



FRANKLY SPEAKING ABOUT CANCER: A NATIONAL MODEL OF SUCCESS FOR CANCER EDUCATION AND PATIENT EMPOWERMENT

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Abstract

For ten years, *Cancer Support Community* has developed and provided *Frankly Speaking About Cancer* (FSAC), an educational series offering an in-depth look into a variety of concerns faced by cancer patients and their loved ones. The FSAC model is guided by Social-Cognitive Theory, and combines educational booklets, professionally-led workshops, and tailored web-content to educate and empower those affected by cancer to become active partners with their healthcare team. FSAC topics span a variety of tumor types as well as commonly-faced issues.

In 2009, 1,195 FSAC workshop participants completed post-workshop evaluations (approximately 70% response rate, averaged across six workshop types). Across workshops, nearly all participants (98.3%) recommend the workshop to others facing similar concerns. All workshop participants reported a significant gain in knowledge about the topic post-workshop compared to pre-workshop levels ($F = 76.7, p < .01$). Workshop outcomes varied across topic, but large gains were seen in the critical role of communicating openly and being an active participant with their healthcare team.

Cancer Support Community (CSC)

The CSC is a non-profit organization that provides free emotional support and education for cancer patients and their loved ones.

FSAC: Program Background

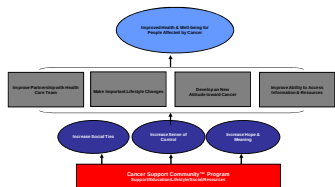
Launched in 2001 with unrestricted support from pharmaceutical companies, the FSAC program provides in-depth coverage of topics of relevance to those affected by cancer, guided by the Patient Empowerment concept, that are often not otherwise available in a comprehensive format.

Program topics are either cancer-specific or span across cancer diagnoses. Program materials, representing the most up-to-date content and updated with new advances, include:

- Web-based materials
- Booklets
- Professionally-led workshops held across the country
- Online radio series and podcasts

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.



FSAC Program Evaluation

In 2009, six FSAC programs ran nationwide. Program attendees were invited to complete a post-workshop evaluation onsite. Workshops topics included: Advanced Breast Cancer, Colorectal Cancer, Liver Cancer, New Discoveries, Coping with the Cost of Care, and Cancer Treatment. 1,195 workshop participants completed evaluations (~70% response rate, averaged across workshop topics).

Evaluations addressed

- Demographics and cancer history
- Participant satisfaction
- Pre- and post-workshop knowledge on workshop topic
- Concerns and topic-related experiences of workshop participants
- Gains in patient empowerment from attending workshop

Attendees

- 80% of workshop attendees were Caucasian
- 5% were African-American; 6.5% were Hispanic
- 44.5% were between 56-69 years old
- Workshop attendees included:
 - Individuals diagnosed with cancer/ survivors (65.2%)
 - Family members (6.7%)
 - Spouse/ partner (11.7%)
 - Health care professionals (9.9%)
 - Other (6.5%)

Participant Satisfaction

Nearly all participants (98.3%) would recommend the workshop to others facing similar concerns.

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

—Workshop Participant, FSAC Advanced Breast Cancer

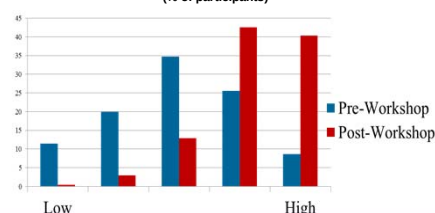
"I liked the personal group setting. The facilitator did a good job of making everyone feel comfortable about talking."

—Workshop Participant, FSAC Coping with the Cost of Care

Participant Knowledge

Participants rated their level of knowledge of the topic addressed in the workshop on a 5-point scale. Workshop participants reported a significant gain in knowledge about the workshop topic, post-workshop compared to pre-workshop levels ($F = 76.7, p < .01$).

Changes in Workshop-Related Knowledge
(% of participants)



Patient Empowerment

Workshop participants rated on a 5-point scale (strongly disagree to strongly agree) whether, as a result of attending the workshop, they plan to:

- Increase communication with healthcare team
- Discuss side-effects with/ ask questions to healthcare team
- Ask about clinical trials that might be relevant to them

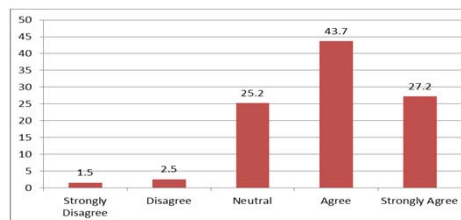
Large gains were seen in the critical role of communication with the healthcare team and being an active participant with one's healthcare team.

Most workshop attendees reported increased self-efficacy in:

- Asking questions to their healthcare team (88%)
- Asking questions to inform treatment decisions (82%)
- Discussing side effects with their doctors (88%)

Most participants (71%) reported planning to discuss clinical trial options with their health care team.

Intention to Discuss Clinical Trial Options
(% of participants)



FSAC Program Outreach

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.

FSAC Program Reach

- Over 960 workshops nationwide
- Over 28,000 workshop attendees
- Over 1 million people have sought tailored information from the website
- Over 500,000 kits and educational booklets distributed
- Over 250,000 online radio listeners

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 running

For More Information Contact the CSC: 1-888-793-9355

www.cancersupportcommunity.org



Summary

- Evaluation data highlight the positive impacts of the workshops across all topics, particularly that nearly all participants recommend that others attend the workshop
- Results strongly support that this patient empowerment model is an effective model for cancer patient education

Future Directions

- Continue to meet the informational and support needs of cancer patients and their loved ones
- Continue program evaluation and review of program data across topics
- Continue to use evaluation results to inform future iterations of program
- Expand the FSAC program series to address other tumor types and topics

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ABC: GlaxoSmithKline, AstraZeneca, Abraxis/Celgene; & Eisai.
Breast Reconstruction: Mentor. **CRC:** AZ & Roche. **COC:** Genentech; Eli Lilly; & Celgene. **Cancer Treatment:** Amgen.
Lung: GSK; AZ; & Lilly. **Liver:** Bayer HealthCare & Onyx Pharmaceuticals. **Lymphoma & Ovarian:** GSK. **Melanoma:** BMS. **Clinical Trials:** GM & Genentech. **Vaccines:** Sanofi Aventis & EMD. **New Discoveries:** Genentech & Pfizer.



Frankly Speaking About Cancer (FSAC): A national model of success for cancer education and patient empowerment

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In 2009, 1,195 FSAC workshop participants completed post-workshop evaluations (approximately 70% response rate, averaged across six workshop types). Workshops topics included: Advanced Breast Cancer, Colorectal Cancer, Liver Cancer, New Discoveries, Coping with the Cost of Care, and Cancer Treatment. Nearly 80% of workshop attendees were Caucasian, and 44.5% were between 56-69 years. Across workshops nearly all participants (97%) would recommend the workshop to others facing similar concerns. All workshop participants reported a significant gain in knowledge about the topic post-workshop compared to pre-workshop levels ($F = 76.7$, $p < .01$).

Workshop outcomes varied across topic, but large gains were seen in the critical role of communicating openly and being an active participant with their healthcare team. Most workshop attendees (88%) reported increased self-efficacy in being able to ask questions to their healthcare team to inform treatment decisions and discussing side effects with their doctors. Workshop results strongly suggest the educational model is an effective model for cancer patient education. Workshop evaluation results are being used to inform future iterations of program.