3-13-2003

Discussing Prognosis: Documented Communication with Elderly Patients with Cancer at the End of Life

Anna Gibb Hallemeier
Yale University

Recommended Citation

Hallemeier, Anna Gibb, "Discussing Prognosis: Documented Communication with Elderly Patients with Cancer at the End of Life" (2003). *Yale Medicine Thesis Digital Library*. 130.
http://elischolar.library.yale.edu/ymtdl/130

Discussing Prognosis: Documented Communication with Elderly Patients with Cancer at the End of Life

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements of the
Degree of Doctor of Medicine

by
Anna Gibb Hallemeier
2002

DISCUSSING PROGNOSIS: DOCUMENTED COMMUNICATION WITH ELDERLY PATIENTS WITH CANCER AT THE END OF LIFE. Anna Gibb Hallemeier and Elizabeth H. Bradley. Department of Epidemiology and Public Health, Yale University, School of Medicine, New Haven, CT.

Abstract

The purposes of this study were to evaluate the frequency of documented prognosis discussions among terminally ill cancer patients, to identify correlates of having documented prognosis discussions, and to describe the content of prognosis discussions as documented in patient medical records. Sample data were collected from the randomly selected medical records of inpatients (n=210) aged 65 years or older and admitted with diagnoses of brain, pancreas, liver, gall bladder, or inoperable lung cancer from six large Connecticut hospitals. A standardized instrument was used to extract data concerning patient demographics, hospital course, prognosis discussions, and evidence of advance care planning. Prognosis discussions were recorded in 79 (38%) of medical records and were correlated with emergency admission status (p=0.004) and longer length of hospital stay (p=0.003) on multivariate analysis. Of the documented prognosis discussions, 63% were within one week of admission but after the first day, and 57% included the patient, 76% included the family, 77 % included the doctor, and 69% did not include another health staff member (n=79). Life sustaining treatment discussions and DNR orders were both associated with prognosis discussions (p=0.001 and p=0.001, respectively) and were more often documented after the prognosis discussions. Prognosis discussions included planning for care and treatment in 33 (42%) of discussions documented. In conclusion, we found that prognosis discussions were infrequently documented during the hospitalization of terminally ill patients diagnosed with cancer. We also found that advance care planning, such as discussions of life sustaining treatment and DNR orders, was significantly associated with prognosis discussions and more often occurred after prognosis was discussed.

Acknowledgements

Supported by grants from the Etta S. Chidsey Award in Cancer Research, the National Institutes of Health—NHLBI, Medical Student Research Training Fellowship, the John D. Thompson Hospice Institute for Training, Education, and Research, and the Nathan Cummings Foundation. Special thanks to Emily Cherlin. Thanks also to Nicholas Christakis and Kinari Webb for their helpful comments.

Table of Contents

I. Introduction

In the last decade, the quality of end-of-life care in the hospital setting has been criticized. Some have argued that death in America has become medicalized over the course of the century, with the result that death is often unseen, impersonal, and fear-provoking.[1-3] Many people fear a prolonged death with excessive pain, loss of control, suffering, and financial expense,[2, 4-7] and recent empirical evidence concerning hospital deaths has reinforced this fear.[8]

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), a multi-center trial of hospitalized patients with severe illnesses, has provided the most recent data about the experience of dying in the United States.[8] Its findings indicated that extensive technological intervention is commonplace prior to death. Half of the dying patients studied received life-sustaining treatments within the three days preceding death. Further, of those who were conscious before death, half experienced moderate to severe pain in the last three days of life, and many suffered from dyspnea, fatigue, emotional distress, and dysphoria, according to surrogate reports.[9] The data from SUPPORT suggested that communication about end-of-life issues such as cardiopulmonary resuscitation (CPR) occurred infrequently. In SUPPORT, fewer than half of the patients reported ever discussing their CPR preferences,[8] and, of those, only 23% discussed their preferences for CPR with their physicians in the first few days of their hospitalization.[10] In addition, fewer than half of the subjects reported ever discussing advance directives with their physicians.[11, 12] From these and other data, the shortcomings of physician-patient communication at the end of life have been highlighted as a central limitation of care of the dying.[12]

Several previous studies have examined the nature of communication at the end of life among the medical staff, patient, and family. However, the majority of this research has focused on communication regarding life-sustaining treatments, identifying several problems with discussions of life-sustaining treatment, including their infrequency and limited scope.[10, 12-20] Studies have suggested that only 10-25% of inpatients discuss life-sustaining treatments with their physicians.[10, 14, 15, 18] This pattern of poor communication has been found in nursing homes as well. Studies of discussions about life-sustaining treatment in nursing homes reported that only about one-third of nursing home residents have discussions about life-sustaining treatment with their physicians.[13, 21] These studies found that discussions about life-sustaining treatments with nursing home residents occur rarely in inpatient and nursing facilities. Despite this, a study by Markson et al.[22] found that a majority of physicians felt that the physician should be responsible for initiating discussions about preferences for end-of-life care.

While the evidence suggests that discussions about life-sustaining treatment are infrequent, research in this area has found that patients are eager to have such discussions and that discussions are necessary for understanding patients’ wishes. Steinhauser et al.[4] found that patients, families, and providers all stressed the need for good communication and clear decision-making at the end of life as important for achieving a good death. In another study,[17] 68% of the cancer patients interviewed wanted to discuss their preferences regarding life-sustaining treatments, and the majority of these wanted their physician to instigate the discussion. Reilly et al.[23] and Emanuel et al.[24] also found that a large majority of inpatients and outpatients were interested in discussing advance directives with their physicians. In addition to patients' interest in discussing life-sustaining treatment preferences, studies have indicated that individuals' preferences for life-sustaining treatment are difficult to predict, and that discussions are necessary to ensure that patients will receive the care they desire.[25-30]

Although life-sustaining treatment discussions have been well studied, the current status of communication regarding prognosis at the end of life is less fully understood. Studies have suggested that patients frequently wish to know their prognoses. A national survey in the United States conducted in 1982 for the presidential commission on bioethics showed that 85% of Americans wanted a "realistic estimate" of how long they had to live if diagnosed with a serious cancer.[31] Similarly, a study of 439 hospitalized patients with cancer found that 92% wished to know as much information as possible, good or bad.[32] Nearly three-quarters of patients with advanced cancer wished to be fully informed in another study.[33] A third study showed that the majority of cancer patients in Scotland wanted physicians to give them as much information as possible and, in particular, wanted to know what the chance for a cure was.[34] Further, while some results have suggested that communication about prognosis is sufficient,[33] ample evidence has suggested that patients feel that information-giving is inadequate. In particular, a retrospective study of bereaved family members highlighted the desire for better communication among patients, families, and physicians, particularly concerning information about prognosis.[12]

Discussion of prognosis by physicians with patients and family members may be particularly important because prognosis appears to influence patients' wishes for various treatments and treatment settings. Open information about prognosis appear to be related to lower levels of anxiety and depression in children with cancer.[35] In addition, previous studies have shown that patients’ beliefs about prognosis can affect treatment preferences and decisions about end-of-life care. Weeks et al.[36] found that patients with cancer who believed that they had a good chance of surviving for six months were significantly more likely to choose life-sustaining therapy than patients who thought that their chances of six-month survival were slim. The influence of patient-estimated prognosis on treatment preferences was particularly apparent among patients who were estimated by their physicians as having little chance of surviving for six months.[36] In the SUPPORT study, patient perception of a worse prognosis was associated with the patient not wanting to be resuscitated.[37] Conversely, patient perception of a better than two-month prognosis was associated with a wish to be resuscitated.[38] In addition, under the Medicare Hospice Benefit, patients must be given a prognosis of six months or less to be reimbursed for hospice care.[39] In order to receive the Medicare benefit, patients must sign an informed consent about their illness and prognosis.

While a patient’s estimate of his or her own survival may influence patient treatment choices, research has indicated that patients are often inaccurate when asked to predict their survival. Patients tend to overestimate their chances for survival, as Weeks et al.[36] found in their study of 917 patients with cancer in SUPPORT. Weeks et al. found that patients' estimates of six-month survival were both more optimistic and less accurate than physician estimates, that 82% of patients were more optimistic about their prognosis that their physicians were, and that physicians were significantly more accurate than patients at predicting prognoses.[36] Patients' inaccuracy in estimation of prognosis has also been highlighted in other studies of patients with metastatic cancer.[33, 38, 40-43] Because prognosis can influence patient therapy choices, and because patients' prognosis estimates are often inaccurate in the absence of discussion with a physician, prognosis discussions may be fundamental for patients and families to make informed and autonomous decisions about their treatment alternatives at the end of life. In addition, the importance of preparation for the end of life has been highlighted,[5] suggesting that prognostication is necessary to achieve a good death, from the perspective of patients and families.

Yet, many reports have suggested that physicians are reluctant to give prognostic estimates or to have discussions about prognosis with their dying patients.[44] A recent study by Lamont and Christakis investigated the self-reported likelihood that physicians would give frank survival estimates to their terminally ill cancer patients being referred for hospice, if they asked the physician directly.[45] The survey found that physicians would give frank survival estimates to approximately one-third of patients who asked, would give no prognostic estimate to approximately one-fifth of patients who asked, and would give knowingly optimistic or pessimistic estimates to the remaining patients.

Another survey of physicians showed that most physicians believed that they should avoid being too specific when making predictions, and almost half will wait to be asked before giving the patient a prognostic estimate.[46] Of the physicians surveyed for the presidential commission on bioethics, fewer than half would either give a “straight statistical prognosis” or “stress that in most cases [of advanced stage lung cancer] people live no longer than a year.”[31] Similarly, in a qualitative study with 32 physicians, Miyaji concluded that often physicians are consciously vague about prognoses, allowing for misunderstandings between the physician and patient to go unrecognized.[47]

Although the ethical principles of autonomy and self-determination suggest that patients have a right to know their prognosis, physicians have many reasons for avoiding discussions of prognosis when the news is not good. First, physicians may not like to make predictions because physicians may not know the prognosis themselves, as has been shown in multiple studies.[48-50] Lynn et al.[51] created a statistical model to predict patient survival for the SUPPORT study. Attending physicians were as accurate at predicting prognosis as the computer-generated model, but, overall, predictions at the end of life were not very accurate.[1, 9, 52] Physicians report that they find it stressful to make prognostications for many reasons, including inadequate training and the inherent difficulty of making predictions.[46] A recent study of hospice patients found that physicians were likely to overestimate prognosis, and only about 20% of prognoses were accurate.[53] The current status of training about end of life care has tended to de-emphasize the importance of prognosis as a medical skill.[54-57] Recent reviews of current medical textbooks found that useful information on prognosis and many other issues related to death in severely ill patients was lacking.[57-61]

Second, some physicians may not believe that it is a professional standard to give prognostic information. Although research suggests that the attitudes of physicians towards discussing the diagnosis of cancer openly with patients have changed radically in the past several decades,[59-61] attitudes towards discussing prognosis may have lagged behind. A historical study of the importance of prognosis in medical texts across the twentieth century showed that prognostication has continually diminished in importance over the years as other aspects of medicine, such as diagnosis and therapy, have come to the forefront.[55] A review of the literature on communication with patients with cancer found many ambiguities and conflicts in prognostication recommendations.[62] For example, some articles recommended using euphemisms while other suggested that physicians should not use euphemisms, and some recommended privacy while others recommended having other professionals present. Such professional ambiguity towards prognostication has led to the fear that colleagues could lose respect for fellow physicians by making incorrect prognostications.[46]

A third reason why physicians may not discuss prognosis is because they are waiting for the patient to ask direct questions about his or her condition, in order to allow the patient to control the information that he or she is given. Several articles on how to give bad news have cited the importance of delivering the news "at the receiver's pace," in order to increase the patient's sense of control and avoid overwhelming the patient.[46, 47, 63]

Some physicians have felt that disclosure of prognosis should happen gradually, as the physician-patient partnership evolves.[46, 47, 63-65] Many physicians wait until a patient asks specific questions before they volunteer information.[46, 47] Because this method of providing prognostic information requires that physicians gauge the desire of the patient, some patients may be left unaware of their condition and/or prognosis. A Dutch study[66] found that physicians and patients "colluded" in avoiding discussions of prognosis and allowing optimism to persist during the course of treatment, as neither doctors nor patients really wanted to address the reality of the bad news.

Fourth, physicians may avoid discussing prognosis because prognosis information has less "action-relevance" than information about treatment.[47] Issues other than prognosis often require the physicians' and patients' immediate attention, such as which treatment option to undertake, and as a result, discussions about the long-term prognosis may be delayed indefinitely. Treatments often need to be undertaken rapidly in order to be effective against the disease, while there may be no apparent equivalent time pressure for discussing prognosis. Thus, action and technology are often considered to be primary concerns in medicine, superceding communication about the end of life.[67]

Finally, physicians may be reluctant to discuss prognosis with patients because they wish to maintain the patient's hope. In a study by Christakis and Iwashyna,[46] physicians reported a preference for optimism, shading prognoses to the positive and reinforcing optimistic perceptions of prognosis. In reviewing the literature concerning how to deliver bad news, Ptacek and Eberhardt also cited the importance of conveying hope whenever giving bad news.[63] A survey of physicians by Delvecchio Good et al. found that oncologists considered hope to be an essential aspect of practice, referring to “the mandate to instill and maintain hope in patients” (p. 68).[65] The physicians in Miyaji’s study felt that the principle of patients’ hope was more important than patients’ right to know.[47] One of Miyaji’s five basic principles in communication with the dying patient was to preserve hope, a principle that some physicians believe conflicts directly with a patient’s right to the truth about his prognosis.[47] Christakis described physicians’ fear of a “self-fulfilling prophecy”, a belief among doctors that prognostication may result in a change in patient behavior, ultimately affecting the timing of death itself, a frightening prospect that may result in a reluctance to prognosticate.[44]

Because cultures vary dramatically in how they confront death, ethnic background is an additional factor that may affect the discussion of prognosis. Americans have been shown to differ from other countries, such as Italy and Japan, in their attitudes towards death.[65, 68, 69] In addition, there is a great deal of cultural variation in attitudes towards death within the United States.[70-74] Less is known about how the ethnicity of the physician affects the discussion of prognosis,[70, 75-77] although it is probable that the cultural background of the physician is also a factor. Despite some cultural norms, many have argued that patients’ individual preferences cannot be reliably predicted and should not be assumed from cultural background.[64, 70, 75, 78]

Literature Review

There are a limited number of studies that address the frequency and scope of prognosis discussions at the end of life in the hospital setting, despite the importance of such communication for end of life decision-making. The studies that exist are limited in scope, and the results are greatly disparate, leaving many questions unresolved. Butow et al. and Seale reported that discussions of prognosis may occur as rarely as 27% of the time or as frequently as 64%,[62, 79] but the SUPPORT data suggested that patients very rarely know what their prognosis is.[36] These studies concluded that physicians are usually the health professionals conducting prognosis discussions, but the role of other health professionals remains unclear, and the correlates and contents of discussions have not yet been examined in the current research.

The most recent study of prognosis in terminally ill cancer patients used data from SUPPORT. Weeks et al. analyzed the prognosis data, looking at 917 hospitalized adults with advanced colon or lung cancer.[36] The patients' estimates of the probability of two-month and six-month survival were collected from interviews with the patient and/or a surrogate, and physicians' estimates of six-month survival were also obtained by interview. The study found that only 14% of patients agreed with their physicians about their prognosis, findings that suggested that prognosis discussions occur infrequently. Patients were both substantially more optimistic than their physicians (82% of patients were more optimistic about their prognosis than their physicians) and less accurate than their physicians at predicting prognosis ($p < 0.0001$). The study had many methodological limitations, reducing the validity of the results. The cohort included patients from Phases I and II of the SUPPORT study, including the subjects of an intervention specifically designed to increase communication about prognosis,[8] making it less indicative of actual practice in the hospitals. Further, the study obtained patient estimates of prognosis from interviews with “patients and/or surrogates”, considering either report to be the patient’s estimate of prognosis. This method did not account for the fact that patients and families frequently have different knowledge of prognosis,[79] so it was unclear exactly what patients were told and what families were told. In addition to its methodological limitations, the data by Weeks et al. left many important areas of study unexamined. The study did not address the scope or frequency of prognosis discussions with patients or the family; nor did it address the question of which professionals were involved with discussion. Such information would enable researchers to understand how patients develop an understanding of their prognoses. Another limitation of the SUPPORT data was the use of teaching hospitals, limiting the ability to generalize its findings to the community hospital setting, the setting for this study.

Teno et al. also used data from the SUPPORT trial to assess prognostication in intensive care unit (ICU) patients.[80] In this subset of patients, fewer than 40% of patients or surrogates recalled prognosis discussions. Again, this population cannot be used to generalize to common medical practice, as they were extremely ill patients requiring intensive care, and they were patients at teaching hospitals who were enrolled in a large multi-center trial centered on end-of-life care.

Another study by Butow et al. addressed cancer patients' experiences with communication about cancer.[62] The subjects were 148 inpatients and outpatients who had recently been diagnosed with primary or metastatic breast cancer or melanoma. Subjects filled out a questionnaire concerning the communication of cancer diagnosis and its implications. The study found that 27% of patients discussed life expectancy with their physicians. A general practitioner or surgeon gave the news of the diagnosis or prognosis in 68% of cases, and another health professional was present for 15% of discussions. Approximately half of the patients were alone when they were told their diagnosis.

A variety of issues limited the usefulness of this study for understanding the communication of prognosis in hospitalized patients at the end of life. First, the study relied on patient report of events that had occurred years previously, so the data were subject to recall bias. In addition, the study did not distinguish between discussions of diagnosis and discussions of prognosis, so the data combined many different types of discussion at different stages of disease and treatment, making it difficult to draw conclusions about what occurs during prognosis discussions. In addition to the methodological shortcomings of the data, the study by Butow et al. did not address several important issues, leaving many research questions still to be addressed. First, they excluded patients over age 75, who were more likely to have a worse prognosis. They also did not examine hospitalization status and excluded critically ill patients. Therefore, many of the patients for whom prognosis discussions were most important were not included in the study or were lumped into a larger population of cancer patients. Second, the study was done in Australia, so the results cannot be generalized to an

American population. Third, the subjects were patients at “large teaching hospitals”, substantially reducing the ability to apply these results to patients in community hospitals.

The final study concerning discussions of prognosis in the terminally ill was a cross-sectional study by Seale in Britain, published in 1987.[79] The relatives, friends, caretakers, and neighbors of 639 deceased people were interviewed about the last year of the patient’s life, and the physicians and nurses who cared for the patients were interviewed and surveyed by questionnaire. The survey of relatives and others found that 44% of cancer patients “knew certainly” that they were likely to die, 20% “knew probably”, and the rest either “probably” or “definitely” were unaware, or the respondent was unable to say. About three-quarters of the respondents for the cancer patients reported that they knew that the patient was likely to die, and 12% “half knew.” The study reported that of the cancer patients who knew that they would die, 12% were told by a general practitioner, a hospital physician told 28%, and no one told 52% of the patients.

The methods of this study had many drawbacks, limiting the generalizability and validity of the results. The retrospective design of the study made it subject to recall bias; particularly because the friends and relatives of recently deceased people may have been in denial and not accurately recollecting information. It also relied on a variety of living respondents, who may not have known what the patient knew or what conversations the patient had had. Another problem was that the respondent could have been a spouse, family member, or intimate of the deceased, but it may have been a neighbor or someone who knew the deceased's condition only peripherally, or a staff member who knew the condition due to professional understanding and not communication with the physician. In addition to the methodological drawbacks, the study was done in England, and thus, like the Butow et al. study,[62] this study cannot be used to predict behavior in the United States. All of these limitations make it difficult to use these data to understand the current status of prognosis communication at the end of life.

These three studies leave many important questions unanswered. First, the frequency of prognosis discussions in terminally ill cancer patients in the community hospital setting is still not well understood. The studies that exist are retrospective, include patients who are not terminally ill or in the hospital, come from overseas, are based in the teaching hospital setting only, or exclude patients who are likely to have such discussions. SUPPORT, the largest study on the end of life in America, did not address the frequency of prognosis discussions at all.

Second, the correlates of having discussions about prognosis have not been studied, leaving many unanswered questions about when discussions occur and which people are likely to have such discussions. Although there is a considerable body of literature about how and when to give bad news, there is little empirical data to show what actually occurs. None of the previously mentioned studies on prognosis communication attempted to determine the sociodemographic or biomedical correlates of such discussions. This study attempts to expand the body of knowledge concerning these important facts, increasing our understanding of the practice of prognosis communication and how this area of medicine could be improved and optimized for patients and physicians.

Third, the question of who is present during prognosis discussions has not yet been adequately examined in the literature. While the studies by Butow et al.[62] and Seale[79] both attempted to address this issue, the studies were both done overseas, limiting their relevance to American practice patterns, and were designed retrospectively, leaving the data subject to recall bias. In addition, Butow et al. combined discussions of diagnosis, prognosis, and treatment choices, limiting our knowledge regarding prognosis discussions, per se. Seale's data suggested that physicians were usually present for such discussions, but did not address who else may have been present. Also, relatives or other third parties, who may have been unaware of what discussions actually occurred, reported the data.

Fourth, the relationship between prognosis discussions and advance planning is important for understanding how patients make decisions about the end of life. The SUPPORT data suggested that patients who believed that they had a good prognosis preferred life-sustaining therapy, whether or not their physician believed that they had a good prognosis.[36] However, these data are insufficient for understanding how patients make decisions about their prognosis and their future treatments. By examining how discussions about prognosis with physicians are correlated with discussions about life-sustaining therapy and the presence of DNRs and advance directives, this study may lead to a better understanding of the effects of open communication during end of life care.

Finally, it is necessary to know the content of discussions about prognosis in order to understand what information is being addressed during such discussions. Butow et al. found that approximately half of discussions contained information about cancer support services, but the study did not include more detail about discussion content and did not distinguish between prognosis and other types of cancer care discussions. The value of prognosis discussions may depend upon the information being conveyed during such discussions, and thus it is necessary to know what the discussion content includes.

In conclusion, the existing data concerning prognosis are limited and leave many questions incompletely answered or entirely unaddressed. The importance of communication about prognosis has become increasingly clear in the past few years, and yet research on the subject remains scarce. Scientific understanding of prognosis discussions is still incomplete, and this study attempts to clarify many of these issues. Our study focused on cancer patients, as prognosis is often predictable in cancer, and these patients may gain a great deal from knowing more about their prognostic status. In addition, the population in community hospitals is less well studied, leaving many questions about the current medical practice of prognostication unanswered.

II. Statement of Purpose and Hypotheses

Specifically, the aims of this study were to: (1) document the proportion of elderly hospitalized cancer patients that have a prognosis discussion in their medical records, (2) identify correlates of having documented prognosis discussions, (3) describe the timing of prognosis discussions during the hospital stay, (4) examine who was present during such discussions, (5) assess the association between prognosis discussions and documented advance planning decisions, and (6) describe the content of prognosis discussions as documented in patient medical records.

We hypothesized that older patients would be more likely to have such conversations than younger patients, as they, their families, and their physicians are all more likely to be better prepared for the inevitability of death and therefore they may be more willing to have discussions about it. We further hypothesized that married patients would be more likely than unmarried patients to have prognosis discussions, as the spouse may be available for discussion and have a particular concern for the prognosis of the patient. We also expected that prognosis discussions would be more likely to occur during stays that began with an emergent versus elective admission, as these are probably sicker patients who are not electing to stay in the hospital for curative treatment. In the case of an acutely sick patient, the patient, the family, and the physician may have less hope for the eventual survival of the patient and thus be more ready to discuss the prognosis status to prompt advance care planning. In addition, we hypothesized that prognosis discussions would occur more frequently during longer hospital stays. Because prognosis is a subject that is often avoided or postponed.[46, 47, 65] discussions are unlikely to occur during a brief stay. In terms of the timing of discussions, we expected that prognosis discussions would take place during the first few days of stay of the patient, as soon as the prognosis of the patient became clear from the test results and the assessment of patient's condition.

Based on findings from the studies by Seale and Butow et al.,[62, 79] we expected that physicians would be involved in most discussions. We also hypothesized that the physician would not be accompanied by another medical professional during the discussions, as physicians are uncertain about prognosticating and, as others have suggested,[44, 46] may prefer to avoid discussing prognosis with other professionals around. Our expectation was that family would also be involved in many discussions, frequently without the patient, as that would be consistent with the notion of "closed awareness," in which the family is told the patient's prognosis but the patient is not.[79]

We hypothesized that the occurrence of prognosis discussions would have a positive influence on the frequency of end-of-life treatment decision-making such as documented advanced directives, discussions about life sustaining treatment, and DNR orders, since awareness of death may encourage families and patients to begin planning end-of-life care. In addition, we predicted that prognosis discussions would precede documented advance care planning.

Finally, we theorized that explicit estimates of the time until death would be rare in prognosis discussions, given the discomfort associated with prognostication and the difficulty in making accurate prognostications. We did, however, expect that prognosis discussions would frequently contain discussions of plans for future care or treatment, including both patient and family preferences for alternative therapies and sites for end-of-life care.

III. Methods

Sampling and Eligibility Criteria

The Hospice Outreach Project and Evaluation (HOPE) study was a medical record review that sampled patient hospital records in order to determine the frequency of documented prognosis discussions between terminally ill hospitalized cancer patients and their physicians. The medical student author of this thesis, in conjunction with Elizabeth Bradley and Emily Cherlin, was primarily involved with the analysis of the prognosis data from the HOPE study and literature review of the topic. Others trained in medical record abstraction completed project development, data collection, and analysis of other aspects of the data. The study sample was selected from six out of twelve total large (200+ licensed medical/surgical beds) hospitals in Connecticut. Size and location were controlled for in order to limit unforeseen confounding factors. The hospitals were randomly chosen from the greater New Haven, Bridgeport, and Hartford areas, excluding university-based hospitals in order to control for teaching status, using PROC in the Statistical Analysis System (SAS), or RANUNI, to assign random numbers and selecting the first six eligible hospitals. As most hospitals in Connecticut with 200+ licensed medical/surgical beds are not university-based, this exclusion did not substantially limit the generalizability of the results.

Sample data were collected from forty randomly selected medical charts at each hospital, resulting in a sample size of 240. Randomization of eligible patients was achieved with RANUNI, which assigned random numbers, and then selecting the first forty patients from each hospital. When a chart was not available or consent could not be obtained, the patient was replaced with another eligible, randomly selected patient from the same hospital. At the time of data analysis, the collection of data from one hospital had not been completed. As a result, this analysis was performed on 210 samples. Three trained abstractors collected the medical record data for the patients, including all admissions for patients who were admitted more than once during 1997. In order to be eligible for selection, a patient must have been admitted at least once to one of the study hospitals during the 1997 calendar year, using the date of admission as the reference point. In addition, the patient must have had a diagnosis of cancer of the brain, pancreas, liver, gall bladder, or lung listed as the primary ICD-9 code and must have been sixty-five years or older at the time of admission. The Institutional Review Boards at Yale University School of Medicine and at each of the hospitals approved the consent procedures and research protocol.

Data Collection Instrument

The HOPE Medical Record Review Instrument was used to collect information concerning the hospital stays of each subject. The instrument was used as a tool to collect demographic data from the admission forms, including age, gender, ethnicity, marital status, payer, and religious affiliation. The instrument also was used to record admission and discharge data, including the admission date, type and source of admission and discharge date, discharge diagnoses, and discharge disposition. The admission source was the location where the patient was living prior to admission to the hospital, including home, hospital, nursing home, hospice, or other.

The hospital course was charted, including major procedures, ICU admissions, ventilation and artificial nutrition and hydration, and do-not-resuscitate (DNR) orders documented. Information about hospice care, comfort care, and decisions to withhold or withdraw treatment was also collected. The instrument differentiated between DNR orders, advance directives, and life-sustaining treatment preferences, as they each represent different levels of legal status and patient participation and planning.

A supplement to the instrument was used to collect more detailed information about discussions of prognosis. The prognosis supplement recorded the date of each discussion, the content of discussions, the persons involved, the person who noted the discussion, and the severity of the prognosis discussed. Prognosis discussions were defined inclusively, including any discussions concerning prognosis, medical condition, or death. A discussion was noted as having occurred if the physicians', nurses', or social services' notes mentioned it in the medical record. The content of the discussions was recorded, quoting progress notes from the medical record. These progress notes were then coded using standard content analysis techniques[81] by two coders. Inter-rater reliability was good to excellent for all codes (kappas ≥ 0.60).

Variables and Measurement

The marital status, ethnicity, and religion or the patients were all abstracted from the medical records. Marital status was coded as Married, Divorced/Separated, Widowed, or Never Married. Ethnicity was categorized as White, Non-Hispanic; Black, Non-Hispanic; Hispanic; Asian; or Other. Religious affiliation was coded as Roman Catholic, Protestant, Jewish, Other, or None. For our analysis, patients were categorized dichotomously as married or unmarried, white or non-white, and Catholic or non-Catholic. Patient age was recorded as a continuous variable and coded as 65 to 69 years, 70 to 79 years, or 80 and older. Admission type was classified as emergency or elective. Length of hospital stays and ICU stays were noted as continuous variables and categorized as two days or less, 3-7 days, or more than seven days. Length of stay in the hospital was calculated as the difference between the admission date and the date of discharge or death. ICU stays were noted individually as separate admissions or transfers to the ICU and combined to calculate the total time spent in the ICU. Prognosis discussions were noted when present, and the date, content, and persons involved with each discussion were recorded. Persons involved with the prognosis discussion were recorded as patient, family, physician, nurse, social worker, both patient and family, or physician plus another staff member. Presence or absence of an advance directive, recorded discussions of life sustaining treatment preferences, and DNR orders in the medical record were noted, and the date of each one was noted. These variables were characterized as occurring before or after a prognosis discussion, if such a prognosis discussion took place.

Data Analysis

Statistical analysis was performed using the SAS, Version 6.12. Frequency statistics were used to describe the study population, the proportion of patients who had prognosis discussions recorded in the medical record, and the timing of prognosis discussions in relation to admission and discharge. The timing of prognosis discussions relative to the timing of advance planning documentation, the people involved in discussions, and the content of prognosis discussions were described with frequency statistics.

Bivariate associations between having a prognosis discussion recorded and having documented advance directives, life sustaining treatment preference discussions, and the presence of a DNR order were measured with unadjusted odds ratios, and chi-square statistics were used to test the statistical significance of the associations. The bivariate associations between socioeconomic factors and having a prognosis discussion were also measured with unadjusted odds ratios, and chi-square statistics were calculated to test the statistical significance of these associations. The unadjusted associations between the presence of a documented prognosis discussion and continuous variables such as length of hospital stay and ICU stay were measured by the difference of means, and t-tests were used to test for the statistical significance of these associations. Correlation coefficients were used to estimate the association between the number of prognosis discussions and the length of hospital stay and the number of ICD-9 codes. The statistical significance was tested using the correlation statistic, rho.

Logistic regression was used to estimate the independent effects of age, marital status, admission type, length of hospital stay, and ICU stays on the probability of having a prognosis discussion. Stepwise regression techniques were used to fit logistic regression models. The most parsimonious model was chosen, in which only the statistically significant variables ($p < 0.05$) or variables that were judged to confound the analysis were retained. Variables were judged to be confounders if their removal changed the parameter estimates on the remaining variables by 10% or more. Variables that were omitted from the final model did not substantially affect the coefficients or standard errors of the retained variables. Because of missing data, the effective sample size in the logistic regression was 204.

IV. Results

Study Population

The study population (n=210) was 52% male and 48% female (Table 1). The mean age of the population was 75, and half of the subjects (49%) were between 70 and 79. Most patients were admitted from home (83%), and approximately half of the admissions were emergency admissions (57%). About half of the patients were married (54%). Sixty percent of the population were Catholic, while 19% were Protestant and 3% were Jewish. Ninety-three percent of the study population was white; 4% were black, and 2% were documented as being Hispanic. The primary payer was Medicare for 70% of patients. The mean hospital length of stay recorded was 8 days, and 36% of the patients stayed for eight days or more. There was no difference in participants' mean length of stay by hospital. At admission, 15% of patients were documented as having dementia, while 82% of the patients were considered to be cognitively intact. The hospital stays of the participants ended with 36% discharged to home without hospice, 28% discharged to inpatient hospice or home with hospice, 12% dying in the hospital without hospice, and 23% going to nursing homes or other non-hospice facilities.

The Connecticut Tumor Registry data for 1997 gave very similar demographic statistics, suggesting that our sample is reflective of the Connecticut cancer patient population. Fifty-two percent of people who died from cancer in Connecticut in 1997 were female; 59% were married, and 7% were non-white. The average age of death from cancer in Connecticut was 70 years, which is younger than our population, as expected due to our eligibility criterion that participants had to be at least 65 years old at the time of admission.

Frequency of Prognosis Discussions

At least one discussion of prognosis was recorded in 79 (38%) of the medical records (Table 2). Of the entire sample, 18% had only one such discussion, while 20% had two or more discussions. The maximum number of discussions recorded for any single patient was seven (Table 3).

Correlates of Prognosis Discussions

In bivariate analysis, older age was significantly associated with having at least one documented discussion of prognosis (Table 4). Patients who were 80 years or older were 2.3 times more likely than younger patients to have a discussion of prognosis recorded in their medical record (p = 0.04). In multivariate analysis, the magnitude of this effect was attenuated (OR = 1.6) and remained in the expected direction; however it was no longer significant (p = 0.27, Table 5). In bivariate analysis, patients who were admitted on an emergent basis were 2.8 times more likely to have a discussion of prognosis noted in their medical record (p = 0.001, Table 4). This effect continued to be significant in multivariate analysis (OR = 2.6, p = 0.004, Table 5). Having a prognosis discussion was significantly associated with a longer hospital stay in bivariate analysis (p = 0.002, Table 4a). In multivariate analysis, the length of stay remained significantly associated with prognosis discussions (p = 0.003, Table 5). The number of ICD-9 codes was also associated with prognosis discussions in bivariate analysis (p = 0.02, Table 4b).

Unmarried patients were more likely than married patients to have a discussion recorded (OR = 1.5), but the effect was not significant in bivariate analysis or logistic regression ($p = 0.16$, $p = 0.66$, respectively). Gender, ethnicity, and religion were not significantly associated with having prognosis discussions in bivariate analysis.

Timing of Discussions

The average time between admission and the first prognosis discussion, for those with a discussion, was four days, with 20% of discussions taking place on the first day of admission and 83% of the first discussions happening during the first week of admission (Table 6). One quarter of the patients who stayed for less than three days had at least one prognosis discussion. Of those who stayed from three to seven days, 40% had one prognosis discussion. Over 50% of those who stayed in the hospital for more than one week had at least one prognosis discussion.

Participation in Prognosis Discussions

Prognosis discussions included the patient 57% of the time when there was at least one discussion recorded (Table 7). The family was involved in 76% of discussions, and both the patient and the family participated in 35% of the discussions. The physician was involved in 77% of discussions, a nurse in 37% of discussions, and a social worker in 18% of discussions. At least one other health professional, such as a nurse or social worker, was present with the physician in about one-third (32%) of the discussions of prognosis.

Prognosis Discussions and Advance Planning

Patients who had documented prognosis discussions were significantly more likely than those without prognosis discussions to have discussions about life sustaining treatment preferences and to have documented DNR orders (OR = 9.3, p = 0.001 and OR = 3.8, p = 0.001, respectively, Table 8). Life sustaining treatment discussions were recorded after the prognosis discussion in 53% of patients. DNR orders were present in the medical records after discussion in 39% of patients. However, prognosis discussions were not significantly correlated with the patient having an advance directive documented in the medical record (unadjusted OR = 0.78, p = 0.4). Among the patients who had documented prognosis discussions, only 3% had advance directives dated post-discussion (Table 9).

Content of Prognosis Discussions

The major topics that were covered in the prognosis discussions are described in Table 10. Ninety percent of the prognosis discussions addressed the primary subjects of prognosis, medical condition, test results, or discussion about death. Forty-two percent of the discussions included conversation about plans for care or treatment. General information and communication, excluding explicit statements about the course of disease but including topics such as education and support, were included in 33% of prognosis discussions. The contents of the prognosis discussions are described in detail in Appendix One.

Table 1: Demographic Description of the Medical Record Review Population (n = 210).

Characteristic	Number	Percent
Gender		
Male	109	52.0
Female	101	48.0
Total	*210*	*100.0*
Age		
65-69 years	56	26.7
70-79 years	103	49.0
80+ years	50	23.8
Unknown	1	0.5
Total	*210*	*100.0*
Mean Age in Years (SD)	*75 (6.6)*	
Admission Source		
Home	175	83.3
Hospital	6	2.9
Nursing Home	18	8.6
Hospice	3	1.4
Other	3	1.4
Unknown	5	2.4
Total	*210*	*100.0*
Admission Type		
Emergency	119	56.7
Elective	86	41.0
Unknown	5	2.4
Total	*210*	*100.0*
Marital Status		
Married	114	54.3
Divorced/Separated	18	8.6
Widowed	68	32.4
Never Married	10	4.8
Total	*210*	*100.0*
Religion		
Catholic	126	60.0
Protestant	40	19.0
Jewish	6	2.9
None	5	2.4
Other	15	7.1
Unknown	18	8.6
Total	*210*	*100.0*

Table 1 (cont.): Demographic Description of the Medical Record Review Population (n = 210).

Ethnicity		
White	195	92.9
Black	8	3.8
Hispanic	4	1.9
Unknown	3	1.4
Total	*210*	*100.0*
Primary Payer for Admission		
Medicare	148	70.5
Medicaid	6	2.9
Private Insurance	48	22.9
Self-Pay/No Insurance	1	0.5
Unknown	7	3.3
Total	*210*	*100.0*
Length of Hospital Stay		
2 Days or Less	28	13.3
3-7 Days	106	50.5
8 Days to 2 Weeks	52	24.8
More Than 2 Weeks	24	11.4
Total	*210*	*100.0*
Mean Length of Stay in days (SD)	*8.4 (7.8)*	

Table 2: Prevalence of Discussions of Prognosis Among Medical Record Review Population (n = 210).

Discussion of Prognosis Noted in Medical Record	Number	Percent
Yes	79	37.6
No	131	62.4
Total	*210*	*100.0*

Table 3: Frequency of Prognosis Discussions Among Medical Record Review Population (n = 210).

Number of Prognosis Discussions Noted in Medical Record	Number	Percent
0	131	62.4
1	37	17.6
2	21	10
3	14	6.7
4	4	1.9
6	2	1.0
7	1	0.5
Total	*210*	*100.0*

Table 4: Correlates of Having a Recorded Discussion About Prognosis (n = 210).[A]

Characteristic	% Having Prognosis Discussion	Unadjusted Odds Ratio	P Value
Gender			
Female	37.6 (38/101)	1.000	0.999
Male	37.6 (41/109)		
Marital Status			
Married	33.3 (38/114)	0.671	0.162
Unmarried	42.7 (41/96)		
Age			
65-69 Years	28.6 (16/56)	Reference	
70-79 Years	36.9 (38/103)	1.462	0.290
80+ Years	48.0 (24/50)	2.308	0.039
Ethnicity			
White	38.5 (75/195)	1.875	0.350
Non-White	25.0 (3/12)		
Religion			
Catholic	40.5 (51/126)	1.564	0.165
Non-Catholic	30.3 (20/66)		
Admission Type			
Emergency	47.1 (56/119)	2.751	0.001
Elective	24.4 (21/86)		

[A] Missing data account for some totals being less than 210.

Table 4a: Differences of Mean Lengths of Stay for Those with Prognosis Discussions vs. Those Without Prognosis Discussions (n = 210).

	Prognosis Discussion Documented	No Prognosis Discussion Documented	T-statistic	P Value (based on t-test)
Mean Length of Hospital Stay (days)	10.78	6.92	-3.237	0.002

Table 4b: Differences of Mean Number of ICD-9 Codes for Those with Prognosis Discussions vs. Those Without Prognosis Discussions (n = 210).

	Prognosis Discussion Documented	No Prognosis Discussion Documented	T-Statistic	P Value (based on t-test)
Mean number of ICD-9 codes	6.70	5.64	-2.037	0.023

Table 5: Multivariate Logistic Regression: Factors Associated with Likelihood of Having Discussion (n = 204).

Factor	Parameter Estimate	Standard Error	P Value	Odds Ratio (95% Confidence Interval)
Age				
Age 70-79 Years	0.0171	0.3806	0.9641	1.017 (0.27-1.76)
Age 80+ Years[B]	0.4743	0.4317	0.2719	1.607 (0.76-2.45)
Marital Status				
Married	-0.1395	0.3133	0.6563	0.870 (0.026-1.48)
Admission Type				
Emergency	0.9483	0.3272	0.0037	2.581 (1.94-3.22)
Hospital Stay				
Length of Hospital Stay	0.0648	0.0217	0.0028	1.067 (1.02-1.11)

[B] Age less than 70 years is the reference category.

Table 6: Timing of Prognosis Discussions Among Those For Whom There Was At Least One Discussion (n = 79).

Timing of First Prognosis Discussion	Number	Percent
Within one day of admission	16	20.3
Within one week of admission	50	63.3
More than one week after admission	13	16.5
Total	*79*	*100.0*
Mean days after admission (SD)	*4 (5.7)*	

Table 7: Persons Documented as Being Involved in Prognosis Discussions (n = 79).

		Number	Percent
Patient Involved			
	Yes	45	57.0
	No	34	43.0
	Total	*79*	*100.0*
Family Involved			
	Yes	60	75.9
	No	19	24.1
	Total	*79*	*100.0*
Both Patient and Family Involved			
	Yes	28	35.4
	No	51	64.6
	Total	*79*	*100.0*
Physician Involved			
	Yes	61	77.2
	No	18	22.8
	Total	*79*	*100.0*
Nurse Involved			
	Yes	29	36.7
	No	50	63.3
	Total	*79*	*100.0*
Social Worker Involved			
	Yes	14	17.7
	No	65	82.3
	Total	*79*	*100.0*
Physician and At Least One Other Health Staff Member Involved			
	Yes	25	31.6
	No	54	68.4
	Total	*79*	*100.0*

Table 8: Unadjusted Associations between Advance Planning and Prognosis Discussion Among Medical Record Review Population (n = 210).

Characteristic		% Having Discussion	Unadjusted Odds Ratio	P Value
Advance Directive				
	Yes	33.8 (24/71)	0.78	0.415
	No	39.6 (55/139)		
Life Sustaining Treatment Discussion				
	Yes	63.5 (61/96)	9.30	0.001
	No	15.8 (18/114)		
DNR Order Present				
	Yes	52.9 (55/104)	3.8	0.001
	No	22.6 (24/106)		

Table 9: Timing of Advance Planning Among Patients with a Documented Prognosis Discussion (n = 79).

Characteristic	Number	Percent
Advanced Directive Completion		
Before Prognosis Discussion	22	27.8
After Prognosis Discussion	2	2.5
Total	*24*	*30.4*
Life-Sustaining Treatment Discussion		
Before Prognosis Discussion	19	24.1
After Prognosis Discussion	42	53.2
Total	*61*	*77.2*
DNR Order Present		
Before Prognosis Discussion	24	30.4
After Prognosis Discussion	31	39.2
Total	*55*	*69.6*

Table 10: Content Categories Of Prognosis Discussions (n = 79).[C]

Factor	Number	Percent
Prognosis (General) Discussed	71[D]	89.9
Plans for Care/Treatment	33	41.8
Patient’s Preferences Expressed	9	11.4
Family’s Preferences Expressed	9	11.4
Patient Emotion	10	12.7
Family Emotion	4	5.1
Information and Communication	26	32.9

[C] Numbers add to greater than 79 because some discussions had more than one content category.

[D] Number is less than 79 because some prognosis discussions were not classified in the “general” categories.

V. Discussion

The potential benefits and drawbacks of discussing prognosis with terminally ill patients and their families have led to debate about what the best practice for giving such information should be.[32, 47, 54, 62-65, 68, 82, 83] Although there is substantial moral and ethical reasoning that truth about prognosis is necessary in order to support patient autonomy,[31, 44, 46, 76, 84-86] there is still uncertainty about whether, when, and how such information should be given to terminally ill patients or to their families. The purpose of this study was to determine the current medical practice concerning communication of prognosis information.

Our findings indicated that approximately one-third of terminally ill, hospitalized patients with cancer had at least one discussion of prognosis documented in their medical records during their hospital stay. This suggests that the majority of patients may not have direct conversations about prognosis. This may account in part for the well-documented misconceptions that many patients have about their prognoses.[33, 36, 38, 40-42, 66] While most health professionals report that they are willing to discuss prognosis with terminally ill patients and their families,[79] our study suggested the actual occurrence of such discussions is rare, and that the professional tendency may be avoidance of such discussions. This finding is consistent with previous qualitative studies of prognosis discussion,[47, 65] which suggested that prognosis discussions occurred rarely.

We chose to use a patient population in which a great deal is known about prognosis and that is generally considered to be terminal.[79] The National Hospice Organization recommends discussing hospice with patients who fit our criteria,[87] so physicians may be more likely to assess prognosis in these patients than in other terminally ill patients. In addition, patients with cancer have a more predictable course of disease and thus physicians are better able to make prognoses in such patients.[1, 52] So, while we found that only one-third of our patients had documented prognosis discussions, the proportion may be far less among other patient populations, with less predictable diseases.

The patient being more than 80 years of age was significantly associated with documented prognosis discussions in bivariate analysis, and in multivariate analysis, the results were suggestive but not significant. There are many reasons why prognosis discussions are likely to occur with more elderly patients. Elderly patients with cancer are more likely to be more severely ill and closer to death than younger ones. In addition, older patients may be more ready to accept death, having lived longer, while younger patients may be fighting death and not wish to discuss the possibility of failing. Thus, older patients may be more likely to start discussions about prognosis and more inclined to encourage the physician to have such conversations. At the same time, physicians may be more comfortable discussing death with older patients, as it seems more natural for an older patient to be dying, while the physicians may have more hope for the survival of a young person.

Emergency admission was associated with an increased likelihood of having a documented prognosis discussion, when compared with elective admission. This finding suggests that even among the terminally ill, episodes of acute illness may trigger prognosis discussions. The urgent setting may increase the need to discuss difficult topics in order to make treatment decisions. In the emergency admission setting, patients, families, and physicians may have less doubt about the immediacy of death of the acutely ill patient, and thus may be more likely to discuss prognosis. In addition, the difference between emergency and elective admissions may be due to differences in the expectations about the goal of care, with the primary expectation during elective admissions being treatment of disease and often extension of survival. Patients who are admitted for reasons such as elective surgery or chemotherapy may be hoping for a cure or an extended life span.

In this study, physicians were more likely to discuss prognosis with patients who stayed in the hospital for a long period of time. This may have been because physicians tend to put off such discussions as they gather information and discuss more time-sensitive issues. In addition, patients who stay in the hospital longer may be sicker and closer to the end of life, so physicians may be more likely to have prognosis discussions with these patients and their families. This finding suggests that shorter hospital stays may result in fewer prognosis discussions. It also suggests that more seriously ill patients may be more likely to have such discussions than less seriously ill patients. The correlation between number of ICD-9 codes on a patient’s chart and the likelihood of a prognosis discussion is an additional finding that suggests that sicker patients have prognosis discussions while patients who have a longer time to live are less likely to discuss prognosis with their physicians.

The finding that married patients are less likely to have prognosis discussions was unexpected, but it may be related to the perceived need to sustain hope for the spouse. Patients who have a spouse and family may be more hopeful that they will live, or physicians may wish to keep hope alive for a spouse who is not ready to accept imminent death. An urge to sustain hope for the living may prevent the physician or patient from addressing the question of prognosis. Thus, the physician may feel that discussions of prognosis and end-of-life care may destroy hope, as suggested by Miyaji[47] and Delvecchio Good et al.[65]

In this study, the presence of DNR orders and discussions about life-sustaining treatments were both very closely linked with discussions about prognosis, and prognosis discussions frequently preceded the discussions of life sustaining treatments and DNR orders. This finding supports our hypothesis that prognosis discussions influence end-of-life care decision-making, increasing discussion of other end-of-life topics. The data on the content of prognosis discussions show that prognosis discussions do play an important role in planning for future care and treatment, as has been suggested by other studies.[4, 10, 36-38] Plans for care and treatment were the most common topic included in prognosis discussions.

Unlike other forms of advance care planning, very few advance directives were dated later than the prognosis discussion. Most of the advance directives that existed were completed prior to the hospital admission. While we did not predict that this would be the case, advance directives are forms of advance planning which often occur long before a person becomes ill, or early in the course of a disease, as has been shown in the nursing home population.[88] Thus, prognosis discussions in the hospital may be unlikely to result in an increase in advance directives.

This study found that physicians are the primary conveyers of prognosis information, only occasionally including another staff member during the discussion. This finding is consistent with Seale's study,[79] which questioned bereaved family members and physicians about discussions of prognosis. The results of our study suggest that physicians rarely have a colleague present during prognosis discussions. This may occur because physicians want privacy for the patient and for themselves, because they find the topic painful or difficult to broach. In addition, in our study, patients were involved in the discussion 57% of the time. These data are consistent with the notion of "closed awareness", in which physicians may also find it easier to speak to families about death than directly to the patient.[79] Recent evidence, however, finds that European or American patients would rarely prefer to have their physicians speak to the family in lieu of speaking to the patient, as patients usually wish to have all the relevant information themselves.[32-34] Our findings indicate that this may not be the case in a substantial minority of prognosis discussions.

In conclusion, the data reveal that only one-third of terminally ill patients have prognosis discussions with their physicians, despite the potential benefits of doing so. This finding supports the evidence that end-of-life communication about prognosis is frequently inadequate, even among patients who are expected to die within six months to one year.

There were several correlates of prognosis discussions that were consistent with those that we predicted. Elderly patients were more likely to have prognosis discussions than younger patients were, as we predicted. Being married was associated with a decreased likelihood of having a prognosis discussion, although we had predicted that it would be associated with an increased likelihood of discussion. The finding may be due to the tendency of physicians to attempt to preserve hope whenever possible, for the spouse as well as the patient. Emergency admission was significantly correlated with prognosis discussion, probably due to the severe, acute nature of the illness during such an admission. The goals of the patient and the team may also affect the frequency of prognosis discussions. When the physician and patient are aiming to treat the disease and improve survival, they may be less inclined to address issues such as prognosis than they would be if the goal of therapy were to relieve symptoms and palliate the patient. The length of stay appeared to be correlated with prognosis discussion, as we theorized. This effect may be due to the more severe nature of the illness or the opportunity for physicians to address the issue of prognosis after all of the test results had come back. Several of these correlates, including the number of ICD-9 codes on a patient's chart, support the hypothesis that more seriously ill patients are more likely to have prognosis discussions, while patients who are terminally ill but not as close to death are less likely to have honest conversation with their physician about their prognosis.

We had hypothesized that prognosis discussions would happen earlier in the hospital stay, after the first couple of days, however the data revealed that most patients had their discussions sometime after the first day, averaging four days after admission. Further, a physician was present for the majority of discussions, as predicted, and other health professionals were rarely there, probably due to the uncertainty of prognosis information. Families were often present, and, frequently, the discussion did not involve the patient, as we had hypothesized. As expected, many families were told the truth about a patient's illness while the patient was not.

A secondary aim of this study was to assess the association between advance planning and prognosis discussions among this patient population. As we had expected, life sustaining treatment discussions and DNR orders were both significantly associated with discussions of prognosis. In addition, discussions about life sustaining treatment preferences and DNR orders were frequently dated after the prognosis discussion, suggesting that prognosis discussions may promote these types of advance planning. Unexpectedly, having an advance directive itself was not associated with having prognosis discussions, probably because the completion of an advance directive often may occur prior to hospitalization for terminal illness. These findings add to the growing body of literature that suggests that patients who are aware of their prognosis are generally better equipped to plan for their future and for their preferences surrounding death.

Finally, we intended to describe the content of prognosis discussions recorded in medical charts. Notably, the discussions contained a great deal of information about future care and treatment preferences, as we had expected, and specific estimates of the time until death were rare, as we had also predicted. This was likely due to the recognized uncertainty in predicting death itself.[51, 52]

The limitations of this research suggest opportunities for future studies in this area. First, we do not have data on the outcomes of these patients and whether prognosis discussions affected the setting of care or quality of life and death for these patients. In addition, we do not know what the patients and families wished to know or already knew about their prognoses. While patients report wishing to be given all information, good or bad, about their diagnosis,[31-34, 51, 52] they and their families may play a role in discouraging physicians from addressing difficult topics or bad news. While the studies of ethnic and cultural differences towards dealing with death are intriguing,[70, 73, 74, 78] the lack of diversity in this patient population did not allow us to examine these factors. We also did not attempt to assess how the cultural background and biases of the physician may have affected his or her practice of talking about prognosis. In addition, the study is of elderly patients with cancer, and thus cannot be generalized to other populations of terminally ill patients, as the natural history of different diseases may be less predictable.

A final limitation of the data is the fact that the data reflect only those discussions that are documented in medical records. Limiting our study to documented discussions likely underestimates the prevalence of such discussions, as a great deal of communication is never charted in the inpatient setting. However, medical record documentation is the primary mode of communication among clinicians; therefore, undocumented discussions may have less effect on the treatment of the patient. In the future, interviews with clinicians about discrepancies between practice and documentation may help to elucidate what types of communication about prognosis are unlikely to be documented.

This study has many strengths, such as using a subject population drawn from community-based, non-teaching hospitals, and focusing on a population in whom prognosis discussions are vitally important for decisions about location and goals of care. In addition, the population selected was eligible for hospice. Because discussions of prognosis may affect patients' willingness to use hospice, understanding the prevalence of such discussions may shed light on potential underutilization of hospice services. The use of medical records, which is likely responsible for a total underestimate of the true prevalence of communication about prognosis, decreases the problem of recall bias, which is often a limiting factor in studies of dying patients. The data about advance planning were not previously assessed in studies of prognosis discussion, thus this study offers compelling evidence concerning how prognosis discussions may enhance overall advance care planning.

Despite the importance of prognosis discussions in the terminally ill, this study points out the infrequency of such discussions in hospitalized terminally ill patients. These results suggest that older, sicker patients are more likely to have prognosis discussions with their physicians, that discussions often do not happen early in the hospital stay, and that patients who stay in the hospital for an extended period of time are more likely to have prognosis discussions with their physicians. Patients are often not included in prognosis discussions, and physicians are typically the primary sources of prognosis information.

This study also shows the influence that prognosis discussions have on advance planning discussions and DNR orders and finds that plans for care and treatment are the most common subject included in prognosis discussions, further emphasizing the importance of prognosis discussions among terminally ill patients with cancer.

VI. Appendix

Appendix One. Detailed Content of Prognosis Discussions (n = 79). Each discussion may have included more than one content area.

Factor	Number	Percent
Prognosis Discussed	**45**	**57.0**
Poor Prognosis	32	40.5
Worsening Prognosis	1	1.3
Uncertain/Unknown	1	1.3
Prognosis Discussed as Okay	1	1.3
Patient Accepts Prognosis	1	1.3
Patient Does Not Accept Prognosis	1	1.3
Family Accepts Prognosis	14	17.7
Family Does Not Accept Prognosis	1	1.3
Time Until Expected Death Given	1	1.3
Time Until Expected Death Requested (When Will I Die?)	1	1.3
Prognosis—Not Otherwise Stated	1	1.3
Medical Condition Discussed	**47**	**59.5**
Poor, Guarded, Not Good, Terminal, etc.	22	27.8
Worsening	10	12.7
Uncertain/Unknown	0	0
Okay	1	1.3
Patient Accepts Medical Condition	21	26.6
Patient Does Not Accept Medical Condition	8	10.1
Family Accepts Medical Condition	25	31.6
Family Does Not Accept Medical Condition	1	1.3
Medical Condition—Not Otherwise Stated	1	1.3
Test Results Content	**15**	**19.0**
Bad News	12	15.2
Good News	0	0
Unknown/Uncertain	0	0
Patient Accepts Test Results	5	6.3
Patient Does Not Accept Test Results	1	1.3
Family Accepts Test Results	5	6.3
Family Does Not Accept Test Results	0	0
Test Results—Not Otherwise Stated	1	1.3

Appendix One (cont.). Detailed Content of Prognosis Discussions (n = 79). Each discussion may have included more than one content area.

Content of Discussion about Death	**13**	**16.5**
Patient Was Told About Dying	2	2.5
Patient Was Not Told About Dying	0	0
Plans For Death Discussed	2	2.5
Patient Wants To Die	3	3.8
Patient Does Not Want To Die	1	1.3
Patient Does Not Want To Discuss Death	0	0
Family Does Not Want To Discuss Death	0	0
Family Told That Patient Is Dying	1	1.3
Family Not Told That Patient Is Dying	0	0
Death—Not Otherwise Stated	5	6.3
Plans For Care/Treatment	**33**	**41.8**
No More Treatment	8	10.1
More Tests/Evaluations	1	1.3
Comfort Care/Palliative Care	12	15.2
Hospice	4	5.1
Future Plans, General	7	8.9
Code Status	3	3.8
Investigating Alternative Treatments	5	6.3
Another Facility (ECF, SNF, etc.)	4	5.1
Plans For Care—Not Otherwise Stated	6	7.6
Patient Preferences Expressed	**9**	**11.4**
For DNR/DNI	3	3.8
For Hospice	0	0
For Site of Death	2	2.5
Fore More Information	1	1.3
Comfort Care/Palliative Care	0	0
No Machines, Heroics, Chemo, etc.	4	5.1
Patient Preferences—Not Otherwise Stated	2	2.5
Family Preferences Expressed	**9**	**11.4**
For DNR/DNI	2	2.5
For Hospice	2	2.5
For Site of Death	0	0
Fore More Information	3	3.8
Comfort Care/Palliative Care	2	2.5
No Machines, Heroics, Chemo, etc.	2	2.5
Family Preferences—Not Otherwise Stated	2	2.5

Appendix One (cont.). Detailed Content of Prognosis Discussions (n = 79). Each discussion may have included more than one content area.

Patient Emotion	**10**	**12.7**
Sad, Tearful	1	1.3
Relieved	0	0
Scared	2	2.5
Anxious, Worried	2	2.5
Depressed	1	1.3
Angry	1	1.3
Lack of Emotion	0	0
Unresponsive	0	0
Discouraged	3	3.8
Patient Emotion—Not Otherwise Stated	3	3.8
Family Emotion	**4**	**5.1**
Sad, Tearful	1	1.3
Relieved	0	0
Scared	1	1.3
Anxious, Worried	1	1.3
Depressed	0	0
Angry	0	0
Lack of Emotion	0	0
Family Emotion—Not Otherwise Stated	1	1.3
Information and Communication	**26**	**32.9**
General Education and Teaching of Patient/Family	15	19.0
General Support or Counseling of Patient/Family	5	6.3
Trying to Increase Acceptance of Information by Patient/Family	3	3.8
Encouragement of Intra-Familial Interactions (visits, discussions, etc.)	2	2.5
Information—Not Otherwise Stated	5	6.3

VII. References

1. Approaching death : improving care at the end of life. In: Field MJ, Cassel CK, eds. Washington, D.C.: National Academy Press, 1997:437 p.

2. Callahan D. Frustrated mastery. The cultural context of death in America. West J Med 1995; 163:226-30.

3. Friel PB. Death and dying. Ann Intern Med 1982; 97:767-71.

4. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. Jama 2000; 284:2476-82.

5. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. Ann Intern Med 2000; 132:825-32.

6. McCue JD. The naturalness of dying. Jama 1995; 273:1039-43.

7. Nuland SB. How we die. New York: A.A. Knopf, 1994:278 p.

8. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. Jama 1995; 274:1591-8.

9. Lynn J, Teno JM, Phillips RS, et al. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Ann Intern Med 1997; 126:97-106.

10. Hofmann JC, Wenger NS, Davis RB, et al. Patient preferences for communication with physicians about end-of-life decisions. SUPPORT Investigators. Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment. Ann Intern Med 1997; 127:1-12.

11. Teno J, Lynn J, Wenger N, et al. Advance directives for seriously ill hospitalized patients: effectiveness with the patient self-determination act and the SUPPORT

intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc 1997; 45:500-7.

12. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. J Am Geriatr Soc 1997; 45:1339-44.

13. Bradley EH, Peiris V, Wetle T. Discussions about end-of-life care in nursing homes. J Am Geriatr Soc 1998; 46:1235-41.

14. Bedell SE, Delbanco TL. Choices about cardiopulmonary resuscitation in the hospital. When do physicians talk with patients? N Engl J Med 1984; 310:1089-93.

15. Blackhall LJ, Cobb J, Moskowitz MA. Discussions regarding aggressive care with critically ill patients. J Gen Intern Med 1989; 4:399-402.

16. Tulsky JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? J Gen Intern Med 1995; 10:436-42.

17. Lo B, McLeod GA, Saika G. Patient attitudes to discussing life-sustaining treatment. Arch Intern Med 1986; 146:1613-5.

18. Frankl D, Oye RK, Bellamy PE. Attitudes of hospitalized patients toward life support: a survey of 200 medical inpatients. Am J Med 1989; 86:645-8.

19. Shmerling RH, Bedell SE, Lilienfeld A, Delbanco TL. Discussing cardiopulmonary resuscitation: a study of elderly outpatients. J Gen Intern Med 1988; 3:317-21.

20. Johnston SC, Pfeifer MP, McNutt R. The discussion about advance directives. Patient and physician opinions regarding when and how it should be conducted. End of Life Study Group. Arch Intern Med 1995; 155:1025-30.

21. Levin JR, Wenger NS, Ouslander JG, et al. Life-sustaining treatment decisions for nursing home residents: who discusses, who decides and what is decided? J Am Geriatr Soc 1999; 47:82-7.

22. Markson L, Clark J, Glantz L, Lamberton V, Kern D, Stollerman G. The doctor's role in discussing advance preferences for end-of-life care: perceptions of physicians practicing in the VA. J Am Geriatr Soc 1997; 45:399-406.

23. Reilly BM, Magnussen CR, Ross J, Ash J, Papa L, Wagner M. Can we talk? Inpatient discussions about advance directives in a community hospital. Attending physicians' attitudes, their inpatients' wishes, and reported experience. Arch Intern Med 1994; 154:2299-308.

24. Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care--a case for greater use. N Engl J Med 1991; 324:889-95.

25. Tsevat J, Dawson NV, Wu AW, et al. Health values of hospitalized patients 80 years or older. HELP Investigators. Hospitalized Elderly Longitudinal Project. Jama 1998; 279:371-5.

26. Miles SH, Koepp R, Weber EP. Advance end-of-life treatment planning. A research review. Arch Intern Med 1996; 156:1062-8.

27. Starr TJ, Pearlman RA, Uhlmann RF. Quality of life and resuscitation decisions in elderly patients. J Gen Intern Med 1986; 1:373-9.

28. Perry E, Buck C, Newsome J, Berger C, Messana J, Swartz R. Dialysis staff influence patients in formulating their advance directives. Am J Kidney Dis 1995; 25:262-8.

29. Garrett JM, Harris RP, Norburn JK, Patrick DL, Danis M. Life-sustaining treatments during terminal illness: who wants what? J Gen Intern Med 1993; 8:361-8.

30. Walker RM, Schonwetter RS, Kramer DR, Robinson BE. Living wills and resuscitation preferences in an elderly population. Arch Intern Med 1995; 155:171-5.

31. Annas GJ. Informed consent, cancer, and truth in prognosis. N Engl J Med 1994; 330:223-5.

32. Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. Soc Sci Med 1988; 27:1139-45.

33. Barnett MM, Devrell C, Barrington M, McMichael H. Information needs of patients with advanced cancer--how much do they know and does this match what they want to know? Psycho-Oncology 1995; 4:83.

34. Meredith C, Symonds P, Webster L, et al. Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. Bmj 1996; 313:724-6.

35. Last BF, van Veldhuizen AM. Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8-16 years. Eur J Cancer 1996; 32A:290-4.

36. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. Jama 1998; 279:1709-14.

37. Krumholz HM, Phillips RS, Hamel MB, et al. Resuscitation preferences among patients with severe congestive heart failure: results from the SUPPORT project. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Circulation 1998; 98:648-55.

38. Haidet P, Hamel MB, Davis RB, et al. Outcomes, preferences for resuscitation, and physician-patient communication among patients with metastatic colorectal cancer. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Am J Med 1998; 105:222-9.

39. Kinzbrunner BM. Ethical dilemmas in hospice and palliative care. Support Care Cancer 1995; 3:28-36.

40. Chan A, Woodruff RK. Communicating with patients with advanced cancer. J Palliat Care 1997; 13:29-33.

41. Petrasch S, Bauer M, Reinacher-Schick A, et al. Assessment of satisfaction with the communication process during consultation of cancer patients with potentially curable disease, cancer patients on palliative care, and HIV-positive patients. Wien Med Wochenschr 1998; 148:491-9.

42. Eidinger RN, Schapira DV. Cancer patients' insight into their treatment, prognosis, and unconventional therapies. Cancer 1984; 53:2736-40.

43. Mackillop WJ, Stewart WE, Ginsburg AD, Stewart SS. Cancer patients' perceptions of their disease and its treatment. Br J Cancer 1988; 58:355-8.

44. Christakis NA. Death foretold : prophecy and prognosis in medical care. Chicago: University of Chicago, 1999:328 p.

45. Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. Ann Intern Med 2001; 134:1096-105.

46. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. Arch Intern Med 1998; 158:2389-95.

47. Miyaji NT. The power of compassion: truth-telling among American doctors in the care of dying patients. Soc Sci Med 1993; 36:249-64.

48. Forster LE, Lynn J. Predicting life span for applicants to inpatient hospice. Arch Intern Med 1988; 148:2540-3.

49. Parkes CM. Accuracy of predictions of survival in later stages of cancer. Br Med J 1972; 2:29-31.

50. Mackillop WJ, Quirt CF. Measuring the accuracy of prognostic judgments in oncology. J Clin Epidemiol 1997; 50:21-9.

51. Lynn J, Teno JM, Harrell FE, Jr. Accurate prognostications of death. Opportunities and challenges for clinicians. West J Med 1995; 163:250-7.

52. Knaus WA, Harrell FE, Jr., Lynn J, et al. The SUPPORT prognostic model. Objective estimates of survival for seriously ill hospitalized adults. Study to understand prognoses and preferences for outcomes and risks of treatments. Ann Intern Med 1995; 122:191-203.

53. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. Bmj 2000; 320:469-72.

54. Bennett M, Alison D. Discussing the diagnosis and prognosis with cancer patients. Postgrad Med J 1996; 72:25-9.

55. Christakis NA. The ellipsis of prognosis in modern medical thought. Soc Sci Med 1997; 44:301-15.

56. Wanzer SH, Federman DD, Adelstein SJ, et al. The physician's responsibility toward hopelessly ill patients. A second look. N Engl J Med 1989; 320:844-9.

57. Carron AT, Lynn J, Keaney P. End-of-life care in medical textbooks. Ann Intern Med 1999; 130:82-6.

58. Rabow MW, Hardie GE, Fair JM, McPhee SJ. End-of-life care content in 50 textbooks from multiple specialties. Jama 2000; 283:771-8.

59. Oken D. What to tell cancer patients. Jama 1961; 175:1120-8.

60. Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. Jama 1979; 241:897-900.

61. Cartwright A. Changes in life and care in the year before death 1969-1987. J Public Health Med 1991; 13:81-7.

62. Butow PN, Kazemi JN, Beeney LJ, Griffin AM, Dunn SM, Tattersall MH. When the diagnosis is cancer: patient communication experiences and preferences. Cancer 1996; 77:2630-7.

63. Ptacek JT, Eberhardt TL. Breaking bad news. A review of the literature. Jama 1996; 276:496-502.

64. Freedman B. Offering truth. One ethical approach to the uninformed cancer patient. Arch Intern Med 1993; 153:572-6.

65. Delvecchio Good MJ, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. Cult Med Psychiatry 1990; 14:59-79.

66. The AM, Hak T, Koeter G, van Der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. Bmj 2000; 321:1376-81.

67. Annas GJ. How we lie. Hastings Cent Rep 1995; 25:S12-14.

68. Gordon DR, Paci E. Disclosure practices and cultural narratives: understanding concealment and silence around cancer in Tuscany, Italy. Soc Sci Med 1997; 44:1433-52.

69. Holland JC, Geary N, Marchini A, Tross S. An international survey of physician attitudes and practice in regard to revealing the diagnosis of cancer. Cancer Invest 1987; 5:151-4.

70. Klessig J. The effect of values and culture on life-support decisions. West J Med 1992; 157:316-22.

71. Gordon M, Singer PA. Decisions and care at the end of life. Lancet 1995; 346:163-6.

72. Caralis PV, Davis B, Wright K, Marcial E. The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. J Clin Ethics 1993; 4:155-65.

73. Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. Jama 1995; 274:820-5.

74. Perez-Stable EJ, Sabogal F, Otero-Sabogal R, Hiatt RA, McPhee SJ. Misconceptions about cancer among Latinos and Anglos. Jama 1992; 268:3219-23.

75. Koenig BA, Gates-Williams J. Understanding cultural difference in caring for dying patients. West J Med 1995; 163:244-9.

76. Cross AW, Churchill LR. Ethical and cultural dimensions of informed consent. A case study and analysis. Ann Intern Med 1982; 96:110-3.

77. Berger JT. Culture and ethnicity in clinical care. Arch Intern Med 1998; 158:2085-90.

78. Hern HE, Jr., Koenig BA, Moore LJ, Marshall PA. The difference that culture can make in end-of-life decisionmaking. Camb Q Healthc Ethics 1998; 7:27-40.

79. Seale C. Communication and awareness about death: a study of a random sample of dying people. Soc Sci Med 1991; 32:943-52.

80. Teno JM, Fisher E, Hamel MB, et al. Decision-making and outcomes of prolonged ICU stays in seriously ill patients. J Am Geriatr Soc 2000; 48:S70-4.

81. Neuman WL. Social research methods : qualitative and quantitative approaches. Boston: Allyn and Bacon, 1994:538 p.

82. Maguire P, Faulkner A. Communicate with cancer patients: 1. Handling bad news and difficult questions. Bmj 1988; 297:907-9.

83. Smith TJ, Swisher K. Telling the truth about terminal cancer. Jama 1998; 279:1746-8.

84. Braddock CH, 3rd, Fihn SD, Levinson W, Jonsen AR, Pearlman RA. How doctors and patients discuss routine clinical decisions. Informed decision making in the outpatient setting. J Gen Intern Med 1997; 12:339-45.

85. Nelson JL. Taking families seriously. Hastings Cent Rep 1992; 22:6-12.

86. Curtis JR, Patrick DL. Barriers to communication about end-of-life care in AIDS patients. J Gen Intern Med 1997; 12:736-41.

87. Massey RM, Hurzeler RJ. Hospice and palliative care. Cancer Therapeutics 1998; 1:117-23.

88. Bradley EH, Wetle T, Horwitz SM. The patient self-determination act and advance directive completion in nursing homes. Arch Fam Med 1998; 7:417-23.