Obtaining Helpful Information From the Internet About Prognosis in Advanced Cancer

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Abstract

Purpose: Prognostic awareness, or knowing that one has a life-ending disease, is associated with a better end-of-life experience, including less depression and anxiety. We sought to determine whether reliable sources on the Internet contained helpful prognostic information about advanced cancer.

Methods: We played the role of a 62-year-old person with stage IV incurable cancer and accessed four commonly used Web sites for the 10 most common causes of cancer death (American Cancer Society, ASCO, National Cancer Institute, Up To Date), as well as disease-specific Web sites.

Results: Approximately half the Web sites (26 of 50; 52%) had some notation of 5-year survival. Only four of 50 (8%) gave any average or median survival. Only 13 of 50 (26%) noted that stage IV cancer was a serious and usually life-ending illness. Nearly all had some information about hospice and palliative care.

Conclusion: Information that can help with patient prognostic awareness is not currently found on cancer-related Web sites. Oncologists should be aware that their patients will not find estimates of survival or treatment effect on the Internet. This may contribute to overoptimistic estimates of survival and subsequent aggressive end-of-life care.

Introduction

People with advanced cancer overestimate their prognosis and the effects of treatment, often dramatically. For instance, nearly three quarters of contemporary patients with incurable colorectal and lung cancer thought it was possible to be cured with chemotherapy¹ or radiation therapy² when there was no possibility of cure and the average survival was short. It can be difficult for patients to find truthful and helpful information about advanced cancer. Oncologists can find it hard to share bad prognoses³⁻⁵ and provide overestimates of survival of at least 30%.⁶ In addition, most information during the visit is related to treatment.⁷ We have listed some of the most telling communication miscues, including the fact that only 17% of patients with advanced lung and colorectal cancer can identify their prognosis (Table 1).

If a person does not get information from their oncologists, they will often resort to the Internet. Nearly 90% of Americans and 59% of seniors routinely use the Internet, and 72% of Internet users looked online for health information. Half of the users are searching on behalf of someone else such as a parent or spouse.⁸ Can a person with advanced cancer learn what will happen to them, what can be done about it, and what to expect? We sought to determine what a seriously ill patient with stage IV cancer could learn from the most commonly used Web sites (ie, the "Big Four") of the American Cancer Society, the National Cancer Institute, ASCO (eg, lung cancer⁹), and Up to Date (eg, breast cancer¹⁰), as well as disease-specific Web sites.

Methods

We (a second-year medical student with a prior MPH, and a 62-year-old medical oncologist with 33 years of practice experience)

searched the Internet in the guise of a 62-year-old person with an advanced (stage IV) case of one of the 10 cancers most likely to cause death in the United States. We accessed Web sites and searched for the information that might be important to most patients. We focused on information that was directed to patients and excluded content that was meant for health care providers and researchers. Web sites were accessed between June 27, 2014, and July 7, 2014, and rechecked in February 2015. We viewed five different Web site for each of the top-10 cancers in the United States (50 Web sites total), and searched for information that would be important to most patients in making informed decisions about their care (giving the diagnosis a name, the natural history of the illness, the likely prognosis, common symptoms, and what caused it¹¹). Review included the following five items: (1) whether there was any mention of this disease being a life-threatening or terminal illness, (2) presence of survival rates (1 and 5 years) and median survival times, (3) any mention of advanced planning, (4) any mention of hospice care, and (5) any mention of palliative care.

Results

Results are shown in Table 2. For the 10 most lethal cancers in the United States, only 13 Web sites stated specifically that this was a serious or life-ending illness. A person searching specifically for 5-year survival figures for stage IV cancers could find some notation of survival in only 26 Web sites (52%). Only four Web sites (8%), two of which came from UpToDate (UpToDate: Breast Cancer, and UpToDate: Non-Hodgkin's Lymphoma), contained any information about the average or median survival, the most meaningful statistic to someone asking "What will most likely happen to me?" For example, the

Table 1. Communication Miscues in Contemporary Oncology

Information	Facts	Comment
No. of patients with an accurate awareness of their prognosis	16.5%; 18.5% if the most important doctor discussed prognosis ³⁰	Patients with metastatic colon or lung cancer who could identify the usual prognosis as < 5 and 2 yr, respectively. Accuracy was directly related to the propensity of the doctor to actually discuss prognosis.
No. who thought chemotherapy could cure their metastatic disease	69% of patients with lung cancer and 81% of those with colorectal cancer ¹	All of these patients had incurable disease.
No. who understood that palliative radiation was not going to cure them	Only 36% of 384 patients with lung cancer understood that radiation would not cure them. ²	All of these patients had incurable disease.
No. of lung cancer patients who had discussed hospice with any doctor, 2 mo before death	Only 53% had discussed hospice with any provider 2 mo before death ³¹	Having this discussion 2 mo before death decreased the in-hospital death rate from 51% to 19%. ³⁰
No. of patients with lung and colorectal cancer with any documented end-of-life discussion	73% overall: 55% occurred in the hospital, 27% of the time with oncologists. Most common time was 33 d before death ³³	Most terminally ill patients never discuss their death with their oncologist, even though we know such discussions do not increase anxiety or depression, or take away hope.
Prognostic awareness, or knowing that one has a terminal cancer	74%	Patients who die in the hospital have more emotional and physical distress, especially ICU decedents, compared with those who die in home hospice. ³⁵
Regret about end-of-life care	At least 50% experience regret about the end-of-life care their loved one receives	Completion of advance care planning strongly associated with reduced caregiver distress. ³⁶

Abbreviation: ICU, intensive care unit.

patient information on Up to Date states explicitly that the average person with metastatic breast cancer lives “. . . 18 to 24 months, although the range in survival spans between a few months to many years and depends very much on the type if breast cancer the patient has.” Currently, approximately 80% of Web sites have links to sites related to hospice and palliative care, but none explicitly recommended concurrent anti-cancer and palliative care, as suggested by national guidelines.¹²

Discussion

We found that the majority of Web sites now mention hospice (39 of 50; 78%) and palliative care (37 of 50; 74%). Approximately half (26 of 50; 52%) give 5-year survival rates. However, only a quarter (13 of 50; 25%) mention that the disease under discussion—for example stage IV pancreatic cancer—is a serious, life-threatening, or even life-ending disease. Finally, only four of 50 (8%) give the statistic most meaningful for treatment and advance care planning: how long will the average person with this serious cancer live? This information can be provided on Web sites, as noted above for the publically available Up To Date and ASCO lung cancer decision aids.¹³ A similar publically available tool for heart failure patients gives actual survival graphs and encourages the patient to print and bring to his or her provider.¹³

This lack of relevant information has an impact on what oncology patients know and understand, and bring to the patient-oncologist encounter. We do know that patients who over-estimate their survival do not live longer but are more likely to receive aggressive end-of-life care including chemotherapy in the last 30 days of life, intensive care unit use, resuscitation, and less use of hospice.^{14,15} Care of Medicare-age patients with cancer is also becoming more aggressive over time, with more patients admitted to hospitals and intensive care

units, and fewer days in hospice.¹⁶ We know that the great majority of patients want to know their prognosis, even if it is bad.¹⁷ We also know that people who actually discuss their end-of-life care wishes with a physician are twice as likely to get care consistent with their preferences¹⁸ such as dying at their preferred place.¹⁹ Patients who have “prognostic awareness” – who know and admit that they have an incurable disease – paradoxically have better mood, less depression and anxiety, and better quality of care at the end of life, in addition to living at least as long if not longer.²⁰⁻²²

The high percentage of Web sites giving information on hospice and palliative care, coupled with the low percentage of information regarding survival time highlights a common challenge in our approach to the terminally ill patient. Data consistently show that actual patients want such prognostic and treatment information,²³ use it for advance care and life planning, and will access a patient-friendly Web site,²⁴ but we now know they will not find realistic information on the Internet. Realistic prognostic awareness is also strongly countered by commercial media campaigns of “Cancer Center _____, where hope lives,” or “Cancer Center _____, where we will never give up on you.” Cancer center advertisements concentrate on hope, while rarely mentioning survival, risks, or benefits of treatment.²⁵

Strengths of this report include that we looked at Web sites for the top ten different cancers and found consistent patterns. Limitations for this study include the fact that Web site content can be interpreted differently by patients based on their medical literacy, culture, and support. Also, even though many Web sites had the information on palliative care, hospice care, and advance care planning, we did not compare the quality of the content and the kinds of information being presented.

Table 2. Information on Web Sites About the Most Common Types of Cancer Deaths in the United States

Type	Included Statement About Serious Illness (%)	Any Stage IV Mortality Rates or Figures Given (%)	If So, What % Alive at 1 or 5 Yr? Median Survival?		Any Note of Need for Advance Care Planning (%)	Any Mention of Hospice Care (%)	Any Mention of Palliative Care (%)
NSCLC	40 ^{a,b}	40	1-yr	None	60	100	100
			5-yr	1%, ^a 4% ^c			
			Median survival	None			
Breast (female)	20 ^a	80	1-yr	None	80	80	80
			5-yr	22%, ^a 25%, ^c 24%, ^d 24% ^e			
			Median survival	18-24 mo ^e			
Colon/rectum	20 ^c	80	1-yr	None	80	80	80
			5-yr	6%, ^a 12.9%, ^c 13%, ^d 12.5% ^f			
			Median survival	3 yr ^f			
Pancreas	40 ^{b,c}	40	1-yr	None	80	100	80
			5-yr	1%, ^a 2.3% ^c			
			Median survival	None			
Prostate	40 ^{d,g}	60	1-yr	None	80	80	80
			5-yr	28%, ^a 28%, ^c 28% ^d			
			Median survival	None			
Liver/intrahepatic BD	20 ^c	60	1-yr	None	60	60	60
			5-yr	2%, ^a 2.8%, ^c 3% ^d			
			Median survival	None			
Non-Hodgkin lymphoma	0	20	1-yr	None	80	80	60
			5-yr	61.6% ^c			
			Median survival	10 yr ^b			
Urinary bladder	20 ^c	60	1-yr	None	60	60	60
			5-yr	15%, ^a 5.5%, ^c 5% ^d			
			Median survival	None			
Esophagus	20 ^c	60	1-yr	None	60	60	60
			5-yr	4%, ^a 3.8%, ^c 4% ^d			
			Median survival	None			
Brain and nervous system	40 ^{a,h}	20	1-yr	None	80	80	80
			5-yr	35.6% ^b			
			Median survival	Anaplastic astrocytoma (2-3 yr) ^h ; glioblastoma (14.6 mo) ^h			
Combined total (N = 50)	13	26	1-yr	0	36	39	37
			5-yr	26			
			Median survival	4			
Combined percentages	26	52	1-yr	0	72	78	74
			5-yr	52			
			Median survival	8			

NOTE. Data adapted.³⁷

Abbreviations: BD, bile duct; NSCLC, non-small-cell lung cancer.

^a American Cancer Society: www.cancer.org/cancer/index.

^b National Cancer Institute: www.cancer.gov/.

^c American Society of Clinical Oncology: www.cancer.net/cancer-types.

^d Up to Date: www.uptodate.com/contents/table-of-contents/patient-information.

^e Lung Cancer Alliance (ALCASE): www.lungcanceralliance.org/.

^f Susan G. Komen: www.komen.org/Default.aspx.

^g Fight Colorectal Cancer: <http://fightcolorectalcaner.org/>.

^h Pancreatic Cancer Action Network (PANCAN): www.pancan.org/.

Some will argue that giving patients such information over the Internet is somehow dangerous and unethical. We read that oncologists should not say “You have [insert number here]

months to live” because patients will take it literally, and no doctor knows for certain.²⁶ We counter that patients understand that if the average survival is 12 months, half will be above

and half below—not all can be above average, the Lake Wobegon effect²⁷—and that physician estimates are in fact accurate, if a little overestimated.²⁸ The current data suggest that patients are not hearing us, are not accepting the facts, or we are not telling them effectively—or all three—and that they are unable to get such information from the next source they will access, the Internet.

One way to increase prognostic awareness is for patients and their families to have access to truthful, helpful prognostic information, for those who want it. National societies of health professionals caring for patients with cancer have the responsibility to provide in their patient-oriented Web sites descriptive prognostic information that uses the technology of decision aides, which we know are effective.²⁹

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