Communicating a Prognosis in Advanced Cancer

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One of the most difficult yet important parts of oncologiy and palliative care is also one of the least addressed in medical training. The study of diagnosis and therapy is the foundation of modern medical training, and prognosis receives little attention, often leaving clinicians unprepared to handle this task.[1] Many medical students and residents lack adequate instruction on formulating and communicating a prognosis, but there are helpful techniques for sharing a prognosis with a patient.[2–7] In many palliative medicine consultations, patients and families have many questions, but the understanding of prognosis often is not openly discussed. Subsequently, understanding a patient's goals become more difficult. This article focuses on communicating a prognosis to the patient with advanced cancer, but many of the areas described may be generally applied to those with various terminal illnesses and patients in the early stages of cancer.

Predicting the course of a disease through prognostication is one way of demonstrating control over cancer, much as diagnosing and treating cancer may define mastery of a disease process.[6] As modern technology has advanced diagnostic and therapeutic options, the science of prognosis has lagged. Formulating a prognosis is not merely "telling the future" or "making a best guess"; it refers to a prediction of the likelihood of a given outcome based on multiple sources of information.

Typically in medicine, the usual outcomes discussed are recovery and death, but a prognosis can be applied to many different outcomes, including those concerning functional status, symptoms, and laboratory values. With the increased focus on supportive care of patients at the end of life, the science of prognosis is beginning to receive more attention from researchers.[3–5,8,9] The push for patient rights in the 1980s and the move from paternalistic to autonomous to collaborative strategies for medical decision-making have impacted full information disclosure, including that of a prognosis.

Formulating a Prognosis

Before a prognosis can be communicated to a patient or family member, it first must be formulated. Physicians formulate prognoses as part of everyday practice because it plays an important role in clinical decision-making. Is this patient too debilitated for a weekly chemotherapy regimen? Can this patient in the intensive care unit survive a trip to the computed tomography scanner to obtain more clinical information? Does this patient have such a short life expectancy that the long-term side effects of dexamethasone are not a real concern?

Although research papers and cancer registries may assist with a general prognosis for a specific stage of disease, formulating an individual prognosis requires physicians to consider the specific factors of each patient's case. An individual patient's formulated prognosis is based on multiple factors, including current clinical information, diagnoses (clinical and pathologic), medications and therapeutics, social issues, functional status, and a physician's knowledge and experience. A formulated prognosis is not necessarily the same as the true prognosis but rather a combination of major variables.

Deciding Whether to Communicate a Prognosis

Formulating a prognosis may be an essential part of daily medical practice, but sharing prognostic information with a patient with advanced cancer is not always routine. Many physicians are reluctant to share an estimated life expectancy with a patient who is near the end of life. And of those physicians willing to discuss a prognosis with a terminally ill patient, many will not communi-

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cate the formulated prognosis; instead, they will be overly optimistic or even pessimistic.[5]

Physicians may defer discussing a prognosis for a variety of reasons. Taking away hope, producing depression or anxiety, and contributing to a patient's death have been cited as harmful results of a shared prognosis.[6,10,11] But patients demonstrate less anxiety and depression and are more satisfied with their physician when the severity of the illness and life expectancy are discussed openly.[2] To build trust and maintain hope, patients need to know symptoms will be controlled[3] and their physicians are honest without being brutal.[12]

Avoidance of discussing death is common in American society, especially in the medical community, and often indicates a surplus of trust. Patients and their families trust their physicians and their medical knowledge, believing that these professionals will initiate a conversation of life expectancy when the "time is right." Meanwhile, physicians trust patients and their families to inform the healthcare team when "enough is enough." Thus, an important issue is left undisclosed, usually until a crisis occurs or either side musters the courage to open the discussion.

Techniques for Sharing Prognostic Information

Helpful techniques for communicating a prognosis are offered in Table 1, although it may be difficult to apply each one to every situation. As with all patient communication, when sharing prognostic information, appearing confident and sincere may help to establish trust.[3]

QUESTIONS BY PATIENTS

Occasionally, the question regarding life expectancy or prognosis may be asked in a purposefully vague way by the patient or a family member. A patient may ask "So, what do you think?" A wife may ask "Is he doing OK?" These vague, open-ended questions may be attempts to search for prognostic information. Avoiding the underlying question with scientific or statistical statements, or equally vague replies, may prevent ongoing clarification of goals and result in unwanted therapies. Instead, physicians need to explore further in addition to sharing a general medical assessment. A good reply may include inquisitive questions, such as "Is there something in particular you are concerned about?" This confirmatory approach shows patients and family members that physicians are willing to talk about difficult topics.

A somewhat different situation involves a patient with advanced cancer or a family member asking a direct prognostic question, such as "Doctor, how long do I have?" This question may catch a physician off guard. Because devising a prognosis takes time, a phrase that allows time to gain one's composure and reflect on the information is helpful. A response such as "That is a good question, and I am glad you asked it" can serve many functions in these situations. First, it immediately affirms the question as important to the physician, the patient, and family members. Second, it validates that opening such a conversation, although difficult, is a good thing.

In any situation, medical or otherwise, a difficult question places the inquirer in a potentially vulnerable situation. For the responder to reply positively relaxes and rewards the inquirer. Family members may fear asking about a prognosis, thinking the physician may believe that the family has ulterior motives not in the best interest of the patient. Patients may hesitate to mention thoughts of death, intensifying symptoms, decreasing functional status, or a prognosis for fear of disappointing family members, friends, and healthcare staff. If all the information is not available, it is acceptable for physicians to say so, deferring such a discussion for a later date so the details of the case may be reviewed.

OPENING THE LINES OF COMMUNICATION

Occasionally, neither the patient nor a family member addresses the question of life expectancy directly or indirectly. Ongoing diagnostics and therapeutics can monopolize most medical discussions, even when addressing prognosis may have the strongest influence on the best clinical approach. To open the discussion on outcome, a statement such as "One thing that influences all of these issues is your prognosis. Have you thought about that before?" might be less intimidating than a blunt approach. If the formulated prognosis is communicated and differs from the patient's perception, the prognostic knowledge may affect the patient's decision-making and alter the goals of medical care. As with all information sharing, it is important to assess how much information a patient may want to know; patients have the right to defer information and decision-making to others.

EDUCATING PATIENTS

It is necessary to assess patients' understanding of their disease and prognosis. Asking whether other medical staff have discussed the disease process or prognosis with patients is helpful. "Sometimes our bodies may tell us how we are doing. Do you have any feelings about time?" may encourage patients to trust their own intuition. Occasionally, patients are uncomfortable with such a direct approach, particularly when in front of family members or friends. However, patients often can share great wisdom and insight into their disease process, surprising the healthcare staff and family members, who assume patients are coping with their disease through avoidance or denial.

Before a prognosis is communicated, patients and families should understand that medical prognostication is an inaccurate science that is constantly changing. Emphasizing the inaccuracy of prognostic formulation allows for some hope to remain, which may be an important coping mechanism. However, it is necessary to share the information used to make a prognosis to demonstrate the validity of such statements. Reviewing the medical facts, functional status, disease trajectory, and psychosocial issues helps to set the tone for the revelation of the prognosis. Although poor accuracy often is a reason physicians offer for not providing a prognosis, positive gains can be attained if patients understand the overall trajectory of their disease and make patient-centered changes to the goals

of their medical care. The projected time frame for death may not be as essential to this exchange as is the understanding of the decreasing benefits or increasing burdens of curative or disease-modifying treatments.

Another aspect for patients to understand is the dynamic nature of a prognosis. Since multiple factors influence the course of disease, a patient's present prognosis may differ substantially from a future one. Patients need to realize that a single prognosis is not infallible. Once patients understand the dynamic nature of a prediction, it is easier for all parties to readdress a prognosis in the future, as disease and functional statuses change.

Because of the inaccurate and dynamic nature of prognosis, life expectancy ranges may be more helpful than direct numbers or calendar dates. Phrases such as "a few days," "several weeks," or "a couple of hours" reemphasize the difficulty in predicting the future and prevent focusing on a specific date or time. Patients and family members will repeat specific prognostic dates over and over again until they become "reality." Every action hinges on these specific times, often to the point of exhaustion on the part of caregivers. In addition, it may be helpful to state different prognoses for different situations; "I would expect his prognosis to be a few weeks if things improve, but right now, he is so critically ill, he may die in the next few days."

Physicians often stumble over potentially intimidating words such as "dying" and "death." A simple exercise of repeating these tough words may ease a doctor's reluctance to use them in a clinical context. Patients and families need clear and understandable language, and the use of euphemisms can be confusing and impact hope.[3] Physician statements such as "God only knows" and "It's not up to us" may avoid the critical issue, but they may help to focus the discussion on the importance of spirituality and the strength it gives a patient and family. To ensure cultural sensitivities, it may be best for physicians to allow patients or families to raise this issue first.

AFTER PROGNOSTIC DISCLOSURE

Learning to be comfortable with the silence that follows prognostication is critical. Physicians often rush to fill the silence with more facts or words of encouragement, but allowing time to comprehend the information conveyed is respectful and allows patients and family members to ask difficult questions. If the silence is prolonged, asking whether they are surprised may help them to share their feelings. Some patients and families will say they are not surprised, but that it was difficult to hear something to confirm their suspicions.

Once the information has been expressed to all, patients may want to readdress the goals of their medical care. Asking a question such as "Does knowing this impact how you want to proceed?" emphasizes that a prognosis is a factor in shared medical decision-making, just like a diagnosis or treatment. If patients are unwilling to address this outcome now, time may be needed to adjust to the news. Offering to contact family members who were not able to share in the disclosure of this information is frequently helpful and kind.

To close the discussion, it is critical to reinforce nonabandonment and commitment to patient care, whatever the outcome. Patients and families may see this as a sign of caring and empathy, which may foster a better patient-physician relationship during times of changing goals.

Table 1

Techniques for Communicating a Prognosis

Technique	Description
Review case information	Before revealing a prognosis, review factors used to formulate the prognosis, such as disease state and functional status.
Clarify the question	Occasionally, the patient or family may not be asking about prognosis or may defer discussing a prognosis directly.
Affirm the question	"That's a good question, and I am glad you asked it."
Raise the question	"One thing that influences all of these issues is your prognosis. Have you thought about that before?"
Elicit patient understanding	"Sometimes, our bodies may tell us how we are doing. Do you have any feelings about your prognosis?" "Have other doctors shared a prognosis with you?"
Find humility	Emphasize that healthcare professionals cannot predict the future but there are factors to consider. Sit down, and use open body language.
Use ranges, not numbers	Referring to hours, days, weeks, and months with adjectives of couple, few, or several emphasizes the unknowable nature of the outcome.
Pause after revelation of a prognosis	Allow time for patient and family members to comprehend the news.
Manage expectations	"Does hearing this surprise you?" "Is that similar to what you had thought?"
Select the difficult words	Although words such as "death" and "dying" are difficult to express, patients need clear language and not euphemisms.
Readdress goals of care	"Does knowing this prognosis impact how you want to proceed?"
Reaffirm openness	"I'm glad we got a chance to talk about this. It is important."
Ensure follow-up and commitment to patient care	"If you want to talk about this again, I am always open to it." "I will be happy to care for you wherever this road leads."

Conclusion

Communicating a prognosis should be seen as an ethical duty of physicians to ensure shared decision-making. It can be accomplished without the destruction of hope and in a caring and empathetic manner that encourages goal-directed medical care. Each situation is unique, and the approach should be tailored to the specific patient and family. Patients and families can benefit from the allowance of realistic priority setting in their lives; avoidance of increased burdens; increased trust in their physician; and balance of the social, psychological, spiritual, and biologic aspects of their lives. Physicians can alleviate feelings of treating patients to the point of futility, enhance the bond with their patients through all stages of illness, and respond to their patients' social and medical needs in a constructive way.

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