Pessimism Is No Poison

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INTRODUCTION

Dee Jones is 35 years old, married, and the mother of three children, all younger than 15 years of age. She had been healthy all of her life before she presented with a 2-week history of abdominal discomfort and anorexia. Evaluation revealed moderate jaundice, an enlarged liver, and abnormal liver function tests. An image of the abdomen showed a pancreatic mass and widespread metastatic disease to the liver. A liver biopsy confirmed a diagnosis of metastatic pancreatic carcinoma. She received first-line chemotherapy for pancreatic cancer and returned 6 weeks later for re-evaluation. She had evidence of disease progression, increasing pain, weight loss, and was bedridden more than 50% of her waking hours.

A staff oncologist, accompanied by a first-year oncology fellow, visited with the patient. With the patient acknowledging that she wanted to hear prognostic information, the medical oncologist had a heart-to-heart discussion with the patient. The senior oncologist noted that survival is typically measured in weeks. They discussed treatment options ranging from additional chemotherapy to participation in an early-phase clinical trial. They talked about symptom management and hospice care. They agreed that no further cytotoxic chemotherapy would be used. The conversation was difficult for all: the patient and her husband cried and the oncologist was visibly moved.

After leaving the room, the staff oncologist and fellow discussed the consultation. The fellow asked the oncologist why he was so pessimistic when talking with the patient. Why did he say things to make the patient and her husband cry? Shouldn’t he have given the patient more hope? Would it not have been better for the patient to hear this dire news in fragments over the course of several clinic visits? After all, the patient was so young she may just beat the odds.

DISCUSSION

There is ample evidence that oncology patients in Western cultures prefer to be well informed about their diagnosis, treatment options, and the possible adverse effects of treatments.1-3 However, their need for information, both quantitative and qualitative, may change over time and may be influenced by many factors. Physicians are frequently asked to give prognostic information, and more specifically, to estimate how long an individual patient is likely to live. This is challenging on multiple levels. It is almost impossible to be precise in providing a prognostic estimate of life expectancy unless the patient is imminently dying. Communicating uncertainty and providing numerical estimates to patients in a way that is both clear and supportive is difficult. It is not surprising that physicians often avoid this altogether with consequences that are well known and later regretted—too many patients receive intensive or aggressive care in the final days of life without benefit. The end results of such medical decisions are far reaching, given that they affect family and professional caregivers. Bereaved relatives and friends may suffer and later regret the use of aggressive treatment in the final days of life, which consumed their time, attention, and resources. Nurses and young physicians are often distressed when they become unwilling participants in futile efforts to prolong the life of a patient with a terminal illness. Clearly, the answer lies in avoiding such situations through improved communication between patients and doctors.

Providing clear prognostic information is a sine qua non for reasonable decision making. Armed with a clear understanding of the natural history of the illness with and without treatment and a numerical estimate of life expectancy, a reasonable person can sort through his goals and priorities, prepare for treatments with uncertain outcomes, and think about death and its aftermath. In practice, physicians balance the ethical mandate to inform patients with the need to protect them from harm, including the anxiety and hopelessness engendered by a poor prognosis. Medical views regarding prognostic discussions reflect this tension and can lead to different behaviors or recommendations on the basis of the beliefs of the individual clinician. If one believes that beneficence requires that a physician act in the good of another, then one can justify withholding upsetting information or obfuscating important facts.
This may lead to short-term benefits and calm the physician’s anxiety over conveying bad news, but can cause long-term harm by depriving the patient and his/her family from using the time left to complete important tasks. Doctors endorsing this philosophy argue vehemently that the modern practice of full disclosure is cruel and insensitive, contrary to patients’ best interests and disruptive to the benefits arising from denial and hope.4,5 If one is guided by paternalism, then perhaps one can justify making important decisions on a patient’s behalf on the basis of a perception of what is presumed best for that individual. In contrast, if one is guided by the conviction that every adult with capacity has the right to make their own autonomous decisions, then all data and facts should be made available to the patient. This is not to say that we encourage dumping of truth, but rather endorse open and frank communication.

In fact, few physicians would dispute the ability and right to self-determination; however, soft paternalism remains very common, as physicians constantly sort through and censor the type and quantity of information that needs to be conveyed.6 This was well illustrated in an ethnographic study of communication between oncologists and patients with small-cell lung cancer that documented just how conversations shifted from the bad news of diagnosis and prognosis to the good news of treatment planning.8 Patients infrequently asked about prognosis and physicians rarely offered such information, assuming that when patients did not ask, they did not want to know. Other studies have noted similar collusive tendencies in physician-patient communication in oncology.10,11

Multiple studies demonstrate that a clear majority of patients with cancer want prognostic information. Two recent systematic reviews encompassing more than 100 studies concluded that most patients want specific information about their risks and prognosis, including the chances of cure, the extent of disease spread, their life expectancy (eg, the chances of living 1 or 5 years), best- and worst-case scenarios, the possible effects of cancer on their lives, and possible adverse effects of treatment. For many patients, these needs for information do not diminish as their prognosis worsens.3,12,13 In fact, they may become more important as the need to prepare and assemble family members, reach important milestones, and get their affairs in order become more acute.

This brings us to the question of hope. Hope has been described as an essential element in human life, and one that is integral to a person’s quality of life and well-being.14,15 Having things to hope for is an important coping strategy for all patients with cancer.16,17 It is in the name of preserving hope that information is most often withheld. The desire to preserve and foster hope, no matter how poor the prognosis, drives the individual doctor to decide in the moment how much is actually discussed and how it is framed.13 It is worth noting that the physician too needs to feel hopeful in order to convey this important sentiment that has resisted proper characterization. Medical literature has taken a rather narrow view on hope by placing undue emphasis on the object of such hope and framing the discussion in terms of tangible outcomes, such as remission or cure of disease.18 However, one can hope for many things, such as to be pain free, to have meaningful relationships, to reach an important goal or event, to maintain dignity, and to have a good death. The best way to help individual patients is to ask them directly what they hope for and use that as a focal point for discussing prognosis and setting realistic expectations.

Thirty years ago, Spiegel19 showed that patients who were able to openly acknowledge and discuss their fears were also more able to express positive and hopeful feelings. Factors that influence a patient’s hopefulness are the physician’s willingness to talk about prognosis, to answer questions and provide information openly and honestly when asked, to offer the most up-to-date treatment, and to also provide emotional support.20 In a systematic review of the literature on sustaining hope in the context of terminal illness, Clayton et al20 quote evidence suggesting that if the oncologist can talk about death and dying comfortably and without fear, the patient will be more able to do so, and this can be very comforting. This suggests that offering reassurance that the patient/caregiver will be supported throughout the illness trajectory and emphasizing what can be done are of value to patients.

There is a delicate balance between fostering realistic hope and creating false expectations of longevity. Robinson et al21 analyzed audio-recorded encounters between 51 oncologists and 141 patients with advanced cancer with good (n = 69) or poor (n = 72) concordance about chance of cure. Encounters were coded for communication factors that might influence oncologist-patient concordance, including oncologist statements of optimism and pessimism. When oncologists made at least one statement of pessimism, patients were more likely to agree with their oncologist’s estimated chance of cure (odds ratio, 2.59; 95% CI, 1.31 to 5.12). Statements of optimism and uncertainty were not associated with an increased likelihood that patients would agree or disagree with their oncologists about chance of cure. The authors concluded that the best communication strategy to maximize patient knowledge for informed decision making, while remaining sensitive to patients’ emotional needs, may be to emphasize optimistic aspects of prognosis, while also consciously and clearly communicating pessimistic aspects of prognosis. A fitting metaphor is that of a seesaw or pendulum, with optimism and pessimism on each end and realism in the middle. The oncologist then assists the patient in this balancing act by moving towards pessimism if that is what is needed to bring the patient closer to the middle—the safest place to be.

So, is a little pessimism actually helpful in prognostic conversations? One can easily imagine that a sincere doctor who acknowledges his own concern about future outcomes and is willing to say so to the patient may earn the patient’s trust.22 In so doing, the therapeutic alliance is strengthened and allows the patient to come to terms with the sad reality of the situation. This is the essence of therapeutic engagement. The evidence suggests that discussion of prognosis does not take away hope, but rather leads to greater patient satisfaction, lower anxiety, and lower depression. Several recent studies reinforce the concept that knowing one’s prognosis and discussing preferences for care at the end of life does not lead to despair and depression, and on the contrary, allows for a better adjustment to serious illness.2,23

The senior oncologist in this scenario decided to share prognostic information without censoring. We can only imagine that this took considerable discipline and effort, since oncologists are typically expected to focus on treatment-oriented solutions. Responding to such poignant situations requires a willingness to recognize the fundamentally human and deeply personal nature of suffering.

**AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

The author(s) indicated no potential conflicts of interest.
REFERENCES