

Breast Cancer Patient Distress Associated with Difficulties Navigating the Costs Associated with Care: Results from a National Education Program



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Abstract

Compounding the stressors related with a diagnosis of breast cancer can be the associated direct and indirect costs of cancer care. To address this need, the Cancer Support Community (CSC) in 2009 developed an evidence-based, professionally-led national education workshop for cancer patients and caregivers entitled *Frankly Speaking About Cancer: Coping with the Cost of Care*. As part of this workshop, participants completed a survey describing their experiences coping with the cost of cancer care. Responses from 105 women diagnosed with breast cancer were included in this analysis.

Most attendees (72.8%) reported experiencing some degree of emotional distress from trying to manage cancer care costs, and nearly one-third of attendees (30.1%) reported significant distress. Most (64.8%) reported that their healthcare team did *not* discuss financial aspects of care with them. Not surprisingly then, attendees reported they have looked elsewhere for information about managing the costs of care, such as patient support organizations (40.2%), the Internet (43.5%), and other patients (41.3%).

A positive to arise from the workshop is that most participants (69.9%) reported the intention to discuss financial aspects of their care with their healthcare team based on what they had learned from the workshop. Intention to have this discussion with their healthcare team was both positively correlated with having experienced emotional distress about the cost of their care ($r = .29, p < .05$) as well as negatively correlated with their level of pre-workshop knowledge about financial issues in breast cancer care ($r = -.28, p < .05$). Taken together, these data highlight significant obstacles that individuals face in receiving meaningful information relevant to managing the costs associated with breast cancer care.

Objectives

- Understand how women with breast cancer learn about costs associated with cancer care and how this information is communicated to them by the healthcare team
- Evaluate whether patient education and empowerment program bridges information gap

Methods

- Participants:
- Survey participants attended the CSC workshop: *Frankly Speaking About Cancer: Coping with the Cost of Care*
 - Though participants represented a wide variety of cancer diagnoses, half of cancer patients attending were affected by breast cancer. No significant differences between breast cancer and other cancers patients was found.
 - Of the 465 workshop participants including cancer patients, caregivers, and others (representing 46 workshops, nationwide), 105 women had breast cancer. Analyses are based on this subgroup.

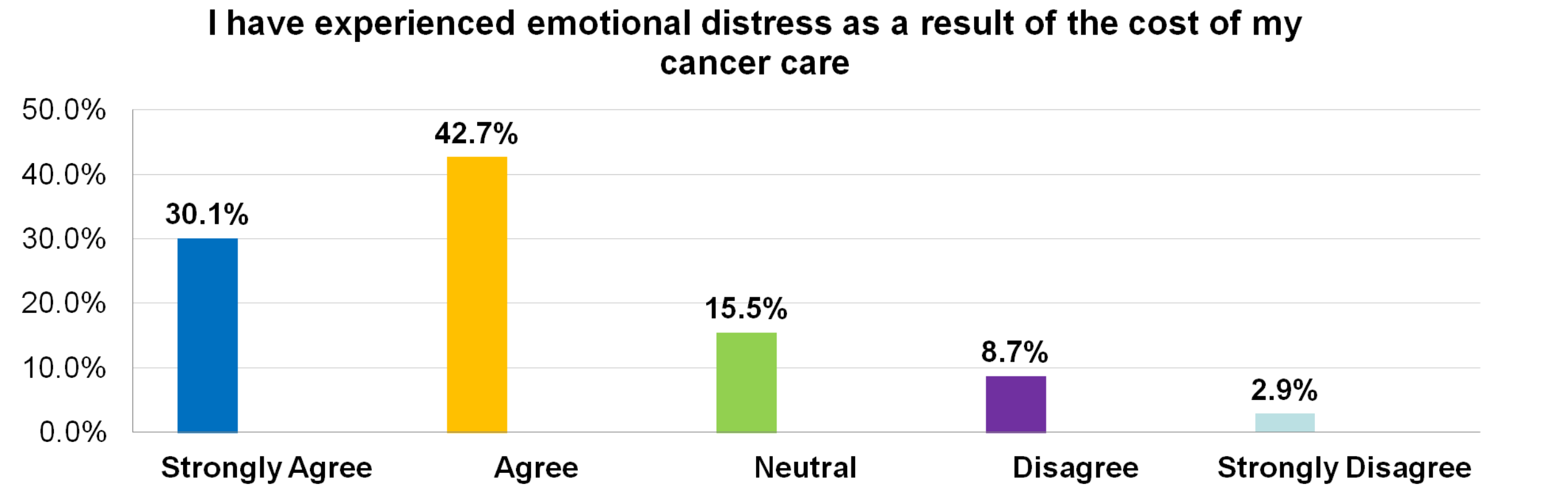
- Measures:
- In addition to demographics and cancer history, women provided information about:
 - Emotional distress as a result of the cost of their care
 - Level of knowledge of issues related to cost of care, pre- and post-workshop
 - Communication about cost of care by healthcare team
 - Information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

Participant Characteristics (n=105)

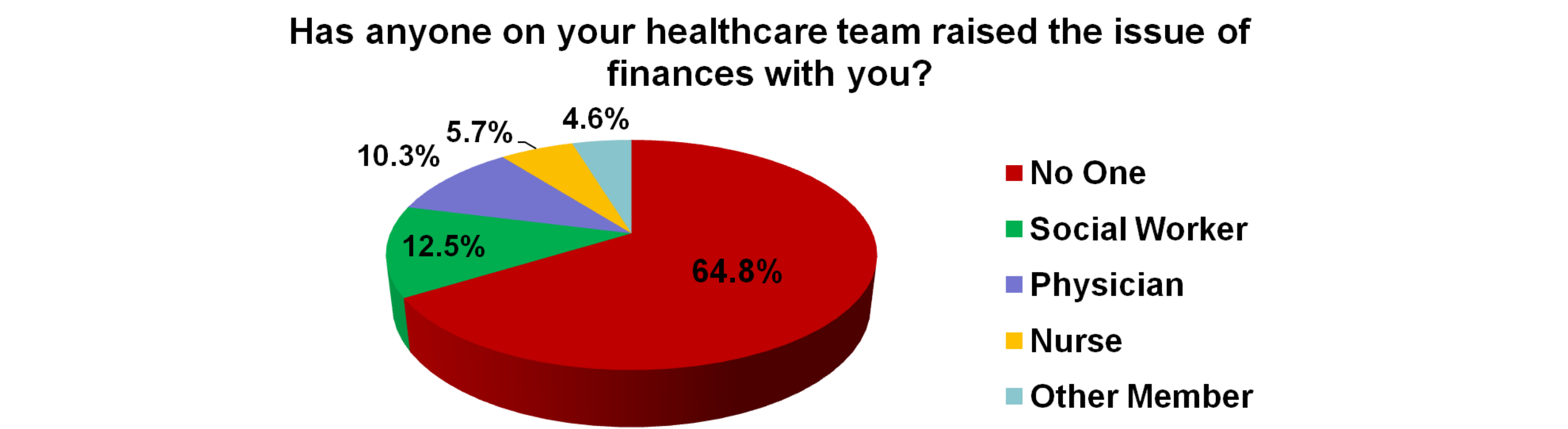
- Race/Ethnicity
- 74.0%** Caucasian
 - 13.5%** Black
 - 1.9%** Latino
- 91.3%** had health insurance at diagnosis
- 34.4% had experienced a change in insurance status since diagnosis
 - 7.7% were currently uninsured
 - Majority had switched insurance policies

Distress Associated with Cost of Care

- 72.8% reported experiencing some degree of emotional distress from trying to manage breast cancer care costs
- Nearly one-third of attendees (30.1%) reported significant distress



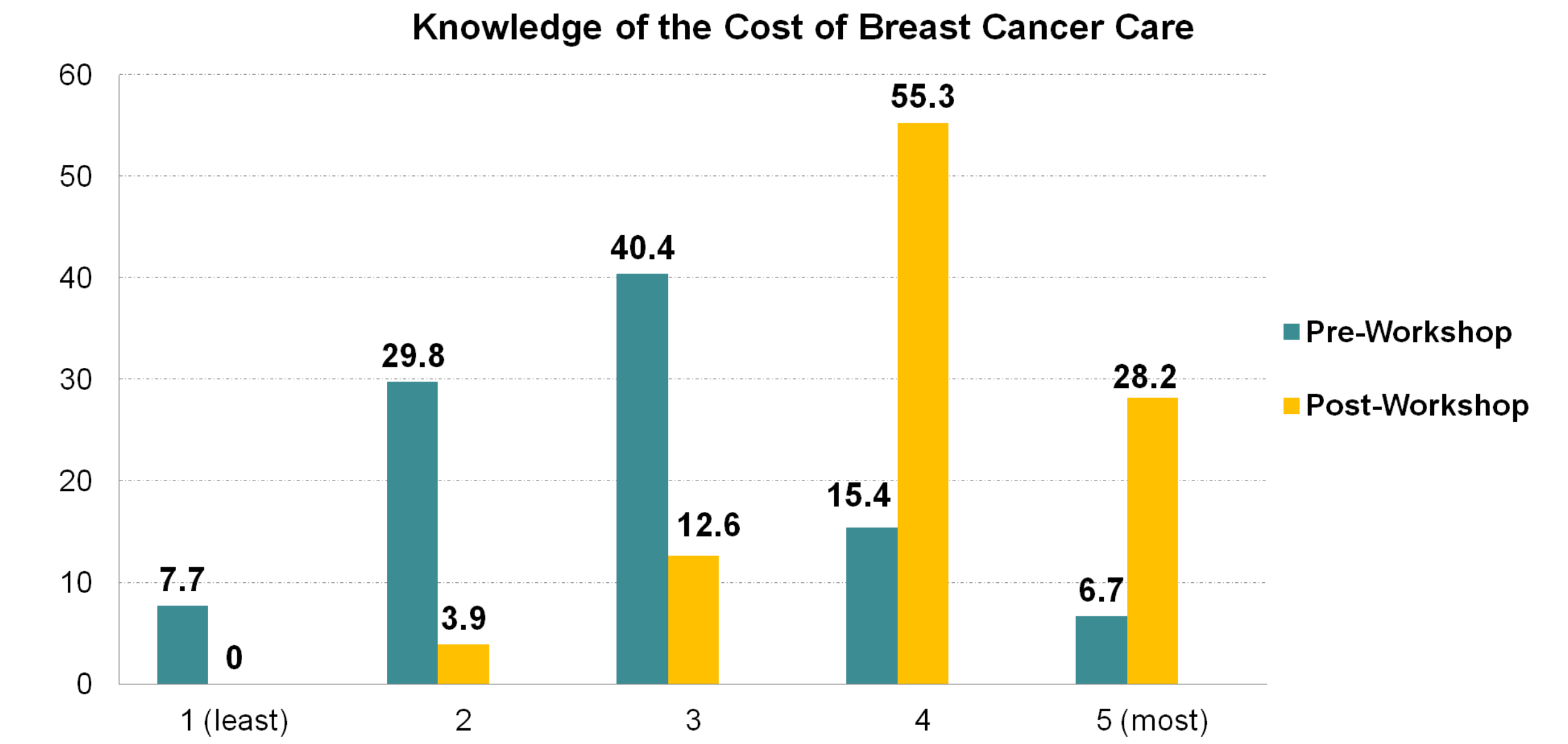
Communication About the Cost of Care



- 64.8% reported that their healthcare team **did not discuss financial aspects of care**
- 35.2% of women whose team did discuss costs with them, typically it was a social worker, physician, or nurse
 - Only 34% of this group reported the information **useful**
- Attendees reported seeking information from other sources about managing the costs of care, such as patient support organizations (40.2%), the Internet (43.5%), and other patients (41.3%)

Outcomes of Workshop

Participants' pre-workshop rating of their understanding about the financial aspects of their breast cancer care was low ($m = 2.8, s.d. = 1.0$) and was significantly less than their level of knowledge post-workshop ($m = 4.1, s.d. = 0.7, p < .05$)



- Most participants (69.9%) reported the intention to discuss financial aspects of their care with their healthcare team based on what they had learned from the workshop
- Intention to have this discussion with their healthcare team was both positively correlated with having experienced emotional distress about the cost of their care ($r = .29, p < .05$) as well as negatively correlated with their level of pre-workshop knowledge about financial issues in breast cancer care ($r = -.28, p < .05$)

Summary of Findings

These data highlight significant obstacles individuals face in receiving meaningful information relevant to managing the costs associated with breast cancer care, and illustrate how this process can increase the level of emotional distress already likely present when faced with a diagnosis of breast cancer

Data suggest that patient empowerment and education programs can help bridge the information gap which can then help:

- Reduce distress associated with cost of care
- Better enable patients to ask relevant questions to their healthcare team
- Better equip patients with tools necessary to find relevant resources to assist with cost associated with breast cancer care

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BREAST CANCER PATIENT DISTRESS ASSOCIATED WITH DIFFICULTIES NAVIGATING THE COSTS ASSOCIATED WITH CARE: RESULTS FROM A NATIONAL EDUCATION PROGRAM

Compounding the stressors related with a diagnosis of breast cancer can be the associated direct and indirect costs of cancer care. To address this need, the Cancer Support Community (CSC) in 2009 developed an evidence-based, professionally-led national education workshop for cancer patients and caregivers entitled *Frankly Speaking About Cancer: Coping with the Cost of Care*. As part of this workshop, participants completed a survey describing their experiences coping with the cost of cancer care. To date, responses from 465 participants (representing 46 workshops) have been analyzed. Of those participants, 105 are women diagnosed with breast cancer.

Though workshop participants were affected by a wide variety of cancer diagnoses, half of those with cancer attending the workshop (50%) were affected by breast cancer. No significant differences between breast cancer patients and individuals with other cancers were found. Analyses are based on responses from breast cancer patients only. Participants' pre-workshop rating of their understanding about the financial aspects of their breast cancer care was low ($m = 2.8$, $s.d. = 1.0$) and was significantly less than their level of knowledge post-workshop ($m = 4.1$, $s.d. = 0.7$, $p < .05$).

Most attendees (72.8%) reported experiencing some degree of emotional distress from trying to manage cancer care costs, and nearly one-third of attendees (30.1%) reported significant distress. Most (64.8%) reported that their healthcare team did *not* discuss financial aspects of care with them. Of attendees whose team did discuss it with them, typically it was a social worker, physician, or nurse. Of those who had this discussion, only 34% reported that this information was actually useful to them. Not surprisingly then, attendees reported they have looked elsewhere for information about managing the costs of care, such as patient support organizations (40.2%), the Internet (43.5%), and other patients (41.3%).

A positive to arise from the workshop is that most participants (69.9%) reported the intention to discuss financial aspects of their care with their healthcare team based on what they had learned from the workshop. Intention to have this discussion with their healthcare team was both positively correlated with having experienced emotional distress about the cost of their care ($r = .29$, $p < .05$) as well as negatively correlated with their level of pre-workshop knowledge about financial issues in breast cancer care ($r = -.28$, $p < .05$). Taken together, these data highlight significant obstacles that individuals face in receiving meaningful information relevant to managing the costs associated with cancer care.