Communication in Advanced Disease

Susan B. LeGrand, MD

Address
Harry R. Horvitz Center for Palliative Medicine (A World Health Organization Demonstration Project), Palliative Medicine Fellowship Program, The Cleveland Clinic Foundation, M76, 9500 Euclid Avenue, Cleveland, OH 44195, USA.
E-mail: legrans@ccf.org

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Communication between physician, patient, and family becomes intense and fraught with problems in the setting of advanced disease. Protocols for end-of-life communication have been developed by various authors, but they have focused primarily on delivery of "bad news" in an individual encounter. This article addresses the need for ongoing coversation throughout the progression from life-prolonging treatment to hospice care. A case study illustrates the utility of this approach.

Introduction

Although communication is important in every physician–patient encounter, there is little doubt that it becomes more intense and more fraught with potential problems when dealing with advanced disease. Intense emotions exist in both parties and can be complicated by feelings of failure, concern about maintaining hope, and personal fears of mortality. As interest in communication and end-of-life care has increased, more articles have been published and protocols developed for the "bad news" conversation. These protocols have focused on delivering bad news in an initial encounter, but experience suggests that these are ongoing conversations over time. Because the vast majority of patients treated with chemotherapy for metastatic disease will die of their disease, palliative medical care should begin with the initial consultation to allow a seamless transition from aggressive life-prolonging treatment to hospice care as disease progression occurs. This article reviews recent literature on communication in advanced disease and suggests an approach that can be used throughout the disease continuum.

Importance

Reviewing the evidence for the importance of good communication in a recent article, Stewart *et al.* [1] make several key points: 1) poor communication is associated with greater risk of malpractice claims; 2) positively perceived encounters do not necessarily last longer; 3) good communication can improve compliance; and 4) good communication can have positive effects on outcome, such as anxiety reduction and elevated mood. These authors conclude that four dimensions of communication have evidence-based support: 1) provision of clear information; 2) active patient role in decision making; 3) empathy, support, and positive affect demonstrated by physician; and 4) establishment of mutual goals [1].

In a study of communication between AIDS patients and their primary care physicians, focus groups of AIDs patients offered comments that were remarkably similar to these evidence-based dimensions [2]: "1) The clinician knows the kind of treatment I want; 2) the clinician listens to what I have to say; 3) the clinician gives me his/her full attention; and 4) the clinician cares about me as a person" [2]. Of some concern in this study is the fact that 26% of physician–patient pairs disagreed about whether they had discussed end-of-life preferences. This study also demonstrates that several categories of patients—African-Americans, Hispanic patients, and those cared for by advanced practice nurses or physician's assistants—were less likely to have their preferences discussed. Results from the SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) also indicate that African Americans wanted to discuss preferences but were more likely not to have done so [3].

Providing Information

Studies confirm that most individuals in this culture want full information about their disease, treatment, and prognosis [4]. The SUPPORT studies have also shown that most people want to discuss preferences for end-of-life care [3]. Various protocols have been developed to facilitate the initial discussion (Table 1). Although the protocol summarized in Table 1 was initially described as the first conversation on a difficult subject, Buckman suggests (and I would agree) that the same approach could be useful in subsequent discussions as well [5]. The problems with patient retention of complex and emotionally difficult information are also well known. [6]. Therefore, delivery of clear information must be an ongoing process.

Different coping styles have been identified in the psycho-oncology literature, with two main styles emerging:

Table 1. Six-step Protocol for Breaking Bad News

Step 1	Get started.
	Establish comfortable private physical setting.
	Identify who should be present.
	Use appropriate social courtesy.
Step 2	Find out how much patient knows.
	Determine patient's understanding of medical situation.
	Identify style of the patient's statements.
	Identify emotional content of the patient's statements.
Step 3	Find out how much the patient wants to know.
Step 4	Share information.
	Determine meeting objectives.
	Give information in small pieces—"warning shot."
	Avoid jargon.
	Check reception frequently.
	Reinforce and clarify.
	Be prepared to adjust objectives as needed.
Step 5	Respond to patient's feelings.
	Identify and acknowledge reactions.
Step 6	Plan and follow through.

Adapted from Buckman [5].

1) "monitoring" or "cognitive confrontation," which involves active information seeking; and 2) "blunting" or "cognitive avoidance," which involves seeking distraction [7,8]. A recent study demonstrates that, whereas individuals with a "monitoring" style are more likely to ask detailed questions about their diagnosis and treatment, those with a "blunting" style have the same desire for information and involvement in decision-making [9]. Younger patients and women are more apt to have "monitoring" styles, suggesting that physicians should carefully assess the information needs of a given patient, especially if few questions are asked.

Defining the Patient Role

The establishment of mutual goals of care, by definition, requires active patient involvement. Choices in advanced disease are primarily value driven. How much toxicity one is willing to tolerate to gain some potential prolongation in life is a personal decision. Only through the physician's careful and repeated explaining of the treatment options, potential benefits, and toxicity can informed choice occur. As disease progresses and chemotherapeutic options are limited, the option of a "symptom control only" focus should always be included. In my clinical experience, individuals often need reassurance from the physician that a purely supportive approach can be an appropriate choice. Physicians must never underestimate their power to persuade patients to their own viewpoint. In a study that evaluated the contribution of physician and patient preferences to end-of-life decision-making, one factor influencing choices was the manner in which the information was provided [10]. Treatment described positively was chosen by 30% of patients, whereas negatively described treatments were chosen by 12%. Seventeen percent of patients changed their minds when the characterization of a treatment was changed. Orentlicher [10] notes, "When physicians discuss end-of-life decisions with their patients, their own views about the desirability of treatment will inevitably color their presentations to their patients." Although not studied in this trial, therapeutic choices may follow the same pattern. Competing interests may also have an effect on how information is presented, as Porter [11•] suggests: "Too many academic oncologists…exploit the needs and expectations of desperate patients to bolster their research or the priorities of their institutions. Of course there are analogous incentives, largely economic, for oncologists in private practice to recommend chemotherapy."

Establishing Goals

Establishing goals is one of the key elements in providing good oncologic and palliative medical care. It is an important way to include the patient as an active member of the care team. Only by adequately defining the goals for a particular patient within the context of what is realistic in the disease process can the patient and the physician develop an appropriate plan of care. This plan becomes the basis for treating a person, not an illness. Goals will change as the disease progresses and can be a means of seamless transition.

Initial diagnosis/first recurrence of incurable disease

It is important to establish at the beginning of the physician–patient dialogue what is possible. Treatment goals include cure, prolongation of life, improvement in symptoms, and comfort. If cure is not possible, this should be stated. It is also important to realize that the patient's perception of the value of chemotherapy may be different from that of the physician [12]. Data from the SUPPORT study show that patients' perception of their prognosis and the potential benefit of intervention are often overly optimistic [13••]. This study also suggests that patients who felt that their probability of surviving more than 6 months was less than 90% were less likely to choose life-extending treatment. These findings demonstrate that a realistic understanding of prognosis is important. If life-prolonging therapy is available and that is the patient's goal, then it is begun. It is not critical to ascertain whether the patient has the same understanding as the physician about the likely outcomes at this time. The initial "warning shot" has been fired. It has been stated that the disease will not be cured.

Relapse/treatment failure

If relapse occurs or treatment fails, the physician gently reminds the patient that he or she had stated that the disease was not curable but had hoped to prolong a good quality of life. If additional life-prolonging therapy exists and performance status warrants, it may be reasonable to continue to pursue this goal. Discussion of the value of quality over quantity should be initiated, with the suggestion that a time will come when the treatment has little to offer, and at that point the goal might change to comfort only. This is the next warning shot. Treatment is not forever. Then, each time a new chemotherapy treatment is considered it can be evaluated in the context of quality versus quantity from the patient's viewpoint. Again, a realistic expectation of prognosis is important to allow patients to arrive at truly informed consent.

Comfort care

If additional life-prolonging therapy is no longer possible, the physician should gently remind the patient of the earlier discussion about stopping treatment if it had little to offer. Assuming that the patient agrees, the goal would then shift to comfort care. In the event of disagreement, further discussion of the patient's goals is appropriate. Conversation can then shift to hospice care and advanced directives. If this process has been handled well, the patient is not days away from dying. Such patients are better able to benefit from a longer involvement in hospice care and good quality of life without the burden of treatment side effects. Some patients may actually feel better as the side effects of chemotherapy resolve.

Throughout the continuum of disease, this discussion should take place within the context of the family whenever possible. One of the features of good palliative medicine is that both the patient and the family are part of the treatment plan. At our institution, family conferences are routinely done to help establish the goals of care.

Team communication

Another cardinal feature of good palliative medicine is the interdisciplinary team, which can include the primary physician, medical oncologist, radiation oncologist, palliative medicine specialist, and nursing, social work, and pastoral care staff. It is imperative that the established goals of care be communicated throughout the team. One method used at our institution is the problem list. This allows a summary of symptoms, treatments, and complications to follow the patient to various clinic appointments. The value of personal communication between specialists cannot be underestimated.

Clinical Scenario

A striking clinical scenario that demonstrates what can and unfortunately often does happen when goals of care are not established was included in a recent article in the *Journal of Clinical Oncology* [14]. This scenario, summarized below, alternates with comments to illustrate how an approach of defining goals of care could have been utilized.

Case study

The patient is a 73-year-old gentleman with diabetes and coronary artery disease diagnosed with stage IIIB non–small-cell lung cancer presenting with dyspnea. The patient and his wife are in the office for an initial discussion of the diagnosis and treatment. He elects aggressive concurrent chemoradiation.

Suggested approach

In discussing the treatment options, the first thing to do is to define realistic goals. The ability to cure stage IIIB lung cancer is debatable, but recent studies suggest the ability to prolong life with aggressive chemoradiotherapy with or without surgery [15,16]. The discussion then is directed to the potential consequences of an aggressive approach. Because the patient is symptomatic with dyspnea, another reasonable goal could be relief with palliative radiation. In the course of discussion, the importance of balancing quality of life with quality can be stressed as side effects are discussed.

Case study

In the course of treatment, the patient is hospitalized with dysphagia, progressive weakness, and a decline in performance status. He is still dyspneic and felt to be too ill for further treatment with "curative intent." He is discarged with "plans to consider further treatment when he recovers" [15].

Suggested approach

This is an opportunity to redefine the goals of care. The idea of quality versus quantity was introduced at the initial discussion. A family meeting should be held that looks at the results of treatment so far and future plans. The patient's quality of life has been severely compromised, and his symptoms are not improved, suggesting that treatment has not been effective. What are possible goals of treatment now? Prolongation of life? At what cost? Symptom control and comfort may be more reasonable alternatives. This also becomes an opportunity to discuss how aggressive the patient would like the team to be in supporting his nutrition. Would he want a feeding tube if he cannot maintain his supplements? Advanced directives can be discussed, and hospice care mentioned if supportive care is chosen. This would not preclude the possibility of further treatment if performance status improves but would allow preparation in the more likely case that it does not.

Case study

The patient is readmitted with poor intake, a feeding tube is placed, and pneumonia develops. He develops respiratory distress, and his wife agrees not to resuscitate. The patient's daughter arrives and disagrees, prompting emergency ethics consultation and, ultimately agreement, with subsequent death.

Suggested approach

The discussion suggested at the time of admission could have prevented the distressing end of this scenario with nasogastric feeding tube, probable aspiration pneumonia, family discord, ethics consultation, and, ultimately, hospital death. The patient might well have been discharged with hospice care and died peacefully at home without family discord because family members had been involved in the plan from initiation.

Conclusions

Most of the literature on communication in advanced disease focuses on determining preferences for resuscitation and ventilation. One of the results of the SUPPORT trial was the realization that having this information did not change the patterns of care. As Weeks *et al.* [13••] note, "To achieve the goals of making care at end of life consistent with patient values and minimizing futile therapy, we need to change what physicians tell patients about their prognoses and be sure that patients hear and understand what their physicians have said." These investigators also found that physicians' estimates of more than 6 months of survival probability were accurate enough to share with patients. We should begin to look at the impact of this form of direct, clear communication on therapeutic choices, hospice referral, length of stay, and, one hopes, improved quality of life in advanced disease.

This article offers a protocol for delivering bad news and identifying goals of care as a means to facilitate ongoing communication during the progression of advanced, disease-specific malignancy. This is the standard for communication in the Palliative Medicine Program at the Cleveland Clinic Foundation and one that has been personally successful for the author in other settings. Research should now be directed at identifying the best ways to discuss treatment options in the setting of advanced disease rather than on discussions of one isolated element of end-of-life care.

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