

Encouraging 'Patient Active' in the treatment of Advanced Breast Cancer: Results from the Frankly Speaking About Advanced Breast Cancer Psychoeducational Program

Ivy Ahmed, MPH, Natalie Haskins, MAT, Marni S. Amsellem, PhD

ABSTRACT

The Cancer Support Community's (CSC) Frankly Speaking About Advanced Breast Cancer, a comprehensive psychosocial education program created for women diagnosed with metastatic breast cancer and their families, provides valuable information about current treatments, side-effect management, and social and emotional challenges of an advanced breast cancer diagnosis. The program's clinically facilitated evidence-based education workshops have reached over two thousand patients and caregivers since its inception in 2006. Materials and workshop content were developed within the framework of the Patient Active Concept®, aiming to empower patients to become actively engaged with their healthcare team.

Participants from over 100 workshops from 2006-2009 completed program evaluations (77% response rate) and provided self-report data on factors including pre- and post-workshop knowledge, and intentions for patient-provider communication post-workshop. Taken together, findings from the post-workshop evaluations demonstrate how teaching patient empowerment can affect intention to become active participants in care for advanced breast cancer.

BACKGROUND

CANCER SUPPORT COMMUNITY

The Cancer Support Community (uniting The Wellness Community (TWC) and Gilda's Club Worldwide) is a non-profit organization that provides free emotional support and education for cancer patients and their loved ones. CSC is an international, non-profit organization that provides free support, education and hope to people with cancer and those who care for them.

PATIENT ACTIVE CONCEPT

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

ABOUT THE PROGRAM

TWC launched this program, the first of its kind, in 2006, and is comprised of professionally-led workshops held nationwide, widely-disseminated print materials, and web-based content. The program receives support from GlaxoSmithKline, AstraZeneca, and Abraxis, and was launched in partnership with Living Beyond Breast Cancer (LBBC).

Frankly Speaking About Advanced Breast Cancer (ABC):

- Provides sound clinical information in easy-to-understand terms.
- Clarifies scientific advances for advanced breast cancer diagnosis and treatment.
- Provides tools to improve communication for trusting and productive relationships among advanced breast cancer patients, family members and medical professionals.
- Provides tools that enable patients to better manage emotional and physical side effects of advanced breast cancer for a better quality of life.
- Empowers people affected by advanced disease to ask and discuss important and personal questions with their health care team, and loved ones.
- Engages and creates a supportive community of survivors – where people affected by advanced breast cancer can share thoughts and feelings to better cope with the challenges, successes, and life lessons that cancer brings.

PROGRAM OUTREACH

The ABC program is ongoing; data analyzed encompasses through 2009:
Over 100 workshops nationwide
Over 2,000 workshop attendees
Over 36,000 website hits for program materials or information
Over 26,000 kits and educational booklets distributed

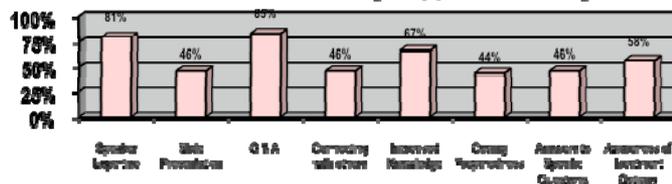
"I am so happy I found out about this and was able to attend it. Thank you!"

-TWC Workshop Participant

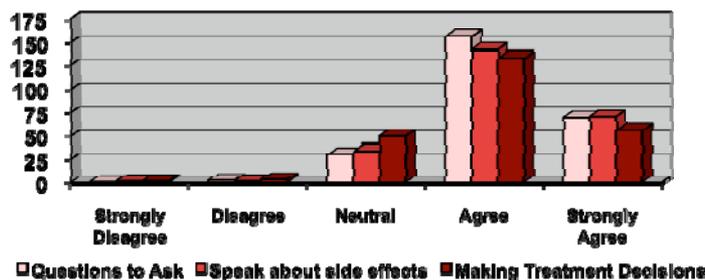
"This workshop was comforting and made me feel better about myself and my treatment."

-CSC Workshop Participant

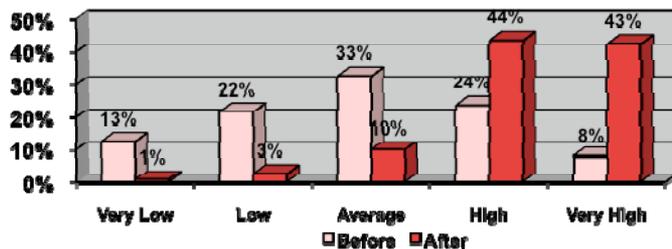
Most Valuable Aspect(s) of Workshop



Participant Intentions regarding Healthcare and Involvement



Change in Knowledge about Advanced Breast Cancer



SURVEY GOALS AND METHODS

The **purpose** of the post-Advanced Breast Cancer (ABC) workshop evaluation is:
➢ To understand the unique needs and experiences of persons living with ABC
➢ To assess whether the ABC Workshop is associated with gains in patient empowerment and communication, as guided by the Patient Active Concept

The evaluation assessed:

- Demographics
- Attendee type (survivor, caregiver, professional)
- Baseline and post-workshop ABC knowledge
- Specific changes in knowledge, attitudes, and behavioral intention
- General perceptions of ABC
- ABC information-seeking
- Cancer-related social support
- Cancer history; other aspects of their cancer diagnosis and treatment
- Overall evaluation of workshop

Most participants (77%) completed a survey post-workshop.

RESULTS OF POST-WORKSHOP SURVEY

- ❖ 90% of participants reported gaining a high/ very high level of knowledge about advanced breast cancer-- significant increases compared with pre-workshop levels (p <.01)
- ❖ 90% reported intent to increase communication with their clinical team
- ❖ Most reported that as a result of the workshop, they had a better understanding of questions to ask their health care team (91%), and felt confident in their ability to make decisions with their healthcare team (76%)
- ❖ 85% of attendees felt confident that they, after the workshop, could speak knowledgeably about side effects of cancer treatment with their doctor, a key issue in regards to quality of life
- ❖ **97% of attendees recommend the workshop to other women and families coping with advanced disease**

SUMMARY

Workshop data indicate the success of this program and support the need for materials and programs such as this one to address the unique needs of women with advanced breast cancer and their loved ones.

For more information about this program, please visit:
<http://www.cancersupportcommunity.org>

Acknowledgement of Funding:
GlaxoSmithKline, AstraZeneca, and Abraxis

Demographics of Workshop Attendees

- Attendees were cancer patients, caregivers, and professionals:
 - 61% women with breast cancer/ survivors
 - 11% healthcare professionals
 - 17% spouse/partner or family member
 - 8% were friends
- 60% were Caucasian, 36% African-American, 2% Hispanic
- 43% were between 56-69 years of age
- 37% were between 40-45 years of age
- 10% were under 40 years of age

CANCER SUPPORT COMMUNITY