SEPTEMBER
8–10, 2011

HYATT REGENCY BUFFALO
BUFFALO, NEW YORK

2011 INTERNATIONAL
CANCER EDUCATION
CONFERENCE
Global Cancer Education: Building Strength through Research
and Best Practices
Joint Annual Meeting for AACE CPEN EACE

# PATIENT DISTRESS DUE TO DIFFICULTIES NAVIGATING THE COSTS ASSOCIATED WITH CANCER CARE: RESULTS FROM A NATIONAL EDUCATION PROGRAM.

Since 2009, CSC has held an evidence-based professionally-led educational workshop entitled *Frankly Speaking About Cancer: Coping with the Cost of Care,* nationally throughout its affiliate network. To date, there have been 46 workshops serving 760 people affected by cancer, 465 of whom (61.2% response rate) have reported their experience coping with the cost of cancer care and evaluated the workshop.
The majority of workshop attendees (64%) were people with cancer or survivors, with spouses/ partners and health care professionals accounting for 12% of the participants. Most (77.5%) were Caucasian, and 43.4% were 56-69 years old.

Most attendees (66.3%) reported experiencing some degree of emotional distress from trying to manage cancer care costs, and over one quarter of attendees (26.7%) reported significant distress. Most (66.9%) reported that their healthcare team did *not* discuss financial aspects of their care with them. Of attendees whose team did discuss it with them, typically it was the social worker, physician, or nurse discussing. Of those who had this discussion, 42.3% of attendees said that this information was not actually useful to them. Not surprisingly then, attendees reported they have looked elsewhere for information about managing the costs of care, turning to patient support organizations (46.7%), the Internet (40.1%), and other patients (40.8%). Taken together, these data highlight significant obstacles that individuals face in receiving meaningful information relevant to managing the costs associated with cancer care.

# Navigating the Costs Associated with Cancer Care: Results from a National Education Program

Kasey Dougherty, M.A.
Research Manager
Ivy Ahmed, MPH, CHES
VP, Education & Outreach
Cancer Support Community

## About the Cancer Support Community

- In July 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. By helping to complete the cancer care plan, the Cancer Support Community continues to optimize patient care by providing essential, but often overlooked, services.

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

## Cancer Support Community Mission

- To ensure that all people impacted by cancer are:
- Empowered by Knowledge
- Strengthened by Action
- Sustained by Community

## Affiliate Network Services

50 Affiliates,100 satellites that offer:

- Support Groups (Cancer Patients, Caregivers, Bereavement Groups)
- One-on-One Counseling
- Education Programs
- Healthy Lifestyle Courses
- Mind/Body Classes
- Networking Groups
- Community Initiatives

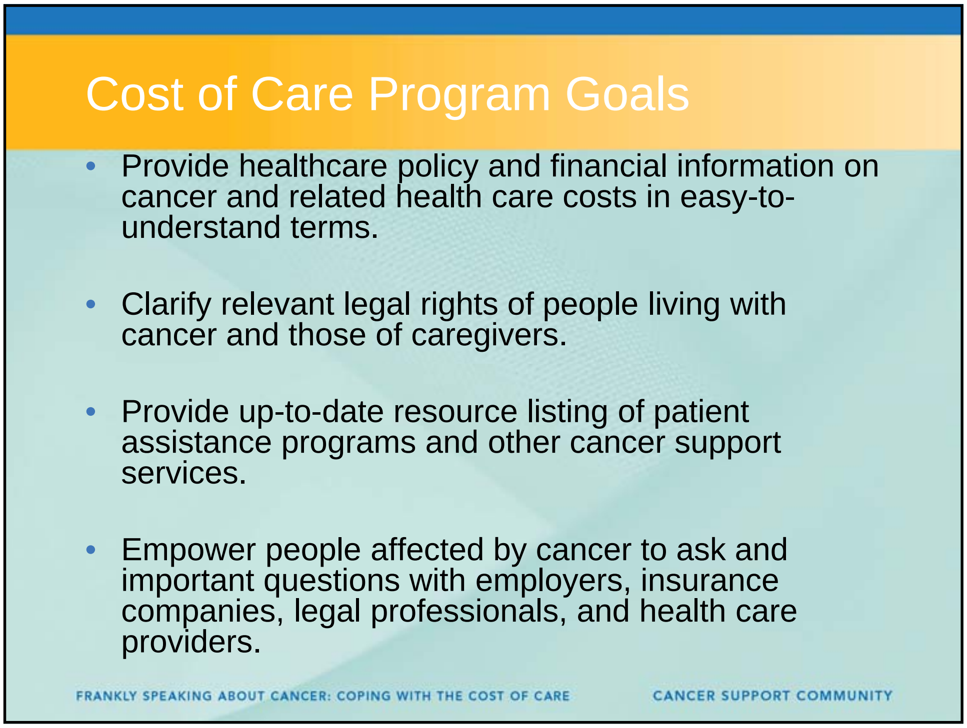
# The Call to Action

- Study conducted by Harvard Law School, Harvard Medical School and Ohio University found medical bills are involved in more than 60% of US bankruptcies[1]
  - More than 75% of these families reported having health insurance
- CSC conducted a study on hidden costs of cancer and barriers to accessing assistance[2]
  - 47% of patients were not aware of pharmaceutical access or co-pay services
  - 34% of patients and 47% of caregivers felt too overwhelmed to apply for financial help
  - 81% of patients and 72% of caregivers reported stress within moderate to severe levels (based on clinical cut-offs)
  - Patients reported high levels of post-traumatic stress similar to what African-American survivors of Hurricane Katrina[3] experienced

[1] **Himmelstein, D. et al. (2009). Medical bankruptcy in the United States, 2007:Results of a national study. *American Journal of Medicine.***
[2] **Buzaglo, J. et al. (2010). Hidden costs of cancer: Barriers to accessing financial assistance. *[Abstract] ICBM 2010 Annual Conference.***
[3] Chen, A. et al.(2007). Economic Vulnerability, Discrimination, and Hurricane Katrina: Health Among Black Katrina Survivors in Eastern New Orleans. *Journal of the American Psychiatric Nurses Association, 257-266.*

# CSC Responds

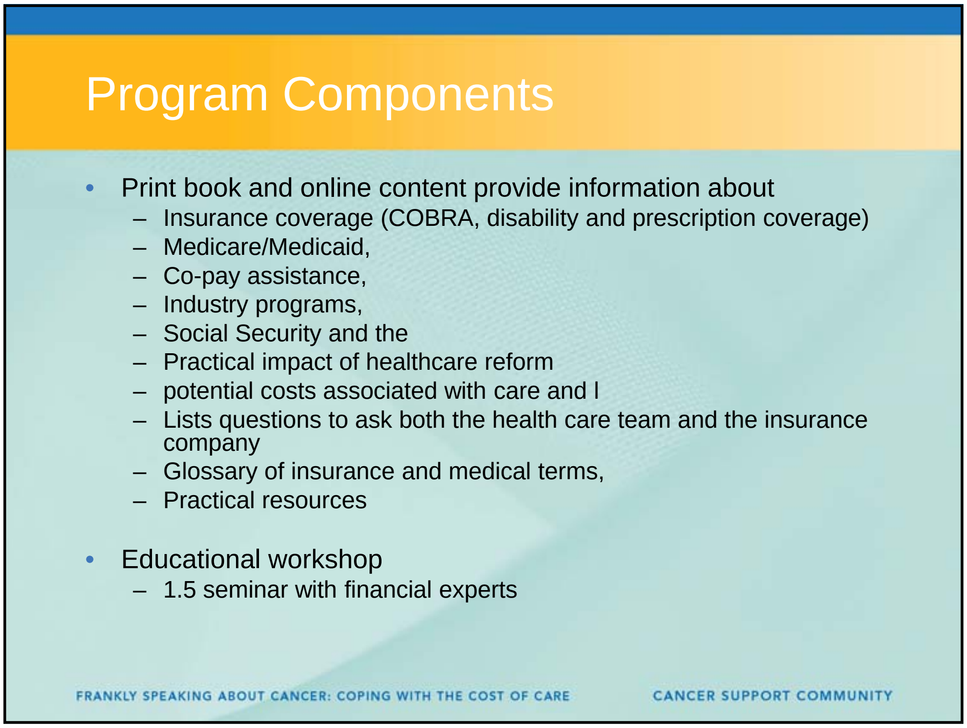
- Generous support from Lilly created *Frankly Speaking About Cancer: Coping with the Cost of Care Program*
  - three-tiered educational program that includes a **print book, an education workshop, and online content**
- To develop and promote partnered with:
  - Association of Oncology Social Work
  - Cancer Legal Resource Center
  - Lance Armstrong Foundation
  - National Coalition for Cancer Survivorship
  - Patient Advocate Foundation
  - Survivorship A-Z



## Cost of Care Program Goals

- Provide healthcare 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 and important questions with employers, insurance companies, legal professionals, and health care providers.

FRANKLY SPEAKING ABOUT CANCER: COPING WITH THE COST OF CARE CANCER SUPPORT COMMUNITY



## Program Components

- Print book and online content provide information about
  - Insurance coverage (COBRA, disability and prescription coverage)
  - Medicare/Medicaid,
  - Co-pay assistance,
  - Industry programs,
  - Social Security and the
  - Practical impact of healthcare reform
  - potential costs associated with care and l
  - Lists questions to ask both the health care team and the insurance company
  - Glossary of insurance and medical terms,
  - Practical resources
- Educational workshop
  - 1.5 seminar with financial experts

FRANKLY SPEAKING ABOUT CANCER: COPING WITH THE COST OF CARE CANCER SUPPORT COMMUNITY

## Key Program Messages

- Many people affected by cancer encounter challenges in financing their cost of cancer care.
- Certain laws, policies, and programs exist that can help patients and their families more effectively cope with the cost of cancer care.
- Empowers the patient
  - Learning how to effectively navigate the financial system, may give those with cancer a greater sense of control over their lives.
  - Those who are better informed and more proactive in their decisions towards navigating their finances may experience an improved quality of life and may enhance the possibility of their recovery.

FRANKLY SPEAKING ABOUT CANCER: COPING WITH THE COST OF CARE CANCER SUPPORT COMMUNITY

---

## Workshop Evaluation: Method

- To date conducted 46 workshops nationwide
- 765 people attended; 465 returned evaluations

Ivy how did they get the evaluation, pen/paper email, conducted right after?

FRANKLY SPEAKING ABOUT CANCER: COPING WITH THE COST OF CARE CANCER SUPPORT COMMUNITY

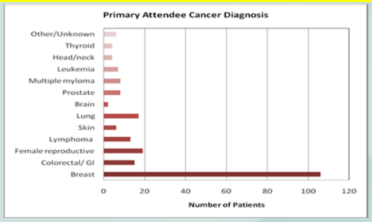
## Sample Characteristics (N=465)

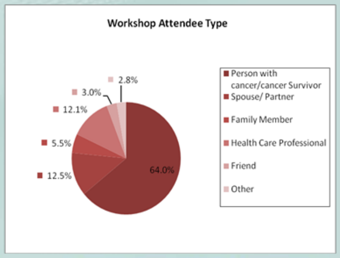
- 64% of attendees had been diagnosed with cancer

N from Abstract is different than N from Annual Report

Need other demos race, age, gender

t cancer

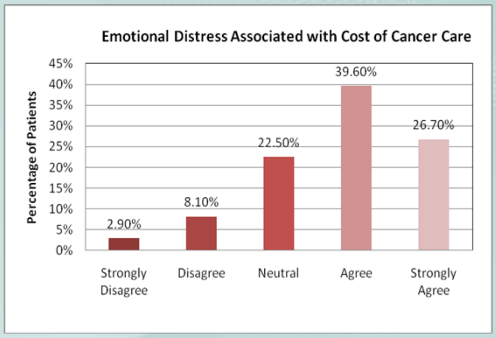

Primary Attendee Cancer Diagnosis


Workshop Attendee Type

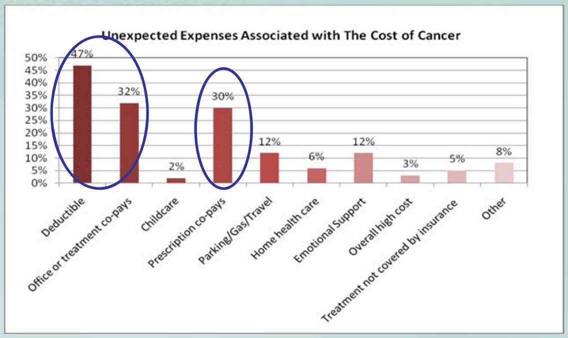
---

## Emotional Distress

- Almost two-thirds (63%) agreed or strongly agreed that they had “experienced emotional distress due to cost of care”


Emotional Distress Associated with Cost of Cancer Care

## Insurance and Unexpected Expenses

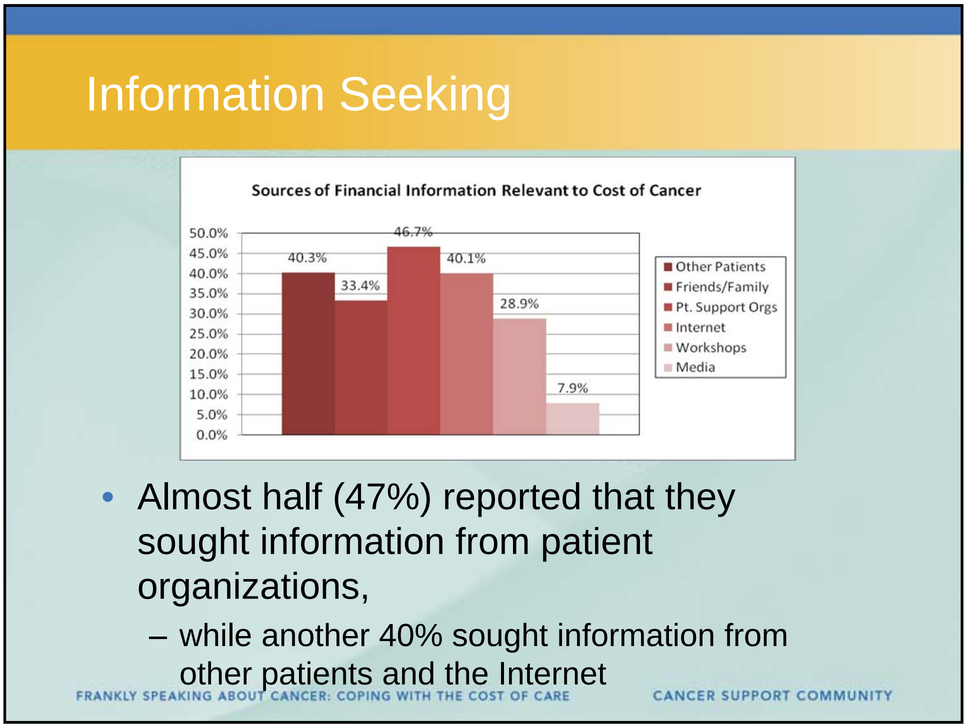


- Most (92%) had health insurance at the time of diagnosis
- 28% experienced a change in insurance status since diagnosis; 28% had applied for disability
- 16% had applied for co-pay assistance

## Working with Healthcare Team

- Of those (n=182) who raised the issue of financing their cancer care with their healthcare team, 42% reported that their healthcare team was *not* helpful

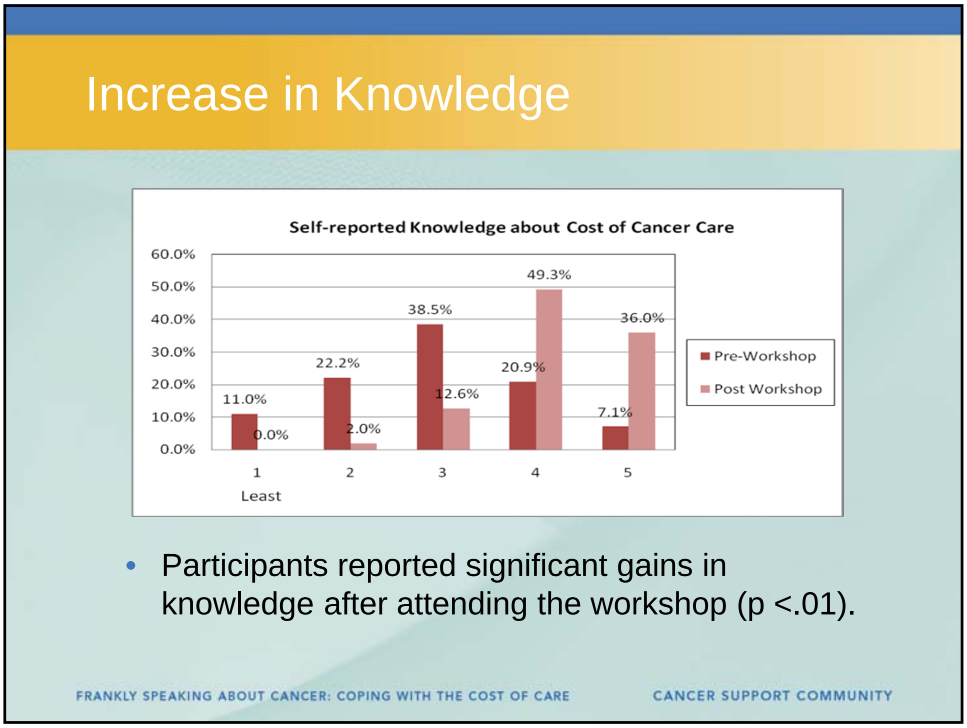
- Almost three-quarters (70%) reported their healthcare team did *not* discuss financial aspects of their care.



## Information Seeking

Sources of Financial Information Relevant to Cost of Cancer

- Almost half (47%) reported that they sought information from patient organizations,
  - while another 40% sought information from other patients and the Internet



## Increase in Knowledge

Self-reported Knowledge about Cost of Cancer Care

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

## Behavior Change and Overall Impact

- Over three-quarters (77%) “agreed” or “strongly agreed” they *“feel a greater sense of control over dealing with and managing the cost of cancer as result of this workshop”*
- 68% “agreed” or “strongly agreed” they *“would discuss financial issues related to their health care team”*
- Over 80% indicated the expertise of the lecturer was the most valuable aspect of the workshop.
- Nearly all (99.5%) recommend the workshop to others with cancer and their loved ones.

## Conclusions

> “This should be the first workshop newly diagnosed people should attend very empowering.’’
> - *Frankly Speaking About Cancer: Coping with the Cost of Care* Program Participant

- This program proves to be effective in:
  - Increasing knowledge about the financial system as it relates to cancer care
  - Empowering the participant to speak to their healthcare team
  - Giving the participant a greater sense of over control
- Future directions
  - Update materials
  - Hold workshops at CSC affiliates and cancer centers/hospitals across the country

For more information about FSAC

**Contact the CSC: 1-888-793-9355**

**www.cancersupportcommunity.org**

**Thank You**