Support utilization amongst individuals with cancer attending patient education workshops:

Trends by cancer stage and time since diagnosis

Allison Harvey, MPH, CHES
Marni Amsellem, PhD
Rhea Suarez

Conflict of Interest Disclosure

I do not have any potential conflicts of interest to disclose.
Objectives

- To investigate emotional support seeking in those affected by cancer.

- To compare emotional support seeking in those recently diagnosed versus those years from diagnosis.

- To examine emotional support utilization by type of cancer, stage of disease and individual differences.

Cancer Support Community Mission

To ensure that all people impacted by cancer are:
- Empowered by Knowledge
- Strengthened by Action
- Sustained by Community
Frankly Speaking About Cancer
Program History and Development

• FSAC Programs: Provide easy to understand in-depth coverage of topics of relevance to those affected by cancer
• Guided by Patient Empowerment Model
• Up-to-date content reflecting new advances, materials updated regularly
• Programs evaluated regularly (post-workshop)

Frankly Speaking About Cancer:
Scope and Delivery

Topics are tumor type-specific or more general:
• Workshop Topics:
  ▪ Metastatic Breast Cancer
  ▪ Coping with the Cost of Care
  ▪ Lung Cancer
  ▪ Multiple Myeloma
  ▪ New Discoveries
  ▪ Breast Reconstruction
  ▪ Treatments & Side Effects

Program delivery:
• Web-based materials
• Print materials
• Professionally-led workshops
• Online radio series
Background: Emotional Support in Cancer

- The psychosocial concerns and emotional needs of individuals with cancer are significant
  - Emotional needs often vary by:
    - Type of cancer
    - Type of treatments being faced
    - Characteristics of the diagnosis (e.g. stage of disease)
    - Individual differences
  - Needs may change over time
    - Recently diagnosed vs. in treatment vs. survivorship

Do these differences translate into differences in seeking emotional support?

Overarching Research Question

Do differences in emotional support needs translate into differences in how those with cancer seek emotional support?
Overview of Analyses

• To better understand emotional support needs of individuals diagnosed with cancer, the Cancer Support Community (CSC):
  – Explored utilization of emotional support in samples of individuals attending psychoeducational workshops focused on a cancer-related topic
  – Looked at differences in emotional support utilization based on time since diagnosis and stage of disease

Methods: Participants

• FSAC Workshop attendees diagnosed with cancer
  • Attendees with cancer represented 66% of workshop attendees (remainder were friends, family, or healthcare professionals)

• Attended a psychoeducational workshop at a CSC affiliate in 2009-13
  • Workshops held nationwide at CSC affiliates (partners)

• Completed paper/pencil post-workshop evaluations
  • n=5,419
Methods: Assessment of Emotional Support

Post-workshop evaluation questions assessed:

- Demographics
- Cancer history and treatment
  - Type of cancer
  - Time since diagnosis
  - Early v. late-stage cancer
- Emotional Support:
  - Usual sources
  - Primary source
  - Support group member
- Workshop-specific support:
  - Value of emotional support in this workshop
  - First workshop attended

Results: Participant Characteristics

- Gender:
  - 81.6% female
- Race:
  - 80.4% Caucasian
  - 4.3% Asian-American
  - 9% African-American
  - 4.4% Hispanic/Latino
- Age:
  - Mean= 60.0 years (s.d. = 11.3)
Results: Workshop Characteristics

- Year of Workshop:
  - 2009: 14.3%
  - 2010: 13.6%
  - 2011: 19.2%
  - 2012: 29.5%
  - 2013: 23.5%

- ~830 workshops

- Over 50 CSC affiliates and more than 100 satellite locations nationwide (and partners)

---

Results: Cancer Type of Attendees

- Breast: 52.1%
- Colorectal: 12.8%
- Gynecologic: 4.0%
- Brain: 0.6%
- Prostate: 1.8%
- Lung: 15.0%
- Multiple myeloma: 3.2%
- Lymphoma: 2.1%
- Skin: 1.7%
- Leukemia: 1.4%
- Liver: 0.8%
- Other primary tumor: 2.9%
- Multiple primary tumors: 1.8%
Results: Cancer History

- 35.2% diagnosed in the past year
- 23.4% diagnosed five+ years ago
- 37.4% diagnosed with metastatic disease

Results: Sources of Emotional Support
Results: Primary Source of Emotional Support

- 59.2% of respondents cited friends and family as their primary source of emotional support.
- 15.7% utilized face-to-face support groups.
- 8.9% relied on spiritual support.
- 3.9% sought help from patient support organizations.
- 3.4% turned to other patients as a source.
- 4.9% used other methods.

Results: Emotional Support Utilization by Demographics

- **Gender:**
  - There were no statistically significant differences between men and women with cancer in either typical sources of utilization for emotional support in coping with cancer or their primary source, with one exception - women were more likely than men to turn to other individuals with cancer as a source of emotional support.

- **Age:**
  - Individuals who were older were less likely than those who were younger to receive support via individual counseling and online support groups.
  - No other age-related differences were observed.
Results: Support Group Utilization

- 52.9% were currently in a support group
  - Those currently in a support group were:
    - More likely to report ‘Patient Support Organization’ as their primary source of support (4.7% vs 2.7%; \( \chi^2 = 179, p < .01 \))
    - More likely to report ‘face-to-face support group’ as their primary source of emotional support (28.8% vs 4.5%; \( \chi^2 = 179, p < .01 \))
    - Less likely to report ‘friends/family’ as their primary source (49.8% vs 70.8%; \( \chi^2 = 179, p < .01 \))
  - This was the first psychoeducational workshop for 47.6%
    - Those who attended a psychoeducational workshop for the first time were less likely to have utilized face-to-face support groups than those who have previously attended workshops (8.7% vs 21.7%; \( \chi^2 = 106.1, p < .01 \)) and more likely to utilize their friends/ family for emotional support (69.2% vs 50.7%; \( \chi^2 = 106.1, p < .01 \))

Results: Emotional Support Utilization by Cancer Type (Breast v. Lung)
Results: Face-to-face Support Group Participation by Cancer Type

Results: Emotional Support Utilization by Cancer Stage

- Compared to attendees with non-metastatic cancer, those with metastatic disease were more likely to:
  - Participate in online support groups ($\chi^2 = 7.8$, $p < .01$)
  - Seek outside support in general ($\chi^2 = 7.7$, $p < .01$)

- There was no difference in primary source of support by stage of cancer
Results: Emotional Support Utilization by Time Since Diagnosis

- Those recently diagnosed (< 1 year) were compared to those years from diagnosis (3+ years):
  - Several differences in the types of emotional support sources utilized based on time since diagnosis.
    - Those diagnosed within the past year were more likely to utilize:
      - Friends and family ($\chi^2 = 32.1, p < .01$)
    - Those diagnosed 3+ years ago were more likely to utilize:
      - Other patients ($\chi^2 = 12.5, p < .01$)
      - Face-to-face support groups ($\chi^2 = 17.9, p < .01$)
      - Patient Support Organizations ($\chi^2 = 5.9, p < .05$)

The Role of the Workshop in Emotional Support Provision

- 34.4% endorsed “connecting with others with cancer” was a valuable aspect of attending the workshop.

- Examples of illustrative participant responses:
  - “(This workshop) became like a support group more than receiving all the new info” - 2011 FSAC CRC participant, CSC San Francisco Bay Area
  - “Great speaker, very tactful, compassionate and caring and thoughtful and kind” - 2010 FSAC Cancer Treatment participant, Gilda’s Club South Florida
  - “I was glad I came to the workshop because it has helped me deal with my cancer and gave me more knowledge” - 2012 FSAC Lung Cancer participant, American Lung Association, Jackson, Florida
Conclusions

• Looking more closely at the utilization of emotional support enables a better understanding of the diverse psychosocial needs of individuals with cancer facing a range of issues

• Understanding emotional needs and how they are typically met will better inform interventions addressing the emotional health of cancer patients

Generalizing the Findings

• Sample geographically diverse and spanned many cancer diagnoses

• Limitations:
  – Individuals choosing to attend psychoeducational workshop:
    • Younger cancer patients under-represented
    • Racial minorities under-represented
For More Information

1050 17th Street, NW
Suite 500
Washington, DC 20036
Phone: 202-659-9709

www.cancersupportcommunity.org