

# Patient attitudes about the cost of cancer care: Expectations and realities in the current health care climate

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## ABSTRACT

**Introduction:** Effective health care reform has been slow, in part due to patient expectations and demands. We solicited cancer patients and their friends or family about the cost of cancer care. **Materials and Methods:** Individual demographics, opinions about expenditures in curable and incurable settings, for strangers and who should primarily be responsible for costs were included. **Results:** A majority of respondents were female (57.9%), over 50 years old (74%) and Caucasian (81.5%). In a curable setting, 44.4% and 56.7% of respondents believed there should be no limit to the amount the individual or insurance should pay for 1 year of life, respectively. Respondents believed that less should be spent on care in an incurable setting. There were no differences between patients and family/friends ( $P = 0.95$ ), gender ( $P = 0.33$ ), age group ( $P = 0.94$ ) or ethnicity ( $P = 0.20$ ) with regards to spending for curable versus incurable scenarios. Non-Caucasians were significantly more likely to believe that more should be spent on themselves than strangers; 7.1% versus 2.0% ( $P = 0.03$ ). **Conclusions:** The amount that respondents believed should be spent on cancer care far exceeds sustainable health care spending in the United States. To contain health care costs, attitudes among patients, the public and policy makers must be understood aligned.

**Key words:** Cost effectiveness, cost of care, palliative care, patient attitudes

## INTRODUCTION

Health care costs are increasing at a rapid rate, projected to rise 5.7% annually from 2011 to 2021 and at this rate spending will reach 25% of the national gross domestic product by 2025.<sup>[1,2]</sup> This pace of spending is clearly unsustainable, though it continues even as public discourse grows louder and ostensibly more serious. The hazardous implications of this spending cannot be overstated, both from individual and national perspectives. Currently, medical bills are the most common reason cited for individuals declaring bankruptcy, even when a significant proportion of those patients have health insurance.<sup>[3]</sup> As wages are stagnant

or increasing only slowly on an annual basis, patients will become increasingly unable to pay for their health care, either directly or through insurance premiums, having profound impacts on access to care.<sup>[4-6]</sup>

On a macroeconomic level the impact of health care costs have profound consequences for the financial health of our country. Unabated, these costs either limit spending on other societal needs (such as defense, education and other governmental services) or raise our already sizeable national debt.<sup>[7-11]</sup> While the national will may support spending significantly more on health care as time goes on, current taxation or personal premium payments for health care do not meet current spending patterns.<sup>[12,13]</sup> While there are current efforts to mitigate the growth of health care spending (accountable care organizations, electronic medical records, individual insurance mandates, etc.), no demonstrable progress has been made.

There are, of course, barriers to cost containment. One is that policy makers and politicians are frequently unwilling to demand fewer services, or lower payment for such services,

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from providers, insurers and patients themselves.<sup>[14-16]</sup> This fact likely reflects the beliefs and culture of Americans, who may see limiting individual care as an infringement on personal rights.

On this individual patient level, attitudes on health care spending are not well-documented, particularly in cancer care. To better understand these attitudes, our research group constructed a survey to assess patient demographics and beliefs regarding health care costs, payer responsibility and the relationship of these beliefs to outcomes in cancer care.

## MATERIALS AND METHODS

A 20 question survey was constructed and approved by The University of Texas MD Anderson Institutional Review Board. The surveys were mailed to patients who were seen in the following clinics: melanoma, sarcoma, breast and liver, pancreas, colorectal, endocrine, gastrointestinal/gastric or other. Two surveys were included in each envelope mailed to the address on file. The survey did not explicitly ask about a respondent's education level, but was created for the reading level and understanding of a 8<sup>th</sup> grader in the United States.

The survey initially asked respondents about detailed individual demographic information, including whether a respondent was a patient or family member/friend, gender, age, ethnicity, combined household income and payer status (private insurance, Medicare/Medicaid, out-of-pocket or combination). Respondents were then asked whether those under 18 or over 65 years of age should receive more or less financial support, respectively, for their cancer care. The final nine questions asked respondents about specific scenarios and dollar amounts that should be spent for certain outcomes. These scenarios included spending for 1 year of life in a curable setting, 1 year of life in an incurable setting, 3 months of life in an incurable setting, the amount to be spent on the respondent, the amount to be spent on a stranger and the role of insurance versus out-of-pocket spending.

Statistical analysis was performed using SAS, version 9.3 (SAS, Cary, NC, USA). Chi-square methods were employed to test for association between categorical variables.

## RESULTS

A total of 335 surveys were returned, for an overall response rate of 34%. A majority of respondents were female (57.9%), over 50 years old (74%) and Caucasian (81.5%) [Table 1]. Over half of respondents had a household annual income of less than \$100,000, while fewer than 15% had a household income of greater than \$200,000.

**Table 1: Responses to survey by demographic**

Respondent characteristics	Number (%)
Respondent type	
Patient	237 (70.8)
Family member/friend	96 (28.7)
No response	2 (0.6)
Gender	
Male	140 (41.8)
Female	194 (57.9)
No response	1 (0.3)
Primary clinic	
Melanoma	61 (18.2)
Sarcoma	28 (8.4)
Breast	56 (16.7)
Liver	7 (2.1)
Pancreas	11 (3.3)
Colorectal	43 (12.8)
Endocrine	27 (8.1)
Gastrointestinal/gastric	60 (17.9)
Other/don't know	11 (3.3)
Multiple	21 (6.3)
No response	7 (2.1)
Age group	
18-34	24 (7.2)
35-50	60 (17.9)
51-65	152 (45.4)
Over 65	95 (28.3)
No response	4 (1.2)
Ethnicity	
African American	15 (4.5)
Caucasian	274 (81.5)
Asian	15 (4.5)
Latino/Hispanic	26 (7.8)
Other/mixed	2 (0.6)
No response	3 (0.9)
Combined household income	
\$0-49,999	74 (22.1)
\$50,000-99,999	111 (33.1)
\$100,000-199,999	85 (25.4)
\$200,000 or more	49 (14.6)
No response	16 (4.8)
How respondents pay for health care	
Medicare/Medicaid	33 (9.9)
Private insurance	165 (49.3)
Out of pocket/no insurance	5 (1.5)
Combination	131 (39.1)
No response	1 (0.3)
Should more money be spent on cancer care for patients under 18 (compared to patients over 18)?	
Yes	89 (26.6)
No	229 (68.4)
No response	13 (5.1)
Should less money be spent on cancer care for patients over 65 (compared to patients under 65)?	
Yes	35 (10.4)
No	287 (85.7)
No response	13 (3.9)
Is there an age at which we should spend less money for cancer care	
Yes	94 (28.1)
No	236 (70.4)
No response	5 (1.5)
If there is an age at which we should spend less on cancer care, what is that age*	
60	3 (3.2)
65	3 (3.2)
70	4 (4.3)
75	9 (9.6)
80	27 (28.7)
85	16 (17.0)
90	28 (29.8)

Contd...

**Table 1: Contd...**

Respondent characteristics	Number (%)
No response	4 (4.3)

Percentages may not equal 100.0% due to rounding. \*Percentage of people who responded yes to previous question

Nearly 26.6% of respondents believed society should spend more on cancer care for those under 18 years of age compared to those over 18. 10.4% of respondents believed that we should spend less on cancer care for those over 65 years of age compared to those under 65. Nearly 28.1% of respondents did believe there was an age at which society should start paying less for cancer care. Of respondents who believed an age limit was appropriate for lowered cancer care expenditure, the most common ages were 80 (28.7%), 85 (17.0%) and 90 (29.8%).

Given a scenario of curable disease, 44.4% and 56.7% of respondents believed there should be no limit to the amount the individual or insurance should pay for 1 additional year of life, respectively [Figure 1a]. If, in the same scenario, the patient was theoretically a stranger, there was no change in what respondents believed insurers should pay for 1 year of a strangers' life.

Respondents believed that less should be spent on care in an incurable setting. Still, large proportions of respondents replied there should be no limit for what individuals (29.5%) and insurers (44.3%) pay for cancer care in this scenario and this difference between individual and insurer expenditure was statistically significant ( $P < 0.001$ ) [Figure 1b]. Furthermore, there was no significant difference in what respondents believed insurers should pay to extend a stranger's (when compared with the respondent's life). To gain a theoretical 3 extra months of life in an incurable setting, respondents believed even less (compared to 1 year) should be spent by themselves and insurers; 27.5% and 37.9% believed there should be no limit, respectively [Figure 1c].

To understand whether attitudes about the cost of cancer care reflect respondent age, we stratified responses to the payment that was appropriate for 1 year of life in a curable or incurable setting [Figure 2a and b, respectively] by age groups: 18-50, 51-65 and over 65. For 1 year of life in a potentially curative setting, 64.7% of respondents aged 18-50 believed there should be no limit, in contrast to 51.6% of respondents over age 65 who believed the same. For 1 year of life in an incurable setting, this pattern continued, as 40.7% of those over 65 years of age and 48.8% of those aged 18-50 believed there should be no payment limit.

In assessing whether respondents generally believed that more should be spent on curable versus incurable

situations, responses were stratified by various respondent categories. For 1 year of life in a potentially curative setting, there were no differences between patient and family friend responses ( $P = 0.95$ ), gender ( $P = 0.33$ ), age group ( $P = 0.94$ ) or ethnicity ( $P = 0.20$ ) [Figure 3a-d]. However, patients with lower incomes tended to believe that a curable scenario did not warrant increased expenditure by insurance providers, whereas higher income respondents (annual household income  $> \$100,000$ ) believed more should be spent when a potentially curable therapy exists [ $P = 0.06$ , Figure 3e].

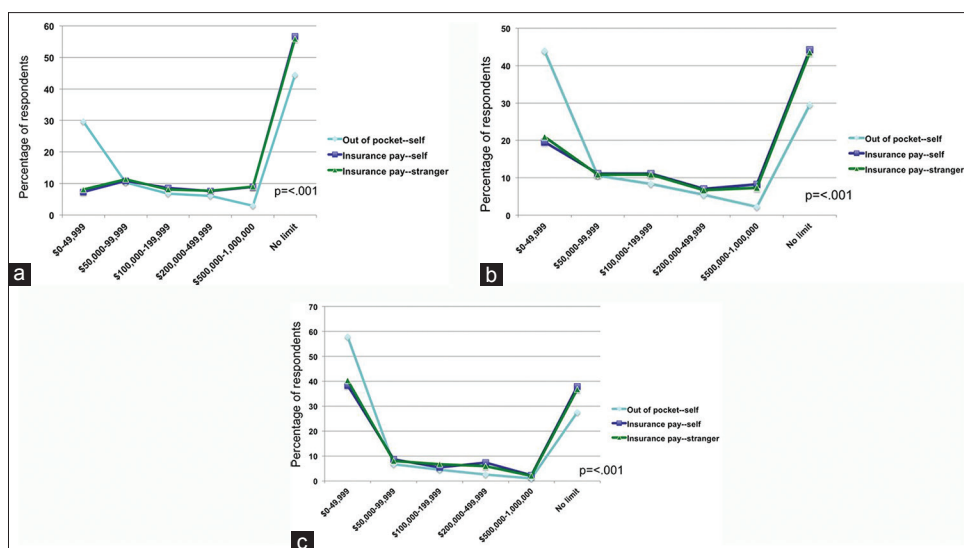
Finally, attitudes about the relationship between insurance payments and the patient being "self" or "stranger" were stratified by demographic [Table 2]. For 1 year of life in a curable scenario, there was no significant difference in opinions by survey respondent category (patient vs. family member/friend), gender, age or annual household income (range in  $P$  values from 0.47 to 0.86). However, non-Caucasians were significantly more likely to believe that more should be spent on themselves than for a stranger; 7.1% versus 2.0% ( $P = 0.03$ ).

## DISCUSSION

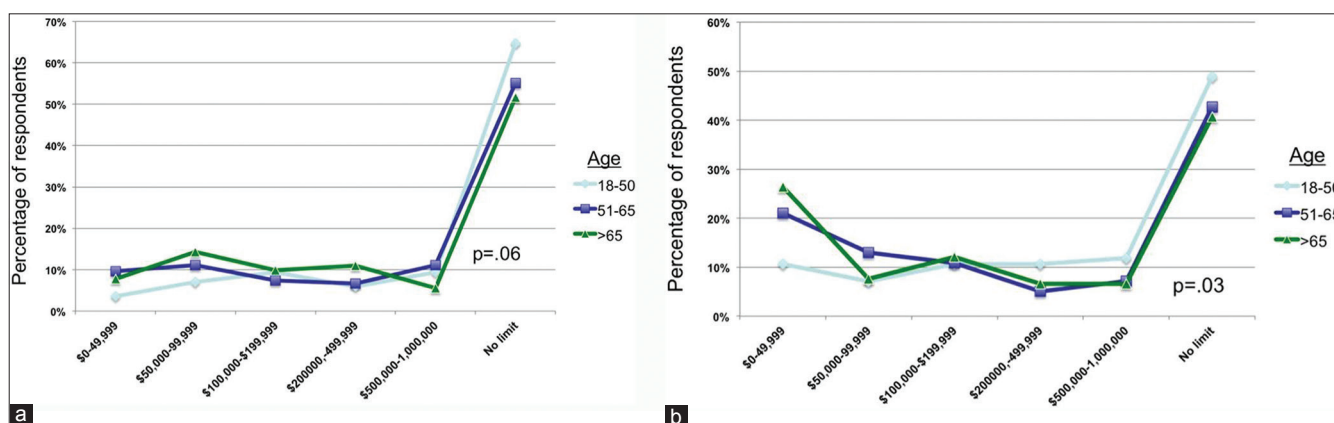
Our goal in conducting this survey of cancer patients and their family members or friends was to evaluate attitudes about the costs of cancer care, costs per perceived benefit (survival) and the responsibility of specific payers in cancer care delivery. Most strikingly, over 50% of respondents believed that there should be no limit to what insurance should pay for 1 year of life in a potentially curative situation and only slightly fewer respondents (44.4%) believed that to be true in an incurable setting.

These findings are troublesome, particularly when generally accepted cost per quality-adjusted life year in the United States is frequently quoted to be between \$50,000 and \$100,000 (though in reality this number may in fact be doubled).<sup>[17-19]</sup> While these numbers are not absolute, nor even recognized by payers, they are based on reimbursement to sustain real years of life on a historical basis (e.g. dialysis).<sup>[20]</sup> If the findings in this study were to be generalized, with over 50% of patients demanding limitless spending by insurers, we would be faced with a tremendous moral hazard – more money spent on "me" than can reasonably be spent on "all."<sup>[21,22]</sup>

It is possible that respondents recognize this conundrum and wish that more money should be spent on health care in general. That interpretation, however, is very unlikely, although we did not ask respondents the follow-up question of whether health care should be a larger portion of our national expenditure. Previous studies have demonstrated



**Figure 1:** Survey respondents' answers about how much individuals and insurers should pay for cancer care for themselves and others, for the following scenarios: (a) one year of life in a potentially curative scenario, (b) 1 year of life in an incurable setting and (c) three months of life in an incurable setting



**Figure 2:** Respondent opinion, by age group, regarding appropriate payment amounts for 1 year of life in an (a) curable and (b) incurable setting

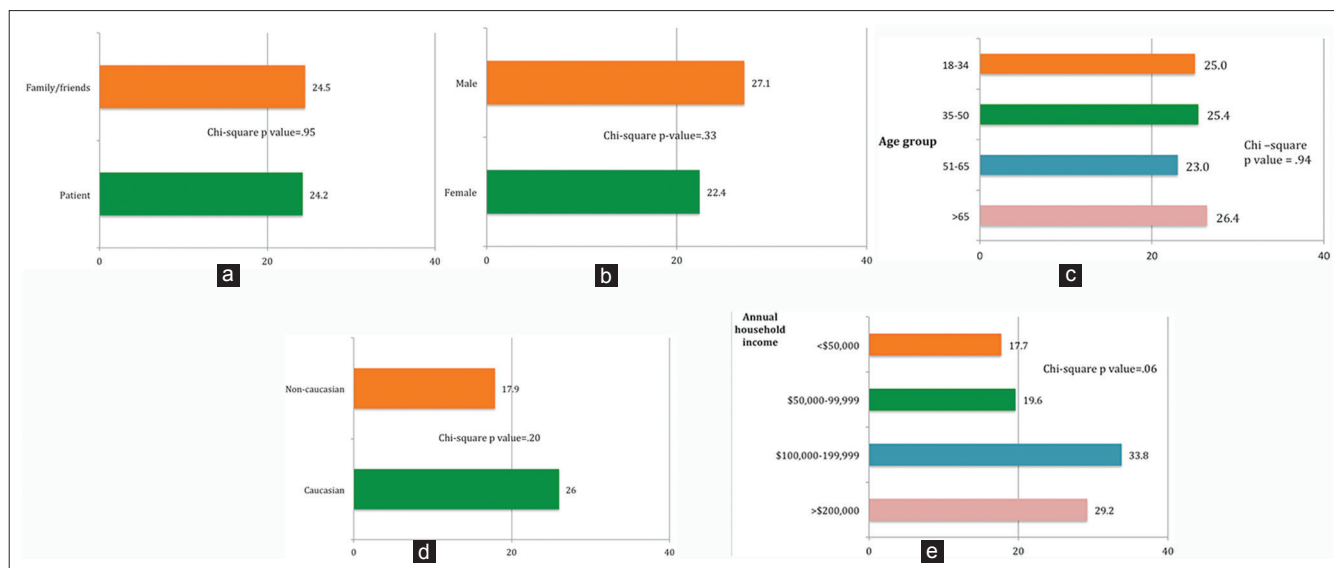
that, in fact, reducing the cost of health care services is the highest priority in reform, compared with other interventions such as lower prescription drug prices.<sup>[23]</sup>

Despite this purported interest in lowering health care costs, there are data that patients – both in the United States and Europe – do not necessarily feel they should bear the burden of those costs. For example, in a study of French cancer patients, when costs of home blood transfusions are shifted to patients, they are actually willing to pay only a nominal amount to receive their transfusion at home.<sup>[24]</sup> However, cancer patients in Europe are actually willing to pay higher premiums for higher quality cancer care, a notion that is also gaining traction in the United States.<sup>[25]</sup>

It is interesting that when asked directly whether a “stranger” should receive the same financial consideration as themselves, respondents routinely answered in the affirmative. This is in direct opposition to the answers given regarding how much insurers should pay for

health care, as unlimited amounts spent on “self” cannot translate into unlimited amounts spent on everyone else. Two possible explanations for this are (1) people, when asked directly about others, say that the same expenditures should apply even if they don’t believe it to be true, or (2) the public doesn’t understand pooled insurance and that cases of high reimbursement for expensive care cannot reasonably be applied to all people at current insurance premium/taxation levels. Either circumstance does not reflect positively on societal understanding and/or application of health care.

Two other interesting findings should be noted. First, lower income households (those with an annual income <\$100,000) were generally more likely to believe that more money should not be spent on a curable versus an incurable clinical situation. Perhaps a greater percentage of lower income individuals have a more fatalistic attitude toward cancer, or don’t understand the distinction between “curable” or “incurable”. Second, non-Caucasians were more likely to believe that more



**Figure 3:** Percentage of respondents who believed insurance should pay more for a curable situation, by demographic; (a) respondent type, (b) gender, (c) age, (d) ethnicity, (e) household annual income

**Table 2: Comparison of respondent beliefs, by demographic, relating how much insurance should pay for themselves versus a stranger (for 1 year of life in a curable setting)**

Demographic	Respondent type	Less than for stranger	Same as for a stranger	More than for a stranger	P value*
Survey respondent	Patient	0.5	96.3	3.2	0.47
	Family member/friend	1.1	96.7	2.2	
Gender	Female	0.0	97.3	2.8	0.58
	Male	1.6	95.3	3.1	
Age	18-34	0.0	100	0	0.58
	35-50	0.0	94.9	5.1	
	51-65	0.8	96.3	3.0	
	Over 65	1.1	96.7	2.2	
Ethnicity	Caucasian	0.8	97.2	2.0	0.03
	Non-Caucasian	0	92.9	7.1	
Annual household income	Under \$50,000	0	97.1	2.9	0.86
	\$50,000-99,999	1.0	97.1	1.9	
	\$100,000-199,999	0	96.3	3.8	
	Over \$200,000	2.2	93.5	4.4	

\*Cochran-Mantel-Haenszel test used to determine P value

should be spent on themselves rather than a stranger in a curable setting. While the absolute value of that response is low (7%), there may be cultural or ethnic differences that need to be better understood as we seek to modify health care costs.

Within survey responses are indications that there is a degree of public understanding or agreement on some realities of health care. Respondents believed that in both cases of self and insurance payment, less money should be spent on an incurable scenario than a potentially curable one. Furthermore, in absolute terms, respondents believed less should be spent (again, both by themselves and insurance) on 3 months of life versus 1 year of life in an incurable situation. These trends in responses do reflect some rational

thought in these clinical scenarios, although approximately 30-40% of people still believed there should be no limit in spending for 1 year of life in an incurable setting.

This study has limitations. As noted, some follow-up questions that might have clarified responses to particular questions were not asked as we attempted to keep the survey to a reasonable length without compromising thoroughness. Second, this survey was mailed and only about a third of envelopes were returned. Though this response rate is quite reasonable, self-selection (e.g. those who had the strongest opinions) may skew our results. Finally, the question of whether wealthier individuals should be entitled to higher health care expenditures was not specifically addressed. While some of our results were stratified by income, this notion is certainly a real possibility.

In summary, these findings highlight particular patient attitudes that cannot feasibly form the basis for public policy. We cannot have limitless spending on cancer care in general and especially in situations when the unfortunate reality is that mere months are the best extension of life that can be reasonably offered. Thus far, it has been easy to blame policy makers and politicians for health care fiscal irresponsibility, but at some point patients, loved ones and friends must be more realistic about how much we can afford to pay for care. Such a culture shift will be critical as we align cost containment, optimized outcomes and sustaining our health care infrastructure.

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