Giving Honest Information to Patients With Advanced Cancer Maintains Hope

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Oncologists often do not give honest prognostic and treatment-effect information to patients with advanced disease, trying not to “take away hope.” The authors, however, find that hope is maintained when patients with advanced cancer are given truthful prognostic and treatment information, even when the news is bad.

Oncologists often do not give patients honest and truthful information about their prognosis and treatment options,[1-3] despite the fact that many patients say they want candid clinical information even if the outlook is poor.[4] Most cancer patients never receive information from their physicians about prognosis[5] or even imminent death.[6] That lack of knowledge is associated with worse quality of care, worse quality of life (QOL), and worse QOL for the surviving caregivers.[7]

One of the main reasons that oncologists state they do not give patients such information is that they “do not want to take away hope.”[8] We could find only limited information in the medical literature showing the effect of truthfulness on hope, so we tested the effect on hope of decision-aids that provided patients with explicit average benefits of treatment-effect, chance of cure, and survival.

Methods

APPENDIX 1

The Herth Hope Index

We created state-of-the-art tables of information for patients with advanced breast, lung, colon, and hormone-refractory prostate cancers, based on expert review and comparison with the online electronic data source, UpToDate. Appendix 1 illustrates representative information for a patient with metastatic prostate cancer facing first-line treatment. The information was approved by all three oncologists involved. This bar-graph method is also in common use by Adjuvant! Online (www.adjuvantonline.com), a tool that has been shown to improve decision-making in the treatment of women with breast cancer.[9,10]

We tested the intervention in a heterogeneous sample of 27 patients recruited through the Dalton Oncology Clinic; one person chose not to complete the exercise. Our primary outcomes are reported separately (Smith T, et al., submitted). Patients were accrued by reviewing the daily clinic list with the treating oncologists to find patients on active chemotherapy treatment for metastatic, incurable breast, colorectal, non–small-cell lung, or hormone-refractory prostate cancer. Patients were not contacted about the study if the primary oncologist or primary oncology nurse determined that a patient was experiencing significant distress or had significant psychiatric problems or difficulty with adjustment to illness, or when the oncologist or primary oncology nurse believed the patient would have great emotional difficulty handling the information.
In addition, eligible patients were told via the informed consent form that the study included detailed information about prognosis that could be upsetting, and those who said they did not want to receive such information were excluded. The number of patients excluded by each oncologist owing to concern about distress was estimated to be less than 10% of the total available; because these patients were not enrolled in the study, we did not collect information about them.

We assessed the impact of truthful information on hope, as measured by the Herth Hope Index,[11] a valid and reliable instrument used to assess hope in patients with cancer and other serious illnesses.[12-16] Our study was approved by the Massey Cancer Center Protocol Review and Monitoring System, and the VCU Institutional Review Board for the Conduct of Human Research.

Results

The patients were typical for our urban, tertiary referral and safety net hospital and National Cancer Institute (NCI)-Designated Cancer Center. The average age was 63 years, 56% were women, 56% were African-American, most had completed high school, and the most common income range was $15,000 to $30,000. Twenty seven patients were recruited to the study; one declined to continue after reviewing her prognostic information, stating that she “wanted to remain positive.”

There was no change in responses to the Herth Hope Index after the intervention (see Figure 1). In most cases the responses were completely unchanged. For this 12-point scale, respondents mark “strongly disagree” (1 point), “disagree” (2 points), “agree” (3 points), or “strongly agree” (4 points); the most optimistic score is 48. The average preintervention score was 44.2 ± 3.9 and the post intervention score was 44.8 ± 3.86, with a change of 0.63 ± 2.078 (P = .55 by paired Student’s t-test). There were no responses that moved more than one response (eg, from “strongly agree” to “agree” or “disagree” to strongly disagree), and in general the responses were more positive after the intervention.

**What is the chance of my being cured by chemotherapy?**

**Prostate Cancer**

**First-Line Chemotherapy**

What is my chance of being alive at 1 year if I take chemotherapy, or receive best supportive care, such as in a hospice?
How much longer will I live if I take chemotherapy?

What is the impact of chemotherapy on my quality of life?

What is the chance of my cancer responding to chemotherapy?

In this setting, there is no chance of cure. The goal may change to controlling the disease and any symptoms for as long as possible. You may want to talk with your doctor about your own chances and goals of therapy.

**How long before my cancer begins to grow again?**

The average time before the PSA (prostate serum antigen) began to rise was about 8 months. Pain relief lasted 4–6 months.

**What are the most common side effects?**

The most common side effects will vary with the type of treatment given. Some of the most common ones include the following:

- Mucositis (mouth sores)
- Nausea/vomiting, usually controllable
- Alopecia (hair loss)
- Neutropenia (low white blood cell count) and infection requiring antibiotics
- Neuropathy (numbness and pain in the hands and feet)

**Are there other issues that I should address at this time?**

Many people use this time to address a life review—what they have learned during life that they want to share with their families, and planning for events in the future (like birthdays or weddings). Some people address spiritual issues. Some people address financial issues like a will. Some people address advance directives (living wills). For instance, if you could not speak for yourself, who would you want to make decisions about your care?

If your heart stopped beating or you stopped breathing due to the cancer worsening, would you want to have resuscitation (CPR), or would you prefer to be allowed to die naturally without resuscitation? Some people use this time to discuss with their loved ones how they would like to spend the rest of their life. For instance, where do you want to spend your last days? Do you want to have hospice involved?

**These are all difficult issues, but important to discuss with your family and your health care professionals.**

**Discussion**

Oncologists commonly state that they do not want to give patients honest prognostic information
because they are concerned that doing so may cause patients to abandon hope. Our findings suggest that for patients who want such information, hope is maintained even if the news is bad. This is a critical recognition, as oncologists are uniquely positioned to help patients redefine hope, even if cure is not possible.\[17\]

Most cancer patients do not receive such information about their prognosis, treatment options, and expected outcomes.\[18\] Even if terminally ill patients with cancer requested survival estimates, doctors would provide such estimates only 37% of the time,\[19\] often overestimate survival time,\[20\] and are uncomfortable about discussing estimated survival time with patients.\[21\] Fallowfield and Jenkins note that physicians’ “failure to disclose information honestly to patients might be an attempt to protect their own emotional survival as much as to help protect the patient.”\[22\]

The finding that honesty about prognosis, treatment benefit, and curability did not decrease hope is supported by other studies. Mack and colleagues found that parents of children with cancer who received more prognostic disclosure remained more hopeful, even when the news was bad.\[23\] Lin and colleagues in Taiwan found that truthful disclosure of the cancer diagnosis was associated with higher levels of hope.\[24\] There are no data that show hope can be taken from patients, or that patients can be harmed by truthful prognostic information, if it is desired by the patient and presented in a reasonable way by his or her physician.

Patients want us to be truthful, compassionate, and clear, and to stay the course with them.\[25\] Such truthful decision-aids, including a statement regarding chance of cure and the expected treatment benefit, have been incorporated into the American Society of Clinical Oncology (ASCO) decision-aids for non–small-cell lung cancer patients. As our study illustrates, “taking away hope” is no longer a valid reason to withhold valuable information about prognosis and treatment effects that can help patients to plan their remaining lives.

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References:


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