

# Response To Psychoeducational Programs In Long-Term Cancer Survivors: Results From A National Sample



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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



# Cancer survivors: A growing population

- According to NCI's SEER registry database, Americans living with cancer increased from 3 million (1.5% of U.S. population) in 1971 to 9.8 million (3.5%) in 2001
- In 2016, > 15.5 million cancer survivors living in the US.
- Prevalence projected to be 20.3 million by 2026
- 67% of cancer survivors (10.3 million) in the US are longer-term survivors (5+ years past diagnosis)
- Experts recommend "A coordinated agenda for research and practice...to address cancer survivors' long-term medical, psychosocial, and practical needs across the survivorship trajectory."  
-De Moor et al (2013). *Cancer Epidemiol Biomarkers Prev*; 22(4); 561-70.

# Psychosocial Needs of Long-term Cancer Survivors

- As with many subpopulations affected by cancer, long-term survivors (2+ years from diagnosis) have unique needs, including:
  - Psychological needs, including fears of recurrence
  - Physical needs, including long-term side-effects from cancer treatment or other changes resulting from cancer
  - Social needs, including understanding the impact of cancer on relationships
  - Spiritual needs, including understanding the meaning of the cancer experience to the survivor\*

\* Ferrell BR (1996). The quality of lives: 1,525 voices of cancer. *Oncol Nurs Forum* 23:907-916.

# “Treatment Gap” in long-term cancer survivors

- A meta-analysis recently published in *The Lancet* of 43 studies comparing incidence of depression and anxiety in those diagnosed with cancer 2+ years ago vs. non-affected individuals found depression was 14% more common and anxiety 29% more common in cancer survivors (Mitchell et al, 2013)
- Despite increasing prevalence, needs of cancer survivors not always met, and not always receiving comprehensive follow-up
  - Little emphasis on any aspect of survivorship besides recurrence prevention prior to 2005 (IOM report on Survivorship)
  - Lack of reimbursement for support services or long-term follow-up
  - Despite growing awareness of the needs of long-term cancer survivors, awareness is not uniform across the board and is often low

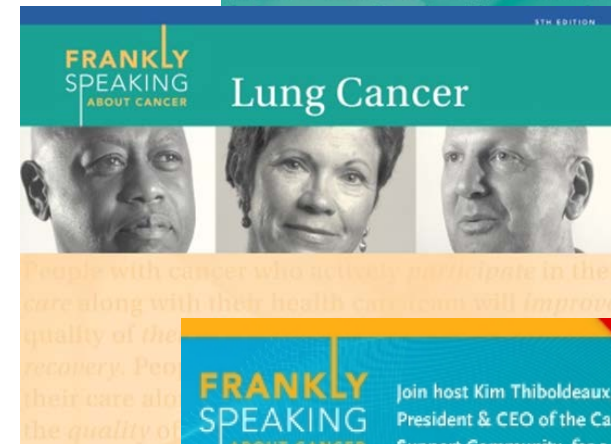
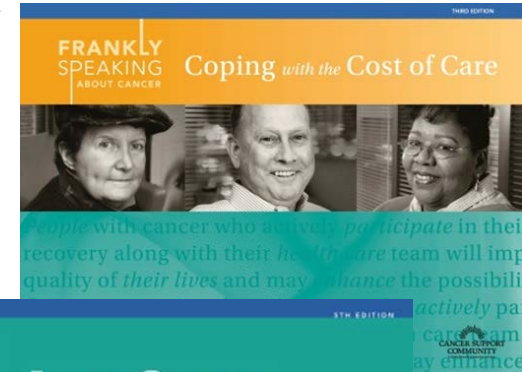
# Frankly Speaking About Cancer: Scope and Delivery

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



# 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
  - Topics are tumor type-specific (e.g. melanoma) or cross-tumors (e.g. immunotherapy, coping with the cost of care)
  - Up-to-date content and reflect new advances in knowledge





# Purpose of CSC's Analyses

- Many attendees of psychoeducational workshops through the Cancer Support Community (CSC) are long-term survivors
- The CSC sought to better understand the benefits of participating in a psychoeducational workshop in long-term survivors and to evaluate how the program has met their needs. Specifically:
  - To assess program outcomes (e.g. gains in knowledge, increases in patient-provider communication) in this population
  - To better understand how long-term cancer survivors are generally meeting their informational and support needs
  - To highlight distinct psychosocial needs of long-term cancer survivors who utilize services post-treatment

# Methods

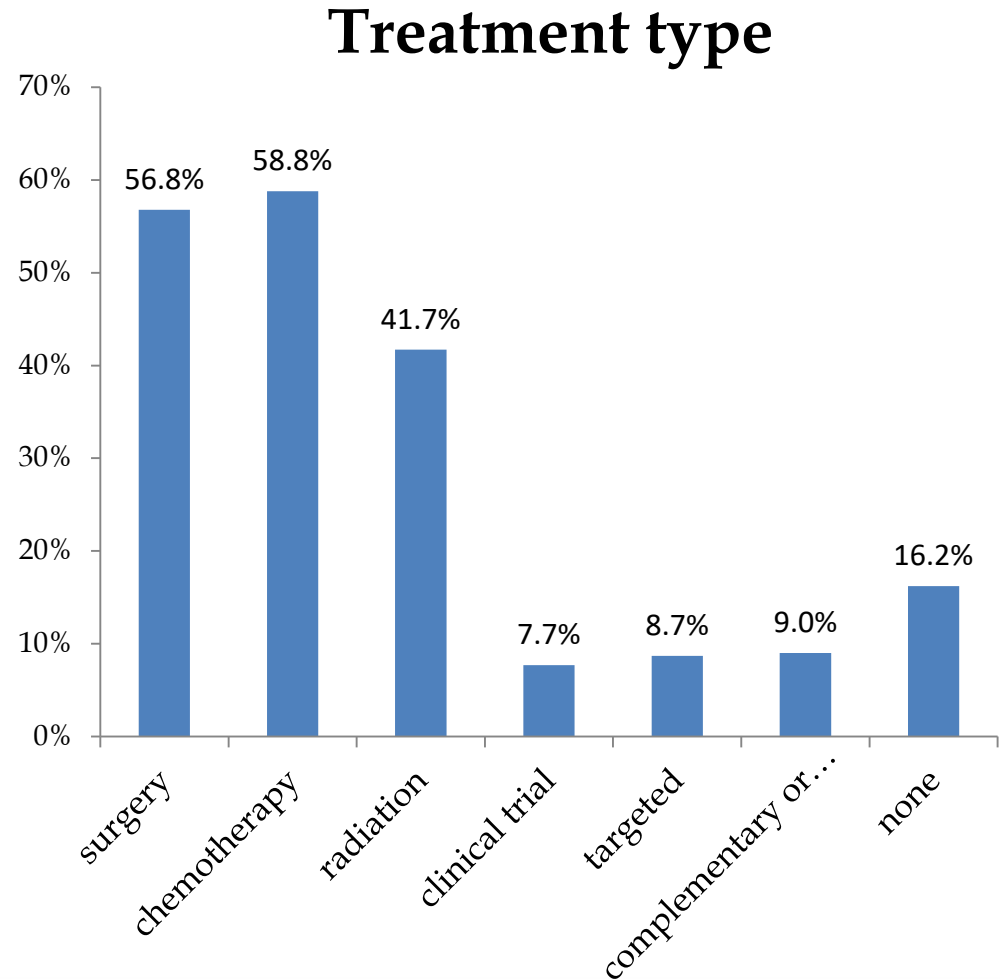
- From 2010-2015, 10,492 FSAC workshop attendees across CSC's national affiliate network completed a post-program evaluation (75% response rate)
- The evaluation assessed a variety of demographic, cancer experience-related, and workshop outcomes, including:
  - Demographics
  - Cancer history (e.g. cancer 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
  - Comfort discussing workshop content with healthcare team
  - Overall workshop satisfaction

# Participant Characteristics

- 6,196 attendees were diagnosed with cancer (59.2% of all attendees)
  - remainder were caregivers (25.2%), healthcare professionals (10.7%), or “other” (4.8%)
- Current analyses focused on attendees diagnosed with cancer at least two years ago (**n=2,206**; 46.3% of survivors\*)
- Time since diagnosis:
  - 36.4% diagnosed within the past year
  - 23.8% diagnosed between 2-5 years ago
  - 22.7% diagnosed 5+ years ago
- Age: 62.3 (s.d. =10.8) – *5 years older on average than other workshop attendees*
- Racial identification
  - 79.6% Caucasian
  - 4.5% Asian
  - 9.8% Black/ African-American
  - 4.4% Hispanic
- Gender:
  - 76.8% female

# Cancer history and treatment

- 52.4% breast cancer
- 10.4% colorectal cancer
- 7.3% lung cancer
- 6.9% gynecologic
  
- 34.8% had metastatic disease



# Distress and Support Utilization

## Cancer-related distress in individuals diagnosed with cancer 2+ years ago:

- **Depression**

Over one quarter (38.8%) experience depression as a result of their cancer

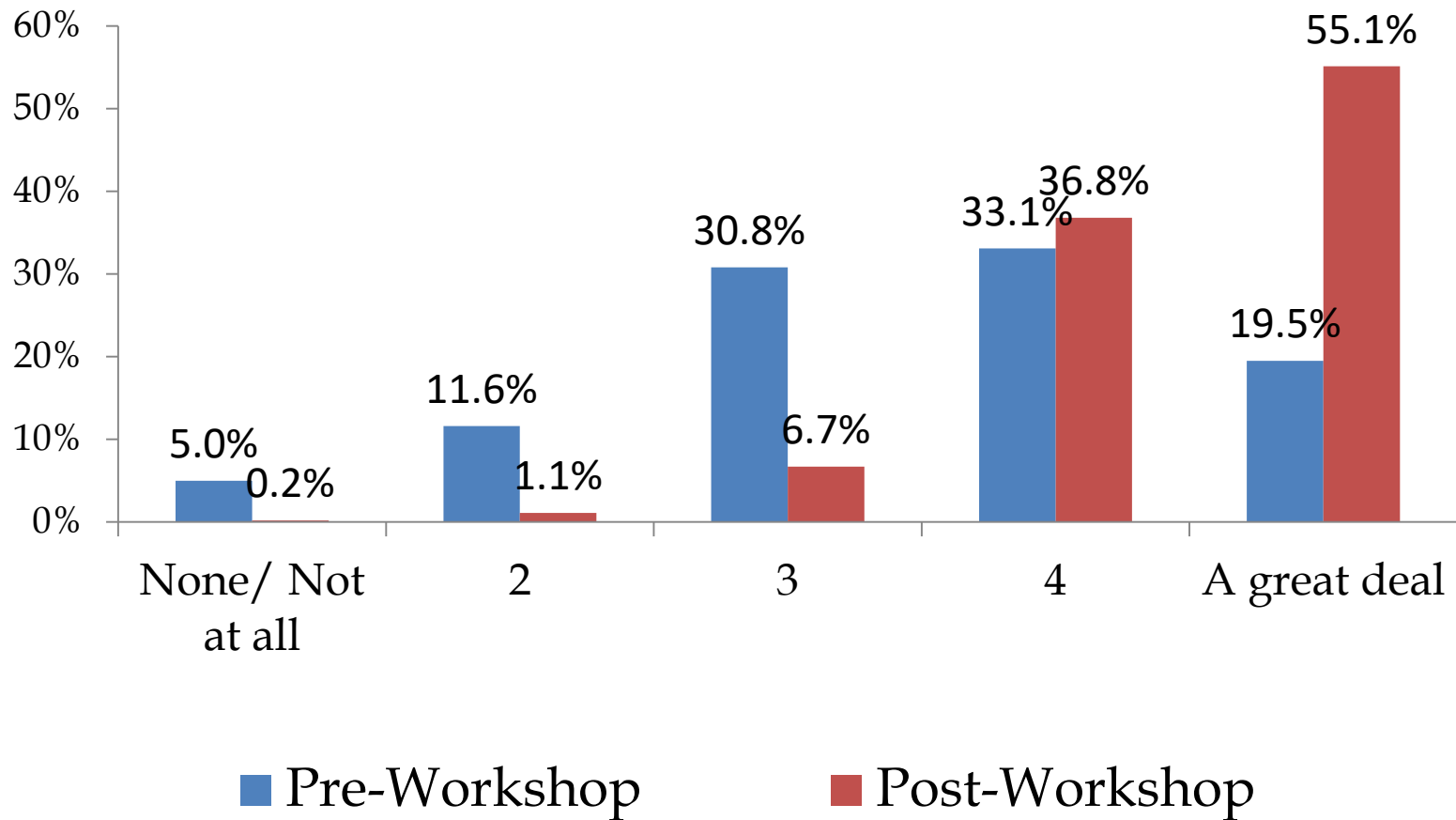
- **Anxiety**

Over one third (43%) experience anxiety as a result of their cancer

- **Psychoeducational/ support group utilization of long-term cancer survivors:**

- 52.6% currently are in support group (vs. 52.2% overall)
- 36.6% reported this was their first psychoeducational workshop (vs. 37.1% overall)

# Changes in Knowledge



# Results: Knowledge

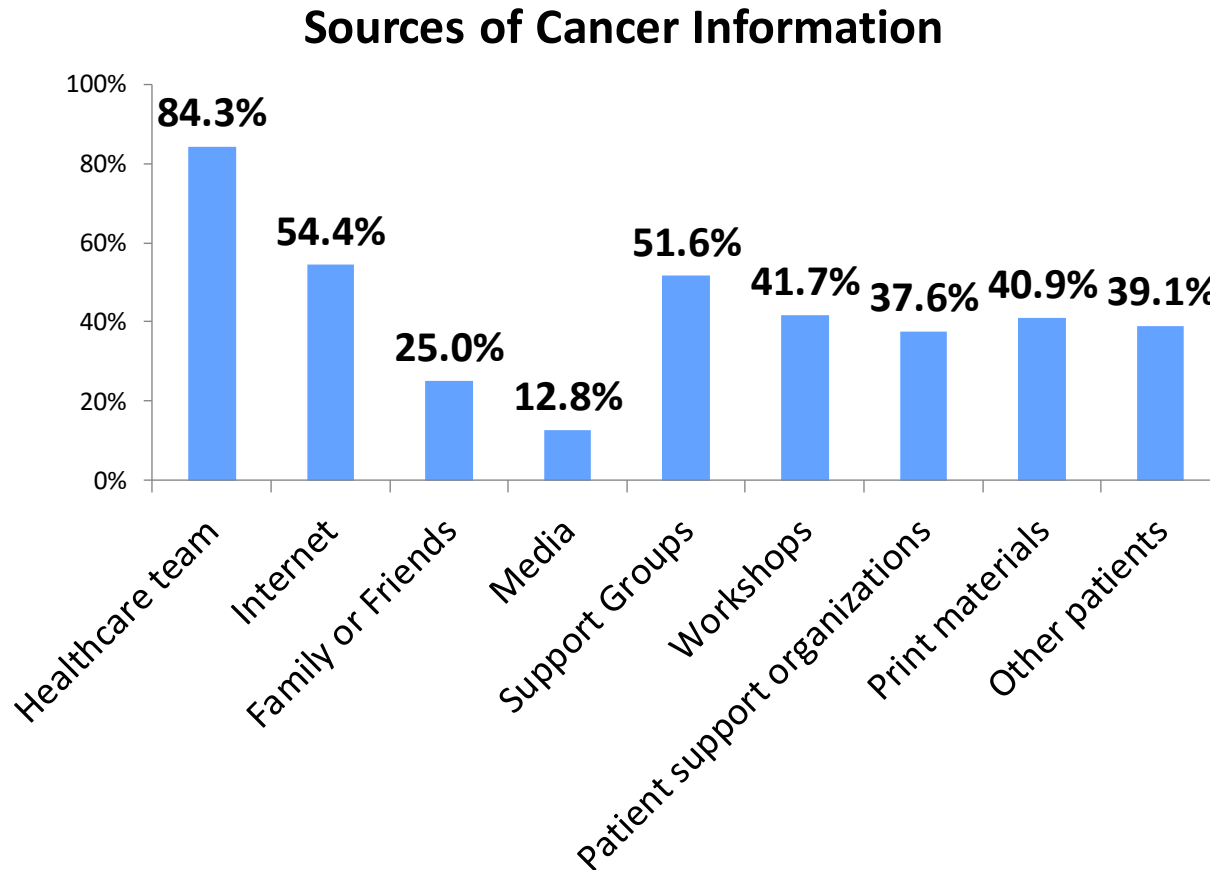
- The majority of long-term survivors (91.9%) reported a 'high' or 'very high' level of knowledge after participating in the workshop
- Post-workshop levels among long-term survivors were significantly higher than their pre-participation knowledge levels ( $F = 127.3$ ,  $p < .01$ ). This is in spite of the fact that many reported a good degree of knowledge pre-workshop.

# Results: communication gains

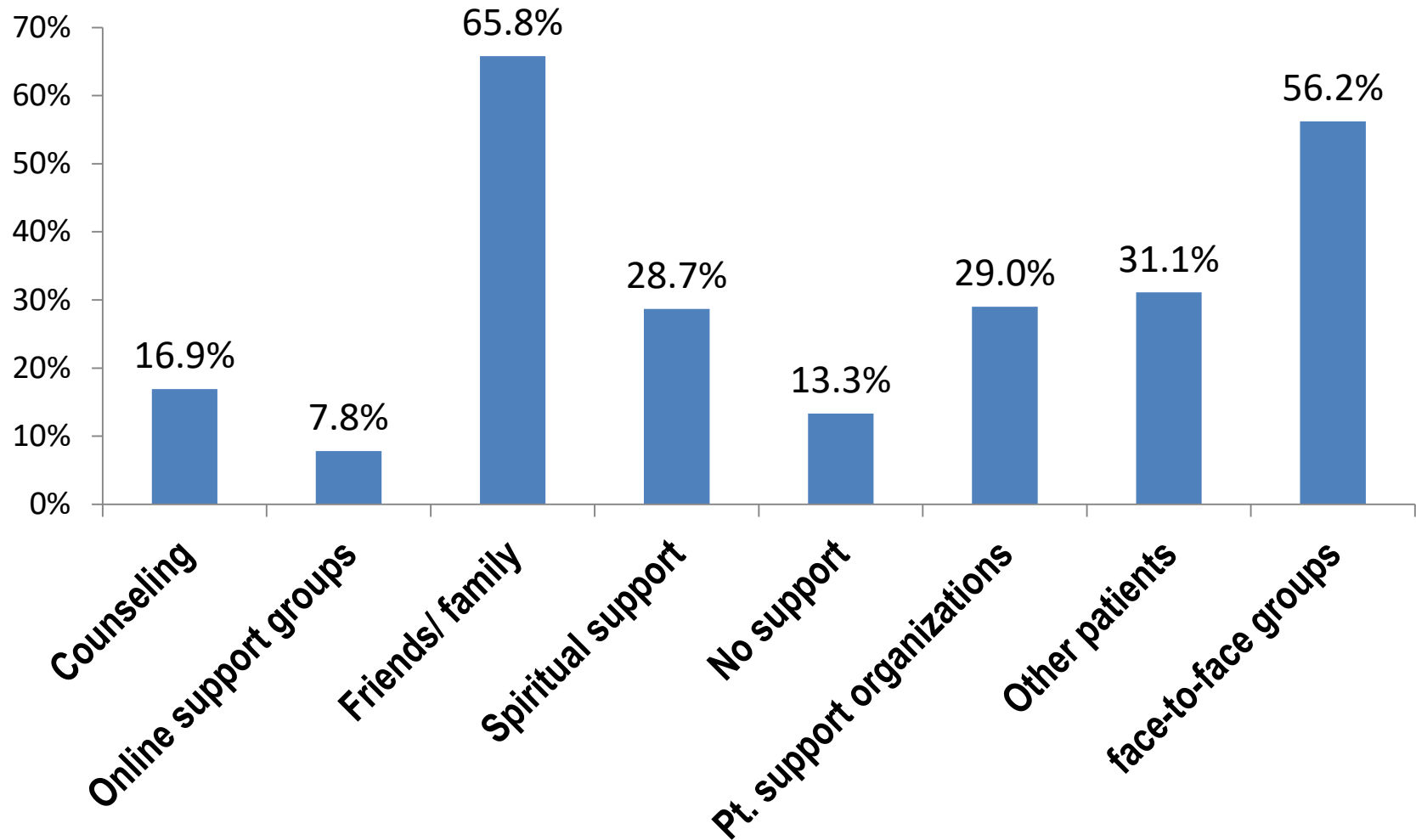
- After participating in workshops:
  - 86.1% reported increased knowledge about treatment options
  - 86.4% feel more comfortable speaking about treatment side effects
  - 65.9% plan to discuss clinical trials with their health care team to see whether they would be an appropriate option for them
  - 86.5% reported increased confidence about discussing treatment options with their health care team



# Sources of Cancer Information



# Sources of Social Support



# Results: Participant feedback

Representative feedback from workshop attendees diagnosed with cancer 2+ years ago:

“The workshop was very informative. I wish I had the information at the beginning of my cancer journey.” -2014 FSAC Cost of Care workshop participant

“It was helpful to know there are more options.” - 2014 FSAC Lung Cancer workshop participant

“Very informative and well done.” – 2013 FSAC Metastatic Skin Cancer workshop participant

“This workshop had an excellent balance between medical issues and psychosocial concerns.” 2012 FSAC New Discoveries workshop participant

# Results: Workshop Recommendation

- Nearly all (93.5%) of long term cancer survivors would recommend the workshop to others affected by cancer
- This is similar to findings of overall workshop participants (96.5%)

# Value of attending workshop

- The most valuable aspects of attending the workshop for long-term survivors include\*:
  - 57.1% Increased knowledge about the workshop topic
  - 48.6% Better prepared to cope
  - 38.2% Connecting with others with cancer

\* 2010-2013 participants only

# Summary

- Results indicate that distress levels in a population of long term cancer survivors is significant, and there is sustained need to search for cancer-related information and support
- Results suggest the FSAC workshops successfully deliver comprehensive topic-specific information to long-term cancer survivors. Attendees report significant benefits from attending workshop, including increased knowledge and confidence in discussing treatment concerns with their providers.

# Discussion

- Results suggest that even years later, comprehensive information and supportive services are highly relevant in meeting the psychosocial needs of cancer survivors
- Cancer educators and professional providers of psychosocial support have an obligation to meet the needs of cancer survivors. In addition to meeting their initial psychoeducational and psychosocial needs in diagnosis and treatment, it is important to effectively meet these needs and understand preferences and utilization patterns years after diagnosis

# Generalizing the Findings

- While workshop participants were:
  - geographically diverse
  - spanned many cancer diagnoses
  - represented a range of age (more older adults in face-to-face format vs. online)
  - range of familiarity with topic of workshops
- Caution in generalizing to all long-term cancer survivors:
  - Participants chose to attend psychoeducational workshop
    - Perhaps participants more engaged, connected, already accessing services compared with long-term survivors on whole
  - Racial minorities and less educated under-represented



# For More Information



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