



**Coping with the Cost of Cancer Care:  
Findings from a National Evidence-Based Educational Program**

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# Presenter Disclosure

I, Liliana Zigo, have no financial relationship(s) to disclose.

# 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 Cancer 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

# The Hidden Costs of Cancer Care

- Evidence suggests that patients and caregivers managing cancer costs experience clinically significant stress levels
- Managing costs of cancer can negatively affect treatment outcomes and reduce quality of life
- Communication with the healthcare team and awareness of financial assistance is low

# Frankly Speaking About Cancer: Coping with the Cost of Care

- CSC created the *Frankly Speaking About Cancer: Coping with the Cost of Care* program.
- Guided by Patient Empowerment Model educational program includes:
  - Print book & booklet
  - Professionally-led education workshop
  - Online content



# Program Goals

- Provide financial information on cancer and related health care costs in easy-to-understand terms
- 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 Survey

- In 2017:
  - 166 cancer patients and caregivers attended FSAC Cost of Care workshops provided at CSC affiliates across the country and 147 attendees completed an optional workshop evaluation survey
- Goals of workshop evaluation survey:
  - Collect information on the experiences related to the financial impact of cancer
  - Assess how participants meet their informational and assistance needs in regard to cost of care
  - Assess satisfaction with workshop and whether the workshop is associated with positive gains



# Study Objectives

1. Explain the need for patient support materials and programs to address the critical gap in communication between cancer patients and providers around managing the cost of cancer care
2. Highlight the importance of providing meaningful information that can help patients and caregivers regain some control and formulate a plan for how to best deal with the financial aspects of care

# Respondent Characteristics

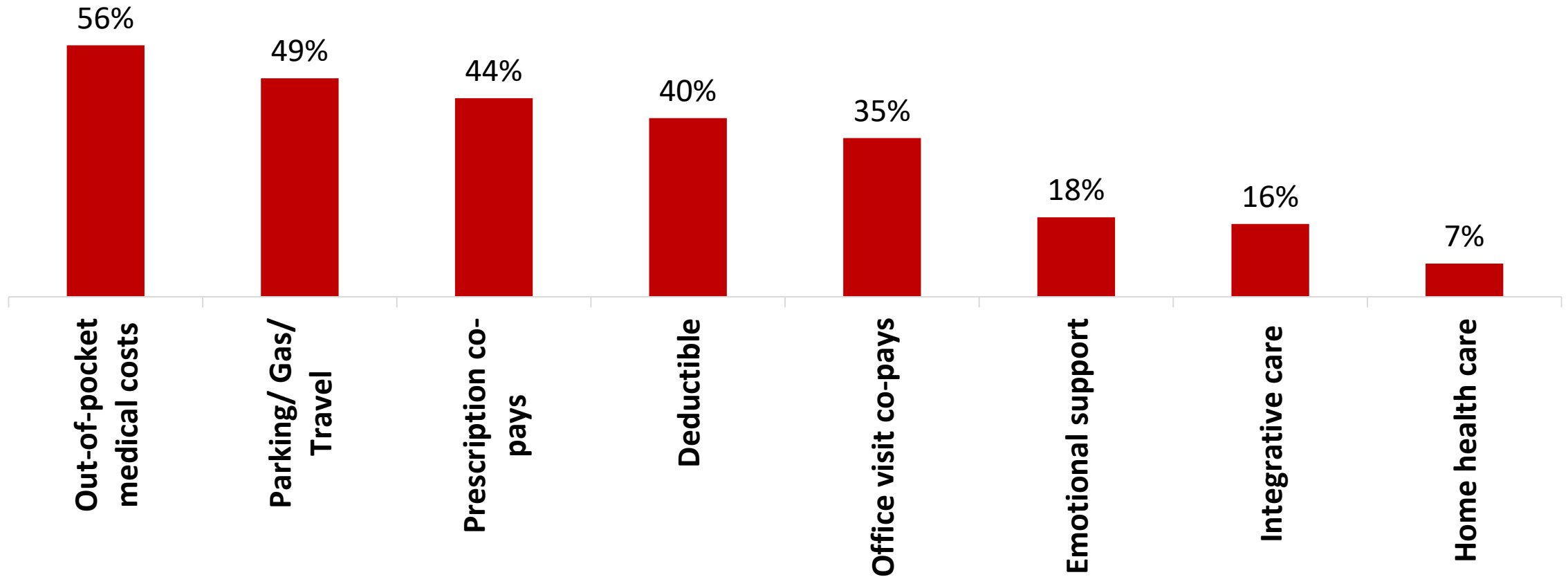
- Total number of respondents (N= 144)
- Average age= 68 years old (s.d. = 10 yrs)
- Race/ Ethnicity: Caucasian (66%)/African-American (18%)/Asian (9%)/Hispanic (4%)
- Type of Attendee: **People diagnosed with cancer (55%)**/ Spouses and partners (22%)/Other family members (21%)/ Friend (2%)

# Respondents with Cancer

- 40% had been diagnosed with breast cancer
- 31% diagnosed within the past two years
- 69% diagnosed in the past 3-5 years
- 92% had health insurance at diagnosis at the time of diagnosis
- 33% experienced a change in insurance status since diagnosis mainly due to changes in employment or insurance policies

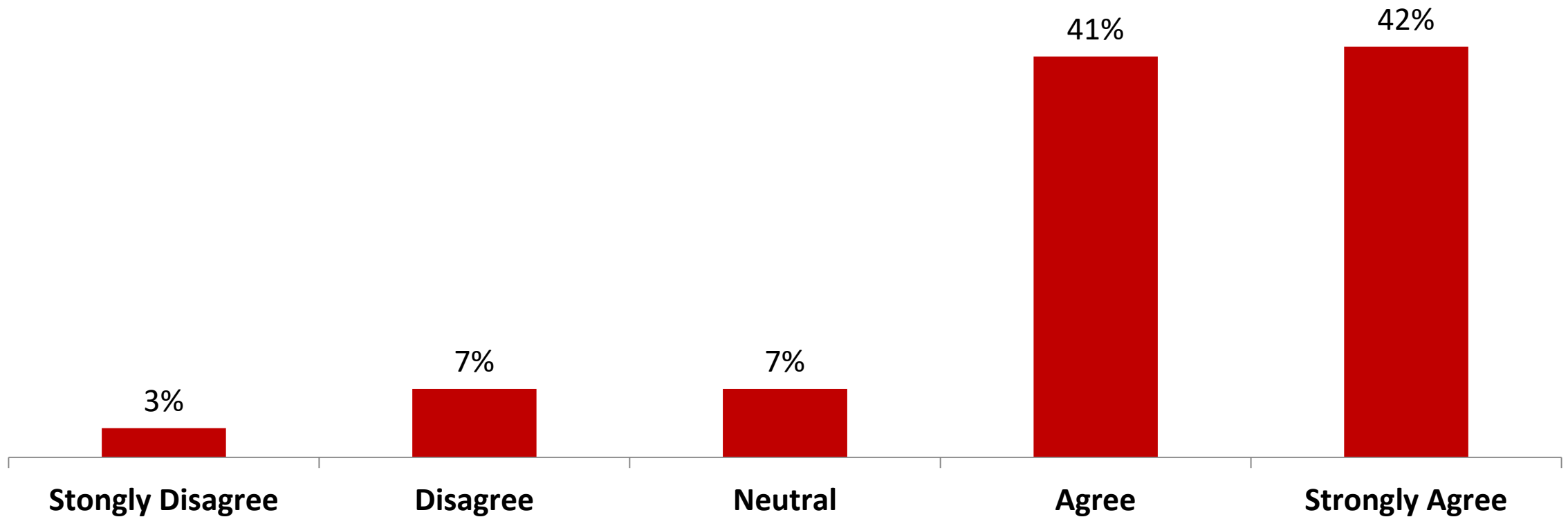
# Unexpected Expenses

What unexpected expenses did you experience?



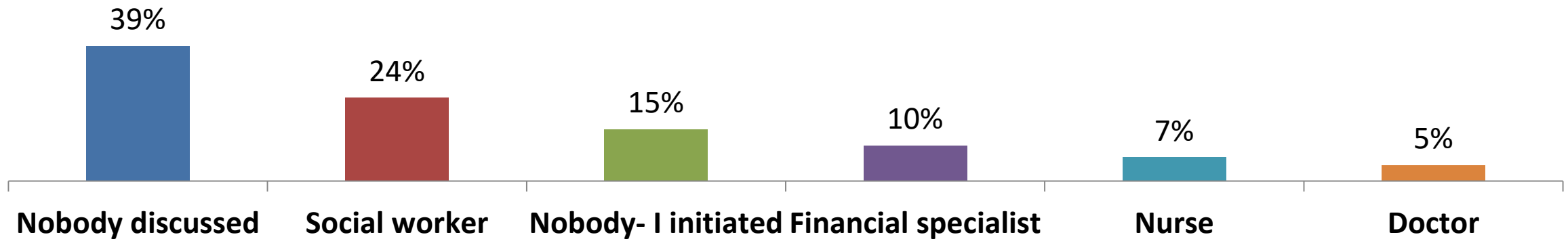
# Emotional Distress

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

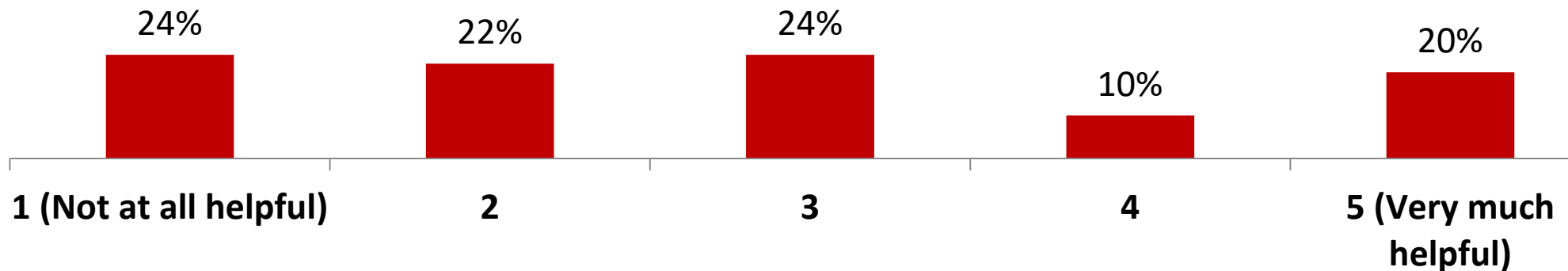


# Communication with Healthcare Team

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

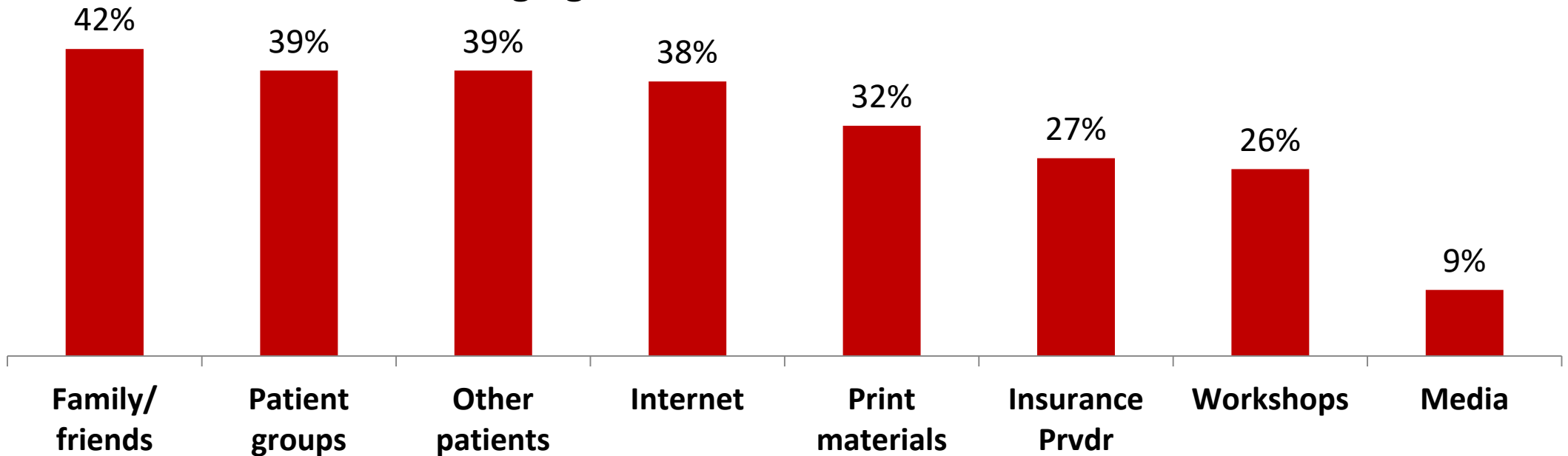


How helpful was this information that you received?



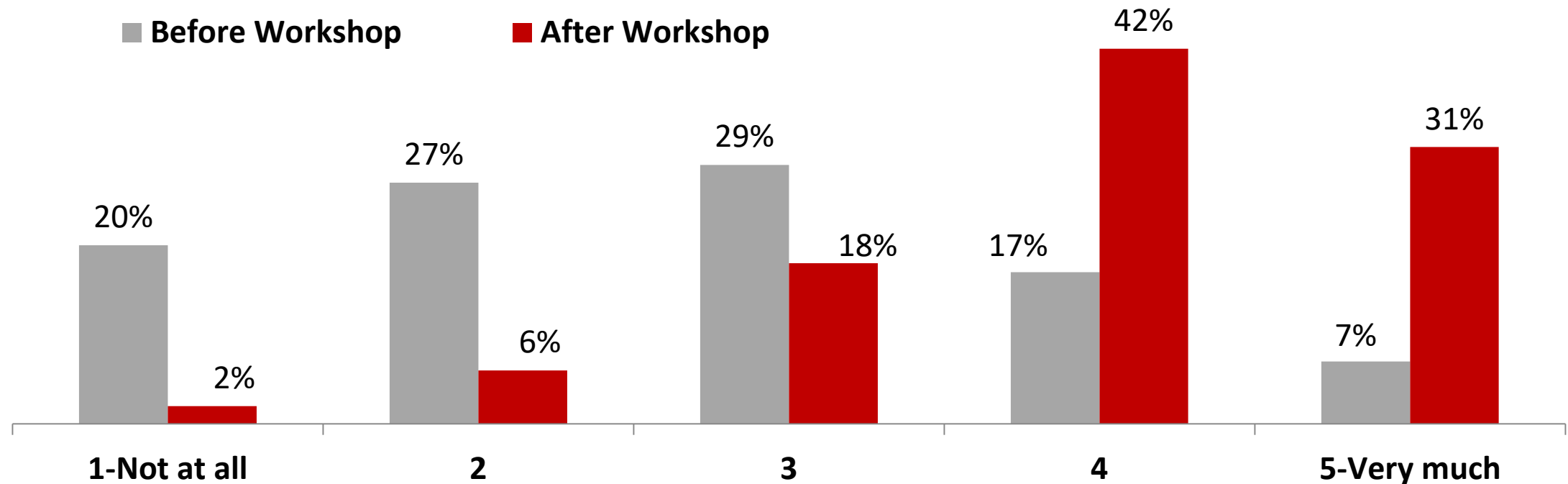
# Seeking Information about Cost of Care

Other than your health care team, where do you seek information about managing the cost of cancer care?



# Workshop Outcomes

How knowledgeable were you about the cost of cancer care BEFORE/AFTER this workshop?



Participants reported significant gains in knowledge after attending the workshop ( $p < .05$ )



# Workshop Outcomes

After attending the *FSAC: Coping with the Cost of Care* 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 (87%)
- Plan to discuss financial issues related to their cancer care with their health care team (88%)
- Would recommend the workshop and booklet to others facing cancer (97%)

# Limitations of this study

- Self-reported data
- Self-selecting sample
- No additional follow-up after workshop

# Conclusions

- Data further highlight the financial burdens and emotional distress associated with coping with the cost 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 over cost of cancer care

# For More Information



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