

CLOSING THE GAP: MEETING THE NEEDS OF LIVER CANCER PATIENTS THROUGH EDUCATION

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Program Rationale

The American Cancer Society estimates that in 2012, 28,720 individuals will be diagnosed with liver cancer in the U.S. While liver cancer incidence is relatively low compared to other cancers, it is the fifth leading cause of cancer deaths among males in the U.S. Most liver cancer cases are diagnosed at advanced stages because many patients are asymptomatic earlier. To meet the needs of this population, the Cancer Support Community (CSC) presented a professionally-led education and support program in 2011, *Frankly Speaking About Cancer: Spotlight on Liver Cancer*.

Program Context and Content

Launched in 2009, *Frankly Speaking About Cancer: Spotlight on Liver Cancer* is part of the Frankly Speaking About Cancer (FSAC) educational series developed by CSC. FSAC programs provide 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. FSAC program materials, representing the most up-to-date content, include:

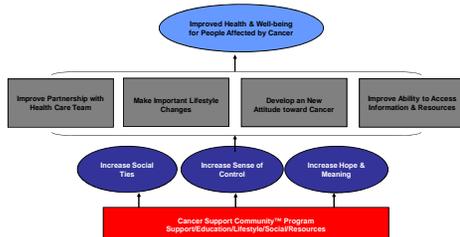
- Web-based materials
- Booklets
- Online radio series and podcasts
- Professionally-led workshops

FSAC: Spotlight on Liver Cancer Reach

- Since 2009, over 10,000 patient education booklets have been distributed
- In 2011, CSC web content on liver cancer received over 188,000 page views
- 7 patient education workshops held throughout the country serving over 100 attendees in 2011

Patient Empowerment Concept

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.



Workshop Evaluation

Evaluation addressed:

- Demographics and cancer history
- Satisfaction with workshop
- Pre- and post-workshop knowledge about liver cancer
- Participants concerns and experiences related to liver cancer
- Empowerment and patient/provider communication:
 - Respondents rated on a 5-point scale whether, as a result of attending the workshop, they plan to:
 - Increase communication with health care team
 - Discuss side-effects/ ask questions to health care team
 - Ask about clinical trials

Respondent Characteristics

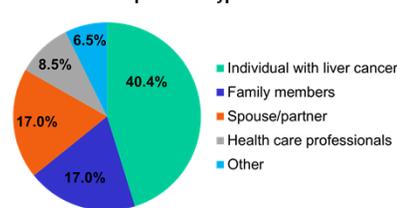
(n= 47)

- 38.3% were Caucasian
- 4.3% were African-American
- 48.9% were Hispanic
- 6.4% Asian
- Average age was 57.3 years

Respondents included:

- Individuals with liver cancer (40.4%)
- Family members (17%)
- Spouse/ partner (17%)
- Health care professionals (8.5%)
- Other (6.5%)

Respondent Type



Workshop Satisfaction

Overall, respondents reported they were very satisfied with the workshop. Nearly all (97.7%) reported that they would recommend the workshop to others affected by liver cancer. *Examples of feedback include:*

"As usual, another great workshop!"
—Participant, CSC San Francisco Bay Area

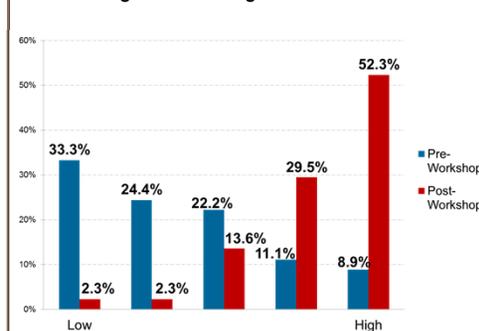
"Most helpful and informative - will tell others!"
—Participant, CSC Redondo Beach

"Excellent presentation by the doctor."
—Participant, CSC Miami

Knowledge Gains

Respondents rated their level of knowledge of liver cancer on a 5-point scale. Respondents reported a significant gain in knowledge about liver cancer, post-workshop compared to pre-workshop levels. Most respondents (81.8%) reported gaining a high or very high level of knowledge about liver cancer, with significant increases compared with pre-workshop levels ($p < .01$).

Changes in Knowledge about Liver Cancer

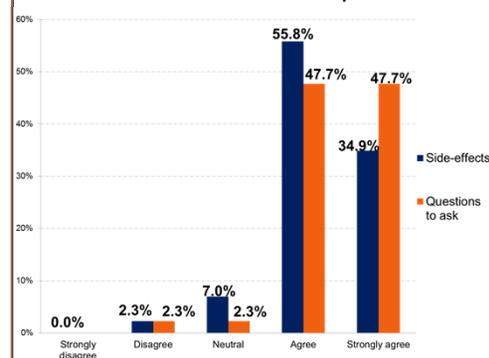


Communication Gains

Most respondents reported increased self-efficacy in:

- Asking questions to their health care team (95.4%)
- Discussing side effects of cancer treatment with their doctors (90.7%), a key issue in regards to quality of life
- Discussing clinical trial options with health care team (80%)

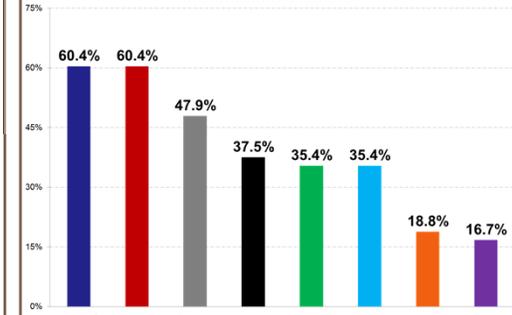
Communication-Related Workshop Outcomes



Information-Seeking

More than half of respondents reported seeking information about liver cancer from their health care team and online.

Information Sources



- Half of respondents are currently in a support group
- 71% of respondents had not attended a CSC-coordinated workshop before

Summary

- Most respondents reported increased knowledge from attending the workshop and recommend that others affected by liver cancer attend
- Large gains were seen in the critical role of being an active participant with one's health care team
- Respondents reported increased self-efficacy in communicating with their health care team about the treatment of liver cancer and side-effect management
- Data indicates the continued relevance of this program for those affected by liver cancer

For More Information contact CSC: 1-888-793-9355 or www.cancersupportcommunity.org

Future Directions

- Program results suggest the need for continued education programs focused on this patient population as well as greater dissemination nationwide of existing programs for those affected by liver cancer
- Continue to review program data and use evaluation results to inform future iterations of program

Acknowledgement of Funding

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Background

The American Cancer Society estimates that in 2012, 28,720 individuals will be diagnosed with liver cancer in the U.S. While liver cancer incidence is relatively low compared to other cancers, it is the fifth leading cause of cancer deaths among males in the U.S. Most liver cancer cases are diagnosed at advanced stages because many patients are asymptomatic earlier.

To meet the needs of this population, the Cancer Support Community (CSC) developed an education and support program, *Frankly Speaking About Cancer: Spotlight on Liver Cancer*. This evidence-based program combines patient educational booklets, professionally-led workshops, and tailored web content. Since 2009, over 10,000 patient education booklets have been distributed to those in need. In 2011, the CSC web content on liver cancer received over 188,000 page views. Seven patient education workshops have been held throughout the country, with over 100 attendees.

In 2011, 47 workshop attendees completed workshop evaluations. The average age of attendees was 57.3 years, and 40.4% were people with liver cancer. Nearly half (48.9%) were Hispanic and 38.3% were Caucasian. Nearly all (97.7%) attendees would recommend the workshop to others and had reported an increase in knowledge on this topic from attending this educational program. In addition, respondents reported increased self-efficacy in communicating with their healthcare team about the treatment of liver cancer (95.4%) and side-effect management (90.7%). Program results suggest the need for continued education programs focused on this patient population as well as greater dissemination nationwide of existing programs for those affected by liver cancer.