

Information and Emotional Support Utilization Among Cancer Caregivers: Results From A National Sample of Education Program Attendees

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Rationale

Cancer caregivers have significant informational needs and often experience emotional and practical challenges for which they need to rely on external support. Despite these pervasive needs, resource utilization among caregivers is not well understood. The Cancer Support Community (CSC) sought to better understand informational and emotional support seeking patterns among cancer caregivers in a national sample of psychoeducational workshop attendees.

Objective

- To investigate the information-seeking behaviors and emotional support utilization of cancer caregivers in a sample of caregivers actively seeking information

Frankly Speaking About Cancer Program Background

The *Frankly Speaking About Cancer* (FSAC) series provides in-depth coverage of topics relevant to those affected by cancer that are often not otherwise available in a comprehensive format.

Topics covered include: metastatic breast cancer, lung cancer, cancer treatments and side effects and coping with the cost of care. *Frankly Speaking About Cancer* is delivered through multiple modalities, including in-person workshops, publications, online and radio show.

Synopsis of Findings

Caregivers of cancer patients who attended one of the CSC's FSAC workshops from 2009-2013 responded to questions about information-seeking and emotional support utilization. The current analyses focus on the 2,189 (24.7% of workshop respondents) who identified as caregivers.

Findings show that caregivers look to a variety of sources for cancer information. Most caregivers utilize doctors/ nurses and the Internet for informational support, though other informational sources include friends and family, support groups, workshops, and patient support organizations.

Most caregivers receive emotional support from family and friends, and typically this is the first place they turn. Over one third report the use of face-to-face support groups, and a quarter are currently in a group. Many caregivers report not seeking emotional support.

Methods

Design

From 2009-2013, 8,928 FSAC workshop attendees from CSC's national Affiliate Network completed post-workshop surveys (75% response rate).

Respondents:

People identifying as caregivers of cancer patients. 2,189 (24.7% of sample) were caregivers; the remainder were cancer patients (61.1%) or health care workers/ other (14.3%). The current analyses focused exclusively on these 2,189 caregivers.

Survey items:

- Sources of informational support
- Usual source(s) (choices from list)
- Primary source (open-ended)
- Sources of emotional support
- Usual source(s) (choices from list)
- Primary source (choices from list)
- Time since diagnosis of patient
- First psychoeducational workshop
- Participation in support group
- Pre/post-workshop cancer-specific knowledge (5-point scale)

Respondent Characteristics

Background Characteristics:

- Average Age = 58.1 years (s.d.=13.8 years)
- Sex: 64.7% female
- Racial Identification:
 - 81.9% Caucasian
 - 7.6% African-American
 - 4.1% Asian
 - 4.6% Hispanic

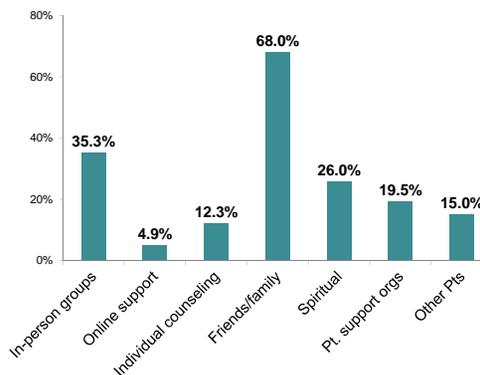
Other Characteristics:

- 25.3% Currently in support group
- 62.3% First psychoeducational workshop
- 47.4% became caregivers within the past year (n=97)

Cancer Knowledge:

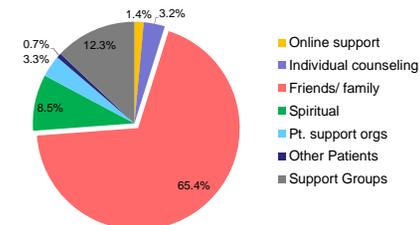
- 44% reported low cancer knowledge prior to workshop
- 0.5% reported low cancer knowledge after workshop
- 82.8% reported high cancer knowledge after workshop

Sources for Emotional Support



- Most caregivers (68.0%) receive emotional support from family and friends
- 35.3% have participated in face-to-face support groups, (25.3% are currently in a group).
- Caregivers also often utilize individual counseling, spirituality, and patient support organizations
- Few caregivers seek emotional support online
- 17% reported that they had not sought emotional support related to cancer or cancer caregiving

Primary Source for Emotional Support



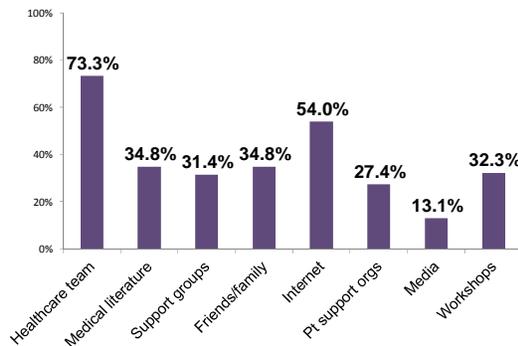
For most caregivers (65.4%), family/friends is the first place they turn for emotional support

Summary & Discussion

- Caregivers rely on a variety of sources of information, though most utilize doctors/ nurses and the Internet
- For most, this was their first psychoeducational workshop
- Most caregivers receive support from family and friends, and typically also this is the first place they turn
- Over one third report the use of face-to-face support groups, and quarter are currently in a group
- 17% reported that they had not sought emotional support related to cancer or cancer caregiving
- Increased understanding of informational and emotional support service utilization can better inform provision of services and programs addressing the emotional and informational needs of caregivers
- Psychoeducational workshops are an opportunity to provide cancer information useful for caregivers and may be useful to caregivers for their emotional support benefits as well

Information-Seeking

Sources for Information on Cancer



- Most cancer caregivers have sought cancer information from a doctor/nurse, half found information online
- "First source" was overwhelmingly healthcare team or Internet, with many hospital websites mentioned by name. Many also reported relying on patient support organizations

Implications

Research Implications:

- There is ongoing research on how to better support caregivers. These findings contribute to this body of work and identify areas for further research and potential areas for intervention development

Practice Implications:

- These findings highlight key areas that are sources for information and support for caregivers. It is important that clinicians further understand where caregivers turn for information and support so that current support services could be further tailored

Acknowledgement of Funding

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