



A four year review of the financial burden of cancer care: Results from a national education program

The financial realities posed by costs associated with cancer care often greatly complicate a cancer diagnosis. According to a 2010 NIH study, direct cancer care expenditures are expected to reach \$158 billion in the U.S. by 2020, significantly impacting millions of Americans. Medical debt is also a significant cause of personal bankruptcy in the U.S., even if insured. To help address this rapidly growing issue, the Cancer Support Community developed *Frankly Speaking About Cancer: Coping with the Cost of Care* in 2009. This evidence-based program combines free professionally-led workshops, educational booklet, and online content to help those affected by a cancer diagnosis.

Since 2009, the Cancer Support Community has surveyed *Frankly Speaking About Cancer: Coping with the Cost of Care* workshop attendees nationwide to continue to explore the impact of the cost of cancer care. All workshop attendees were eligible to complete the survey. To date, 964 attendees (64.6% response rate) have reported their experiences. The survey includes items on an individual's experience with the cost of cancer care as well as relevant medical and demographic information. The majority of respondents (63.9%) were people with cancer/survivors, with the remainder being spouses, family, and friends involved with their care. Nearly all (91.1%) had health insurance at diagnosis, though 33.8% reported a change in insurance status since diagnosis. Most (79.2%) were Caucasian, and the average age was 57.0 years.

The majority of respondents (58.8%) reported experiencing a significant degree of emotional distress due to cost of care. Respondents indicated a variety of unforeseen expenses, including deductibles (43.2%), co-pays for both pharmaceuticals (39.0%) and office visits (35.9%), treatment-related parking and/or transportation (36.4%), and emotional support (19.1%). Nearly one-third (31.8%) had applied for disability insurance to help with expenses, including employer-related disability (21.1%), social security disability (36.0%), and private disability (2.3%). Most (68.5%) reported their highest prescription co-pay in a month was over \$100; and 14.1% paid over \$500 in a month. In spite of these expenses and the sense of financial burden, most (82.8%) had *not* applied for co-pay assistance.

Given the national context, these data further highlight the financial burdens and emotional distress experienced by individuals coping with the costs of cancer care for patients and caregivers. Findings suggest the need for continued education on navigating all aspects of the cost of cancer care, including increasing awareness of relevant financial support options.

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I, Allison Harvey, have no financial relationship(s) to disclose.

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Cancer Support Community Mission

To ensure that all people impacted by cancer are:

- Empowered by Knowledge
- Strengthened by Action
- Sustained by Community

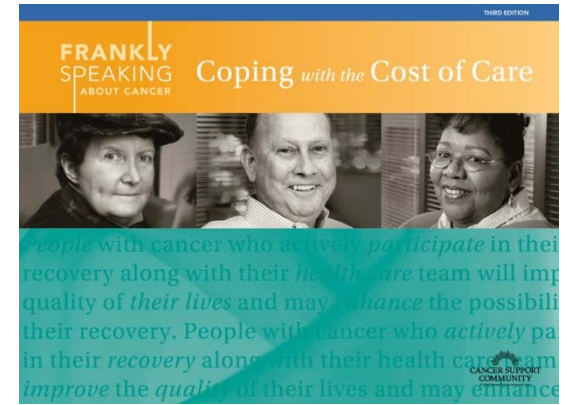


Costs Associated with Care

- Financial realities can greatly complicate a cancer diagnosis
- Direct cancer care expenditures expected to reach \$158 billion in U.S. by 2020
- Medical debt is also a significant cause of personal bankruptcy in U.S., even if insured

Cancer Support Community Responds

- 2009 CSC created *Frankly Speaking About Cancer: Coping with the Cost of Care* Program.
- Guided by Patient Empowerment Model educational program includes:
 - print book
 - professionally-led education workshop
 - online content
- Developed and promoted in partnership with:
 - Association of Oncology Social Work
 - Cancer Legal Resource Center
 - Lance Armstrong Foundation
 - National Coalition for Cancer Survivorship
 - Patient Advocate Foundation
 - Survivorship A-Z



Program Goals

- Provide health care policy and financial information on cancer and related health care costs in easy-to-understand terms.
- Clarify relevant legal rights of people living with cancer and those of caregivers.
- Provide up-to-date resource listing of patient assistance programs and other cancer support services.
- Empower people affected by cancer to ask important questions to employers, insurance companies, legal professionals, and health care providers.

Post-workshop Evaluation

- From 2009-2012:
 - 84 workshops provided
 - 1,522 attendees
- 964 attendees completed optional 27 item paper & pencil evaluation (response rate=63.3%)
- Goals of evaluation was to measure if program provided:
 - meaningful and up-to-date information
 - tools to empower patients and caregivers to take an active role in their healthcare management
- Evaluation also collected data on the impact of the cost of cancer care

Respondent Characteristics

- N= 964
- Average age= 57.0 years (s.d. = 12.2 yrs)
- Race/ Ethnicity:
 - Caucasian (79.2%)
 - African-American (9.5%)
 - Hispanic (5.5%)
 - Asian (3.4%)
- Type of Attendee:
 - people diagnosed with cancer (63.9%)
 - spouses/partners (12.4%)
 - other family members (10.0%)
 - health care professionals (3.8%)



Respondents with Cancer

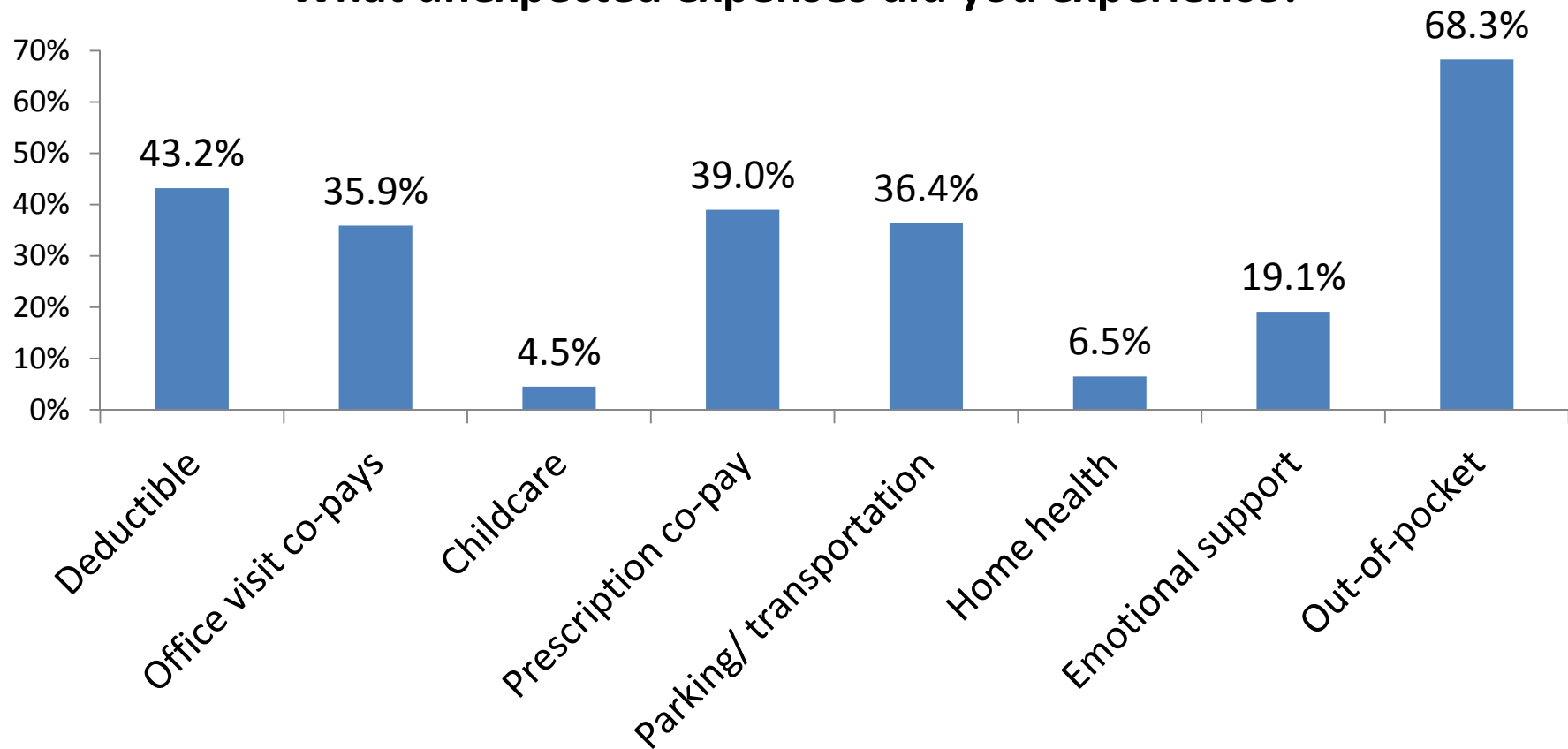
- 47.3% had been diagnosed with breast cancer
- 35.0% diagnosed in the past year
- 25.0% diagnosed in the past 2-5 years
- 91.1% had health insurance at diagnosis
- 36.4% experienced a change in insurance status since diagnosis

Insurance, Co-pay Assistance, Disability

- Nearly one-third (32.8%) had applied for disability insurance:
 - employer-related disability (21.1%)
 - social security disability (36.0%)
 - private disability (2.3%)
- Most (68.5%) reported highest prescription co-pay/ month was \$100+
- Only 17.2% had applied for co-pay assistance

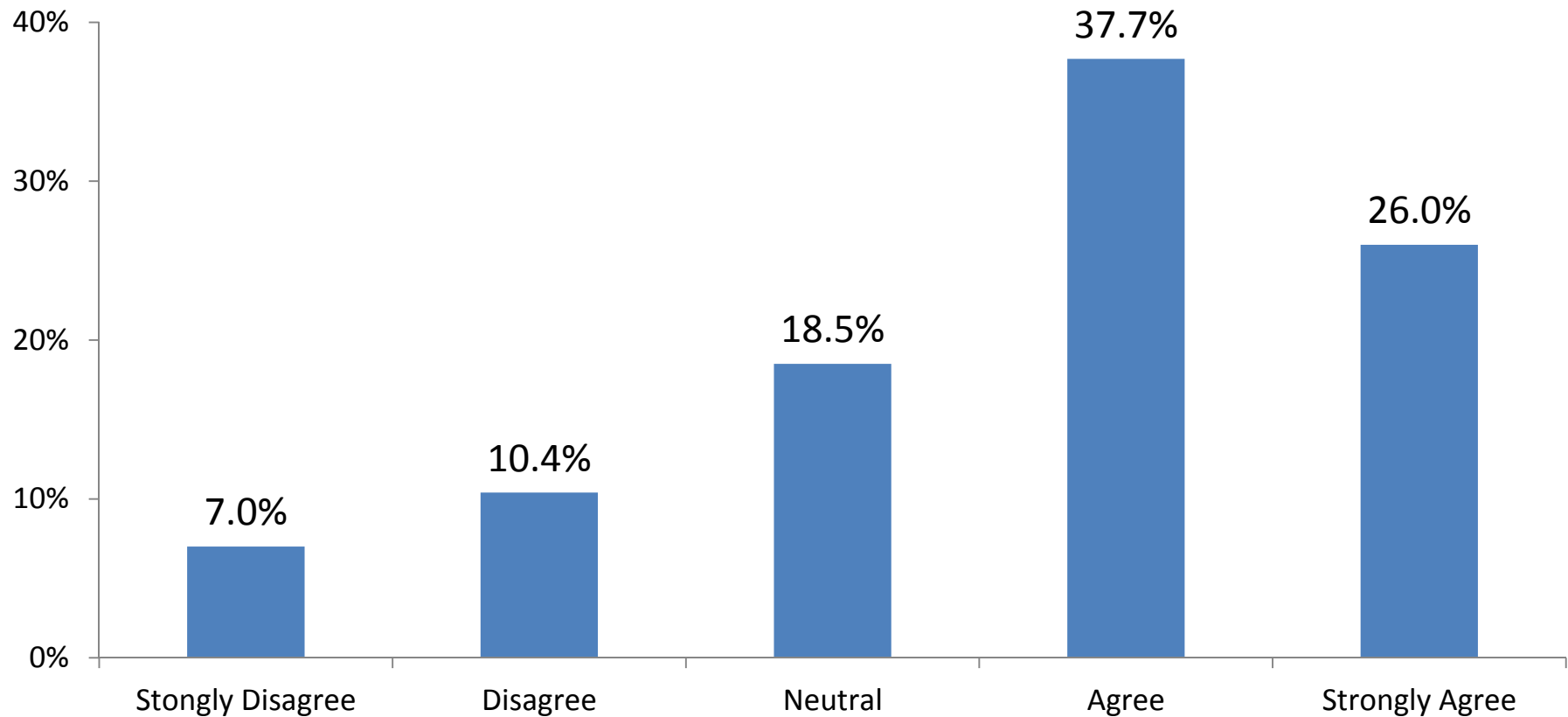
Unexpected Expenses

What unexpected expenses did you experience?



Emotional Distress

I have experienced emotional distress as a result of cost of care



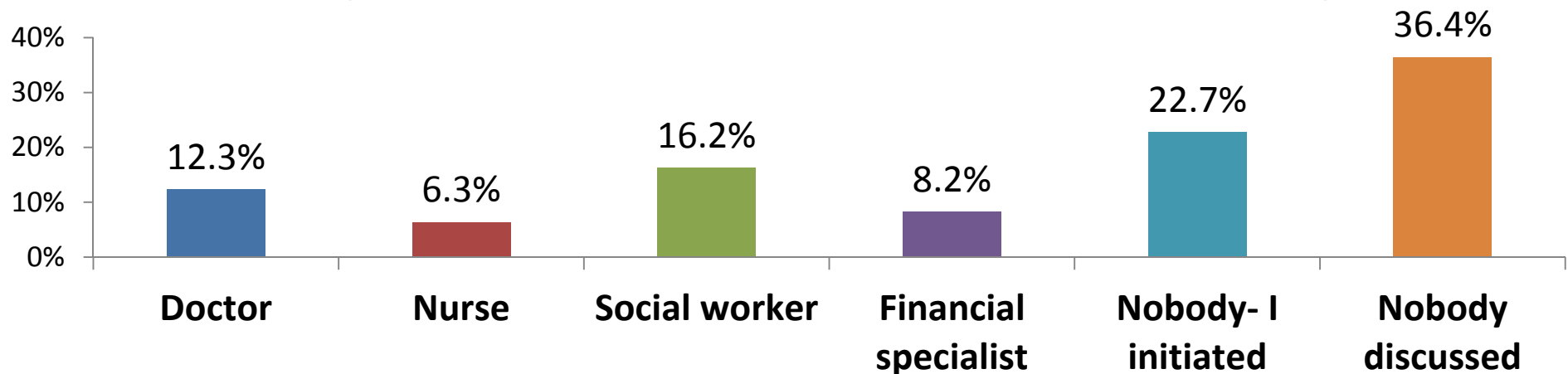
Factors Associated with Emotional Distress

Those reporting more emotional distress over the cost of cancer care:

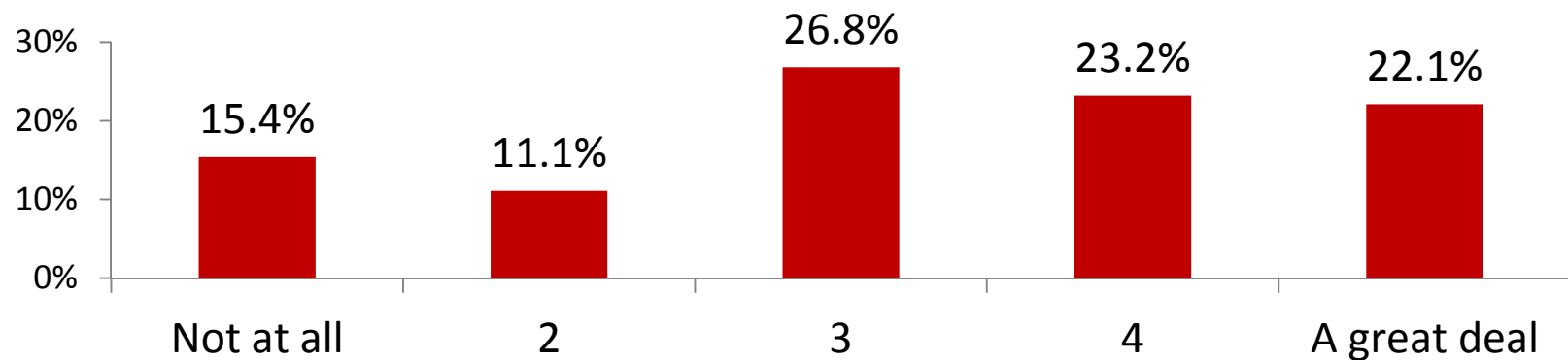
- Reported higher monthly copays ($\chi^2= 25.4, p<.01$)
- Were more likely to have applied for disability assistance ($\chi^2= 7.8, p<.05$)
- Were more likely to have experienced change in insurance status than those who did not have a change in status ($\chi^2= 8.6, p<.01$)

Rating Information Received

Who on your healthcare team discussed cost of care with you?

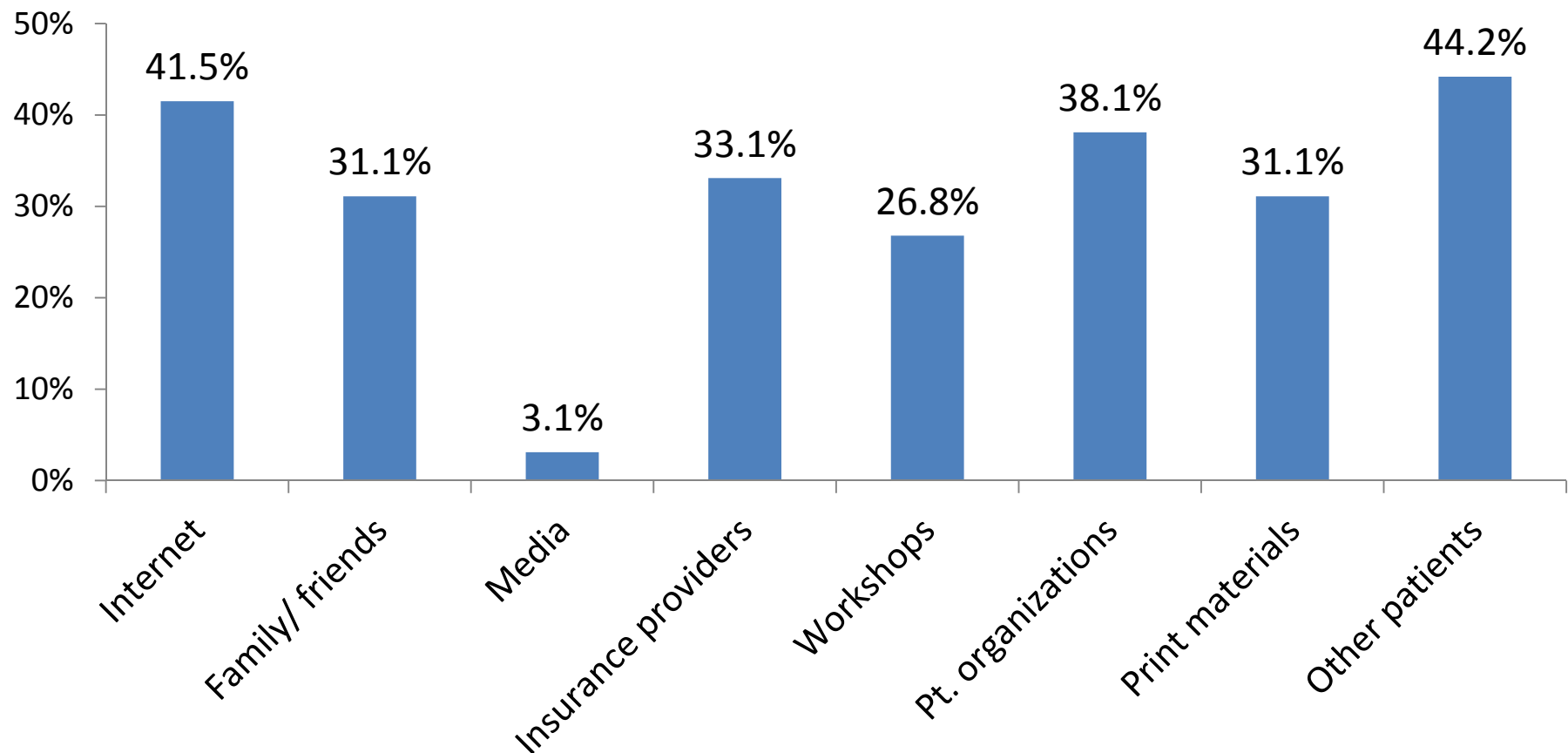


How helpful was this information that you received?

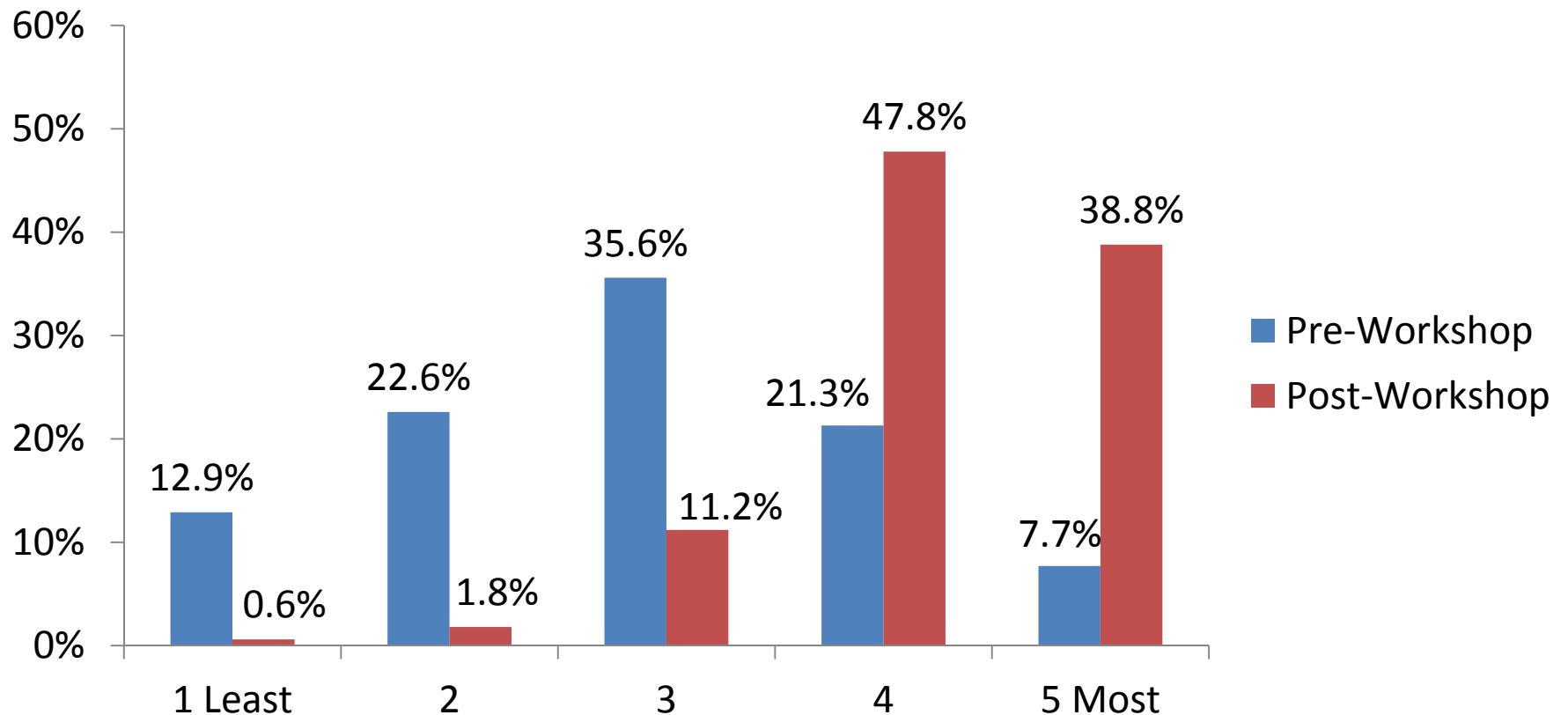


Obtaining Information Elsewhere

Sources of Information of Cost of Care



Workshop Outcomes



- Participants reported significant gains in knowledge after attending the workshop ($p < .01$).

Workshop Outcomes

After attending the workshop, most respondents “agreed” or “strongly agreed” that they:

- Feel a greater sense of control over dealing with and managing the cost of cancer care (78.9%)
- Plan to discuss financial issues related to my cancer care with my health care team (71.5%)
- Recommend the workshop (96%) and booklet (95.5%) to others facing the cost of care of cancer

Limitations

- Self-reported data
- Self-selecting sample
- Limited by number of items therefore unable to control for a variety of factors
- No additional follow-up after workshop

Conclusions

- Data further highlight the financial burdens in national context and emotional distress experienced by those coping with the costs of cancer care
- Findings suggest need for continued education on navigating all aspects of cost of cancer care, including awareness of relevant financial support options
- Workshop effective in:
 - Increasing knowledge about cost of care
 - Empowering the participant to address cost of care needs
 - Giving the participant a greater sense of control

For More Information



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