

Impact of the Cost of Cancer Treatment: An Internet-Based Survey

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Abstract

Purpose: Despite considerable discussion in the medical literature and lay press regarding the increasing cost of cancer care, there is limited information available on the perceived impact of treatment costs on individual patients and their families.

Methods: To directly address this issue, patients with cancer who had participated in an Internet-based oncology decision-support program and agreed to receive information concerning potential future surveys were asked via e-mail to complete a questionnaire dealing with treatment-related medical expenses.

Results: Of 39,882 invitations sent to patients with cancers of the breast, colon, lung, and prostate, 1,767 (4.4%) were returned, which included a wide spectrum of disease, demographics, and annual incomes. Since diagnosis, 20% and 4% of

patients reported having spent out of pocket more than \$10,000 and more than \$50,000, respectively, on treatment and medical care. Overall, 19% of patients and 39% of individuals with a yearly income of less than \$40,000 reported the financial costs of treating their cancer had caused a "large amount of distress." Furthermore, although overall, 9% of patients stated they had decided "to not have a recommended cancer treatment because it was too expensive," this percentage increased to 25% for individuals with an income of less than \$40,000.

Conclusion: This survey suggests that a substantial proportion of patients and their families experience considerable distress associated with the cost of cancer care delivery. Furthermore, these costs affect the decision of patients with cancer to receive recommended treatment. This is a particularly serious issue for individuals with a modest annual income.

Introduction

Much has been written recently regarding the disquieting status of a rather dysfunctional system for the payment of health care services in the United States.¹⁻⁴ Funding for cancer-related services, particularly the costs associated with newer antineoplastic agents, are not immune from this general phenomenon.⁵⁻⁷

Although reports in the lay and medical literature have painted an appropriately grim picture of the current situation,⁸ it would be interesting to learn directly from patients with cancer and their families how well they are (or are not) coping with their personal situations as they attempt to navigate complex third-party payer rules, a variety of pretreatment approval procedures, and coverage strategies that require increasing copayments and deductibles. Are most individuals generally satisfied with their overall ability to pay for required cancer care? What is the perception of the level of financial support provided for such care by their third-party medical funding mechanism? Is there a difference in these perceptions on the basis of type of cancer?

To begin to address these potentially highly relevant personal and societal issues, a survey was conducted among patients with cancer who had previously agreed to participate in a novel Internet-based oncology decision-support program.⁹ Reported here are the results of the responses to this survey received from this patient population.

Methods

Individuals who had participated in the NexCura (Seattle, WA) oncology decision-support program⁹ and previously agreed to receive information on potential future surveys were contacted by e-mail regarding their willingness to complete a questionnaire dealing with treatment-related medical expenses. Patients

were specifically informed that any information they provided would be examined and reported only in the aggregate, and no individual identifiers would be provided to any researcher or other third party.

A total of 39,882 invitations to participate in this survey were sent via e-mail to patients with cancers of the breast, lung, prostate, and colon. These patients were registrants of the NexCura Cancer Profiler tools, which are available on a variety of Web sites, including those of the American Cancer Society and American Lung Association as well as www.cancerfacts.com and www.pdrhealth.com. Invitations were sent the week of May 22, 2008, and all data were collected between May 22, 2008, and May 29, 2008. All completed surveys received in this time period were included in this analysis.

All registrants of the NexCura Cancer Profiler tools meeting the following criteria were included: US resident, user of patient rather than professional tools, and opted to receive e-mail invitations for market research. Regarding the four different cancers, those invited to participate in the survey had registered in the system during the following time periods: prostate and colorectal cancers, between December 1, 2005, and March 1, 2008; breast cancer, between May 1, 2006, and May 1, 2007; and lung cancer, between December 1, 2005, and December 1, 2007.

In completing the survey, patients were asked to provide general information (eg, sex, age, diagnosis) as well as specific financial data, both relatively objective (eg, family income, out-of-pocket expenses) and highly subjective (eg, level of distress associated with costs). The questions are outlined in Tables 1, 2, 3, and 4. Survey respondents were provided with several possible responses for each requested item (no free-text answers were allowed). Patients were not required to answer all questions to have their responses included in this analysis. It is also impor-

Table 1. Demographics and Clinical Characteristics of Survey Respondents (N = 1,767)

Characteristic	Respondents (%)
Time since diagnosis	
< 6 months	3
6 months to 1 year	17
1 to 2 years	52
2 to 5 years	21
> 5 years	7
Sex	
Female	58
Male	42
Age, years	
< 40	4
40-49	18
50-59	36
60-69	29
70-79	11
> 80	2
Payment program	
Medicare	22
Medicaid	4
VA/military	6
HMO	25
Total annual family income, \$	
< 20,000	7
20,000 to < 40,000	15
40,000 to < 60,000	17
60,000 to < 80,000	16
80,000 to < 100,000	12
> 100,000	22
Prefer not to answer	10

Abbreviations: VA, Veteran's Administration; HMO, health maintenance organization.

tant to note that all information was provided by those surveyed (or their surrogate), and no effort was made to independently verify any of the submitted data, including both questions related to disease (eg, stage, length of time since diagnosis) and financial data.

Results

A total of 1,767 completed surveys were returned and were available for analysis. This represents a 4.4% overall response rate. Approximately two thirds of survey respondents stated they had "early-stage cancer"; 40% were older than age 60 years, 58% were female, and 25% belonged to a health maintenance organization. Although 7% reported an annual income of less than \$20,000, 22% declared an annual income of more than \$100,000. Survey findings are listed in Tables 1 to 5.

The major findings of this survey included: first, 12%, 4%, and 2% of respondents reported that since diagnosis, they had spent out of pocket between \$10,000 to less than \$25,000, \$25,000 to less than \$50,000, and \$50,000 to less than \$100,000, respectively, with another 2% stating they had spent

Table 2. Patient Estimation of Cost of Treatment

How much money would you estimate you have spent (out of pocket, not money spent by your insurance company) treating your cancer, including medications to help prevent recurrence? (\$)	% of Patients	
	In Past 12 Months	Since Initial Diagnosis
< 100	15	6
100 to < 500	18	10
500 to < 1,000	17	10
1,000 to < 2,500	18	17
2,500 to < 5,000	15	19
5,000 to < 10,000	10	18
10,000 to < 25,000	4	12
25,000 to < 50,000	1	4
50,000 to < 100,000	1	2
> 100,000	—	2

in excess of \$100,000; second, 16% of patients stated their own medical benefit plan had contributed less money than they had expected for cancer treatment; third, 19% of patients overall, 25% of individuals with cancers of the lung and colon, and 39% of families with a yearly income of less than \$40,000 noted the cost of cancer treatment had caused them a "large amount of distress"; and fourth, 9% of patients overall and 25% of individuals with a yearly income of less than \$40,000 stated that they had decided not to receive a recommended treatment because of cost.

Table 3. Patient and Family Reactions to Cost of Treatment

Question	% of Patients
How would you describe your reaction to the cost of treating cancer?	
Spent more money than I expected	34
Spent about what I expected	32
Spent less than I expected	33
How would you describe your reaction to how your medical benefits covered the cost of treating cancer?	
Contributed more money than I expected	36
Contributed about what I expected	44
Contributed less money than I expected	16
Has the financial cost of treating your cancer caused you or your family distress?	
No	46
Yes, a small amount	36
Yes, a large amount	19
When choosing a treatment course for your cancer, did you consider the cost of treatment?	
No, not at all	65
Yes, a little bit	23
Yes, a great deal	11
Did you decide not to have a recommended cancer treatment because it was too expensive?	
No	89
Yes	9
Do not know/not sure	2

Table 4. Clinical Characteristics and Financial Impact of Specific Cancers

Characteristic	% of Patients				
	Breast (n = 677)	Prostate (n = 427)	Colon (n = 284)	Lung (n = 369)	Overall (N = 1,767)
Stage					
Early	79	77	39	30	62
Late/recurrent	17	17	52	62	32
Time since diagnosis, years					
< 1	5	29	22	33	20
1 to < 2	68	45	39	40	52
> 2	27	26	38	28	28
Out-of-pocket expenses, \$					
Past 12 months					
< 500	32	48	24	22	
500 to < 1,000	20	17	14	14	
1,000 to < 2,500	18	14	24	20	
2,500 to < 5,000	14	12	15	18	
5,000 to < 10,000	10	7	11	13	
> 10,000	6	1	10	12	
Total					
< 500	14	24	13	15	
500 to < 1,000	10	15	7	8	
1,000 to < 2,500	16	22	13	15	
2,500 to < 5,000	20	18	19	18	
5,000 to < 10,000	21	10	21	19	
> 10,000	20	10	25	25	
Impact of treatment cost					
Spent more than I expected	40	18	40	38	
Spent what I expected	32	39	31	26	
Spent less than I expected	28	43	29	36	
Medical benefit plan					
Contributed more than I expected	36	32	38	40	
Contributed about what I expected	43	57	38	37	
Contributed less than I expected	19	8	19	18	
Financial stress caused by cost					
None	40	68	33	39	
Small amount	40	25	42	35	
Large amount	19	7	25	27	

An additional point of interest in the survey was the fact that the stated income (< \$40,000, \$40,000 to \$80,000, and

Table 5. Impact on the Basis of Reported Annual Family Income

Impact	% of Patients by Annual Income (\$)		
	< 40,000	40,000 to 80,000	> 80,000
Decided not to receive a recommended treatment because too expensive	25	11	5
Financial cost has caused a large amount of distress	39		
Spent more money than I expected to treat cancer	52		

> \$80,000 per year) seemed to have a rather pronounced impact on the likelihood an individual would decide not to receive a recommended treatment. Only 5% of patients with an annual income of more than \$80,000 made this declaration, in contrast with 25% of individuals with an annual income of less than \$40,000 per year. Finally, it is notable that patients with prostate cancer seemed to have the lowest risk of experiencing substantial total out-of-pocket expenses (20% paid more than \$5,000), compared with 41%, 46%, and 45% for individuals with breast, colon, and lung cancer, respectively.

Discussion

Before proceeding with a brief discussion of observations generated from this Internet-based questionnaire, it is essential to

first acknowledge the limitations of this effort. First, although this analysis includes responses dealing with the cost of cancer treatment from more than 1,500 patients, this total represents less than 5% of the population initially asked to consider participation in this exercise. However, this response rate is not inconsistent with other reports of Web-based surveys conducted in a variety of settings.¹⁰⁻¹³ It is also reasonable to inquire if the demographics of the patients who agreed to participate in this survey represented the spectrum of patients with malignant disease in the United States. Although it is not possible to provide a definitive answer to this question, it is noted that almost 25% of respondents were self-identified as belonging to an HMO or being insured by Medicare. Furthermore, a wide range of annual incomes was represented in the responding population, and more than 40% were more than 60 years of age.

Second, despite the increasing availability of the Internet in the United States among the general public, it remains a debatable point whether observations generated from a Web-based survey, no matter how many participants are included, can be generalized and considered to be representative of the opinions or views of all elements of US society.¹⁴ Third, although the survey was addressed to the patient, it is unknown who actually answered and submitted the responses. However, it is perhaps reasonable to argue that this is not a major issue, because it is likely that financial matters are often as much of a family concern as they are a concern of the individual patient. Finally, as previously noted, all objective data and subjective responses in this survey were provided by the patient (or his or her family), and no effort has been undertaken to independently validate any of this information (including actual diagnosis, stage of disease, and financial data).

Despite these valid concerns, several points should be noted that provide support for the potential relevance of the responses received from this surveyed population. First, in addition to the not insignificant total sample size, the overall demographic characteristics of this group seem to exhibit a reasonable cross-section of individuals diagnosed with one of the four included malignancies (breast, prostate, colon, lung). For example, the responders were not overly represented by patients with advanced or late-stage cancer (62% reported having early-stage cancer), and there was a wide spectrum of reported times since original diagnosis (52% reported between 1 and 2 years), ages, payment programs, and family incomes.

Second, it is reasonable to note one potential finding that was not observed in the overall responses, which may be viewed as providing an element of credibility to the relevance of the analysis. One might have hypothesized that patients and families agreeing to participate in such a survey and to subsequently submit personal data and opinions would constitute a particularly angry group of individuals as regards the cost of care, lack of payment by third-party medical carriers, or out-of-pocket expenses. Furthermore, they could have viewed this effort as a rational venue to safely (and anonymously) express this anger. However, what was actually seen in the survey was that overall, one third of respondents stated that they had personally spent

less and their medical plans had contributed more money than they had expected.

Despite these relatively favorable observations, it is concerning that fully one in five respondents stated that "the financial cost of treating the cancer has caused a large amount of distress," and approximately 10% of patients stated they had decided not to undergo a recommended cancer treatment "because it was too expensive," a proportion that increased to 25% of individuals with a yearly family income of less than \$40,000. Also, 20% of those who responded to the survey reported that their medical benefits provided less money than they had anticipated.

Perhaps even more ominous are the reported data reflecting individual tumor types, in which 25% of all patients with lung or colon cancer noted "a large amount of distress" related to cost. The relatively recent and rapid increase in the cost of antineoplastic therapy in these settings has been documented.⁵⁻⁷ Finally, it is important to note that this survey was conducted in May 2008, before the recent acceleration in the substantial downturn in the national economy. It is quite possible, perhaps even likely, that the serious concerns expressed by many respondents in this survey would be magnified, both in involvement of a larger percentage of the population and in the overall severity of self-reported distress, if this exercise were repeated today.

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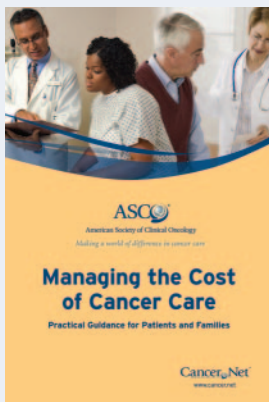
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