Meeting the Educational Needs of Older Adults with Cancer: Results From a National Sample Of Program Attendees



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Cancer Support Community Mission

To ensure that all people impacted by cancer are:

- Empowered by Knowledge
- Strengthened by Action
- Sustained by Community



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Frankly Speaking About Cancer In-Person Workshops

- One component of CSC's Frankly Speaking About Cancer programs
- "Workshops in a box" are prepared by CSC HQ's Education Dept.
- Workshops are held by CSC's 50 local affiliates (Gilda's Clubs & Cancer Support Communities) and 5 hospital affiliates
 - Local presenter (often oncologist, oncology nurse practitioner, social worker or licensed counselor, depending on topic)
 - Have been held for over a decade
 - Since 2009, evaluations were designed to be able to compare answers to questions over time



Frankly Speaking About Cancer: Program Scope and Delivery

Frankly Speaking About Cancer program topics are tumor type-specific or cross-tumors:

Metastatic Breast Cancer Metastatic Skin Cancer

Coping with Cost of Care Colorectal Cancer

Liver Cancer Lung Cancer

Multiple Myeloma New Discoveries

Breast Reconstruction Immunotherapy

Cancer Treatment and Side Effects

Program products:

Print & digital publications (eBooks, pdf)

Web-based materials

Web pages, videos

Webinars (live & archived)

Online radio series

eLearning courses (pilot testing)

Professionally-led, in-person workshops held across US



FSAC Program Series Overview

- Frankly Speaking About Cancer (FSAC) Workshops:
 - Provide easy to understand in-depth coverage of topics relevant to those affected by cancer
 - Guided by Patient Empowerment Model
 - Program goals: To educate and to empower patients and caregivers on workshop topic
 - Up-to-date content and reflect new advances in knowledge

Psychoeducational Needs of Older Adults

- As with many subpopulations affected by cancer, older adults (65+) facing cancer often have significant informational and psychoeducational needs.
- According to a 2012 systematic literature review published in Supportive Care, "The level of unmet needs in newly diagnosed older cancer patients after the start of treatment is high, and the most common needs are psychological and information needs."
- Studies have found that health education for older adult oncology populations can be beneficial in terms of educational outcomes (e.g. Dong et al, 2013).

Population-specific considerations

- Factors that should be taken into account with this population include:
 - Auditory and visual deficits
 - Transportation and mobility considerations
 - Support system
 - Living arrangements
 - Availability of caregivers
 - Health literacy considerations
 - Attitudes and beliefs about cancer and health care in general

Purpose of Analyses

- To better understand how older adults diagnosed with cancer benefit from attending psychoeducational workshops in terms of program outcomes(e.g. gains in knowledge, patient-provider communication)
- To better understand how older adults are meeting their informational and support needs prior to attending the workshop.
- To highlight distinct needs psychosocial of older adults

Methods

- From 2010-2015, 10,492 FSAC workshop attendees across CSC's national affiliate network completed a post-program evaluation (75% response rate)
- The evaluation assessed a variety of demographic, cancer experience-related, and workshop outcomes, including:
 - Demographics
 - Cancer history (e.g. cancer and treatment types, time since diagnosis)
 - Cancer-related knowledge
 - Attendance in previous psychoeducational workshops
 - Current participation in support group
 - Usual sources of cancer-related support
 - Usual sources of cancer information
 - Caregiver-provider interaction
 - Overall workshop satisfaction

Participant Demographics

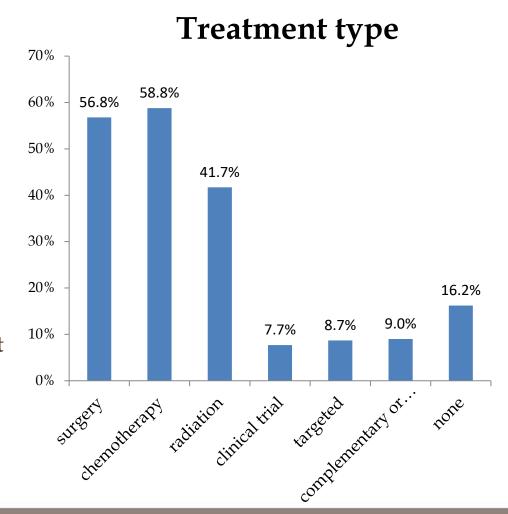
The current analyses highlight attendees with cancer aged 65 or older (n=2,178)

Of workshop attendees who are older adults:

- Most (66.9%) diagnosed with cancer/ survivor (the remainder were caregivers or healthcare providers)
- Racial Identification
 - 86.1% Caucasian
 - 3.5% Asian
 - 6.6% Black/ African-American
 - 2.2% Hispanic
 - 1% American Indian
- Gender: 72.7% female

Cancer history and treatment

- Type of Cancer
 - 51.1% breast cancer
 - 14.2% lung cancer
 - 2.7% melanoma/ skin cancer
 - 12.0% gynecologic
 - 3.1% multiple myeloma
 - 35.5% had metastatic disease
- Time since diagnosis
 - 32.3% first diagnosed within the past year
 - 30.4% diagnosed between 1-5 years ago
 - 29.1% diagnosed 5+ years ago

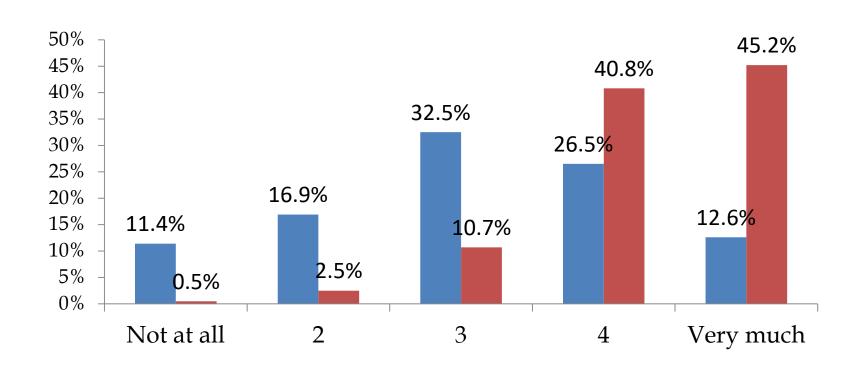


Distress and Support Utilization

Cancer-related distress among older adults with cancer:

- Depression
 - Over one quarter (26.4%) experience depression as a result of their cancer (vs. 33.1% overall attendees)
- Anxiety
 - Over one third (36.3%) experience anxiety as a result of their cancer (vs. 35.9% overall attendees)
- Psychoeducational/ support group utilization of older adults:
 - 44.1% currently are in support group (vs. 52.2% overall attendees)
 - 50.6% reported this was their first psychoeducational workshop (vs. 37.1% overall attendees)

Changes in Knowledge



■ Pre-Workshop

■ Post-Workshop

Results: Knowledge

• The majority of older adults diagnosed with cancer (86%) reported a 'high' or 'very high' level of knowledge after participating in the workshop

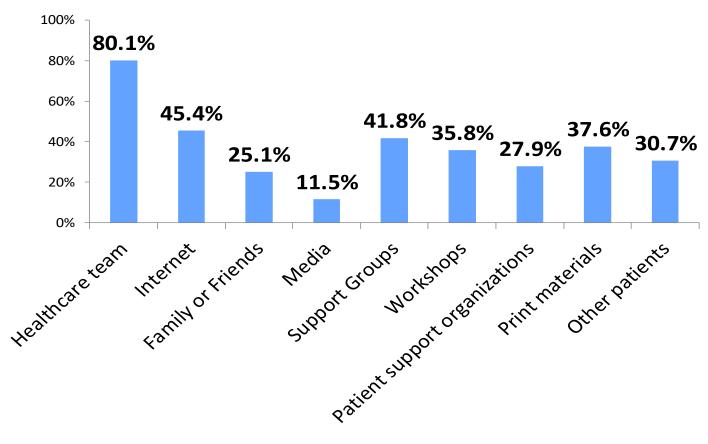
• Post-workshop levels among older adults were significantly higher than their preparticipation knowledge levels (F = 198.2, p<.01).

Results: Communication

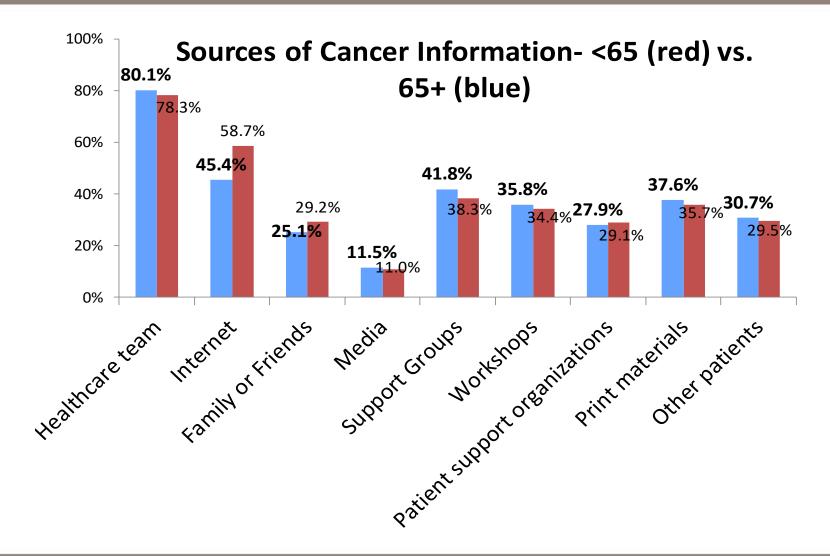
- After participating in the workshop:
 - 87.6% reported feeling confident in speaking with doctors about treatment options
 - 88.2% reported increased knowledge about treatment options
 - 88.6% feel more comfortable speaking about treatment side effects
 - 67.4% plan to discuss clinical trials with their health care team to see whether they would be an appropriate treatment option for them

Sources of Cancer Information

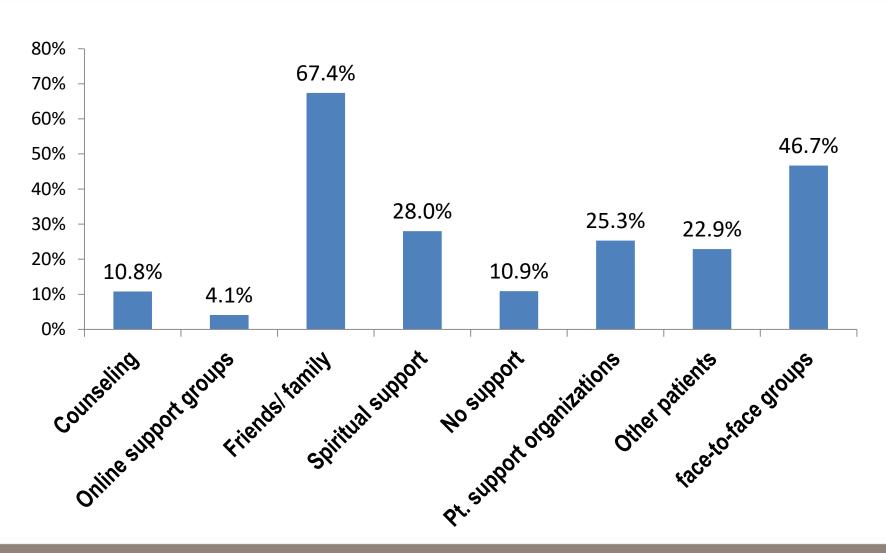




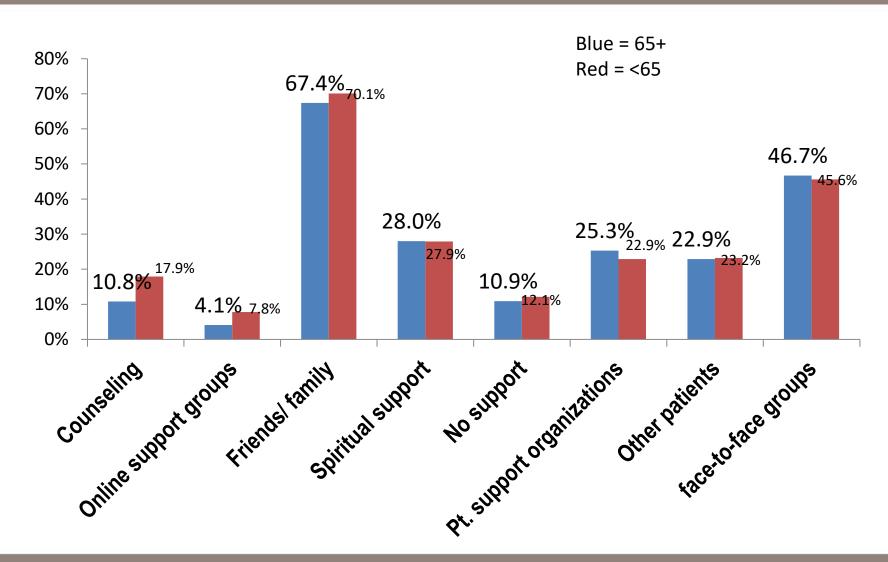
Cancer information: Age-based comparison



Sources of Emotional Support



Emotional support: Age-based comparisons



Results: Participant feedback

Representative feedback from workshop attendees with cancer, 65+:

- "Very informative, both presenters are very knowledgeable"
 -2015 FSAC Cancer Treatment & Side Effects participant (diagnosed with Sarcoma)
- "It was very interesting workshop-especially when people asked questions and the doctor gave excellent answers. Very informative!"
 -2009 FSAC New Discoveries participant
- "Very informative, well presented"
 -2104 FSAC New Discoveries participant (diagnosed with GIST)
- "Found this most helpful. After five years, I still had questions that were answered today"
 - -2012 FSAC Colorectal Cancer participant

Results: Workshop Recommendation

 Nearly all (95.4%) of older adults with cancer would recommend the workshop to others affected by cancer

• Similar to overall workshop participants (96.5%)

Discussion

- Results suggest the FSAC workshops successfully deliver comprehensive topic-specific information to older adults. Attendees report significant benefits from attending workshop.
- Results support the need to provide clear and relevant information and support to older adults affected by cancer
- Results from this sample of workshop attendees are encouraging, based on previous research demonstrating the unmet psychoeducational and support needs of older adults with cancer.

Generalizing the Findings

- While workshop participants were:
 - geographically diverse
 - spanned many cancer diagnoses
 - spanned newly diagnosed and long-term survivors
- Caution in generalizing to all older adults with cancer:
 - Participants chose to attend psychoeducational workshop
 - Perhaps participants more engaged, connected, already accessing services compared with older adults on whole
 - Racial minorities and less educated under-represented

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For More Information



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