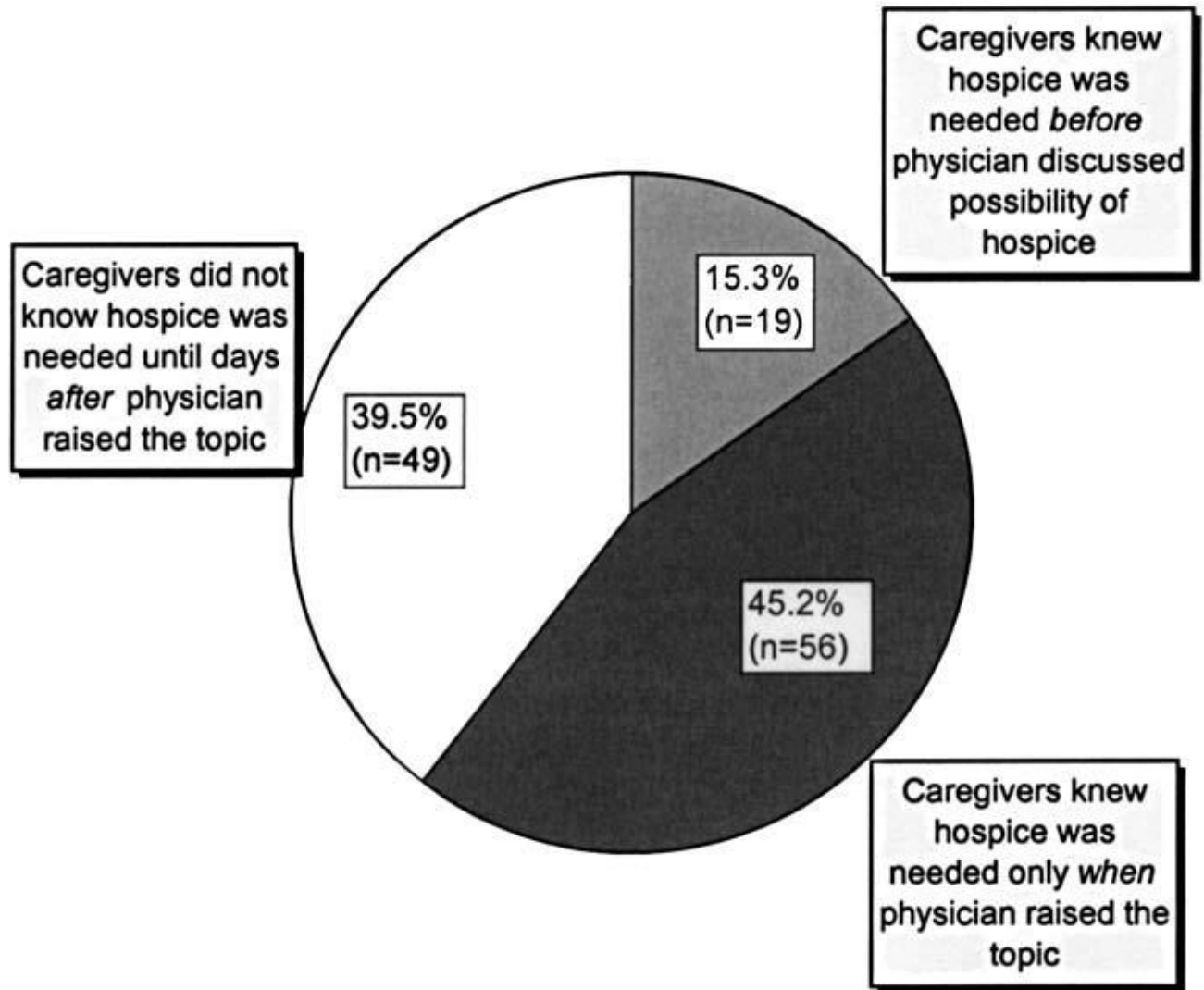
**FIG. 1.**  
Reported timing of first discussion about illness being incurable.



**FIG. 2.**  
Reported timing of first discussion of hospice as a possibility.



**FIG. 3.** Physician-family caregiver communication and caregiver understanding that the illness could not be cured ( $n = 145$ ).



**FIG. 4.** Physician-family caregiver communication and caregiver understanding about hospice (n = 124).

**Table 1.**CHARACTERISTICS OF CAREGIVERS STUDY POPULATION (*n* = 206)

Characteristic	n (%)
Female	147 (71.3)
Age: ≤65 years	149 (72.3)
mean in years (SD)	57.0 (13.0)
Race: White	197 (95.6)
Education	
High school or less	60 (29.1)
> high school	146 (70.9)
Marital Status	
Married	114 (55.3)
Divorced/separated	24 (11.7)
Never married	19 (9.2)
Widowed	49 (23.8)
Relationship to patient	
Spouse	63 (30.6)
Daughter	79 (38.3)
Son	27 (13.1)
Other	37 (18.0)

SD, standard deviation.