An Approach to Understanding the Interaction of Hope and Desire for Explicit Prognostic Information among Individuals with Severe Chronic Obstructive Pulmonary Disease or Advanced Cancer

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ABSTRACT

Background: Physicians often report that they are reluctant to discuss prognosis for life-threaten-ing illnesses with patients and family out of concern for destroying their hope, yet there is little em-pirical research describing how patients and family incorporate their needs for hope with desires for prognostic information.

Objective: We conducted a qualitative study to examine the perspectives of patients, family, physi-cians, and nurses on the simultaneous need for supporting hope and discussing prognosis.

Methods: We conducted in-depth longitudinal qualitative interviews with patients with either advanced cancer or severe chronic obstructive pulmonary disease (COPD), along with their family, physicians, and nurses. We used principles of grounded theory to analyze the transcripts and evalu-ated a conceptual model with four diagrams depicting different types of approaches to hope and prognostic information.

Results: We interviewed 55 patients, 36 family members, 31 physicians, and 25 nurses represent-ing 220 hours of interviews. Asking patients directly “how much information” they wanted was, by itself, not useful for identifying information needs, but in-depth questioning identified variability in patients’ and family members’ desires for explicit prognostic information. All but 2 patients en-dorsed at least one of the diagrams concerning the interaction of hope and prognostic information and some patients described moving from one diagram to another over the course of their illness. Respondents also described two different approaches to communication about prognosis based on the diagram selected: two of the four diagrams suggested a direct approach and the other two sug-gested a cautious, indirect approach.

Conclusions: This study found important variability in the ways different patients with life-lim-iting illnesses approach the interaction of wanting support for hope and prognostic information from their clinicians. The four-diagram approach may help clinicians understand individual patients and families, but further research is needed to determine the utility of these diagrams for improving communication about end-of-life care.

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INTRODUCTION

A TERMINAL OR LIFE-LIMITING DIAGNOSIS is intensely stressful for patients and families and evokes emotions as diverse as fear, anxiety, anger, depression, and helplessness. One of the most common and important responses to a terminal diagnosis is hope. The therapeutic value of hope is well established. Hope helps patients emotionally endure crises and some studies have shown that hopeful patients follow treatment recommendations and tolerate discomfort better than patients who are not hopeful. Among patients with cancer, higher levels of hope have been associated with more active involvement in their self-care and higher levels of psychosocial adjustment. In contrast to hope, hopelessness is associated with depression, suicidal ideation, desire for hastened death and decreased physical health. Despite these associations between hope and better outcomes, it is not known whether specific interventions to improve communication about hope can improve patient and family outcomes.

Although patients with terminal or life-limiting illness value hope highly, the majority also want truthful information about their prognosis. In focus groups with dying patients and their families and clinicians, honest and straightforward information was paramount among communication needs. However, many physicians report concern that honest information about prognosis can damage patients’ hope and, according to physicians, this concern is a leading barrier to discussing end-of-life care. Furthermore, dramatic disagreement is often found between patients’ and physicians’ estimates of prognosis. Patients are more optimistic than their physicians, and physicians’ estimates are more accurate. Among candidates for breast cancer adjuvant therapy, 70% of patients overestimated their chance of cure by 20% or more compared to their physician. Among patients with cancer interviewed in another study, two thirds had poor prognoses with no hope of cure, yet only 21% perceived they had a poor prognosis. Such unfounded optimism influences treatment choices. Patients who believe they are going to live for at least 6 months are more likely to favor life-extending treatment compared to patients who believe there is at least a 10% chance that they will not live 6 months.

Cumulatively, these data suggest that physicians’ inability to balance concerns about providing prognostic information with supporting patients’ hope may be an important barrier to communication with patients and families about end-of-life care. Christakis has described how physicians may see their own optimistic presentations of prognosis, as well as the practice of withholding information, as humane ways of preserving hope in their patients. Others also suggest that physicians are often purposely vague or misleading in prognostic estimates they give to dying patients in order to maintain hope. Physicians often view optimism about prognosis as the central feature of patients’ hope, but there is evidence that this is not true for many patients. Furthermore, there is some evidence that patients are less concerned than physicians about damaged hope. Although there have been recommendations, based on expert opinion, to help patients “redirect” their hopes when facing terminal illness, there has not been research to identify ways to help clinicians, patients, and families integrate support for hope with provision of accurate prognostic information.

The goal of this study was to examine the interactions between the desire to have hope supported and the need to receive explicit prognostic information on the part of patients and family members, as well as the desire to support hope and the need to provide prognostic information for the clinicians caring for them, in order to develop insights that might be helpful for clinicians. We used a qualitative study of patients with severe chronic obstructive pulmonary disease (COPD) or advanced cancer as well as their families, nurses, and physicians to describe these interactions. In this paper, we describe an approach to understanding some potential interactions between supporting hope and providing prognostic information and examine a four-diagram approach that may help clinicians understand patients’ perspectives on the interaction between the dual needs for hope and for explicit prognostic information.

METHODS

Participant recruitment

A purposive recruitment strategy was used to obtain diversity in participants and identify those with relevant experiences to share, as described below for each participant type. All study procedures were approved by the University of Washington Human Subjects Committee.

Physician participants. Our recruitment strategy for physicians was designed to identify physicians with expertise providing end-of-life care who represent a diverse spectrum of approaches ranging from an emphasis on curative or life-prolonging care to a focus...
on palliative care. We targeted physicians who care for patients with severe COPD or advanced cancer. To identify potential participants, we selected an expert panel of physicians from three specialties: oncology, pulmonary, and general internal medicine. The nine panel members were identified as “thought leaders,” three from each specialty in the Seattle–Tacoma area and included physicians in a university setting as well as a community setting. We asked expert panel members to identify physicians they believed had good communication skills around end-of-life care and who were in one of the following three categories: physicians who focus on curative or life-prolonging treatment, those who focus on palliative care, or those “in the middle” of these two categories. We used the physician names identified by the expert panel to create three lists of physicians in the Seattle–Tacoma area and randomly selected physicians from each list. Physicians eligible for the study were those who: (1) spent at least 50% of their time in clinical practice and (2) believed they would be able to refer at least four eligible patients such that two patients would be likely to participate.

**Patient participants.** Physicians were asked to identify patients who met the following criteria: (1) advanced cancer, defined as metastatic solid cancer or non-operable lung cancer or (2) severe COPD, defined as an forced expiratory volume in 1 second (FEV$_1$) less than 35% predicted and oxygen-dependent. As an additional eligibility criterion, physicians were asked to identify patients from these two categories for whom “they would not be surprised if the patient died from any cause in the next year.” This question was devised to capture additional prognostic information beyond the disease-specific criteria and ensure relevance of the study questions for the participants. Patients were excluded if they did not speak English well enough to participate in the interviews.

**Family member participants.** Patients who were enrolled in the study were asked if they had a family member or close friend who was involved in their medical care and who they were willing to have participate.

**Nurse participants.** Patients who were enrolled in the study were also asked if they had interacted with a nurse who had discussed their illness with them. If a patient did not identify a nurse, we asked the patient’s physician if there were nurses with whom the physician worked and who talked with other patients about their illness.

**Interviews**

Interviews with all participants were conducted by two experienced interviewers (J.Y., E.M.) who received at least 20 hours of training from qualitative researchers on the team (B.M., A.B.). Interviewers completed a minimum of 5 hours of interviews observed by an investigator before conducting interviews unsupervised. The investigators periodically sat in on interviews to provide real-time feedback to interviewers throughout the study for quality control purposes.

Interviews were open-ended and guided by a script (scripts available at [http://depts.washington.edu/eol-care](http://depts.washington.edu/eol-care)). All participants were directly asked to respond to each of four diagrams constituting the conceptual model for integration of hope and desire for information about prognosis. Interviewers showed the four diagrams displaying four different perceptions of hope and information needs (Fig. 1) one at a time in random order and read the text associated with each model (Table 1). This four-diagram approach and associated quotes were developed from our prior work using similar qualitative research methods and examining patients’, families’, and clinicians’ perceptions of the quality of end-of-life care. These models have not been published previously. Participants were asked

**FIG. 1.** Potential four diagram conceptual model for the process of hope and prognostic information that may be helpful for clinicians caring for patients with terminal or life-limiting disease.
to discuss each of the diagrams and to identify di-
agrams that represented their experience with the pa-
tient’s illness.

We approached participants for a follow-up interview 4 to 6 months after the initial interview to explore changes over time. We conducted 12-month interviews with a subset of participants. These interviews were conducted with: (1) patients who had a change in their clinical condition and (2) families and clinicians of patients who had died in the intervening period.

Qualitative analyses

Data were analyzed using a limited application of grounded theory with methods we have used previously. Investigators were initially grouped into analysis pairs with each pair including one clinician and one non-clinician. The pairs completed the following steps: (1) open coding, in which specific concepts identified in the transcripts are named and grouped as categories; (2) axial coding, in which categories are associated and related by conditions, interactions and consequences; (3) process coding, in which concept and categories are examined in changing situations or circumstances; and (4) selective coding, in which conceptual models and theories are developed, integrated, and refined.

Trustworthiness

We addressed trustworthiness in three ways. First, the multidisciplinary team of investigators involved in the qualitative analyses brought diverse and complementary perspectives to the analyses; disciplines included medicine, nursing, health services research, educational psychology, anthropology, social work, and hospice care. Second, all coding investigators reviewed and coded all transcripts for the first 10 patients (as well as their associated family, physicians, and nurses) and met as a group to achieve consensus. Third, of the remainder of the interviews, 50% were coded independently by more than one investigator and reconciled between investigators.

RESULTS

Sample

The expert panel identified 129 physicians as potential participants; of these, 123 physicians were actively practicing in the Seattle–Tacoma area. Eighty-four physicians met eligibility criteria and 49 agreed to participate. Thirty-one physicians identified at least 1 participating patient and completed at least 1 physician study interview. Thus, the physician participation rate was 37% (31/84). Primary reasons that physicians declined to participate included lack of time and prior research commitments. Twenty-five nurses were identified and participated (100% participation rate), with 16 identified by patients and 9 by physicians. Participating physicians identified 67 eligible patients, and 55 of these patients participated (82%; 55/67) ranging

<table>
<thead>
<tr>
<th>Model</th>
<th>Quote concerning each diagram</th>
</tr>
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<tbody>
<tr>
<td>A. Back-and-forth</td>
<td>It’s been hard since I heard the bad news about my disease. Sometimes I feel very hopeful and think positively about the future. Other times, I feel fearful and sad because I know how serious my illness is. I seem to go back and forth between those two feelings.</td>
</tr>
<tr>
<td>B. Scales</td>
<td>I have to keep things balanced. I want information about my illness, but too much information makes me depressed. Also, I want to be hopeful but I know that I can’t be too hopeful because that’s not realistic. So I kind of maintain a balance between the two.</td>
</tr>
<tr>
<td>C. Yin-yang</td>
<td>I seem to be able to hear bad news about my illness and yet hold onto my hope—both at the same time. I know that my illness is very serious, and yet I also know that I must maintain my hope, and somehow I’m able to do both of those. They’re both there at the same time.</td>
</tr>
<tr>
<td>D. Redirecting arrow</td>
<td>I used to hope for a cure but now what’s important to me has changed. Now I hope for other things.</td>
</tr>
</tbody>
</table>

*aBased on prior qualitative research although specific quotes were an amalgam of statements made by patients or family members.*
from one to three patients per physician. Of these 55 patients, 42 identified a family member or friend and 36 family members or friends participated (86%; 36/42). Of the 55 participating patients, 24 had oxygen-dependent severe COPD, 30 had metastatic cancer or non-operable lung cancer, and 1 had both COPD and advanced cancer. The demographics for patients and family members are shown in Table 2, and demographics for physicians and nurses are shown in Table 3.

Twenty-one patients (38%) died within 6 months of enrollment. Two hundred seventy-four interviews were completed, representing over 220 hours of interviews. Second interviews were completed by 22 physicians (71%); 38 patients (69%); 27 family caregivers (75%); and 6 nurses (24%). Third interviews were completed by 7 physicians (32%); 16 patients (42%); 10 family caregivers (37%); and 1 nurse (17%).

**Overview**

We found important variability in the ways that patients and families viewed the relationship between their need and desire for prognostic information and their need and desire for support for their hopes. When asked, “How much information do you want?” every patient and family member initially replied that they wanted “all” the information, but during the interviews a substantial minority of these participants went on to express reservations about being given explicit prognostic information. We found that the four diagrams modeling the interaction between hope and information were helpful in understanding the preferences of individual patients and family members. We also elicited two different communication approaches based on this four-diagram model. We describe each of these findings and provide illustrative quotes for major findings.

**Hope and prognostic information**

Variability about desire for explicit prognostic information. Some patients with cancer or COPD and their families believed that frank prognostic information might negatively impact their hope and increase symptoms of anxiety and depression. For example, the wife of a man with cancer explained:

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**Table 2. Characteristics of Enrolled Patients and Family Members**

<table>
<thead>
<tr>
<th></th>
<th>Patients (n = 55)</th>
<th>Family or friend caregivers (n = 36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age (SD)</td>
<td>67.3 (11.4)</td>
<td>60.3 (15.8)</td>
</tr>
<tr>
<td># Female (%)</td>
<td>33 (60%)</td>
<td>18 (50%)</td>
</tr>
<tr>
<td># Ethnicity (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>43 (78.2)</td>
<td>29 (80.6)</td>
</tr>
<tr>
<td>African American</td>
<td>9 (16.4)</td>
<td>5 (13.9)</td>
</tr>
<tr>
<td>Asian</td>
<td>2 (3.6)</td>
<td>2 (5.6)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>&gt;1 ethnic identity</td>
<td>1 (1.8)</td>
<td>0</td>
</tr>
<tr>
<td># Diagnosis (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPD</td>
<td>24 (43.6)</td>
<td>NA</td>
</tr>
<tr>
<td>Cancer</td>
<td>30 (54.5)</td>
<td>NA</td>
</tr>
<tr>
<td>COPD and cancer</td>
<td>1 (1.8)</td>
<td>NA</td>
</tr>
<tr>
<td># In hospice care at some point during study (%)</td>
<td>9 (16.4)</td>
<td>NA</td>
</tr>
<tr>
<td># Died during study (%)</td>
<td>21 (38.2)</td>
<td>5 (21.8)</td>
</tr>
<tr>
<td>COPD</td>
<td>5 (21.8)</td>
<td>NA</td>
</tr>
<tr>
<td>Cancer</td>
<td>15 (50.0)</td>
<td>NA</td>
</tr>
<tr>
<td>COPD and cancer</td>
<td>1 (1.8)</td>
<td>NA</td>
</tr>
<tr>
<td>Length of relationship with physician, median, in years (IQR)</td>
<td>2.0 (0.83, 6.00)</td>
<td>NA</td>
</tr>
<tr>
<td># Living setting (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private home</td>
<td>48 (87.3)</td>
<td>NA</td>
</tr>
<tr>
<td>Assisted living</td>
<td>3 (5.5)</td>
<td>4 (7.3)</td>
</tr>
<tr>
<td># Family’s relationship to patient (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td></td>
<td>20 (55.6)</td>
</tr>
<tr>
<td>Relative (adult child, sibling, in-law)</td>
<td>NA</td>
<td>12 (33.4)</td>
</tr>
<tr>
<td>Friend</td>
<td></td>
<td>4 (11.1)</td>
</tr>
</tbody>
</table>

SD, standard deviation; COPD, chronic obstructive pulmonary disease; NA, not applicable.
We’ve never really talked about the future . . . the end of life. And I don’t know that right now, that it would be a good thing to give him that much information. Because he would . . . take it and run {to depression and anxiety}.

However, for other patients and families, there was no relationship between provision of prognostic information and their hopes about their illness. When asked about this issue, one patient explained:

I guess I just take a day at a time . . . If I got more time than they say, that’s fine, if not, then nothing I can do about it.

Some patients differed from their family members in their desire for prognostic information. The wife of a man with cancer said:

It’s tough and maybe he {the patient} would rather go without knowing that . . . but, I need to know it all . . . I need it to help prepare the children.

Recognition that patients need an individualized approach to communication. Many participants expressed the importance of individualizing the clinician’s approach to hope and prognosis to match the needs of the individual patient and his or her family. Some patients and family qualified their own desire for prognostic information by stating that physicians should be aware of how each individual copes with bad news. A patient with COPD said:

Some patients can take that information upfront and some just can’t handle it. I think it would depend on the type of person.

However, when asked how clinicians could identify the right approach for individual patients and family, few participants could describe specific clinician behaviors that were helpful. For example, many responded that it would be difficult for clinicians to know the best approach for an individual. A patient said:

Every doctor and nurse in the world has the unenviable chore of trying to figure out that one patient; not the patient before; not the patient coming in next; this one person.

A number of participants suggested that physicians in longstanding relationships with their patients will more easily be able to select the right approach for those patients, although none of these clinician or patient participants named specific behaviors, and relied principally on intuition and time. A family member said:

If the doctor has known you for a long time, then they should just know what you need to hear and what you don’t need to hear. . . . Our doctor just knows.

An internist explained:

The nice thing about doing primary care is, you get to know the patient over time and you get a feel for how they would respond and how it’s best for me to tell them about those issues.
A nurse explained, “You just have to sense it out, feel it out.”

Determining “how much information?” Because our goal is to gain insight into how clinicians in practice might individualize prognostic communication, patients and families were directly asked how much information they wanted about the patient’s illness. This question was framed by saying that people vary in how much information they want. In response, all patients and family members responded that they wanted “all the information.” However, in further questioning, a substantial minority of participants made it clear that they did not want explicit information about prognosis such as a median survival, estimated life expectancy, or “worst case scenario” and felt that this information could harm them. When a husband was asked how much information he would like about his wife’s cancer, he initially said:

“Well, I have to say, I prefer to have all the information. I don’t know how everybody else feels, but I would like to know everything.

Subsequently, when asked specifically about wanting bad news about prognosis, he said:

“Well, maybe... I wouldn’t want to know, I guess I wouldn’t want to know everything. I have to take that back, now that you start questioning me.

Throughout the interviews, we found that simply asking patients how much information they want, without exploring their emotions and concerns, did not adequately elicit informational needs.

Four-diagram conceptual model. We developed the four diagram approach to help elicit and describe patient and family views about integrating hope and prognosis (Fig. 1). The four diagrams are labeled as follows to reflect their meaning: (A) “back–forth” diagram (going back and forth between hopefulness and acknowledging a poor prognosis); (B) “scales” diagram (a balance between maintaining hope and acknowledging prognosis); (C) “yin-yang” diagram (holding both hope and prognosis simultaneously); and (D) “redirecting arrow” diagram (a change from hoping for cure to hoping for other things such as quality of life).

Participant endorsements of the four diagrams. Many patients and family members endorsed the compartmentalized existence of hope and truth without any integration (A: back–forth). These participants described being able to focus on their hopes or think about their prognosis, but not at the same time. Some participants struggled to achieve a balance between these concepts, walking a tightrope between “too much hope” (unrealistic expectations) and “too much truth” (hopelessness) (B: scales). Some participants described being able to develop a harmonious integration in which they were able to think simultaneously about their hopes and their prognosis (C: yin-yang). Finally, some participants achieved redirection of their hope, moving from a hope for cure to a hope for other things such as quality of life, symptom control, or life closure (D: redirection). Overall, most participants found the four diagram approach credible for summarizing their experiences or the experiences of others. Most patients endorsed one or two diagrams as effectively summarizing their personal approach to living with hope and explicit prognostic information, but some endorsed more than two diagrams. We are unable to formally quantitate this endorsement because we asked participants to discuss each diagram rather than pick the diagram that fit best. Two patients did not endorse any of the diagrams and neither offered an alternative. Table 4 shows representative examples of patient endorsement of each diagram.

Changes in diagram endorsement over time. Some patients and family members described how their choice of a diagram changed over time with the progression of their illness:

That’s the progress of the illness. I think you start there {back and forth} the minute you hear {the diagnosis} and you hope for a cure, you hope for a fix. And with the progress of the illness, you hope for, you know, for a gentle death.

A patient said:

I used to {go back and forth}, a long time ago, when I first heard. I don’t do that any more. I don’t go back and forth any more. It’s there, it’s going to be there, and I just go on with my life.

Differences in approaches to hope and prognosis based on the diagram endorsed. When a patient or family member endorsed one of the diagrams, the interviewer asked how clinicians might be most helpful for patients and family with this particular perspective. We found that participants described different com-
munication approaches, depending on the diagrams they selected. For diagrams A and B, prognostic information was viewed as a threat to hope; participants suggested that physicians should provide prognostic information cautiously and indirectly, in order to avoid negatively affecting patients’ hopes. By contrast, participants who selected diagrams C or D preferred more direct approaches to prognostic information; they did not report that receiving prognostic information compromised their hopes. These indirect and direct approaches are discussed below.

*Indirect approach (Diagrams A and B):* For patients and families endorsing diagrams A and B, their recommendations suggested that a cautious approach to providing prognostic information might be most helpful. This approach suggests that clinicians take into account the patient’s and family’s emotional state when discussing prognosis, and cautions clinicians about being explicit or precipitous in disclosing prognostic information. Suggestions included developing an understanding of the factors and context that should affect clinician “honesty” or “directness” about prognosis. Some participants described a need for a focus on “human compassion along with the truth.” They also described possible strategies to use when providing prognosis such as: the physician verbalizing a commitment to non-abandonment; identifying and addressing patient fears, such as pain at the end of life; and communicating a clear and comprehensive “game plan” regarding the patient’s care from that point forward; and addressing prognosis in terms of outcomes for groups of patients rather than the individual.

Participants who endorsed diagram A and B often suggested that physicians should discuss prognosis with the family in situations where they cannot discuss prognosis with the patient. A patient said:

*If they can’t communicate with the patient, then maybe they should communicate with the one closest to them in their family.*

A family member underscored the importance of providing family with information about prognosis and also acknowledged the difficulty of the topic:

*I always start out by saying, I hate to do it, but I have to use the P word (prognosis).’ (The doctor) says, ‘We’ve got this treatment and he should respond well and yada, yada.’ And then you have to turn right around and feel like you’re just cutting {the patient} off at the knees, saying, ‘Ok, well then, what are we looking at?’ And it’s tough and maybe he {the patient) would rather go without knowing that. But I need {this information}.*

These comments underscore the participants’ concern that explicit prognostic disclosure is emotionally complex and that clinicians must be aware of the emotional impact.

*Direct approach (Diagrams C and D):* Participants who endorsed diagrams C and D offered specific recommendations that suggested a direct and straightforward approach to prognosis would be most helpful. They expressed the need for physicians to communicate fully and explicitly about what could happen in

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**Table 4. Examples of Participant Quotes Endorsing Each of the Four Diagrams**

<table>
<thead>
<tr>
<th>Model</th>
<th>Example quote</th>
</tr>
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<tbody>
<tr>
<td>A. Back-and-forth</td>
<td>Patient: Sometimes I think, “They’re not going to get the best of me on this. Something’s going to come up and it’s going to improve my condition. And I’m not going to let it make me depressed or anything, today. I’m just going to have a happy day.” And then sometimes, the actual facts set in and then you can’t stop it. And then a friend will call me, “Oh, how are you doing?” you know, and insist on knowing what my condition is and then I have to go in to it and when I hang up I’m just like, “Oh brother! I really don’t feel good.”</td>
</tr>
<tr>
<td>B. Scales</td>
<td>Patient: I want to be hopeful, but I can’t be too hopeful, because that’s not realistic, of course. So I suppose, in a way, I do maintain a balance.</td>
</tr>
<tr>
<td>C. Yin-yang</td>
<td>Patient: That’s true. I know that my illness is very serious, yet I also know that I must maintain my hope and somehow I’m able to do both of those. They’re here at the same time.</td>
</tr>
<tr>
<td>D. Redirecting arrow</td>
<td>Family member: I would agree with this, definitely. A quality of life, not being in discomfort or pain, not being depressed, to get some kind of joy out of every day life. That’s more my hope than that this is going to go away.</td>
</tr>
</tbody>
</table>
the future. One woman with cancer who chose diagram C ("yin-yang") said:

Knowledge {about the future} is empowering, I think the knowledge of what’s going on with you health-wise is the most empowering thing you’ve got.

These participants were able to manage the emotional impact of prognostic information and were less dependent on the clinician to facilitate their emotional adjustment to the news.

DISCUSSION

Our study examined the interaction of support for hope and explicit delivery of prognostic information and found that patients and families differ in their needs and desires for hope and explicit prognostic information. Despite these differences, our participants did not identify methods for clinicians to assess and meet individual needs, and the question “how much information” did not provide patients and families with enough of an opportunity to explain their concerns about receiving explicit prognostic information. This finding may have relevance for clinicians since, based on our study, it seems unlikely that simply asking patients or family members how much information they want in clinical practice will provide useful insights into patient and family needs in this regard. We have described a four diagram approach to explore these issues that successfully elicited differing respondent perceptions about communication preferences for receiving, and providing, hope and prognostic information. However, future studies will be needed to identify the prevalence of endorsement for specific approaches among patients with life-limiting illness and their families as well as the usefulness of these approaches in directing and improving clinician communication.

Although this is the first study to specifically explore different typologies modeling the interaction between support for hope and desire for prognostic information, there are prior studies that have explicitly examined the role of clinicians in influencing hope in patients with terminal or life-limiting illnesses. For example, a study of patients with cancer found that family, friends, and clinicians were the most important sources of support for hope and the majority of patients reported that clinicians were more important than family and friends.\(^1\) A study of patients on an oncology unit found that clinicians both positively and negatively influence hope.\(^38\) Some reported that hope increased when information was given in a sensitive way, when statistics were used compassionately, and when their questions were answered. Ways of decreasing hope included disclosing discouraging medical facts, presenting information disrespectfully, and appearing cold. These findings highlight the importance of clinician communication regarding emotional and informational needs on patient and family hope\(^35\) and, combined with our findings, provide some preliminary direction for future interventions to improve clinician communication.

Prior research provides some specific suggestions that may be useful in the context of our findings to help design future interventions to improve clinician communication about the interaction of hope and prognosis. A study using focus groups and interviews with patients identified some strategies for clinicians to foster hope specifically when discussing prognosis.\(^39\) These strategies include emphasizing proactive plans and substantive activities, such as controlling pain and providing emotional support, exploring realistic goals, and discussing day-to-day living. All patients and families in this study wanted clinicians to be honest, but many also suggested that clinicians should not provide more information than is wanted. Similar to our findings, this study also noted that there was great variability in patients’ endorsements of physicians’ hope-giving behaviors and suggested that a range of demographic, psychological and disease factors affect preferences for physician style and behavior concerning prognosis. Our proposed four-diagram conceptual model provides an approach to address these issues.

Our study has important strengths and limitations. A strength is the insights provided by the in-depth responses that participants made to the issue of hope and prognosis and the detailed responses to the conceptual model. However, our qualitative design does not allow us to determine the proportion of patients who would support each of the approaches nor the prevalence of the finding that some patients and family members move through some of the different diagrams over time. We were also not able to determine whether patients and family members differed in the approaches they would have chosen. Our study design also did not allow us to compare our proposed conceptual model to the work of others regarding communication of bad news or hope in the context of suffering.\(^40,41\) Further study will be needed to address these questions. Another limitation is that the purposive sampling design identified physicians across a spectrum of focus on curative or palliative care but it is not possible to determine how randomly selecting physicians and other participants would have affected the results. A final limitation is that this study was con-
ducted in one geographic region with predominantly Caucasian participants. Although the demographics of patients and families reflect the demographics in our region, our results may not generalize to other regions.

In summary, this study suggests that there is important variability in the way that patients with life-limiting diseases, particularly COPD and cancer, approach the interaction of wanting support for hope and wanting explicit prognostic information from their clinicians. Furthermore, simply asking patients and family members how much information they want seems to be an unrevealing approach to understanding individuals’ needs. The four-diagram model we have developed and used in this study may be a useful heuristic to help clinicians understand individual patients’ and families’ preferences and needs, but further research is needed to assess prevalence and generalizability of our findings and to determine the utility of this model for improving communication with patients and family members.

ACKNOWLEDGMENT

Funding was provided by an RO1 from the National Institute of Nursing Research (RO1-NR-008016).

REFERENCES


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