

Joanne Buzaglo, PhD, Kasey Dougherty, MA, Elynn Micco, MA,
Melissa Miller, PhD MPH, Janiah Sanford, BA, Mitch Golant, PhD

Cancer Support Community

Introduction

- Survival has increased among people diagnosed with cancer creating more demand for support against the backdrop of fewer resources and healthcare reform.
- Cancer care has a huge economic impact on families, yet many questions remain about the direct and indirect costs families incur during the course of care.
- Despite availability, many patients fail to access co-pay assistance programs, and previous research does not make clear *why* people do not utilize these programs.
- Genentech and the Cancer Support Community (CSC) engaged in a unique industry/community partnership to address the hidden costs of cancer and to investigate financial and psychosocial barriers to access.

Purpose

- To describe the hidden costs of cancer and to investigate financial and psychosocial barriers to access through interview, focus group and survey methodology
- To assess intrusive and avoidant ideation around managing the cost of cancer care
- To examine the relationship between symptoms of posttraumatic stress and the financial burden of cancer care
- To tell what it means to struggle with the cost of cancer through the "lived experience"

Survey Methods

- Survey development and qualitative data collection
 - Sixteen 1:1 interviews
 - Five focus groups (four in-person, one online)
 - One focus group — online support group facilitators
- Study design
 - Survey: Web-based and pen-and-paper
 - Cancer patients and caregivers of patients diagnosed over 6 months ago or had active treatment within 2 years
 - ≥ 18 years of age, confident reading and writing in English, and lived in the United States
 - Survey included the Revised Impact of Event Scale to assess intrusive and avoidant ideation around the cost of care

Results

Sample Characteristics

	Patient (n=83)	Caregiver (n=29)
Female	81	48
Race		
White	77	79
Black	11	10
Latino	6	3
Asian or PI	5	7
Unemployed	37	10
Retired	11	14
Income among employed < \$40K	17	37
Cancer diagnosis		
Breast	52	28
Prostate	1	7
Colorectal	8	3

Note: 77% of patients and 62% of caregivers completed the web-based version of the survey.

Emotional Impact of Managing the Cost of Care

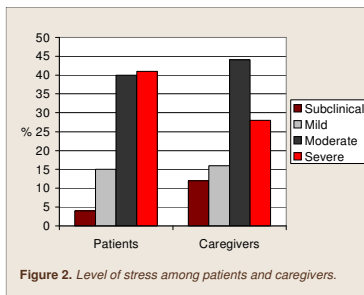


Figure 2. Level of stress among patients and caregivers.

Based on clinical cut-offs, 81% of patients and 72% of caregivers reported stress within moderate to severe levels. Patients reported high levels of intrusion (18.6 ± 9.2) and avoidance (19.9 ± 8.9). Caregiver levels were also high for intrusion (15.0 ± 10.0) and avoidance (17.8 ± 10.1).

Pharmaceutical Assistance Programs

- 47% of patients were not aware of pharmaceutical access or co-pay services.
 - ~33% used access program; 44% said they were difficult to use
- Barriers to use: assumption of not qualifying, fear of potential financial scrutiny, too overwhelmed, learned about it too late. Internet, patient advocacy groups and social workers were top ranked — over medical team — as best resources for accessing financial assistance information.
- 34% of patients and 47% of caregivers felt too overwhelmed to apply for financial help.

Impact of the Costs of Cancer Care

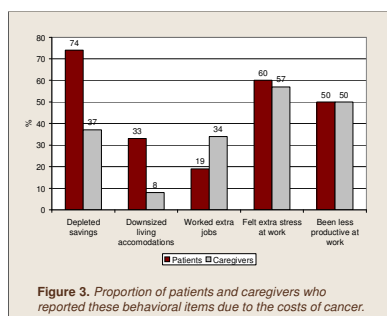


Figure 3. Proportion of patients and caregivers who reported these behavioral items due to the costs of cancer.

Results, cont.

Impact of Managing the Cost of Care Among Patients

- Increased intrusion correlated with having no one to help with insurance questions ($R=0.29$, $p=0.019$) and with delay in seeking psychological counseling or support ($R=0.32$, $p=0.007$).
- Increased avoidance was associated with delay in seeking psychological counseling or support ($R=0.49$, $p<0.001$) and less awareness of co-pay assistance ($R=0.22$, $p=0.070$).

Lived Experience



"It has greatly decreased the quality of my life. My relationship with my spouse is strained all the time, our daughter is only 10...I hate this entire process."

—Caregiver

"The cost of cancer care has led me into a deep, dark hole of depression. Not only has it drained my finances, but my family's as well. It's extremely difficult to maintain hope throughout treatment with the incredible financial burden."

—Patient

Conclusion

- Cancer care includes unexpected financial, emotional and psychosocial costs.
- Patients and caregivers managing cancer costs experience clinically significant stress levels.
- Managing costs of cancer can negatively impact patient and caregiver behavior.
- Patients and caregivers can harbor secret thoughts/feeling (guilt and shame) about cancer costs and related hardships.
- Being able to afford care is a persistent concern.
- Awareness of financial assistance is low; those aware are suspicious.
- Those with greatest need may not seek help, underscoring the need for programs that help families manage the stress related to the cost of care.

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The Hidden Costs of Cancer: Barriers to Accessing Financial Assistance

Joanne S. Buzaglo, PhD, Kasey R. Dougherty, BA, Ellyn Micco, MS, Melissa Miller, PhD and Mitch Golant, PhD

Many questions remain about the direct and indirect costs to families incurred during the course of cancer care. Despite availability, many patients fail to access co-pay assistance programs. The Cancer Support Community and Genentech piloted a national survey investigating psychosocial barriers to accessing co-pay assistance and the hidden costs of care.

Methods: Cancer patients (n=79) diagnosed over 6 months ago or had active treatment within 2 years and caregivers (n=29) of patients who met the above criteria, completed a survey that included the Revised Impact of Event Scale to assess intrusive and avoidant ideation around the cost of care.

Results: Respondents (N=108) were ethnically diverse; 25% patients and 18% caregivers had household incomes less than \$20 K. Patients reported high levels of intrusion (18.5±9.2) and avoidance (20.2±8.8). Caregiver levels were also high for intrusion (15.0±10.0) and avoidance (17.8±10.1). Based on clinical cut-offs, 82% reported stress within moderate to severe levels. Due to care costs, 74% patients depleted savings, 44% downsized living accommodations; 32% caregivers worked extra jobs to help pay for care, 60% reported extra stress at work. To reduce costs, 49% patients delayed seeking psychological counseling. Among patients, increased intrusion correlated with having no one to help with insurance questions (p<.0001). Increased avoidance was associated with delay in seeking psychological counseling (p<.0001) and less awareness of co-pay assistance (p<.0001). 33% patients and 40% caregivers felt too overwhelmed to apply for financial help.

Discussion: These data suggest that managing cancer costs is associated with clinically significant stress levels. Those with greatest need may not seek help, underscoring the need for programs that help families manage the stress related to the cost of care.