

#### PATIENT EDUCATION: NATIONAL FINDINGS ON HOW CANCER PATIENTS MAKE TREATMENT DECISIONS

#### Background

Since 2001, the Cancer Support Community has developed and provided a patient empowerment program, *Frankly Speaking About Cancer Treatment*, which provides an in-depth look at understanding cancer treatments, how to manage the side effects, and communicating with their healthcare team. This evidence-based program combines patient-focused educational booklets, professionally-led workshops, and tailored web content. Since 2009, 1,192 individuals have attended 79 workshops nationwide. 617 attendees completed a workshop evaluation, providing insight into their experiences with cancer treatment and their decision-making process. 64.1% of attendees were cancer patients/survivors, and almost half (44.4%) had been diagnosed within the past year. 83.3% of respondents were Caucasian and the average age was 58.8 years.

41.9% of cancer patients reported receiving multiple treatment options, requiring patients and families to make difficult decisions. Treatment options included chemotherapy (70.5%), surgeries (59.8%), and/ or radiation therapy (43.1%). Nearly half (49.5%) of cancer patients report they were highly involved in treatment decision-making. Factors influential in decision-making include a physician recommendation (50.8%), the greatest chance for survival (36.3%), and the most aggressive treatment (29.8%). However, 34.4% reported they were not involved with decision-making, which indicates there is still a need for additional education at time of diagnosis before treatment decisions are made.

97.2% of respondents would definitely recommend this workshop to others facing similar issues. Results of these evaluations indicate this is a successful model for patient education, which could be replicated by others.



Patient Education: National Findings on How Cancer Patients Make Treatment Decisions

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#### **Presenter Disclosure**

This program was funded through an unrestricted educational grant to the Cancer Support Community from Amgen.

I do not have a personal relationship with the funder.

#### **Presentation Overview**

- I. About Cancer Support Community
- II. Background on Frankly Speaking About Cancer Treatment Program
- III. Findings on treatment decision making from program evaluation
- IV. Summary

# **About the Cancer Support Community**

- In July 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community
- Encompassing a network of more than 50 local affiliates and over 100 satellite locations, CSC provides the highest quality social and emotional support for people affected by cancer



*"From my perspective, the marriage of these two respected organizations marks one of the most significant events in the cancer non-profit community this year. ~Ted Kennedy, Jr.* 

FRANKLY SPEAKING ABOUT CANCER

#### **Cancer Support Community Mission**

To ensure that all people impacted by cancer are:

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



FRANKLY SPEAKING ABOUT CANCER





**CANCER SUPPORT COMMUNITY** 

## Frankly Speaking About Cancer

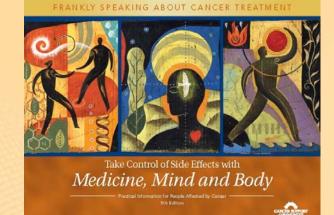
- Provides easy to understand, but comprehensive information on topics relevant to those affected by cancer
- Topics are tumor type-specific or more general (e.g. cancer treatment)
- Evidenced based and medically reviewed
- Series content includes, up-to-date:
  - Web-based materials
  - Print materials
  - Professionally-led workshops
  - Online radio series





# Frankly Speaking About Cancer Treatment

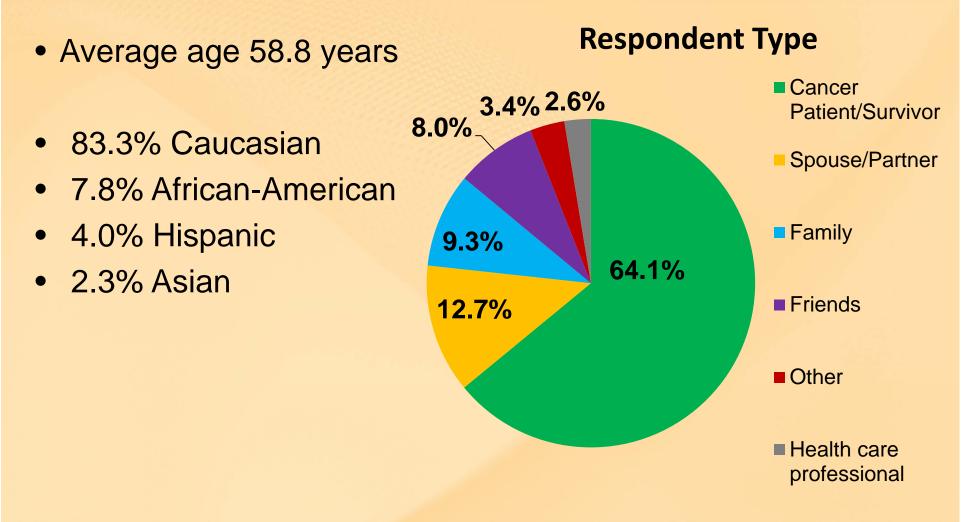
- In 2001, CSC developed program
- Goal of program
- Program Content
  - Book with journal to help track side-effects
  - Web content
  - Professionally-led workshop



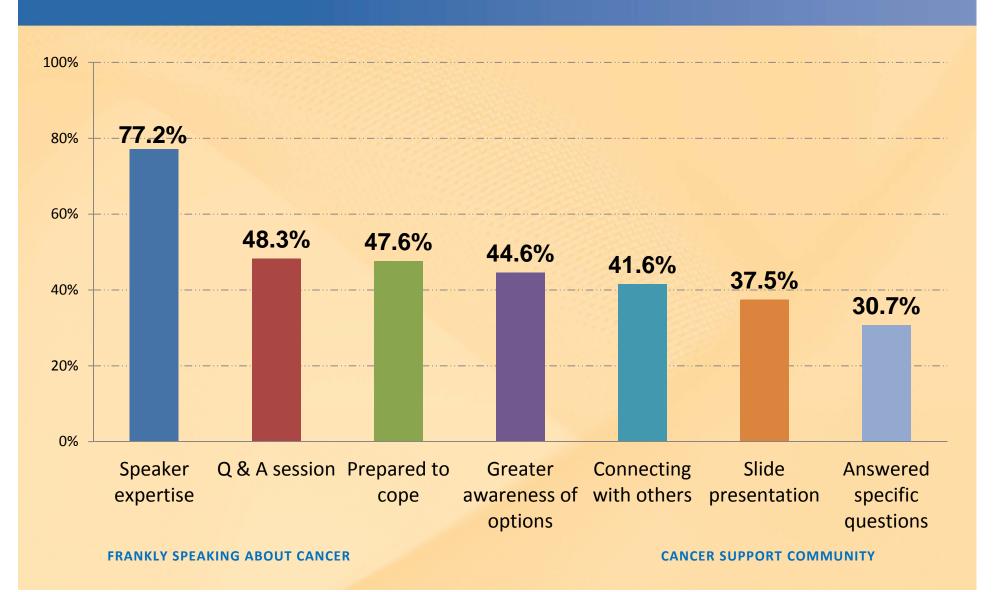
# **Overview of FSAC Cancer Treatment Workshops: 2009-2011**

- 79 workshops
- 1,192 workshop attendees
- 617 attendees completed post-workshop evaluation
- Respondents provided information about:
  - Demographics
  - Cancer history and treatment
  - Information-seeking
  - Knowledge
  - Decision-making
  - Satisfaction with workshop

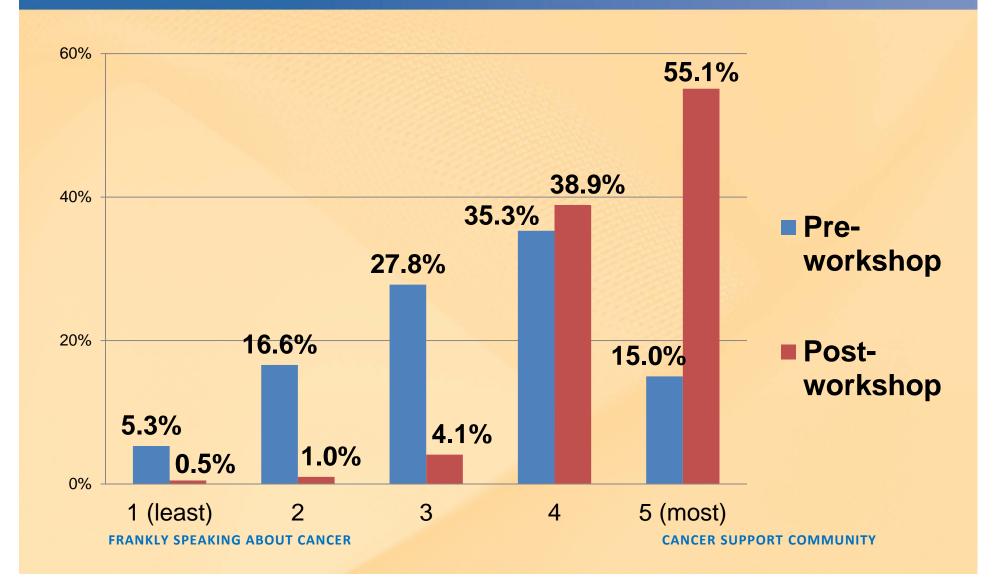
## **Respondent Demographics**



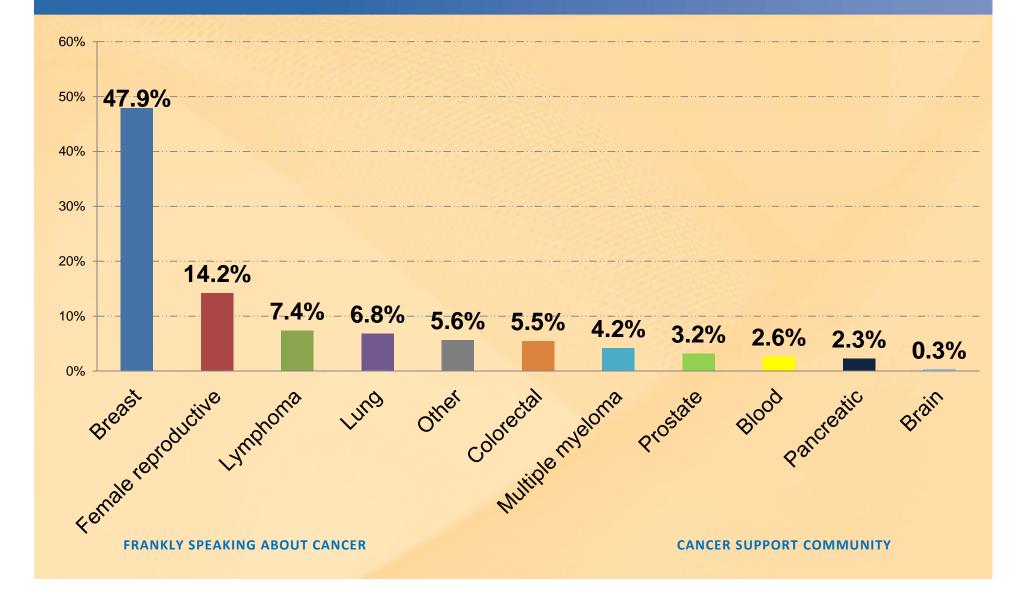
# **Most Valuable Aspects of Workshop**



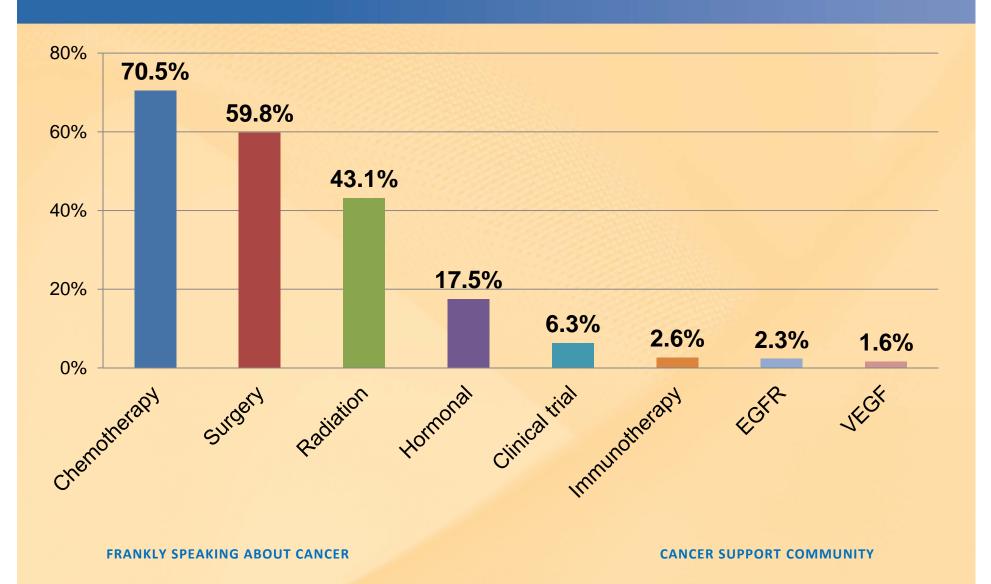
## **Knowledge About Cancer Treatment**



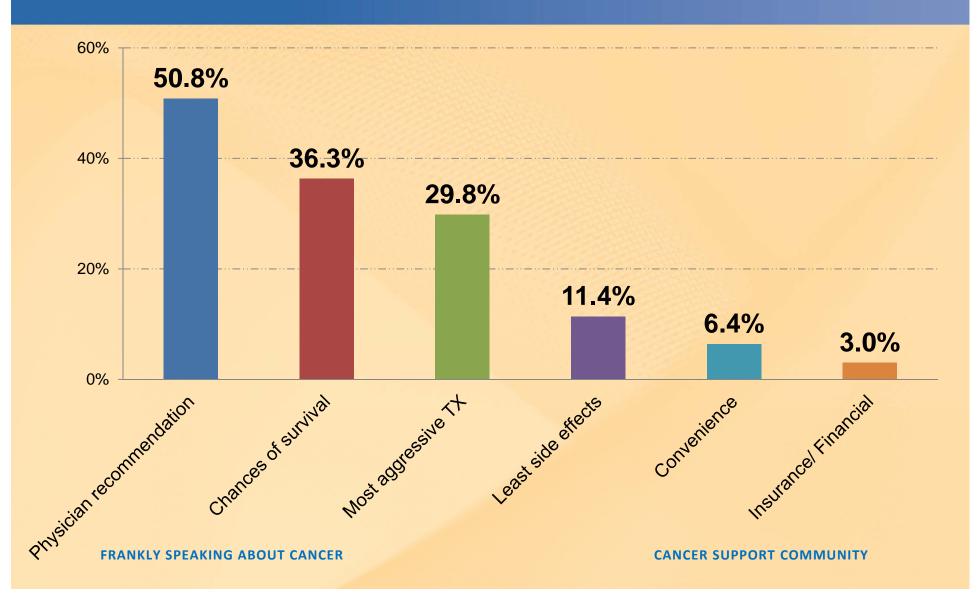
## **Cancer Diagnosis**



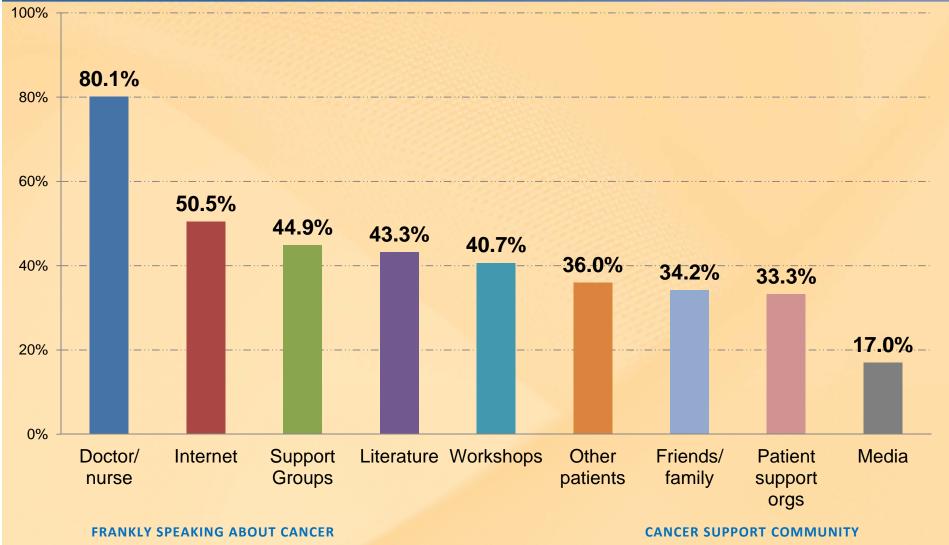
## **Types of Treatment**



# **Factors Influential in Decision-Making**



# Sources of Information About Cancer Treatment



#### Summary

- Not all patients are receiving information about cancer treatment before making a treatment decision
- Importance of physician recommendation in treatment decision making process
- Role of Patient Educators
- CSC's commitment to Frankly Speaking About Cancer Treatment
  CANCER SUPPORT COMMUNITY



#### For more information about FSAC Contact the CSC: 1-888-793-9355 www.cancersupportcommunity.org

People with cancer who actively *participate* in thei *care* along with thei Thank You re team will *improve* quality of *their lives* and may enhance the possibili *recovery*. People with cancer who *actively* participa their care along with *their health* care team will im the *quality* of thei<sup>©</sup> 2012 Cancer Support Community. All rights reserved.