

A DECADE OF SUCCESSFUL OUTREACH AND CANCER PATIENT EDUCATION: FRANKLY SPEAKING ABOUT CANCER (FSAC)

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Cancer Support Community

Abstract

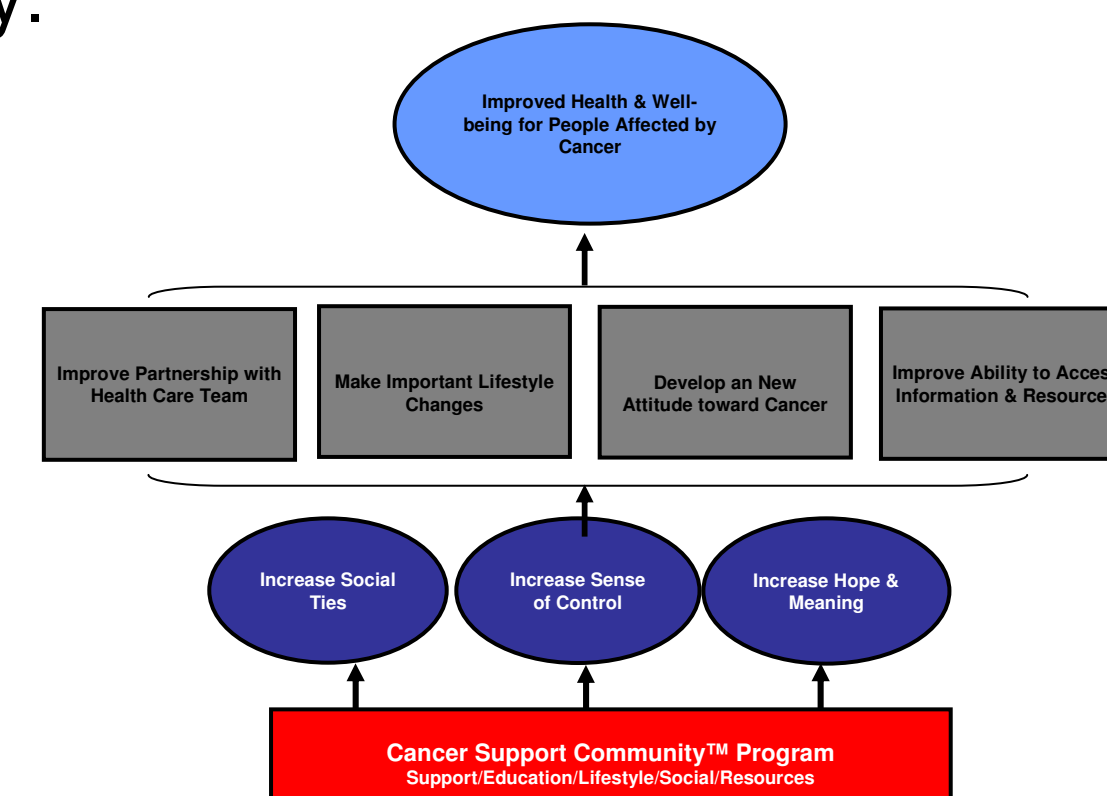
- For the past decade, The Cancer Support Community (CSC) has developed, implemented, and disseminated *Frankly Speaking About Cancer (FSAC)*, an educational series consisting of programs providing an in-depth look into a variety of concerns faced by cancer patients and their loved ones. The model for the program combines evidence-based, patient-focused educational booklets, professionally-led workshops held nationwide, and tailored web-content available on CSC's website. All of the materials and workshops are free-of-charge and come ready to implement in any community or hospital setting. Topics span a variety of tumor types and commonly-faced issues.
- A primary contributor to FSAC's success has been how the programs have been implemented, both at CSC-affiliates nationwide as well as in community health or medical settings, enabling outreach to urban and rural communities alike, with discussions tailored to the community at hand. Program evaluations from over 27,800 workshop attendees indicate that over 99% would recommend the FSAC workshop to others facing similar issues.

Cancer Support Community

- The Cancer Support Community [uniting The Wellness Community and Gilda's Club Worldwide] is a non-profit organization that provides free emotional support and education for cancer patients and their loved ones.

Patient Empowerment 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.



Program Background

About the FSAC Program

- Launched in 2001 with the support of funding from pharmaceutical companies, the FSAC program sought to provide in-depth coverage of topics of relevance to those affected by cancer, guided by the Patient Active concept, that are often not otherwise available in a comprehensive format. Program topics are both cancer-specific (e.g. advanced breast cancer) and of interest to a broad audience (e.g. coping with the cost of care). Program materials represent the most up-to-date content and are updated to reflect new advances in knowledge, and include:
 - Web-based materials
 - Booklets
 - Professionally-led workshops held across the country
 - Online radio series and Podcasts

Those affected by cancer typically account for up to 70% of workshop participants, with the second largest group of attendees being family members and spouses



Every FSAC Program

- Provides sound clinical information in easy-to-understand terms.
- Clarifies scientific advances for specified cancer diagnosis and treatment.
- Provides tools to improve communication for trusting and productive relationships among cancer patients, family members and medical professionals.
- Provides tools that enable patients to better manage emotional and physical side effects of cancer for a better quality of life.
- Empowers people affected by cancer 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 cancer can share thoughts and feelings to better cope with the challenges, successes, and life lessons that cancer brings.

FSAC Program Outreach & Evaluation

FSAC Program Outreach through 2010

- Over 805 workshops nationwide
- Over 28,000 workshop attendees
- Over 1 million people have sought tailored information from the website
- Over 450,000 kits and educational booklets distributed
- Podcasts, media coverage, partners, etc.
- 60,000 online radio listeners



Evaluation

- Formal evaluation of program workshops has been conducted with over 27,800 program attendees across workshops across programs (>70% response rate, averaged across topics)
- Evaluation results highlight the positive impacts of the workshops and strongly support that the educational model is effective across all topics
- Over 95% of workshop participants reported increased knowledge after attending the workshop, across programs
- Most participants (97%) endorsed the critical role of communicating openly and honestly with their medical team
- Nearly all participants (99%) stated that they would recommend the program to others facing similar issues

"I liked the personal group setting. The facilitator did a good job of making everyone feel comfortable about talking."
—TWC Workshop Participant, FSAC Coping with the Cost of Care

"The booklet is exceptional!"
—TWC Workshop Participant, FSAC Coping with the Cost of Care

"This workshop was comforting and made me feel better about myself and my treatment."
—CSC Workshop Participant, FSA Advanced Breast Cancer

FSAC Programs

Frankly Speaking About Advanced Breast Cancer
Frankly Speaking About Colorectal Cancer
FSAC: Spotlight on Breast Reconstruction
FSAC: Lung Cancer
FSAC: Spotlight on Liver Cancer
Frankly Speaking About Cancer Treatment
FSAC: New Discoveries
FSAC: Coping with the Cost of Care
FSAC: Melanoma
Frankly Speaking About Lymphoma*
Patient Active Guide to Living with Ovarian Cancer*
Cancer Vaccines*
Open to Options, Cancer Clinical Trials*
• Not currently being run

More Information on the FSAC Program

Contact the CSC: 1-888-793-9355
www.cancersupportcommunity.org

Future Directions

- Continuing to meet the informational and support needs of cancer patients and their loved ones
- Continued program evaluation and review of program data across topics
- Expanding the FSAC program series to address other tumor types and topics

Acknowledgement of Funding

ABC: GlaxoSmithKline, AstraZeneca, and Abraxis;
CRC: AZ, Roche; Cost: Genentech, Eli Lilly;
Cancer Treatment: Amgen; Lung: GSK, AZ, Lilly;
Lymphoma & Ovarian: GSK; Clinical Trials: GM and Genentech; Vaccines: Sanofi Aventis & EMD;
New Discoveries: Genentech.



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A primary contributor to FSAC's success has been how the programs have been implemented, both at CSC-affiliates nationwide as well as in community health or medical settings, enabling outreach to urban and rural communities alike, with discussions tailored to the community at hand. Program evaluations from over 27,800 workshop attendees indicate that over 99% would recommend the FSAC workshop to others facing similar issues. Similarly, over 95% across program types report a significant gain in knowledge in content from attending the workshop. Program materials are frequently updated to reflect the most current information, and new FSAC programs are developed to meet otherwise unmet needs of the cancer patients and their loved ones. Future directions of the FSAC programs include continuing to meet the informational and support needs of cancer patients and their loved ones, and expanding the line to address other tumor types and topics.