

Reasons Why Physicians Do Not Have Discussions About Poor Prognosis, Why It Matters, and What Can Be Improved

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At a time of controversy about a sick and aging population and fiscal constraint, honest communication about choices and outcomes represents an important solution. Yet evidence consistently shows that doctors are hesitant to divulge prognostic information. We have found several underlying misconceptions held by health care professionals. Much of this work has been done in the cancer population but applies across serious illnesses.

It Will Make People Depressed

Incorrect. In fact, giving patients honest information may allow them and their caregivers to cope with illness better. In the Coping With Cancer study, patients who reported having end-of-life discussions had no higher rates of depression or worry and had lower rates of ventilation and resuscitation and more and earlier hospice enrollment.¹ More aggressive medical care at the end of life was associated with a higher risk of major depressive disorder in bereaved caregivers.

These are associations, and it is possible that in a randomized trial of telling the truth to half and withholding it from others, some of the informed group would object. But such a trial would be unethical. Most people—90% in most recent surveys of patients with cancer—want to know their prognosis. Physicians who ask, “What do you know about your illness? What do you want to know?” allow patients to express their own wishes about the information they want.

It Will Take Away Hope

Incorrect. In fact, evidence suggests that hope is maintained even with truthful discussions that teach the patient that there is no chance of cure. In an advanced cancer population, patients who were given a poor prognosis, low likelihood of response to treatment, and no chance of cure remained hopeful about their futures, as shown in Figure 1.^{2,3} Similarly, hope was increased or at least preserved when parents of pediatric patients were given prognostic information, even if the news was bad.⁴

It is striking that physician honesty, even about difficult news, may actually help patients to feel more hopeful. Among hemodialysis patients, receipt of prognostic information allowed for empowerment about medical care and decision making, an important component of hope.⁵ Because many patients relied on physicians to initiate discussions, however, fears for the worst threatened hope when discussions did not take place. Similarly, 93% of surrogate decision makers for

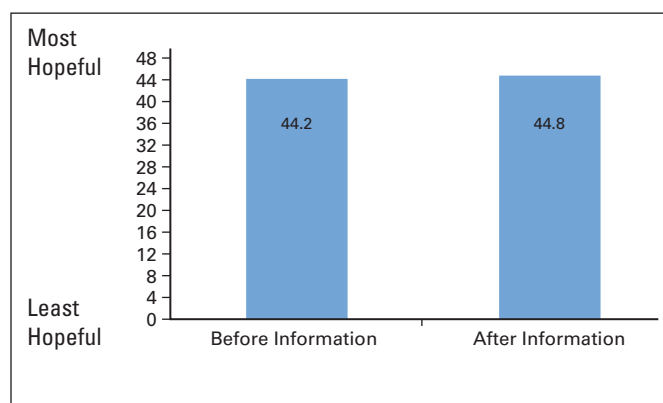


Fig 1. The effect of truthful information on the Herth Hope Index. Hope does not change with honest cancer information about prognosis and options. Data adapted with permission.²

patients receiving mechanical ventilation considered avoidance of discussion about prognosis to be an unacceptable way of maintaining hope.⁶ It is possible that hope is derived not from prognostic disclosure itself but rather from the caring patient-physician relationship in which it occurs.⁷ The perpetuation of false hope may be fundamentally at odds with this kind of relationship.

We have thus far described two concerns about the emotional impact of bad news, with evidence that patients can hear difficult news without devastating emotional consequences. However, one might also ask whether protecting patients from difficult news is a goal physicians should accept. Bad news is difficult, but physicians can help patients by listening to painful feelings, responding to emotion, and providing a consistently caring and trusted presence over the days to come.

Involvement of Hospice or Palliative Care Will Reduce Survival

Incorrect. Multiple studies suggest that survival is equal or better with hospice or palliative care. Among 4,493 Medicare beneficiaries who died after a diagnosis of congestive heart failure or one of five cancers, hospice use was associated with increased survival.⁸ Patients with lung cancer who use hospice have a better chance of being alive at

1 and 2 years,⁹ and chemotherapy use during the last 2 weeks of life did not improve their survival but did delay hospice enrollment.¹⁰ No studies show reduced survival, and use of hospice may increase caregiver survival.¹¹ Palliative care is associated with equal or improved¹² survival in multiple randomized controlled trials.¹³

We Do Not Really Know a Patient's Prognosis

True, but with qualifications. Although we never know precisely how long a patient has to live, uncertainty should not be used as an excuse. Physicians are often able to formulate a reasonable prognosis or range of possible outcomes that can bring the patient's understanding closer to the truth.

Strikingly, physicians give the least honest figures to those with the worst prognoses (and perhaps most in need of information to make decisions).^{14,15} In one study, physicians who had referred patients to hospice reported that if the patient asked about prognosis, they would provide an honest estimate only 37% of the time. Most of the time, physicians would provide no estimate or a conscious overestimate.¹⁶

In addition, physicians exercise discretion about how they communicate such information, using qualifiers, qualitative estimates, and nonverbal cues. Giving just one negative fact will help the patient understand the real prognosis.¹⁷ Physicians can address this issue by checking patient understanding: "Can you tell me what you are taking away from this conversation?"

Talking About Prognosis Is Not Culturally Appropriate

Incorrect. It is true that patients of different ethnic and cultural backgrounds often have different preferences for information. In one study, Korean Americans (35%) and Mexican Americans (48%) were less likely to believe that a patient should be told about a terminal prognosis than African Americans (63%) and European Americans (69%).¹⁸ However, knowledge of different preferences by ethnicity should not dictate communication with individuals. If one were to assume that Mexican Americans prefer not to receive prognostic information, then half of such patients would not be given the information they wanted. Assumptions about the meaning of culture in a particular patient or family should therefore be avoided.^{19,20} Instead, physicians who want to know their patients' preferences for prognostic information should ask.

We Do Not Like to Have These Discussions, and They Are Hard on Us

This final concern holds truth. Most oncologists find breaking bad news to be stressful, and few find it satisfying.²¹ The emotional burdens of disclosing a poor prognosis often emanate from empathy with the patient.²² It is understandable that physicians who have long-term relationships with patients are most likely to overestimate survival.¹⁶ In the one study of its kind, being truthful and present with a simulated 26-year-old patient with a brain tumor and telling her the dismal prognosis were far more troubling than concealing the truth from her.²³

The many reasons we propose for disclosing prognosis do not take away from the fact that this work is hard, and it is particularly hard when we care a great deal about our patients. But if we begin to shift the discourse in medicine toward honest conversation as a fundamental

duty, perhaps we can at least honor this work and those who do it. Importantly, there may be ways to support physicians who do this work. In addition to the classic advice of recognize stress, take time off from work, and find pleasurable time at work,²⁵ of particular note is a program in mindful communication developed at the University of Rochester²⁶ that led to improvements in physician burnout, empathy, and mood. In addition, by creating a reflective space for physicians, the new skills fostered patient-centered attitudes, a finding that suggests that better physician care could lead to better care for patients. And we should remember that our patients want us to have these conversations, difficult as they are for all involved.

Why It Matters

It may be easier on ourselves to keep providing interventions until it is obvious that it is time to stop. Half of all patients with lung cancer get to 2 months before their death without anyone mentioning hospice.²⁷ Sixty percent of medical oncologists prefer not to discuss code status, advance medical directives, or even hospice until there are no more treatments to give.²⁸ This approach allows us to avoid these conversations as long as possible, sometimes entirely.

But there are disadvantages: patients lose good time with their families and for reflection and spend more time in the hospital and intensive care unit.²⁹ Patients and families want prognostic information, and it supports their ability to make decisions that are right for them. Given this, and the lack of evidence that discussing prognosis causes depression, shortens life, or takes away hope, it is hard to argue against honest communication of a poor prognosis. We think this is one way we can improve care, give people more realistic choices, and reduce the rising cost of care.³⁰

Several guidelines provide recommendations about disclosing a poor prognosis, including a fine pair of articles by Back and Arnold^{31,32} and an excellent short book.³³ It is beyond the scope of this article to add to what has already been written so well, except to add a final suggestion: If the major barrier to prognosis communication that holds real credence is the pain physicians experience in these conversations, we should work toward supporting one another as physicians in these difficult tasks.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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