



DEVELOPING A COMPREHENSIVE PROGRAM TO ADDRESS PSYCHOSOCIAL CONCERNS OF YOUNG WOMEN WITH METASTATIC BREAST CANCER

Background

Young women with metastatic breast cancer often face a host of unique challenges. In 2011, the Cancer Support Community (CSC) conducted an online survey to inform the development of a webinar for young women with metastatic breast cancer. Ninety-five women aged 40 or younger with metastatic breast cancer reported their psychosocial concerns they have experienced either at the time of diagnosis or currently. Respondents hailed from 26 states and Canada. Nearly two-thirds received their diagnosis less than two years ago, 48.9% were currently working full time, and 64% were married at the time of diagnosis.

Their greatest concerns at diagnosis were connecting with the healthcare team and making treatment decisions. Yet, respondents indicated more psychosocial concerns at current time than at diagnosis. 46.7% wanted more opportunities to connect with other young women with metastatic breast cancer and 43.3% indicated managing changes in romantic relationships as a significant concern at the current time. However, asking for help (51.1%) remained a significant concern throughout. In addition, physical issues such as managing side-effects were rated more frequently as current concerns.

Based on these findings CSC, along with Young Survival Coalition, developed a webinar. Post-webinar, participants reported an increased understanding of how to deal with issues surrounding relationships, increased ability to communicate with healthcare team about side effects management, and feeling more connected to other young women with metastatic breast cancer.

Though the survey data informed a successful webinar, the need remains for further education and support of young women with metastatic breast cancer.



Developing A Comprehensive Program To Address Psychosocial Concerns Of Young Women With Metastatic Breast Cancer

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Presenter Disclosure

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I do not have a personal relationship with the funders.

Presentation Overview

- I. About Cancer Support Community
- II. Frankly Speaking About Cancer Program
- III. Survey findings from online survey of young women with metastatic breast cancer
- IV. Program development
- V. 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



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"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.

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

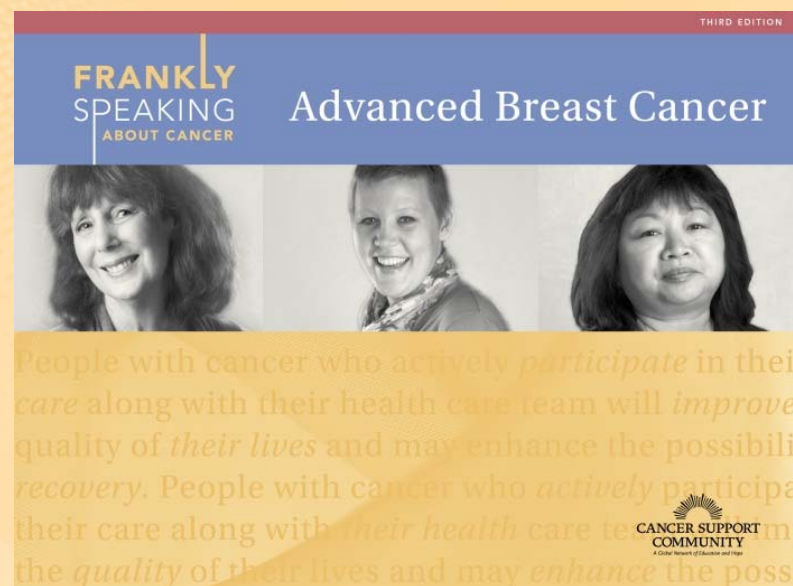
Frankly Speaking About Cancer

- Provides easy to understand in-depth coverage of topics of relevance to those affected by cancer
- Topics are tumor type-specific or more general
- Evidenced based and medically reviewed
- Up-to-date content includes:
 - Web-based materials
 - Print materials
 - Professionally-led workshops
 - Online radio series
 - Webinars



Frankly Speaking About Cancer: Advanced Breast Cancer

- Launched in 2006
- Program Content
- Program Reach



Young Women with Metastatic Breast Cancer Online Survey

In 2011, the Cancer Support Community along with the Young Survival Coalition (YSC) conducted an online survey to investigate the experiences of young women with ABC and how their needs are being met

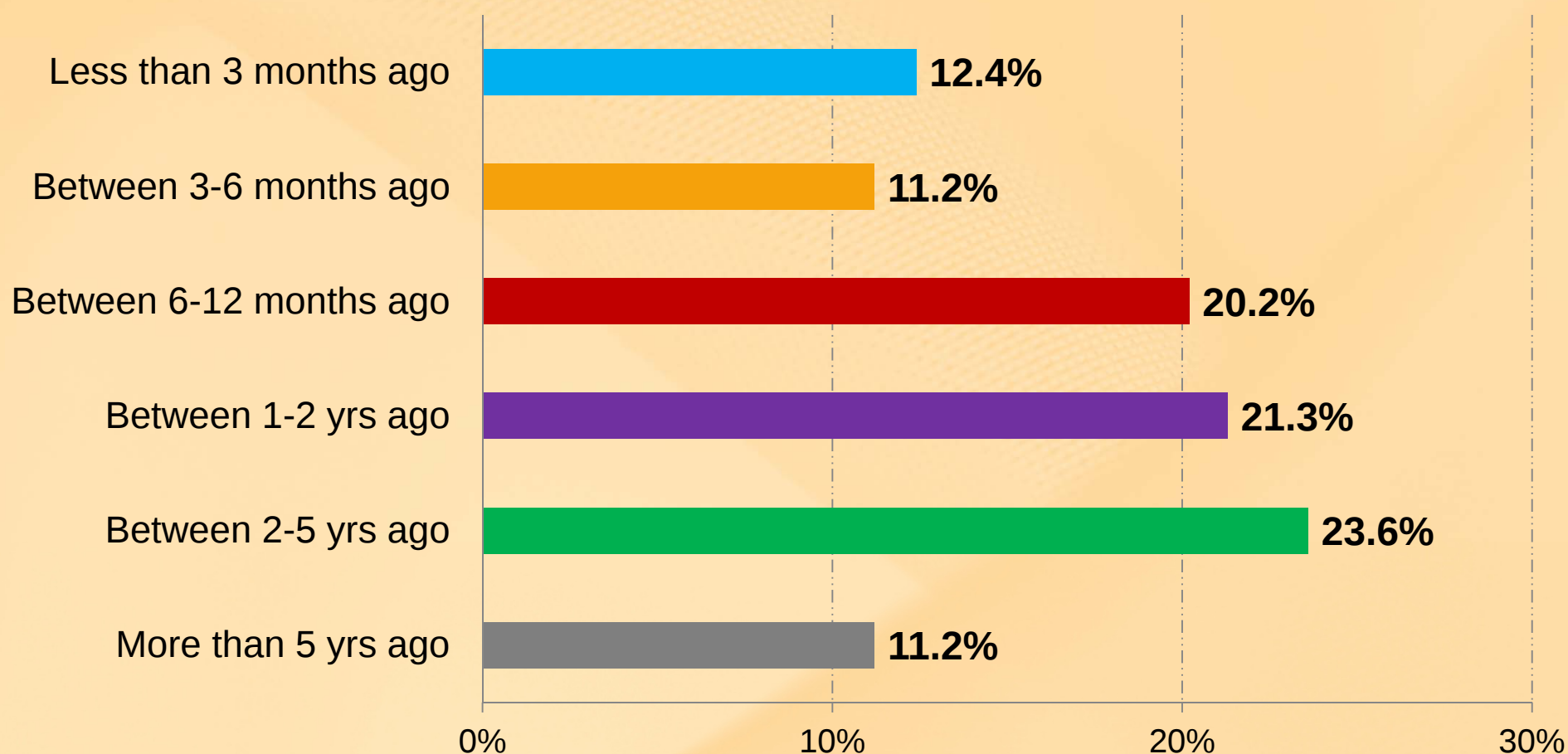
- Survey questions assessed:
 - cancer history, treatment, informational needs, demographic characteristics
 - psychosocial concerns they have experienced both: a) at the time of diagnosis, and b) currently

Respondent Demographics

- 95 women with advanced breast cancer aged 45 or younger
 - 52.4% were between the ages of 36-45
- 81.1% were Caucasian
 - 6.7% were African-American, 6.7% were Latino, 3.3% were Asian
- From 26 states and Canada
- Most participants (80%) received health insurance through an employer insurance plan
 - 2.2% were uninsured
 - 80% currently had the same insurance that they had at diagnosis
- 64% were married at the time of diagnosis

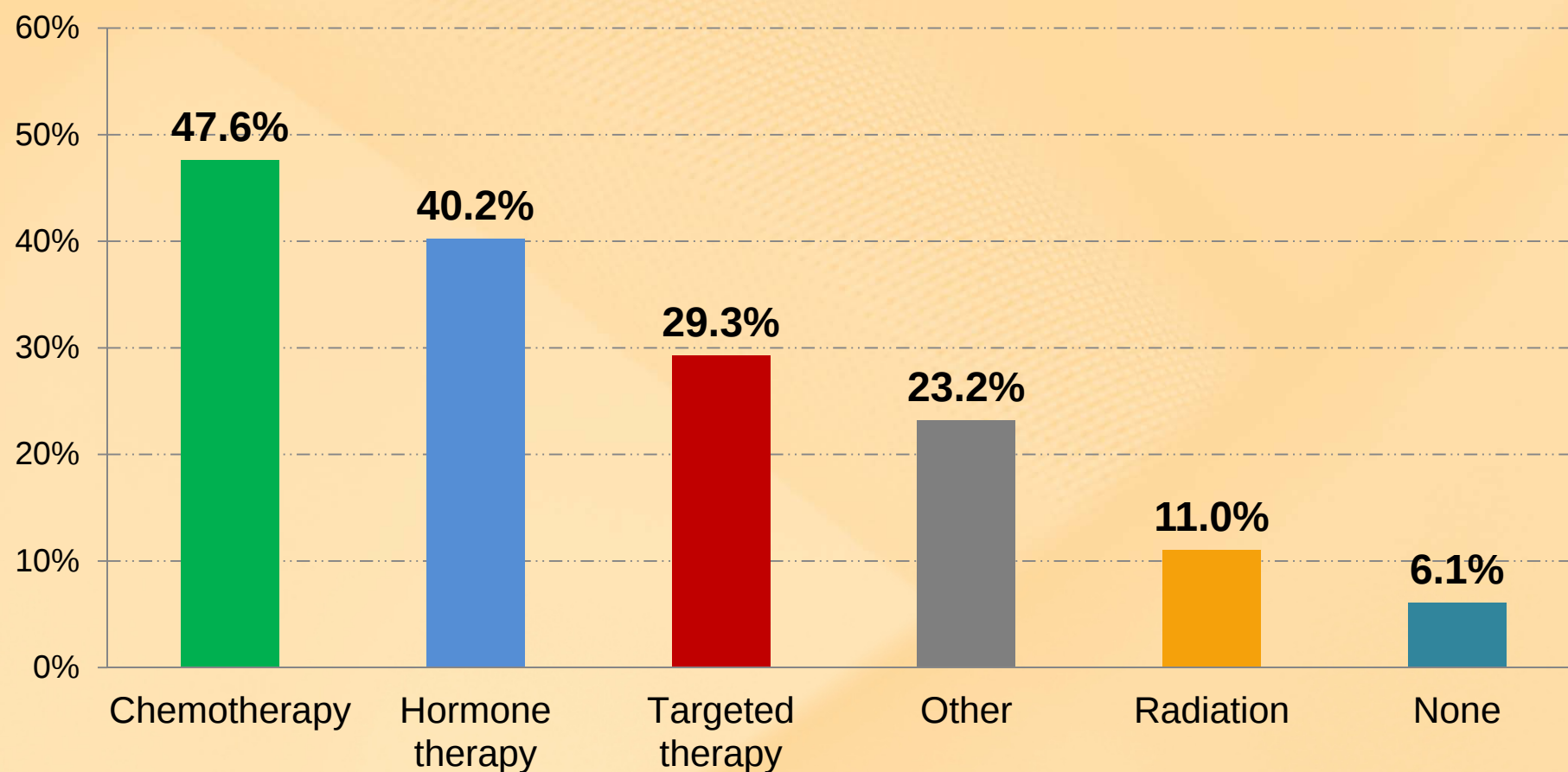
Time Since Diagnosis

When did you receive your advanced breast cancer diagnosis?



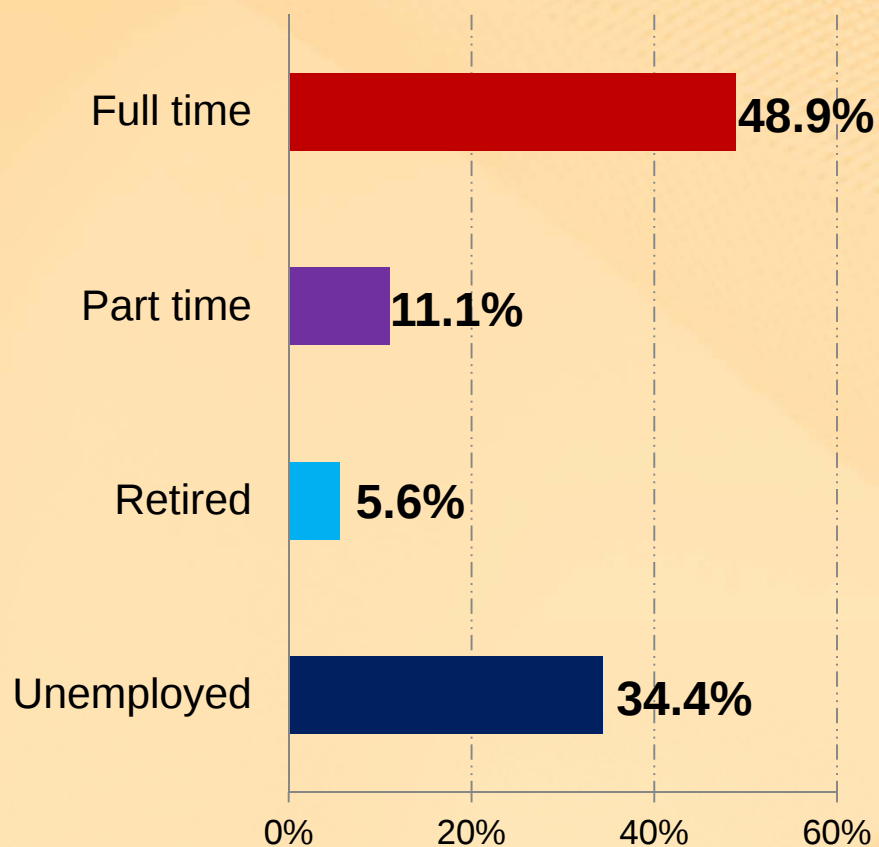
Cancer Treatment

What type of treatment are you currently undergoing?



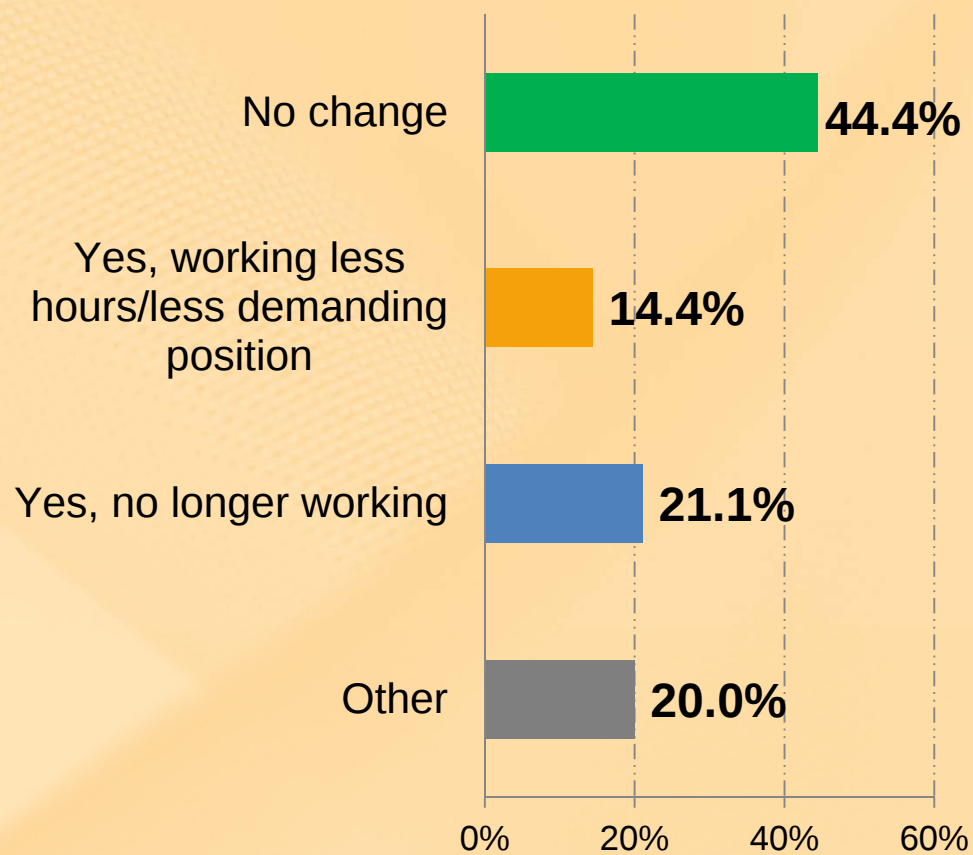
Employment Status

Current Employment Status



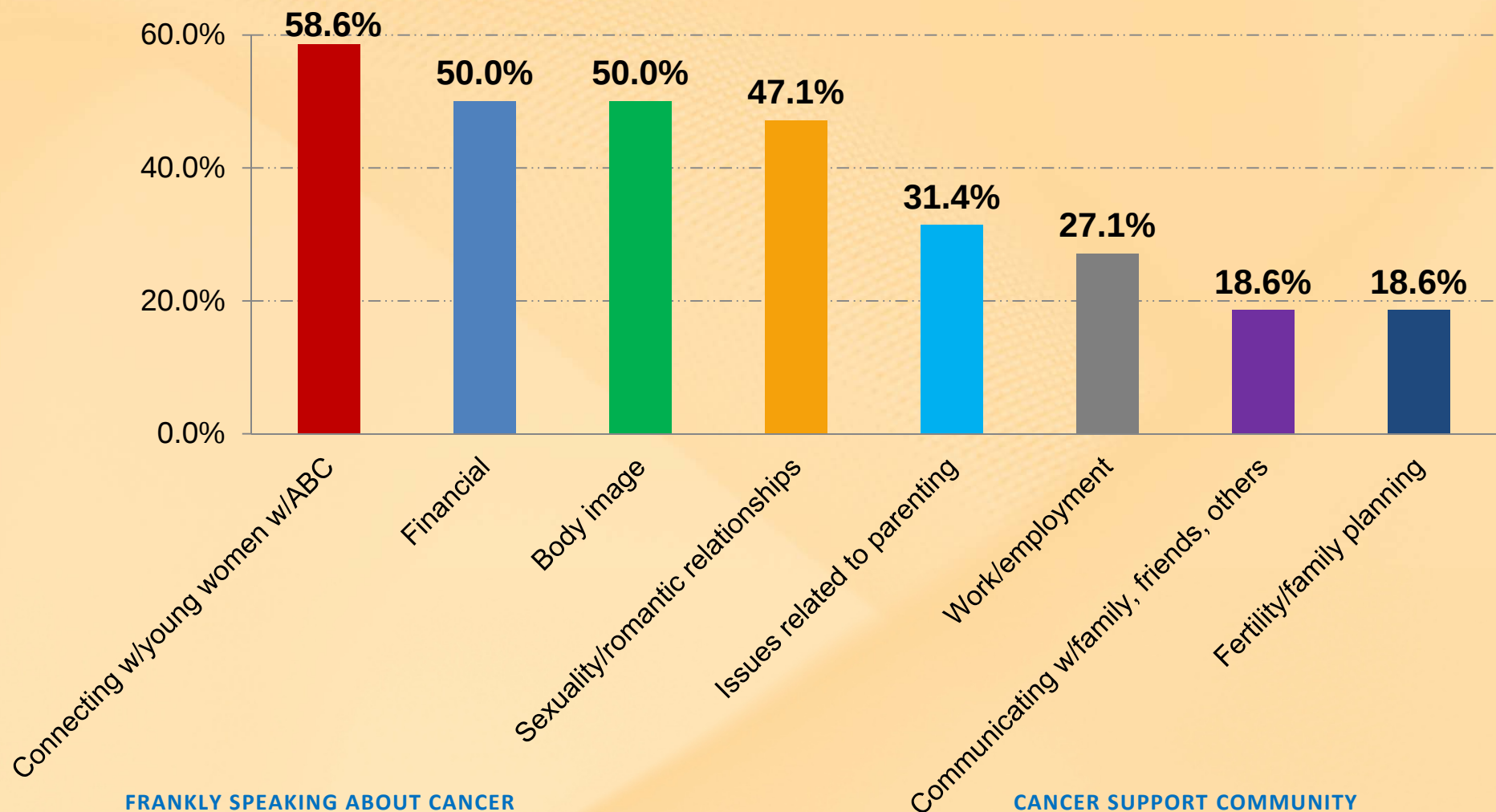
FRANKLY SPEAKING ABOUT CANCER

Change in Employment Since DX

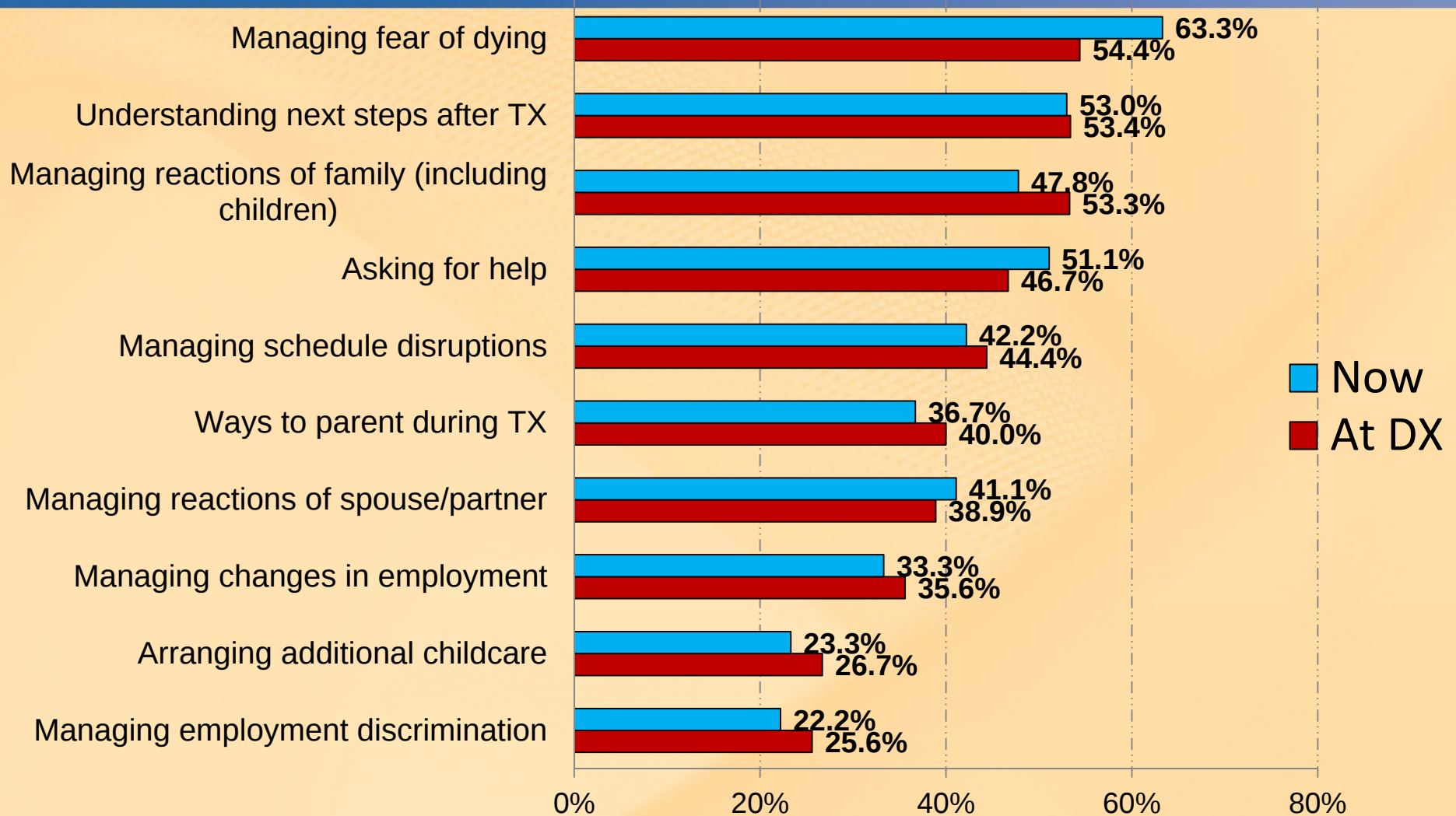


CANCER SUPPORT COMMUNITY

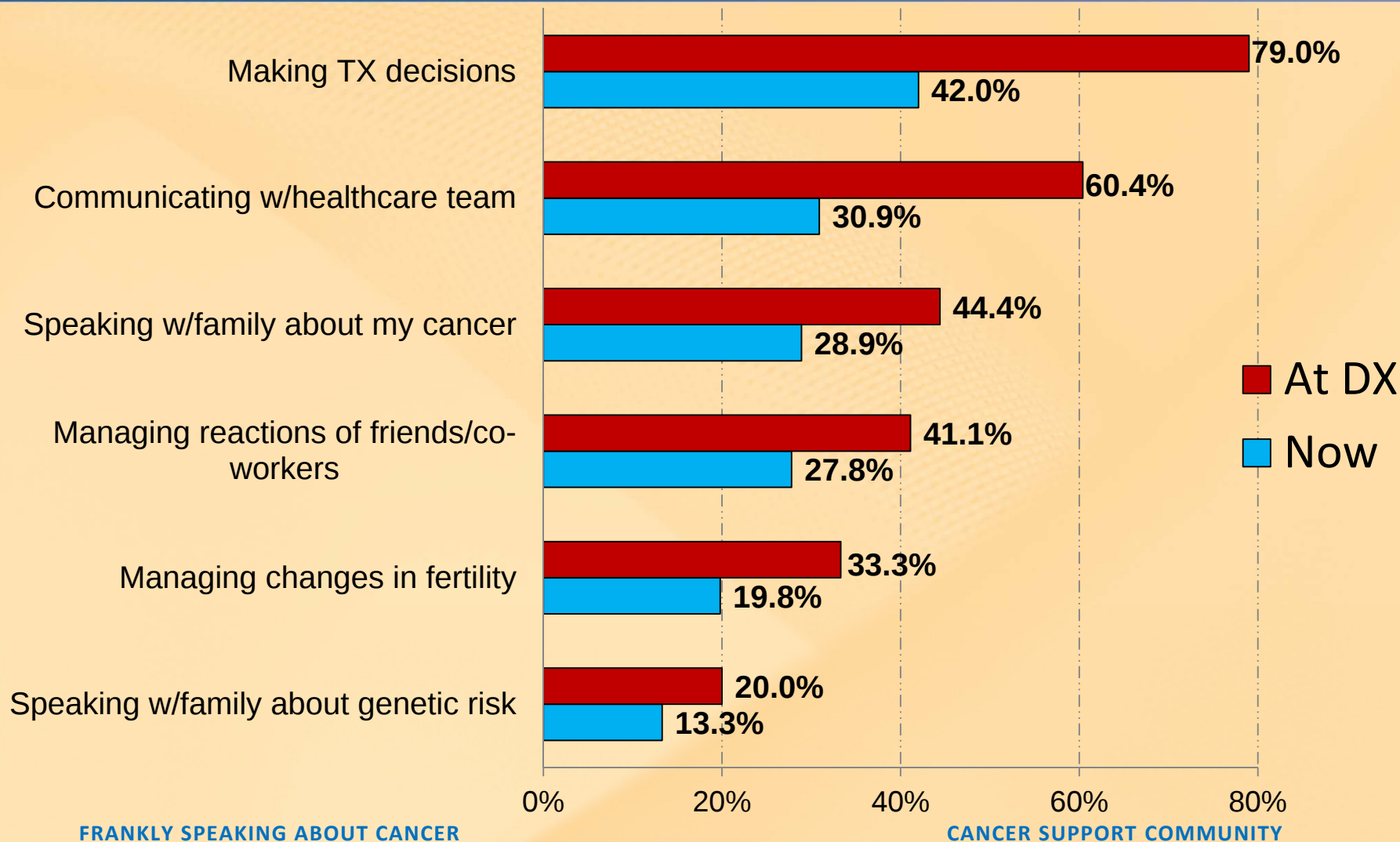
Difficulty of Obtaining Cancer Related Resources



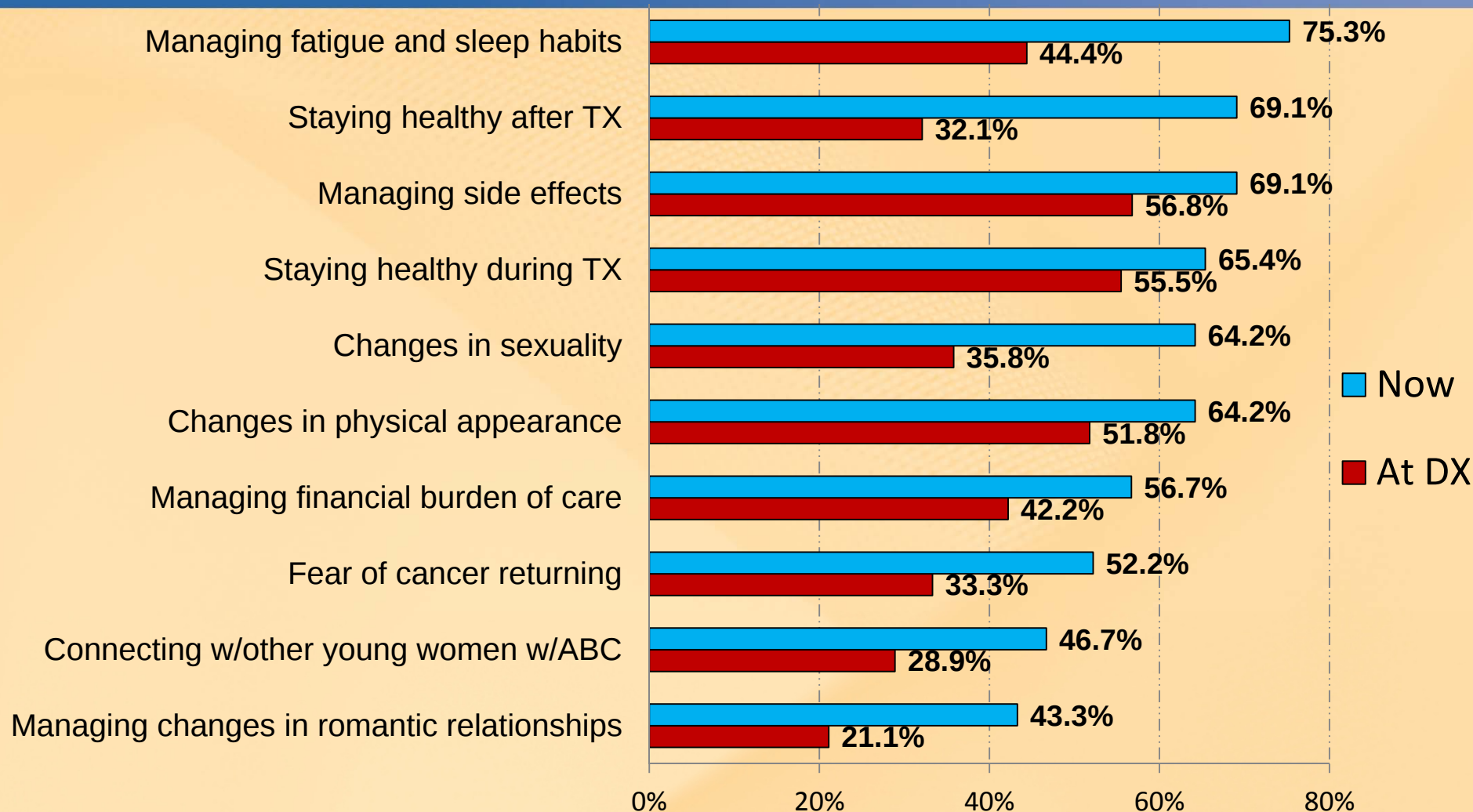
Psychosocial Concerns: Similar at Diagnosis vs. Now



Psychosocial Concerns: Decrease from Diagnosis vs. Now



Psychosocial Concerns: Increase from Diagnosis vs. Now



Unique Needs of Young Women with Metastatic Breast Cancer

Young women with advanced breast cancer face unique challenges:

- Range of unique psychosocial and informational needs
 - Interpersonal relationships
 - Asking for help
 - Staying healthy
 - Financial concerns
 - Employment issues
 - Managing side effects
 - Concerns about the future
 - Connecting with other young women with advanced breast cancer

Webinar for Young Women with ABC

Based on these findings, CSC and YSC developed a psychosocial webinar targeted to young women with advanced breast cancer to specifically address key issues, from survey. Topics covered were:

- Managing side-effects
 - Living everyday with the best quality of life
 - Asking for help and communicating your needs
 - Connecting with others
 - Relationships and intimacy
- Held on October 13th, 2011, Metastatic Breast Cancer Awareness Day
 - Post-Webinar Survey revealed:
 - Webinar well-received
 - Increased understanding of coping with relationship issues
 - A need to still connect with other young women with advanced breast cancer

Summary

- There are unique, often unmet needs in this population
- Survey responses indicate that psychosocial concerns may be under the radar of professionals, largest which continues to be the need to connect to other young women with ABC
- Continue to support program development and dissemination of resources geared to this population



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

Thank You

People with cancer who actively *participate* in their *care* along with their health care team will *improve* the quality of *their lives* and may enhance the possibility of *recovery*. People with cancer who *actively* participate in their care along with *their health* care team will improve the *quality* of their lives and may enhance the possibility of *recovery*.