Caregiver Participation in a Psychoeducational Cancer Support Program:

Results From A National Sample

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

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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

Psychosocial Needs of Cancer Caregivers

- As with many subpopulations affected by cancer, cancer caregivers have distinct and often unique needs, including*:
  - help addressing patients' concerns about physical or mental deterioration (52.7%)
  - managing concerns about recurrence (44.6%)
  - working through feelings of death (40.8%)
  - accessing information about alternative therapies (36.4%)
  - feeling confident that the patient's doctors were coordinating care (36.2%)
  - obtaining the best care for the patient (35.3%)

* Sklenarova, et al. (2015), When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. Cancer, 121: 1513–1519.

Unmet Needs of Cancer Caregivers

- Most often have multiple unmet needs. According to survey respondents:
  - 43.6% of caregivers have more than 10 unmet needs
  - 42% have fewer than 10 unmet needs
  - 14.4% caregivers reported having no unmet needs
- Caregivers had significantly more distress and reported higher levels of anxiety than patients ($P < .01$).
- Patient and caregiver needs often correspond: When patients had a higher unmet number of needs, cancer caregivers were more likely to have all of the following:
  - health care service and information needs
  - emotional and psychological needs
  - work and social security needs
  - communication and family needs

(Source: Sklenarova, 2015)

Identified Research Needs

- “Identifying the needs of informal caregivers of patients with cancer is a necessary step in developing empirically supported treatments that address the unique experience of this population.
- Future research is needed to adapt and evaluate the efficacy of currently available, empirically supported interventions for anxiety and depression for cancer caregivers, as well as interventions to address specific areas of unmet needs highlighted (e.g. fear of disease recurrence, concerns about death and dying).
- The state of the science and empirically supported interventions for cancer caregivers remains in its infancy, and the time is ripe for this area of focus to become a priority for future research in psychooncology.”

- Deshields, T. L. and Applebaum, A. J. (2015), The time is now: Assessing and addressing the needs of cancer caregivers. Cancer, 121: 1344–1346. doi:10.1002/cncr.29226

Frankly Speaking About Cancer: Scope and Delivery

Program topics are tumor type-specific or cross-tumors:

- Metastatic Breast Cancer
- Coping with Cost of Care
- Liver Cancer
- Multiple Myeloma
- Breast Reconstruction
- Cancer Treatment and Side Effects
- Metastatic Skin Cancer
- Colorectal Cancer
- Lung Cancer
- New Discoveries
- Immunotherapy

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

Join host Kim Thiboldeaux, President & CEO of the Cancer Support Community, for a weekly radio broadcast empowering listeners to live well with cancer.

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 cancer caregivers

- The CSC sought to better understand the benefits of participating in a psychoeducational workshop in cancer caregivers 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 cancer caregivers are generally meeting their informational and support needs
  - To highlight distinct psychosocial needs of cancer caregivers 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
  - Caregiver-provider interaction
  - Overall workshop satisfaction

Participant Characteristics

- 2,892 attendees were caregivers of those with cancer (25.2% of all attendees). These attendees are the focus of the current analyses.
  - Remainder were diagnosed with cancer (59.2%) healthcare professionals (10.7%), or "other" (4.8%)

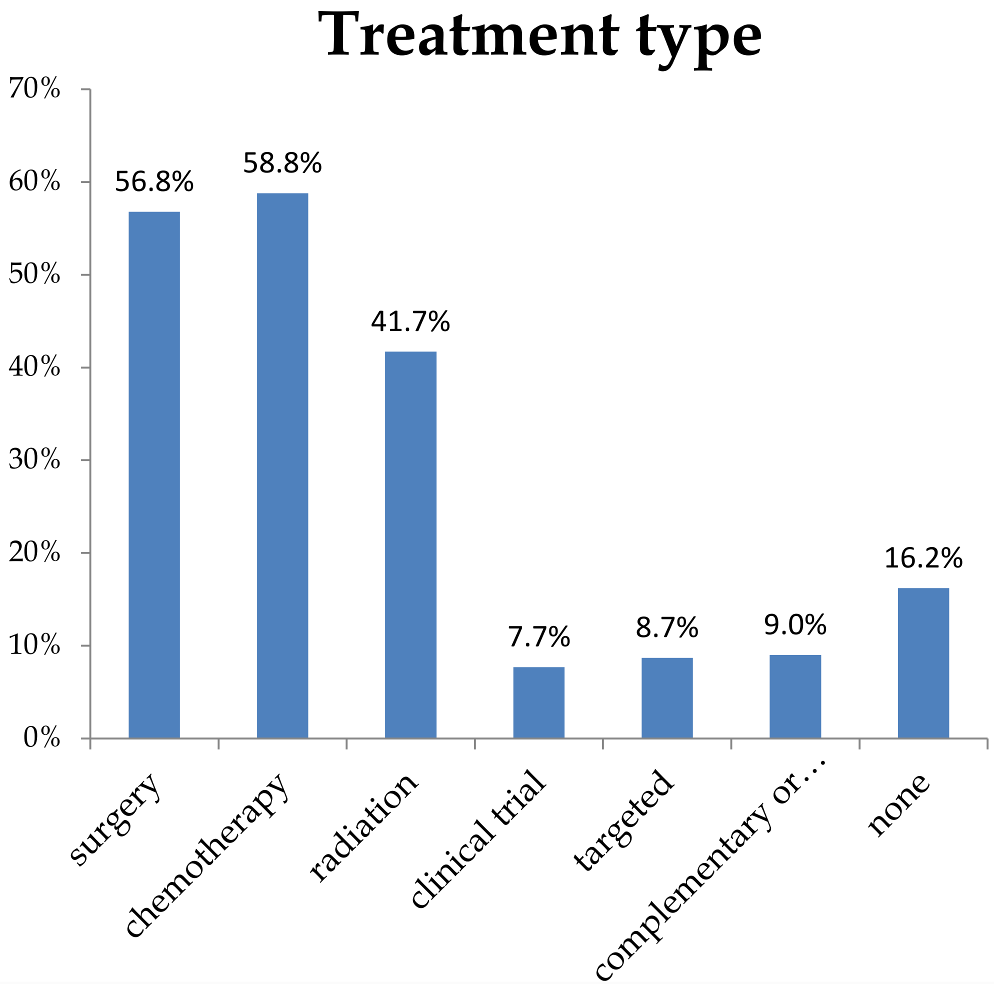
- Age: 58.2 years old (s.d.=13.8)
- Racial identification
  - 81.0% Caucasian
  - 4.5% Asian
  - 7.9% Black/ African-American
  - 4.7% Hispanic
- Gender:
  - 63.9% female (more males attended as caregivers than as patients, 77.8% female across all workshops and all attendees)

Patient cancer history and treatment

- Time since patient diagnosis:
  - 46.7% diagnosed within the past year

- 52.4% breast cancer
- 10.4% colorectal cancer
- 7.3% lung cancer
- 6.9% gynecologic

- 34.8% had metastatic disease

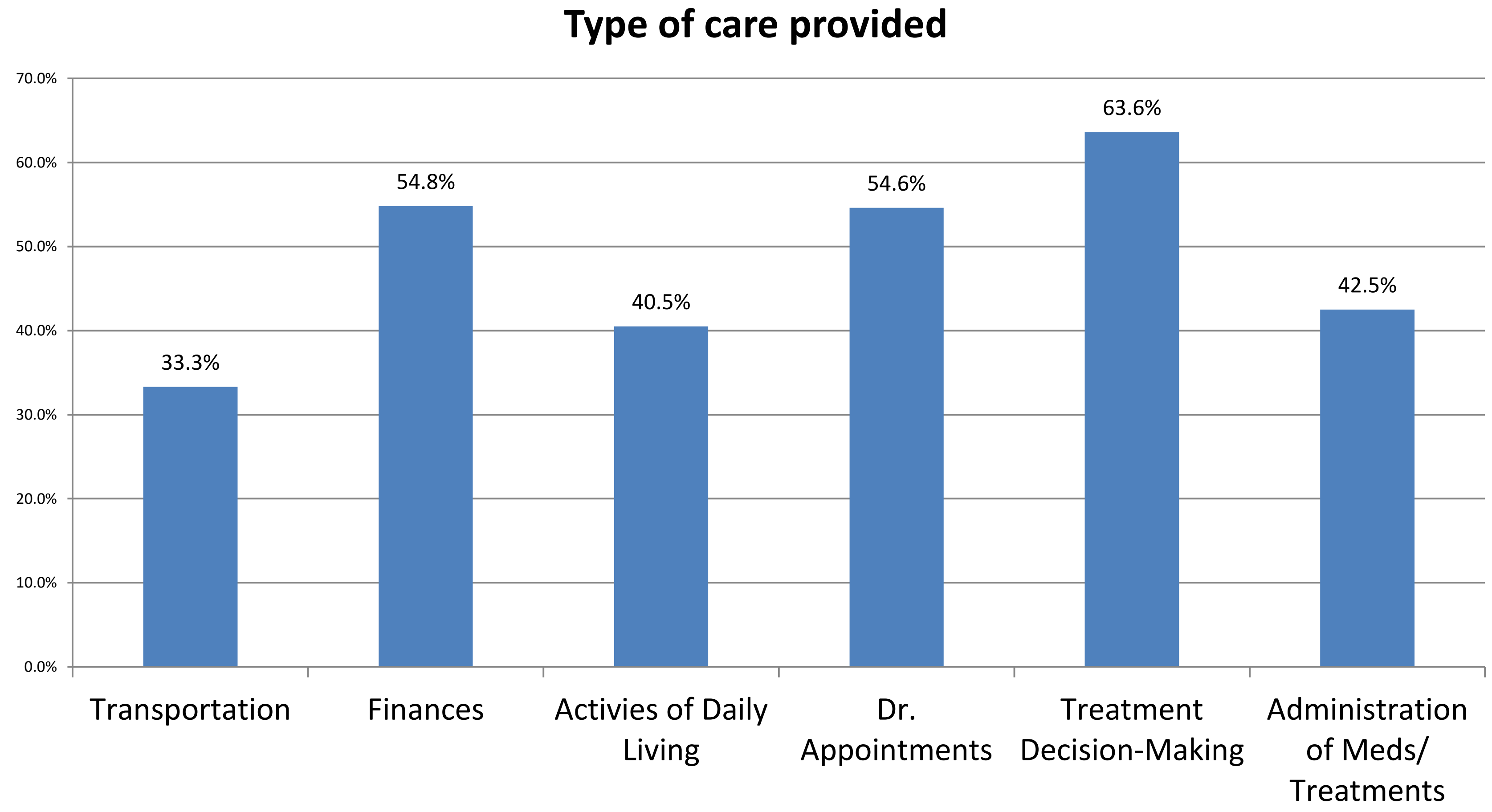


Caregiver role and providing care

- 73.7%* strongly identify as caregivers
- 61.2%* reported they are strongly involved in coordinating the patient's care

*rated a '4' or '5' on a 5-point scale, 2015 data only

Caregiver responsibilities:
Converging data from CSC prostate caregiver survey



Caregiver formal support utilization

Psychoeducational/ support group utilization of cancer caregivers:

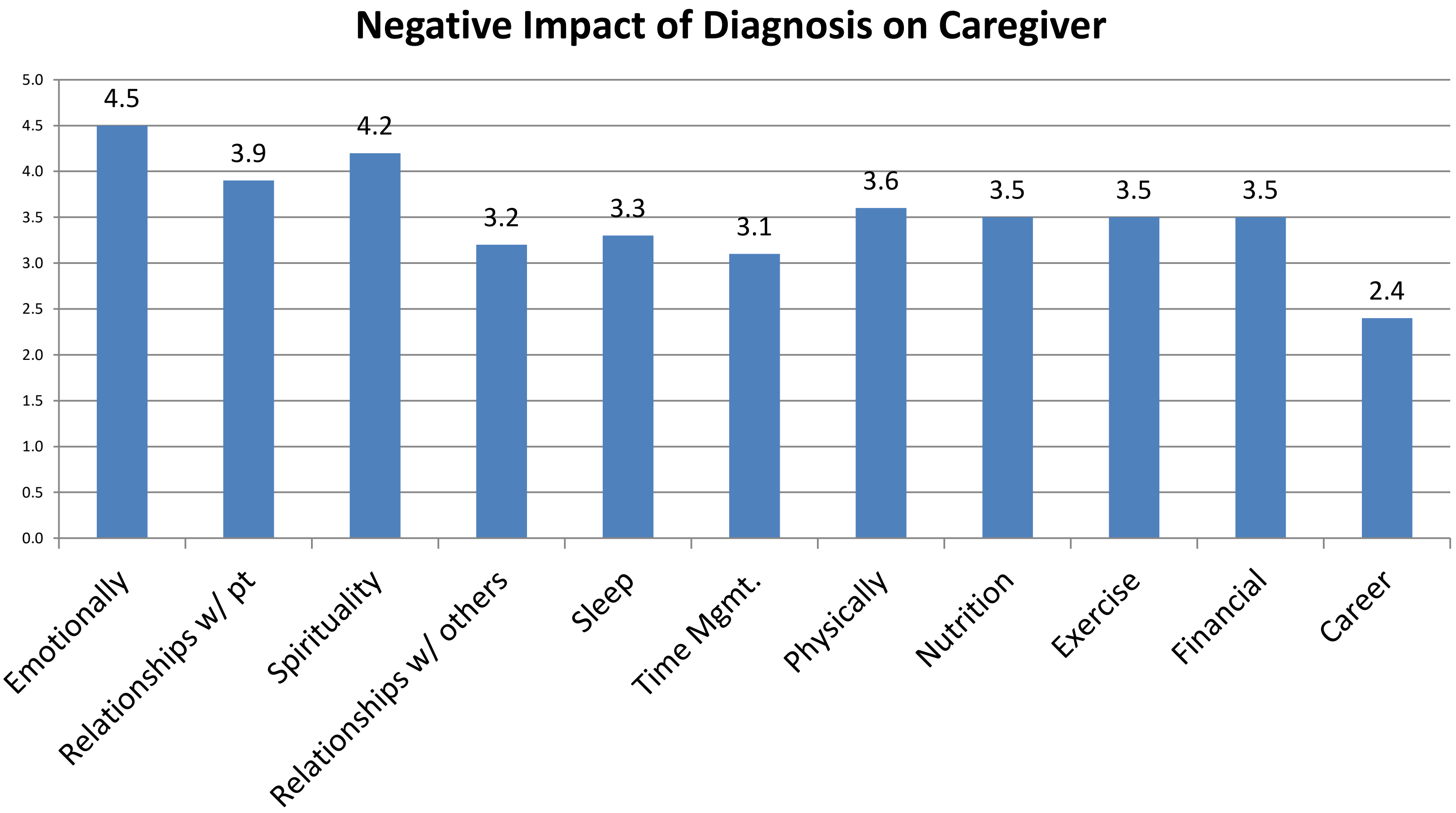
- 26.7% currently are in support group

  (compared with 52.2% overall attendees)

- 62.9% reported this was their first psychoeducational workshop (compared with 37.1% overall attendees)

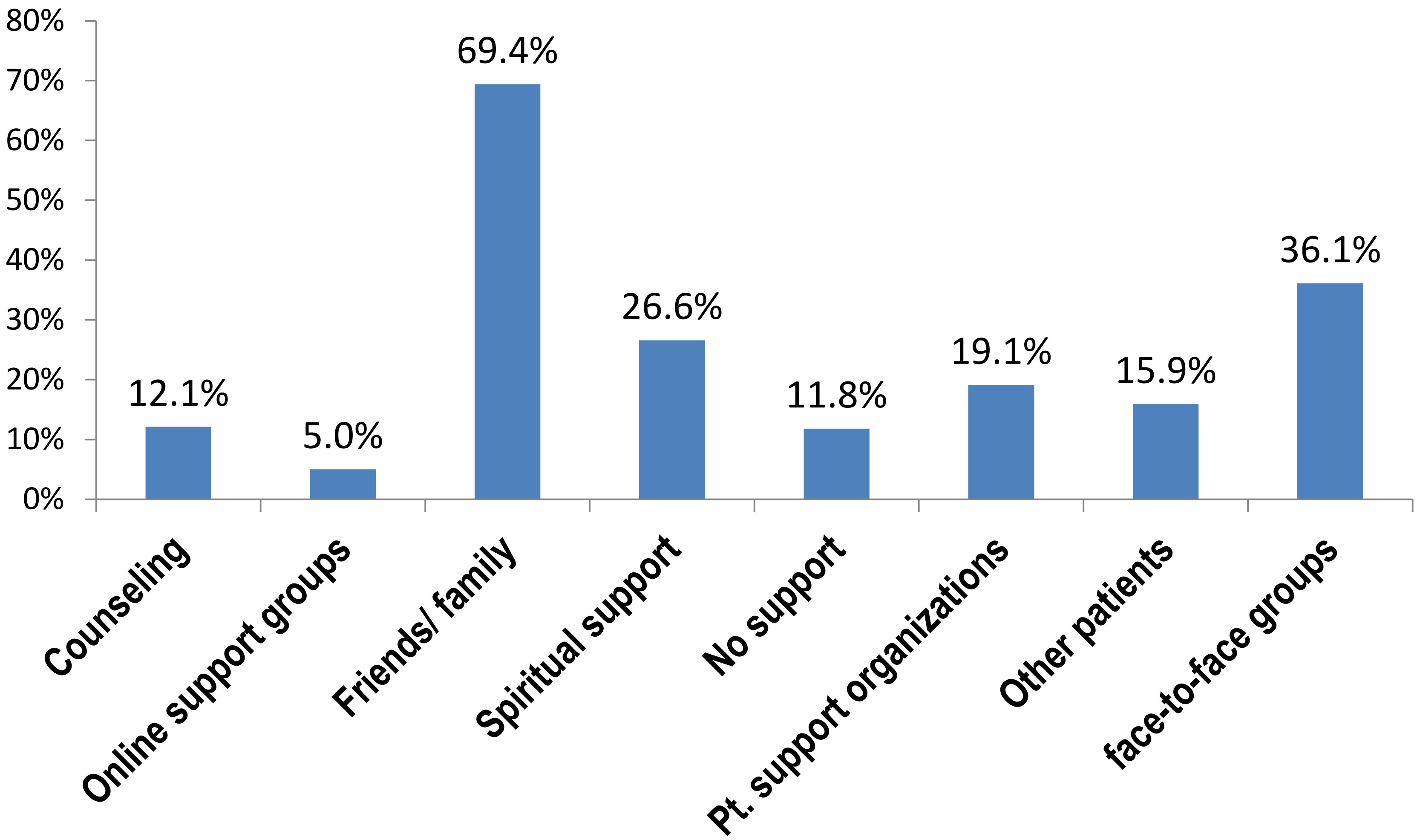
Emotional impact of caregiving

Example data from CSC prostate caregiver survey

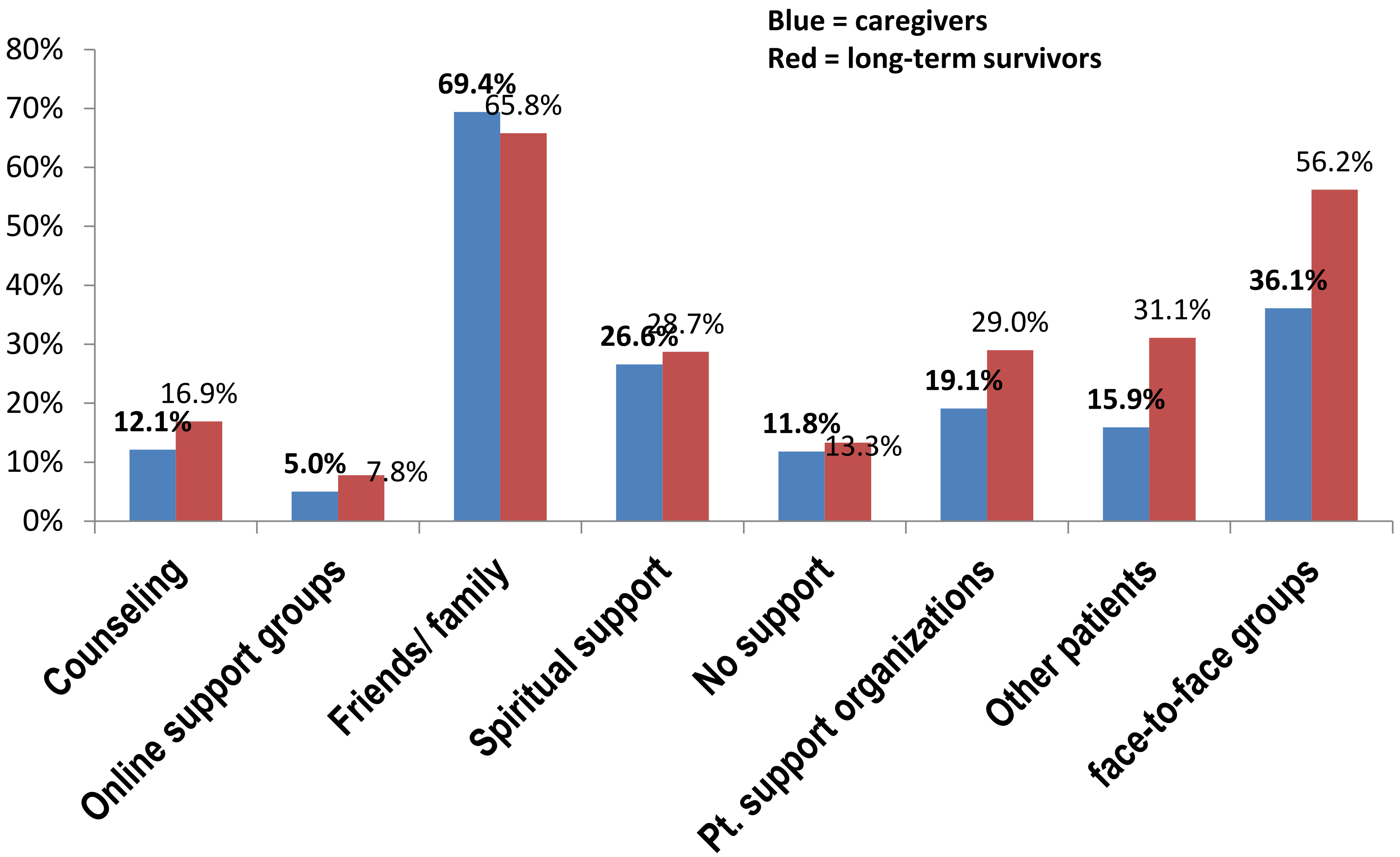


5-point scale (0 = “not at all”; 5 = “extreme” impact)

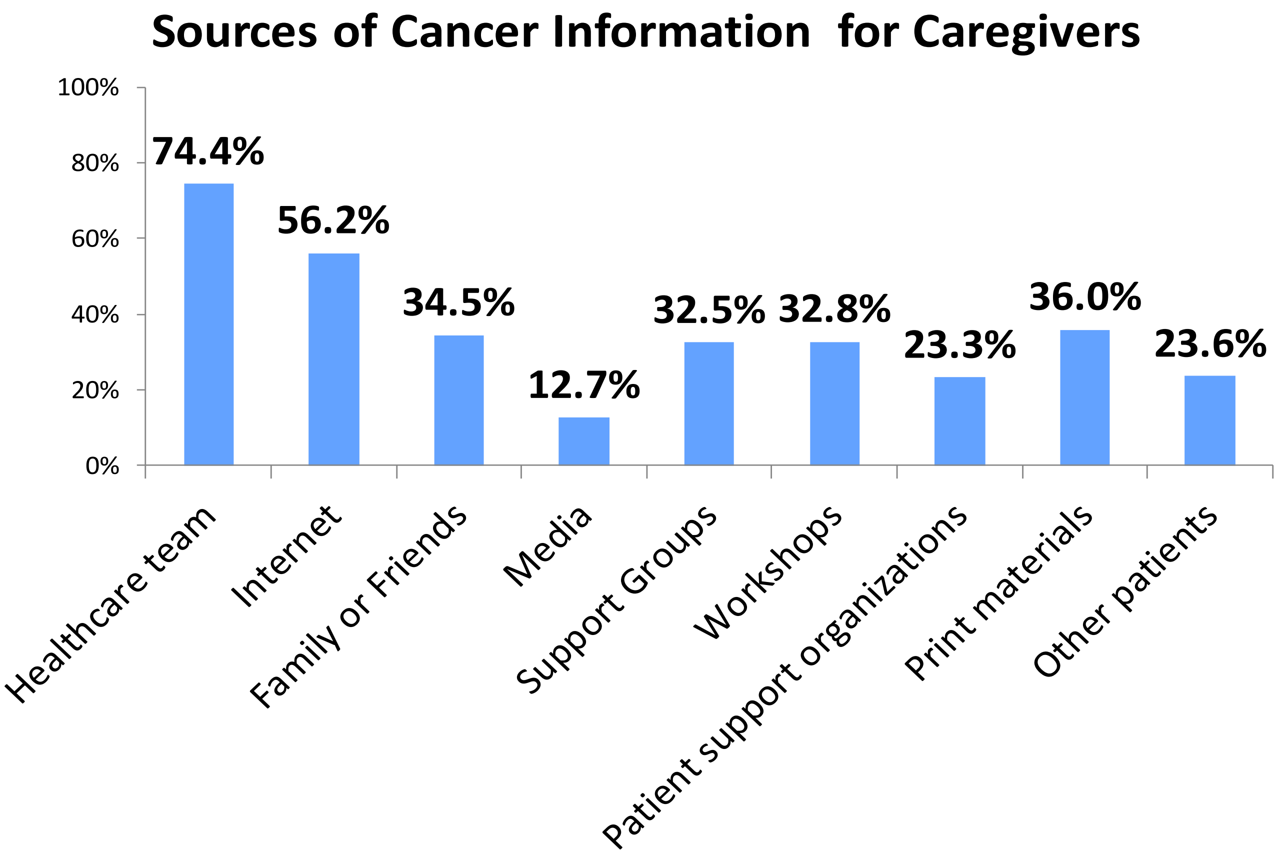
Sources of emotional support



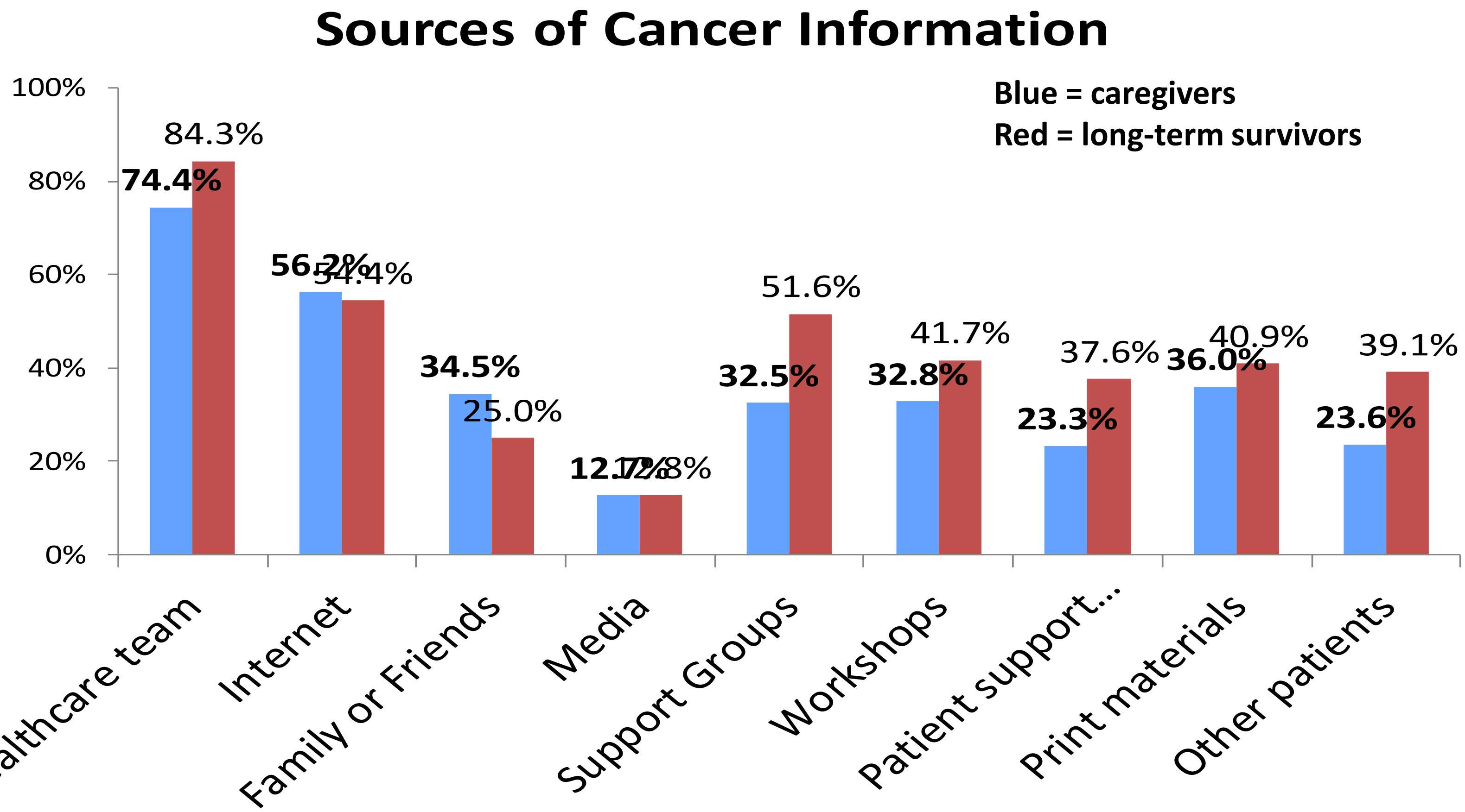
Sources of emotional support: Comparing caregivers and LT survivors



Sources of Cancer Information



Sources of cancer information: Comparing caregivers with LT survivors

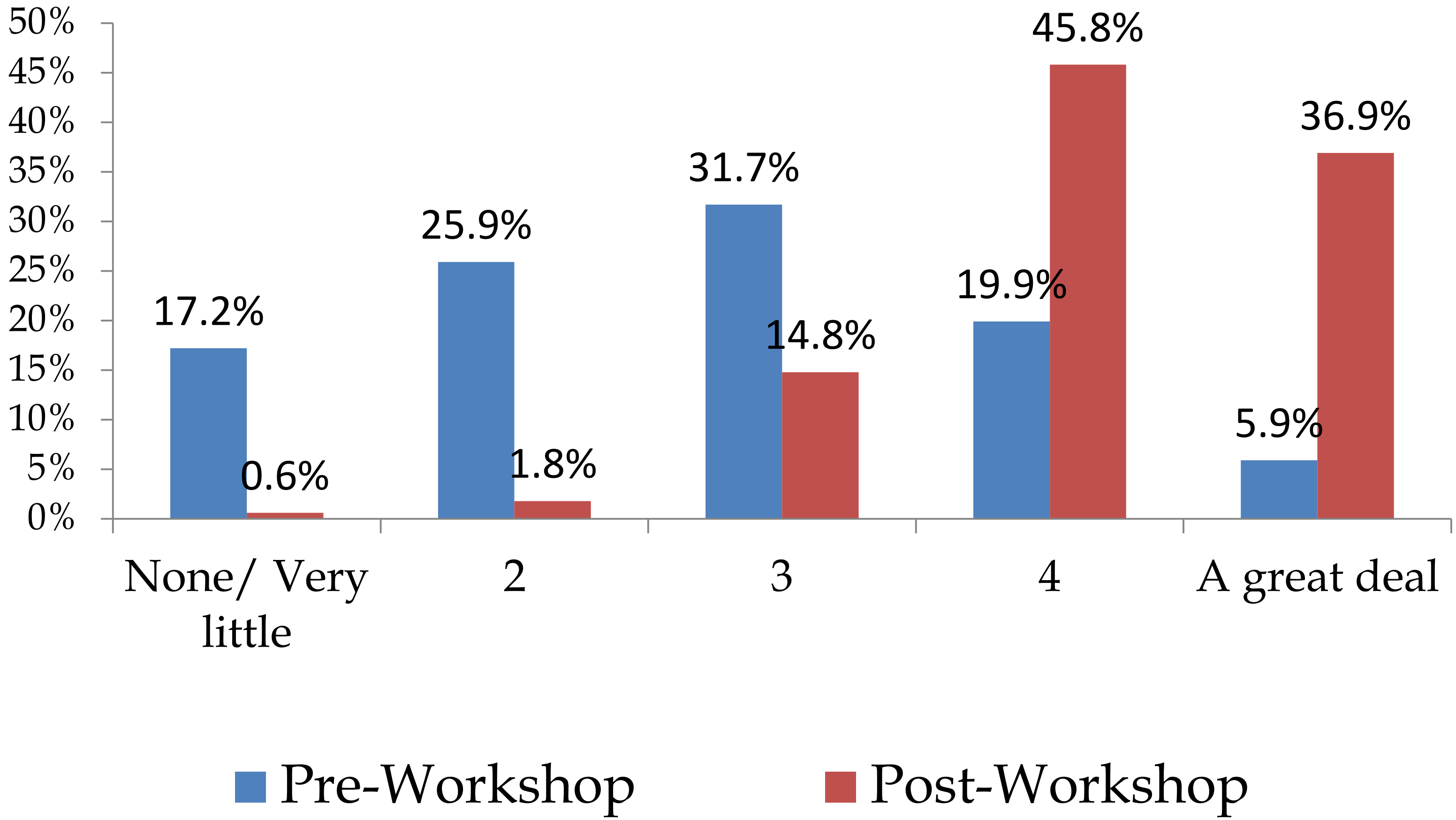


Workshop evaluation results: Knowledge

- The majority of cancer caregivers (82.7%) reported a ‘high’ or ‘very high’ level of knowledge after participating in the workshop

- Post-workshop levels among cancer caregivers were significantly higher than their pre-participation knowledge levels (F =142.3, p<.01)

Changes in Knowledge



Workshop results: communication gains

- After participating in the workshop:
  - 89.2% of caregivers reported increased knowledge about/ confidence in discussing treatment options with the patients' healthcare team
  - 85.7% felt more confident in making treatment decisions in conjunction with the healthcare team

Results: Caregiver feedback

Representative feedback from workshop attendees who attended as a caregiver:

“Really loved it! Very informative.”- 2014 FSAC Cost of Care workshop participant

“This workshop confirmed much that I already knew and got good updated info”- 2014 FSAC Lung Cancer workshop participant

“This was an extraordinary presenter - so knowledgeable.” – 2013 FSAC Metastatic Skin Cancer workshop participant

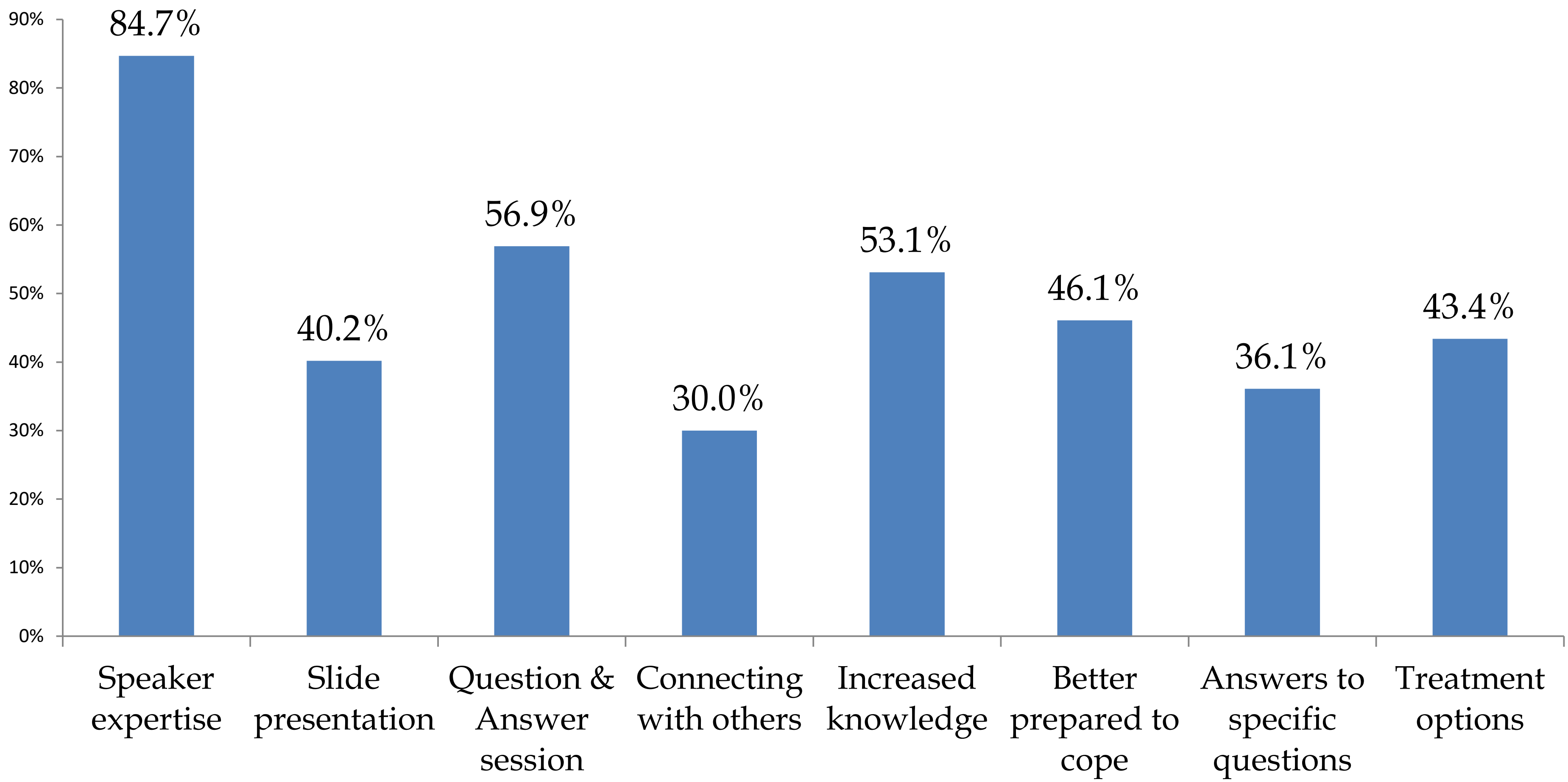
“I would like to repeat this workshop, there was lots of new info to swallow.” 2012 FSAC New Discoveries workshop participant

Results: Workshop Recommendation

- Nearly all (96.3%) of cancer caregivers would recommend the workshop to others affected by cancer

- This is similar to findings of overall workshop participants (96.5%)

Most valuable aspect of workshop



Summary of results

- For over half of caregivers, this was their first psychoeducational cancer workshop, and one quarter have participated in caregiver support groups. The results are suggestive of a demand for services

- While caregivers are searching for cancer-related information and seeking support, overall they seek slightly lower than patients do.

- Attendees report significant benefits from attending workshop in terms of knowledge and confidence in communicating with the patient's healthcare team

Discussion

- Results suggest that comprehensive information and supportive services are highly relevant in meeting the psychosocial needs of cancer caregivers

- Results suggest the FSAC workshops successfully deliver comprehensive topic-specific information to cancer caregivers

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 cancer caregivers:
  - Participants chose to attend psychoeducational workshop
    - Perhaps participants more engaged, connected, already accessing services compared with caregivers generally
  - Racial minorities and less educated under-represented

For More Information

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