



Provider–patient communication about cost of care: Results from a national patient education program

Ivy Ahmed, MPH, MCHES, Allison Harvey, MPH, CHES, Marni Amsellem, PhD, Cancer Support Community;
Thomas J Smith MD, FASCO, Sidney Kimmel Comprehensive Cancer Center of Johns Hopkins Medicine



Background

A 2010 NIH study indicates direct cancer care expenditures will reach \$158 billion in the U.S. by 2020, impacting millions of Americans. The cost of insurance for a family of four has increased from \$6,000 (2000) to over \$16,000 (2011). Medical debt is a significant cause of personal bankruptcy, even if insured. The financial realities posed by costs associated with cancer care greatly complicate a cancer diagnosis. The most recent American College of Physicians Ethics Manual recommends all parties must interact honestly, openly, and fairly.¹ This analysis explores the patient-provider communication surrounding costs associated with care in a national survey of those affected by cancer.

¹ Snyder L, et al. Ann Int Med 2012, p86

Objectives

- To explore the occurrence and value of patient-provider communication about costs associated with care in a national survey of those affected by cancer
- To understand how those affected by cancer attending a workshop about the costs of cancer care are affected by these costs and seek information about these costs

Frankly Speaking About Cancer: Coping with the Cost of Care

This program, launched in 2009, is part of the *Frankly Speaking About Cancer* (FSAC) series of programs developed by Cancer Support Community (CSC). FSAC programs provide in-depth coverage of topics of relevance to those affected by cancer, guided by the Patient Empowerment concept, that are often not otherwise available in a comprehensive format. FSAC materials, representing the most up-to-date content, include:

- Web-based materials
- Booklets
- Internet radio show
- Professionally-led workshops held across the country

Methods

Participants:

- Attendees of 62 CSC *FSAC: Coping with the Cost of Care* workshops, held nationwide throughout 2011-12
- Data obtained from 518 attendees who completed survey (71.3% of workshop attendees)
- All attendees eligible to complete survey

Measures:

- In addition to demographics and cancer history, respondents provided information about:
 - Emotional distress as a result of the cost of their care
 - Level of knowledge of issues related to cost of care, pre- and post-workshop
 - Communication about cost of care with health care team
 - Information sources for covering cost of care

Respondent Characteristics

n=518

Average Age= 56.9 years
Gender: 77.3% female

Race/ Ethnicity

- 80.8% Caucasian
- 8.7% African American
- 5.2% Latino

Attendee Type:

- 61.9% diagnosed with cancer
- 12.0% Spouses/ partners
- 16.6% Other family/ friends
- 9.5% Health care professionals

Cancer-related characteristics

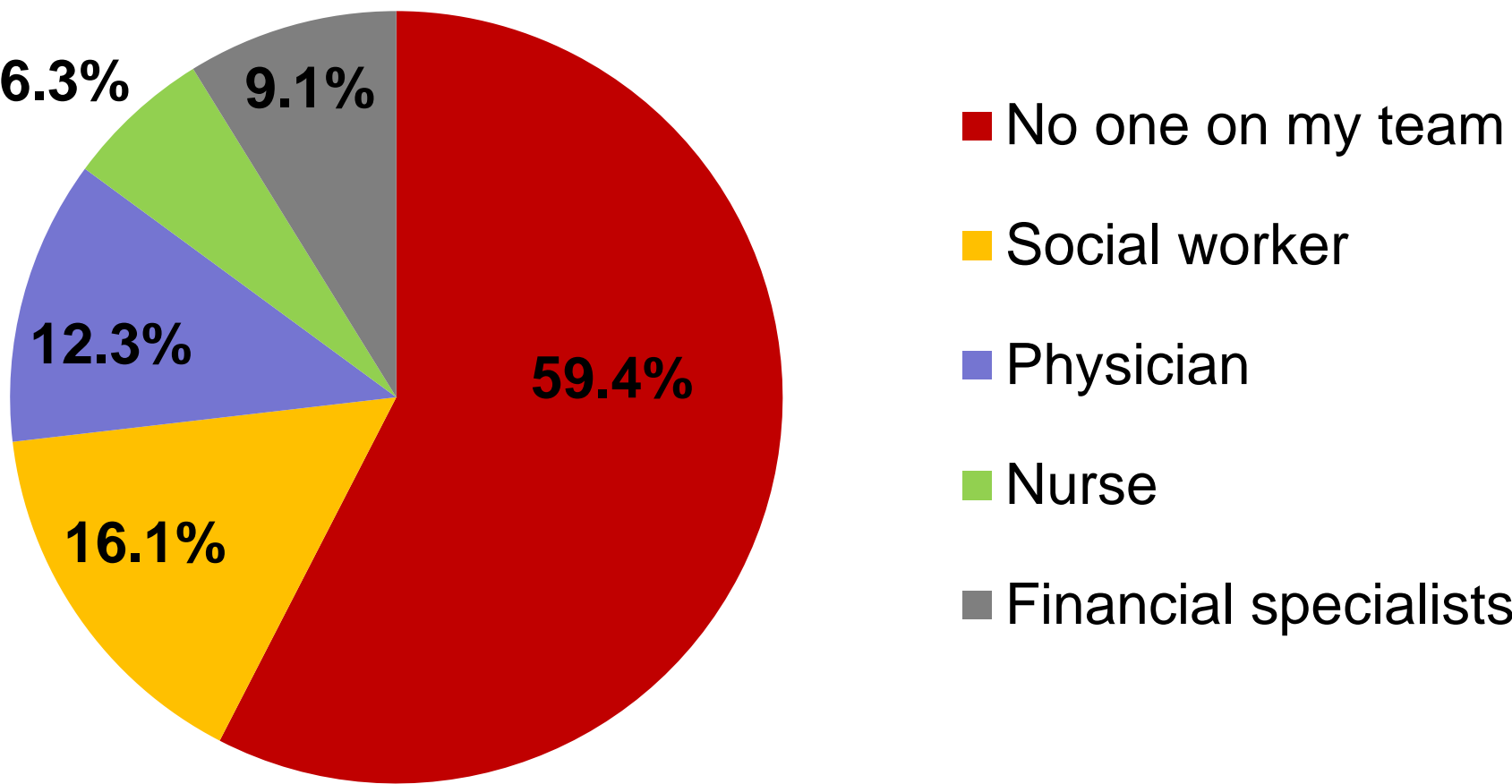
- 44.5% diagnosed had breast cancer
- 33.6% received cancer diagnosis within past year
- 26.2% received cancer diagnosis 5+ years ago

- 90.2% had health insurance at diagnosis
- 40.1% experienced a change in insurance status since diagnosis. Of those:
 - 10.0% were uninsured
 - Majority had switched insurance policies

- 17.9% reported their largest monthly co-pay was \$500 or more
- 35.7% had applied for disability insurance
- 59.5% had not applied for any co-pay assistance

Communication about Cost

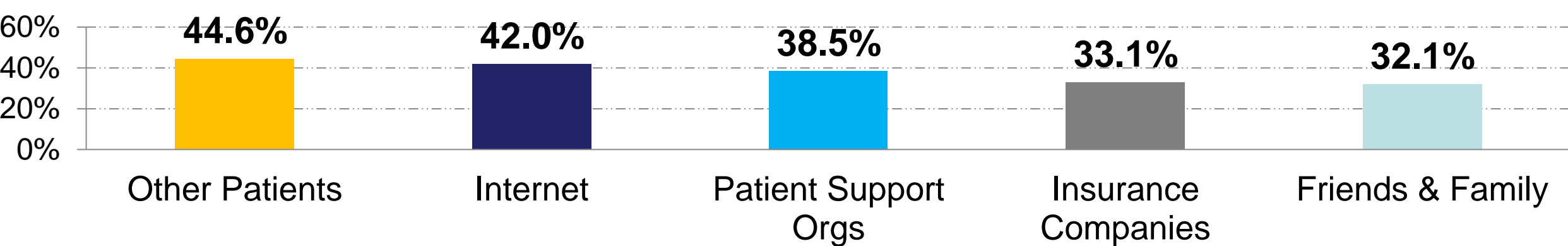
Who on your health care team has raised issue of finances with you?



- 59.4% reported that health care team **did not** initiate discussion about financial aspects of care
- Of this majority, 22.7% actively sought information from health care team, and 36.7% received no information about cost at all
- When topic was initiated by health care team, it was initiated by social workers (16.1%), physicians (12.3%), nurses (6.3%) or financial specialists (9.1%)
- When information was provided by health care team, 46.2% found it somewhat or very useful
- Most participants (74.0%) reported the intention to discuss financial aspects of their care with health care team based on what they learned from the workshop

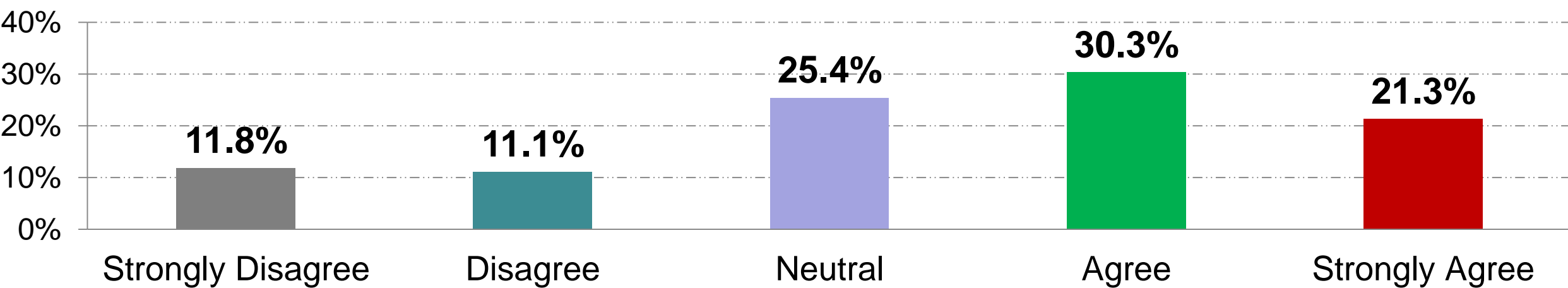
Informational Sources about Cost of Care

Regardless of communication with providers, respondents independently sought information for managing costs from:



Distress Associated with Cost of Care

I have experienced distress as a result of the cost of my cancer care



- Over half of respondents (51.6%) experienced distress due to the cost of care
- Emotional distress was positively associated with highest monthly copay ($F= 3.3, p < .01$) and being uninsured at diagnosis ($t=2.0, p < .05$)
- Whether or not a provider spoke about cost and the perceived usefulness of this information was not significantly associated with emotional distress

Summary

- Most patients reported that their medical team did not raise the issue of cost, despite the fact that over half reported distress due to cost of care
- Data highlights a common gap in communication between providers and patients when it comes to discussing cost and sharing relevant information
- These data highlight the need and value of providers **initiating** a dialogue about the cost of cancer care with patients. Because of this divide CSC recommends:
 - Providers raise issues of cost with patients and caregivers. Sample questions might be: “Do you have concerns about the cost of your care?”; “Do you have the ability to pay for your cancer care?”
 - Health care team provides information about resources that can assist with these questions
 - Those impacted by cancer attend workshops such as *FSAC: Coping with the Cost of Care* that will inform participants, and better enable them to ask relevant questions of their health care team

For More Information Contact CSC: 1-888-793-9355, www.cancersupportcommunity.org

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Background: A 2010 NIH study indicates direct cancer care expenditures will reach \$158 billion in the U.S. by 2020, impacting millions of Americans. The cost of insurance for a family of 4 has increased from \$6000 (2000) to over \$16,000 (2011). Medical debt is a significant cause of personal bankruptcy, even if insured. The financial realities posed by costs associated with cancer care greatly complicate a cancer diagnosis. The most recent American College of Physicians Ethics Manual recommends all parties must interact honestly, openly, and fairly. (Snyder L, et al. *Ann Int Med* 2012, p86) This analysis explores the occurrence and value of patient-provider communication surrounding costs associated with care in a national survey of those affected by cancer.

Methods: From 2011-12, 505 individuals attending *Frankly Speaking About Cancer: Coping with the Cost of Care* workshops completed a survey assessing experiences about the costs of cancer care. This is a Cancer Support Community national evidence-based educational program. All attendees (n=708) were eligible to complete survey.

Results: Most attendees (71.3%) responded. The majority (62.4%) were people with cancer/survivors; the remainder included spouses/partners, family members, and 8.7% were health care professionals. Most (80.8%) were Caucasian, and averaged 57.2 years. Of those with cancer, 89.9% were insured at diagnosis. 59.4% reported no one on their health care team initiated a discussion about the financial aspects of their care. Included in this figure, 22.7% actively sought information from health care team, and 36.7% received no information about cost. When topic was initiated, it was by social workers (16.2%), physicians (12.3%), nurses (6.3%) or financial specialists (8.2%). When information was provided, 72.1% found it somewhat or very useful. Also, regardless of provider discussion, respondents independently sought resources for managing costs, such as other patients (44.2%), the Internet (41.5%), and patient support organizations (38.1%).

Conclusions: Patients want financial information but do not receive it. These data highlight the need and value of providers initiating a dialogue about the cost of cancer care with patients.