OCTOBER
25–27, 2010

CATAMARAN RESORT HOTEL
SAN DIEGO, CA

2010 INTERNATIONAL
CANCER EDUCATION
CONFERENCE
The Impact of Cancer Education on Patients, Practitioners and the Public

Joint Annual Meeting for AACE CPEN EACE

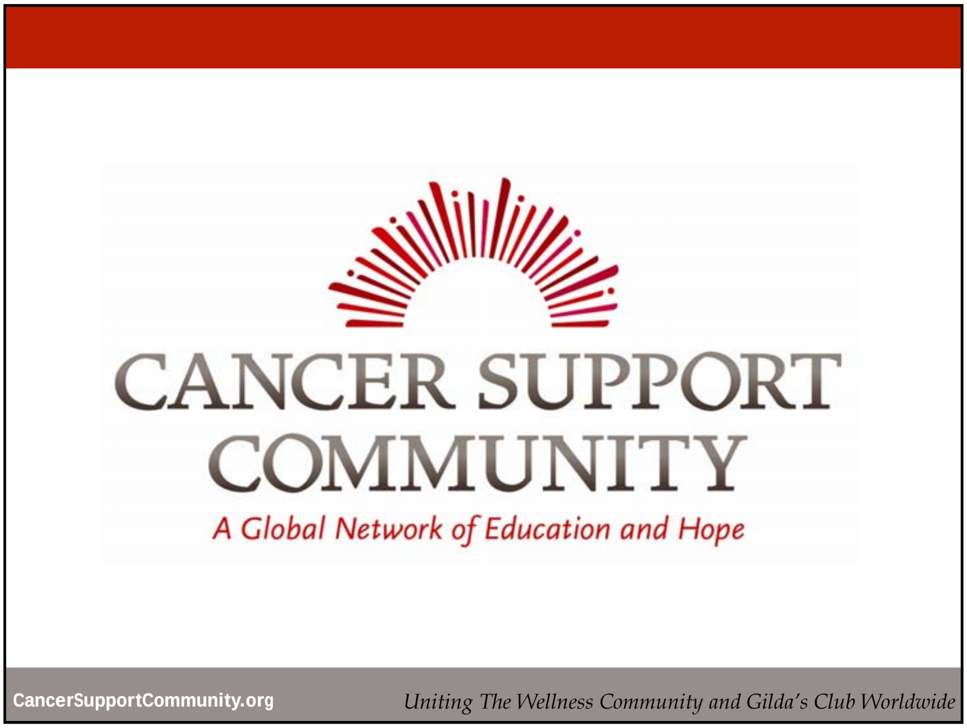
CANCER SUPPORT COMMUNITY'S 'COPING WITH THE COST OF CARE' PROGRAM: AN INDICATION OF THE NEED FOR MORE EDUCATION AND SUPPORT

Ivy Ahmed, MPH, CHES, Natalie Haskins Laukitis, MAT, Marni Amsellem, PhD

The Cancer Support Community (CSC)'s Frankly Speaking About Cancer (FSAC) series of psycho-educational booklets, online content, and face-to-face, professionally-led workshops held nationally throughout the CSC affiliate network have helped thousands affected by cancer. In 2009, CSC developed *FSAC: Coping with the Cost of Care*, holding 21 workshops nationally serving 500 people affected by cancer. 184 workshop participants reported their experience coping with the cost of cancer care and evaluated the workshop. The majority of attendees (68%) were people with cancer or survivors. Most (79%) were Caucasian, and nearly half (45.5%) were 56-69 years old.

Participants reported gains in knowledge after attending the workshop (p <.01). Nearly all (99.5%) recommend the workshop to others with cancer and their loved ones. Most intend to take action influenced by attending the workshop (e.g. discussing financial issues with healthcare team).

Most participants (66.9%) reported emotional distress as a result of the cost of cancer care. Most (92.1%) had health insurance at the time of diagnosis, and over one quarter (27.5%) experienced a change in insurance status since diagnosis. Additionally, 28.4% had applied for disability. Highest monthly co-pay varied widely, and 15.8% had applied for co-pay assistance. Most participants described unexpected expenses, particularly their deductible (47% of participants). Most (71.2%) reported that their healthcare team did *not* discuss financial aspects of their care with them, and half described this information as useful. Taken together, these data suggest a strong need to provide clear and relevant information to persons coping with the cost of cancer care.



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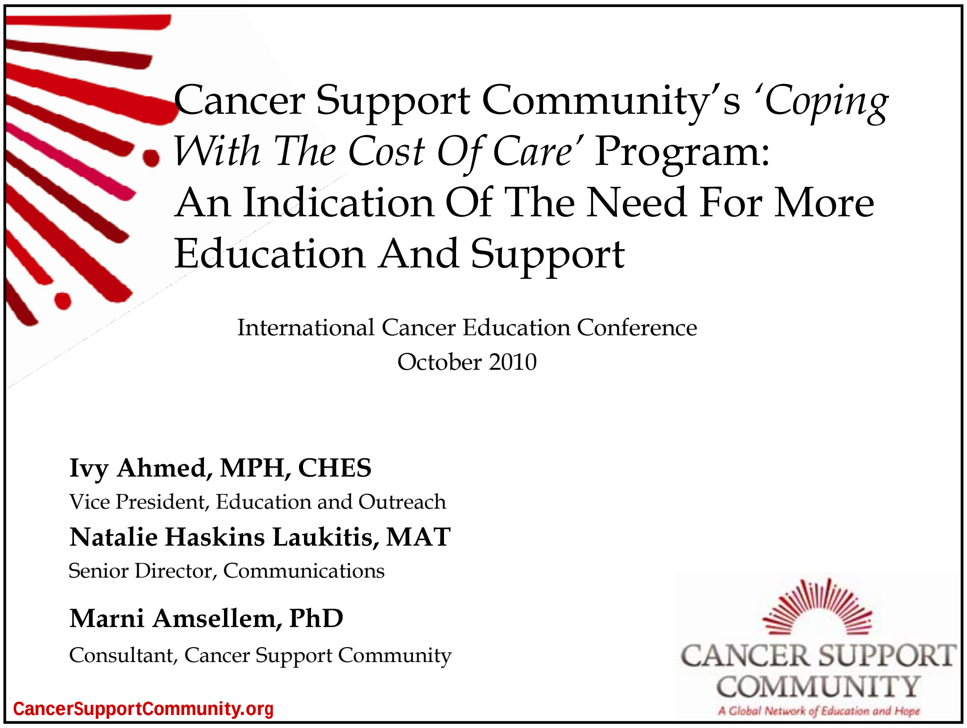
Uniting The Wellness Community and Gilda's Club Worldwide



Cancer Support Community's *'Coping With The Cost Of Care'* Program: An Indication Of The Need For More Education And Support

International Cancer Education Conference
October 2010

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About the Cancer Support Community

- In 2009. The Wellness Community and Gilda's Club Worldwide joined forces to become the largest provider of psychosocial cancer support in North America and the largest employer of psychosocial oncology support professionals
- CSC is an international, non-profit organization that provides support, education and hope to people with cancer and those who care for them.
- Through our community-based affiliates, CSC offers <u>free, professionally-led</u> support groups, educational workshops, nutrition and exercise programs, and stress-reduction classes.

Education and Outreach

- Patient Active Concept©
- Frankly Speaking About Cancer
  - Evidence-based
  - Evaluated
  - Medically-reviewed

Includes:

- Print material
- Face-to-face workshops
- Online information at www.cancersupportcommunity.org

The Importance of Addressing the Impact of Cost

- The Hidden Costs of Cancer
  - Patients and caregivers managing cancer costs experience clinically significant stress levels
  - Managing costs of cancer can negatively impact patient and caregiver behavior
  - Awareness of financial assistance is low and those who are aware are suspicious
  - This conducted by CSC was highlighted in the Wall Street Journal

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

- A comprehensive direct education program for those affected by cancer
- Program includes booklet, workshops and online content
- Launched mid-2009
- CSC sponsored 21 facilitated workshops in 2009 across the country
- Workshops reached approximately 500 participants nationwide

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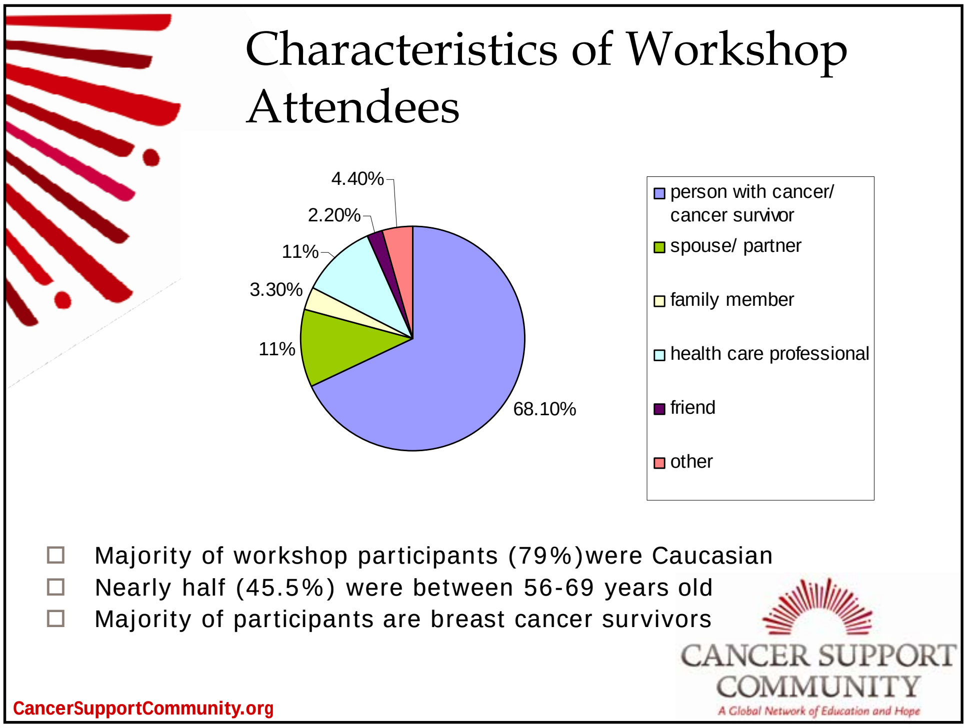
Frankly Speaking About Cancer: *Coping with the Cost of Care* educational program

- Provides practical guidance to navigating the numerous and complex challenges of managing the cost of care
- Streamlines crucial financial resources available to people with cancer
- Provides tools to improve communication
- Engages and creates a supportive community of survivors

Workshop Evaluation and Data Collection

- Post workshop evaluation completed by participants to:
  - 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
- Data collected includes:
  - Demographics
  - Specific changes in knowledge and behavioral intent as a result of the workshop
  - Insurance, disability and expenses



Characteristics of Workshop Attendees

- ☐ Majority of workshop participants (79%)were Caucasian
- ☐ Nearly half (45.5%) were between 56-69 years old
- ☐ Majority of participants are breast cancer survivors

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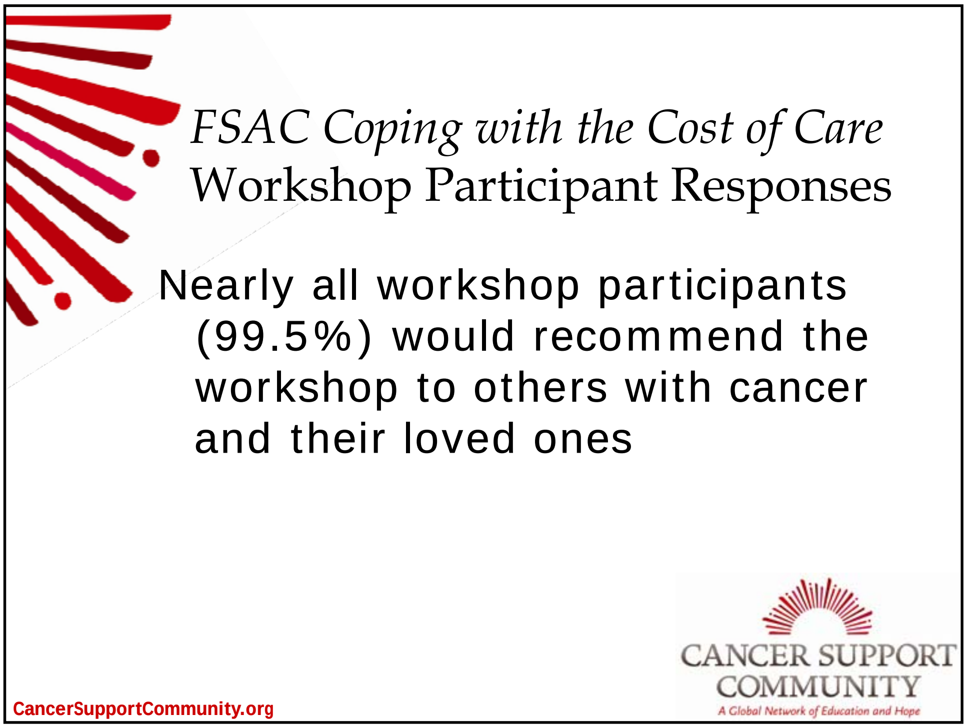

FSAC Coping with the Cost of Care Workshop Participant Responses

Nearly all workshop participants (99.5%) would recommend the workshop to others with cancer and their loved ones

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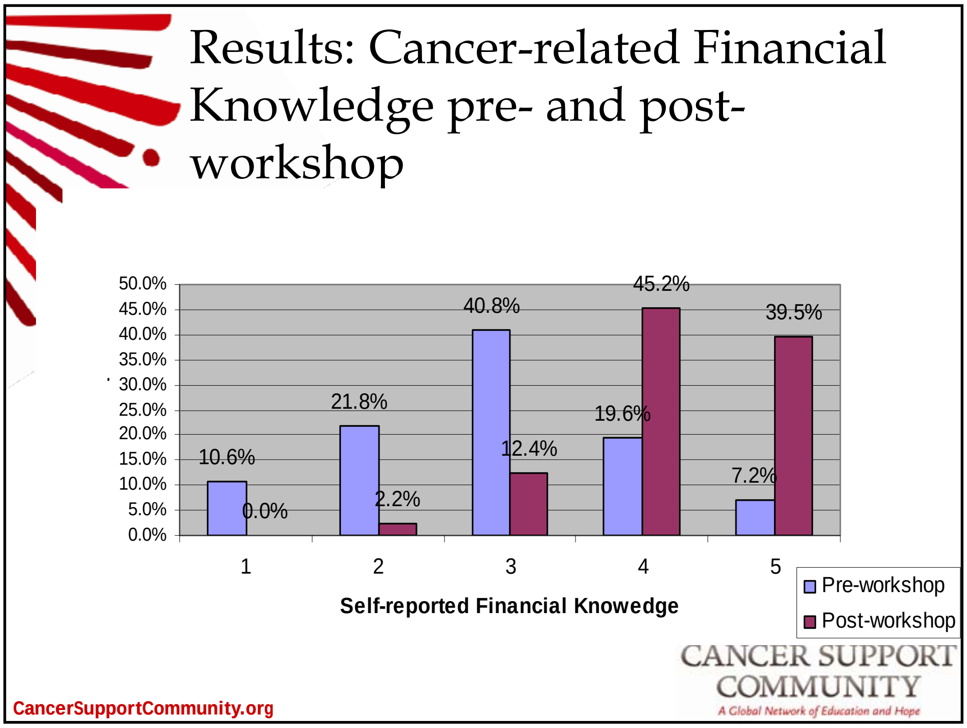

Results: Cancer-related Financial Knowledge pre- and post-workshop

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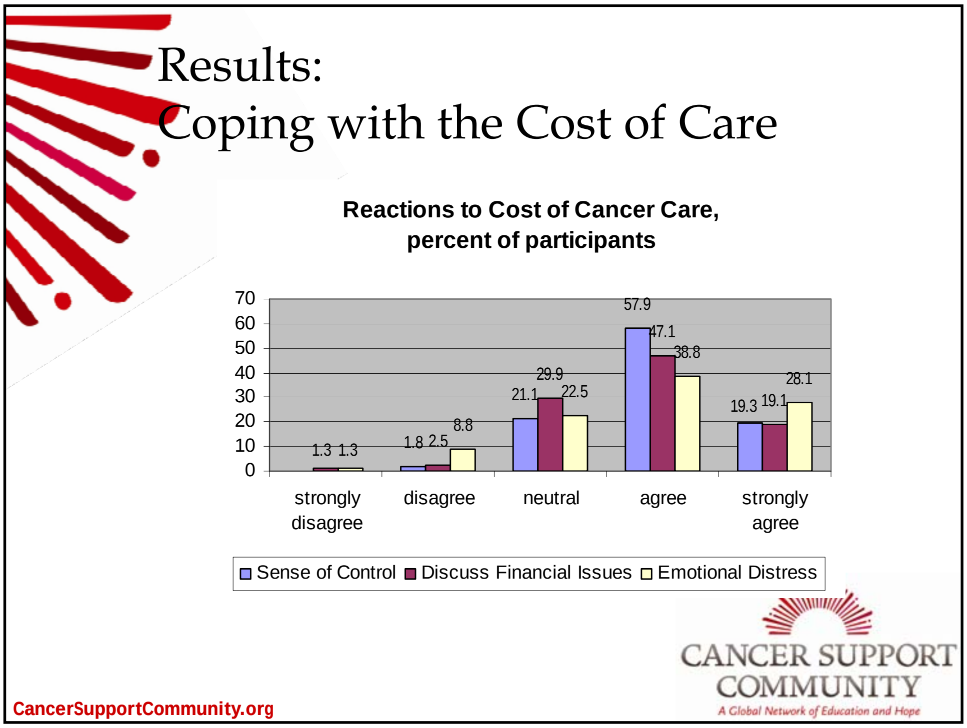

Results: Coping with the Cost of Care

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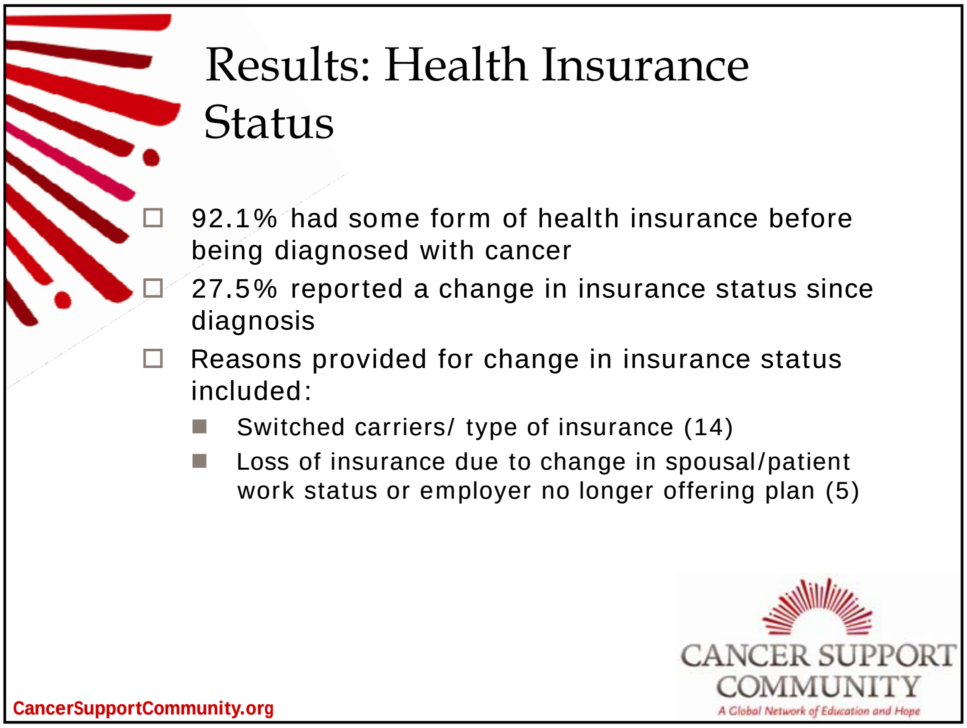
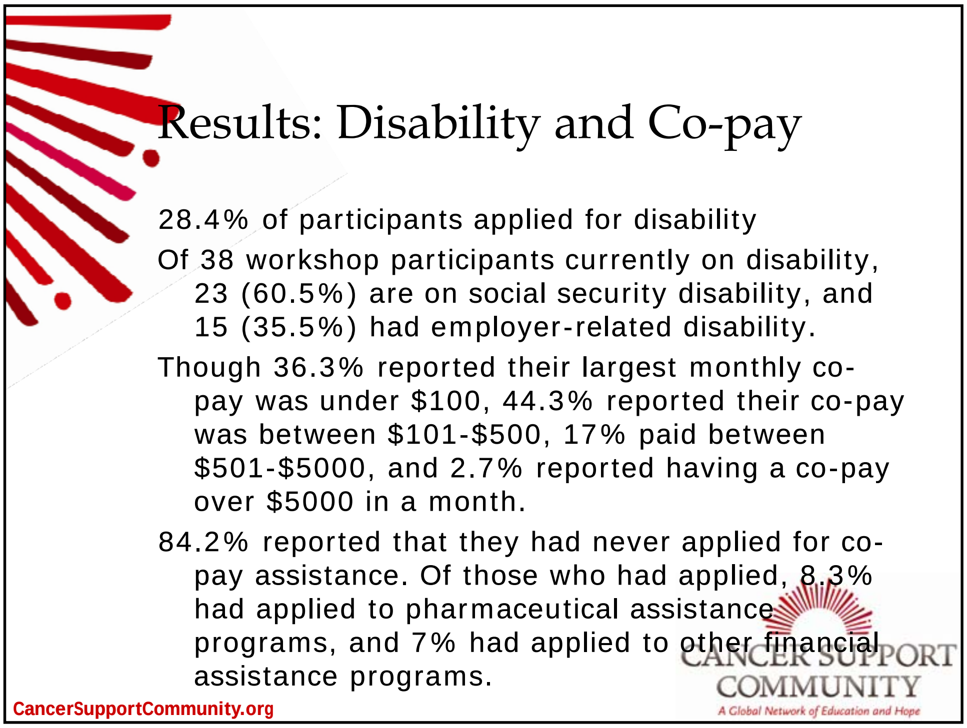


Results: Health Insurance Status

- 92.1% had some form of health insurance before being diagnosed with cancer
- 27.5% reported a change in insurance status since diagnosis
- Reasons provided for change in insurance status included:
  - Switched carriers/ type of insurance (14)
  - Loss of insurance due to change in spousal/patient work status or employer no longer offering plan (5)



Results: Disability and Co-pay

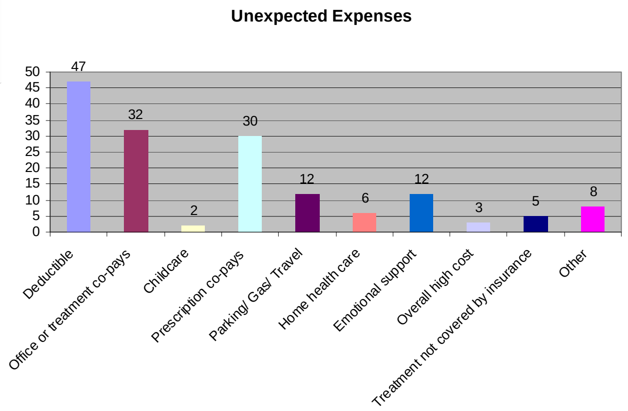
28.4% of participants applied for disability

Of 38 workshop participants currently on disability, 23 (60.5%) are on social security disability, and 15 (35.5%) had employer-related disability.

Though 36.3% reported their largest monthly co-pay was under $100, 44.3% reported their co-pay was between $101-$500, 17% paid between $501-$5000, and 2.7% reported having a co-pay over $5000 in a month.

84.2% reported that they had never applied for co-pay assistance. Of those who had applied, 8.3% had applied to pharmaceutical assistance programs, and 7% had applied to other financial assistance programs.

Results: Unexpected Costs



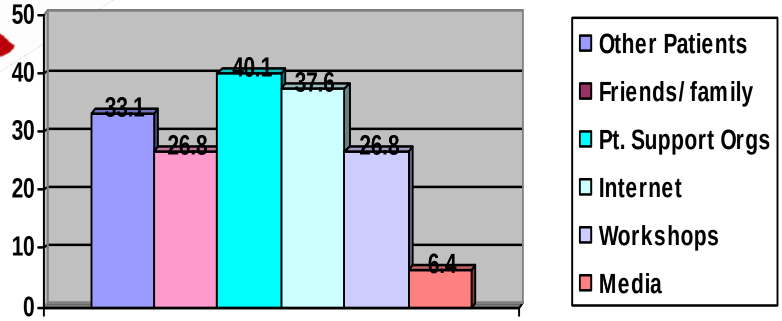
Results: Communicating with Healthcare Team about Cost of Care

Most participants (71.2%) reported that their healthcare team did *not* discuss financial aspects of their care.

Typically, it was the physician (n =12), a social worker (n=12), a nurse (n=6), or some combination of the above had who had spoken to them about finances.

Sixty-six participants had raised the issue of cost with their healthcare team. Respondents perceived this information to be useful by patients only 50% of the time.

Results: Additional Sources of Information about Cost of Care



Summary

Workshop data:

Indicate the success of this program

Support the need for materials and programs such as this one to address the pervasive need of those affected by cancer to have access to quality information about managing finances and related issues related to a cancer diagnosis

Nearly all workshop participants (99.5%) would recommend the workshop to others with cancer and their loved ones.

- **"This was an excellent workshop."** *Participant, TWC- Central New Jersey*
- **"I liked the personal group setting. Facilitator did a good job of making everyone feel comfortable about talking."** *Participant, TWC- Montana*
- **"This was a very helpful session. I felt I knew nothing before this session. I'm much more knowledgeable now."** *Participant, TWC- Cincinnati*
- **"Wonderful compilation of financial information related to the cost of cancer care."** *Participant, TWC- Greater Miami*
- **"The booklet is exceptional!"** *Participant, TWC-Greater Miami*
- **"I have had issues with hospital billing and now feel confident to handle them."** *-Participant, TWC-Atlanta*
- **"Great presenters. Please repeat this program."** *Participant, TWC- SW Florida*

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Thank You

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