

INFORMATIONAL AND EMOTIONAL SUPPORT UTILIZATION AND NEEDS OF LUNG CANCER PATIENTS AND CAREGIVERS: RESULTS FROM A NATIONAL EDUCATION PROGRAM



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Rationale & Overview

Individuals affected by lung cancer often face significant emotional and practical challenges, though the extent to which many utilize informational and support resources is not well understood. To investigate utilization amongst lung cancer patients and caregivers, attendees of the Cancer Support Community's *Frankly Speaking About Cancer: Lung Cancer* reported their utilization of support and informational resources and other correlates that may be related to help-seeking. Differences between patients and caregivers in support utilization are compared as well as general emotional and informational support utilization is reported in this poster.

In 2012-13, 684 patients and caregivers completed a post-workshop evaluation (response rate, 78%). While general utilization is high and similar to patterns of those affected by other types of cancer, there are some differences between patient and caregiver patterns.

FSAC 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. Programs include:

- Your Immune System & Cancer Treatment
- Metastatic Breast Cancer
- Breast Reconstruction
- Lung Cancer
- Treatments & Side Effects
- New Discoveries
- Coping with the Cost of Care
- Multiple Myeloma



Programs are delivered via:

- Digital
- Print
- Online radio series
- Professionally-led workshops

About the Cancer Support Community

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. In 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. As the largest, professionally led nonprofit network of cancer support worldwide, CSC delivers essential services including support groups, educational workshops, exercise, art and nutrition classes, and social activities for the entire family. For more information: 1-888-793-9355; www.cancersupportcommunity.org

Objectives

- To investigate informational and emotional support utilization in those affected by lung cancer
- To compare utilization differences between lung cancer patients and caregivers

FSAC Workshop Sample Methods

All FSAC Lung Cancer workshop attendees in 2012-13 were offered a paper & pencil-based post-workshop evaluation (response rate=78%).

Data on information-seeking and emotional support patterns were analyzed from 684 respondents who attended FSAC Lung Cancer workshops across the U.S. in 2012-13. Most workshops were held at CSC affiliates though 42 were held at chapters for the American Lung Association.

Respondents: n= 684

Workshop attendee composition:

- 51.2% lung cancer patients
- 48.8% family/friend caregivers

Age = 57.3 years
Gender: 70.1% female
Race:

- 81.9% Caucasian
- 9.4% African-American
- 4.7% Asian
- 2.2% Hispanic

Patients were significantly older than caregivers (t=7.3, p<.01), though no other between group differences on demographics emerged.

Patient's Cancer History:

- Time since diagnosis:
- 47.0% first diagnosed within the past year
 - 38.7% diagnosed between 1-5 years ago
 - 14.3% diagnosed over 5 years ago

46.0% diagnosed with metastatic disease

Support-related Survey Items

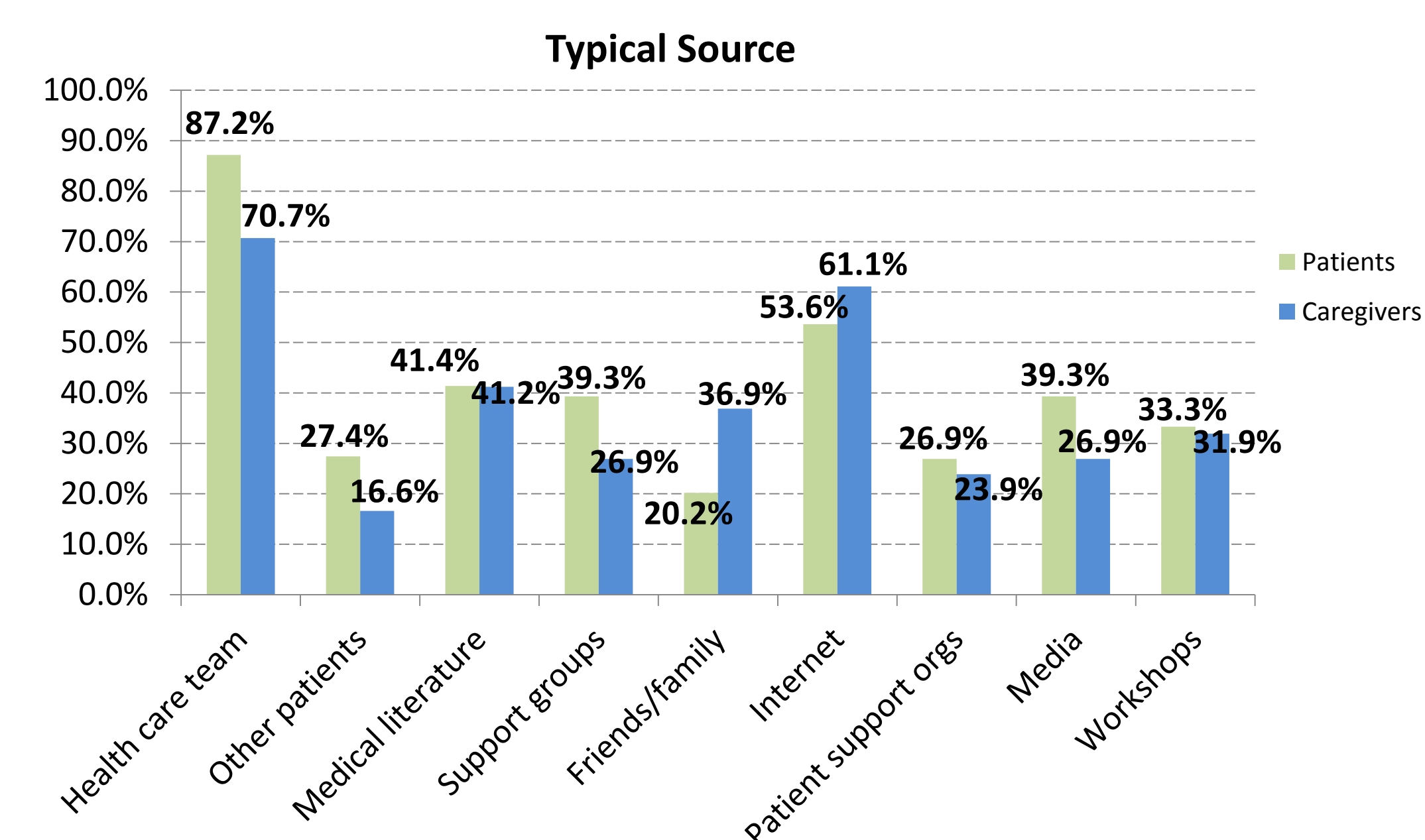
Information-Seeking:

- "Where do you seek information about lung cancer?" (multiple response)
- "The most recent time you sought information about lung cancer, where did you search first?" (open-ended; single response; coded into 10 options)
- Is this the first psychoeducational workshop you attended?

Emotional Support:

- "Where do you seek emotional support when coping with lung cancer?" (multiple response)
- "Are you currently in a support group?"

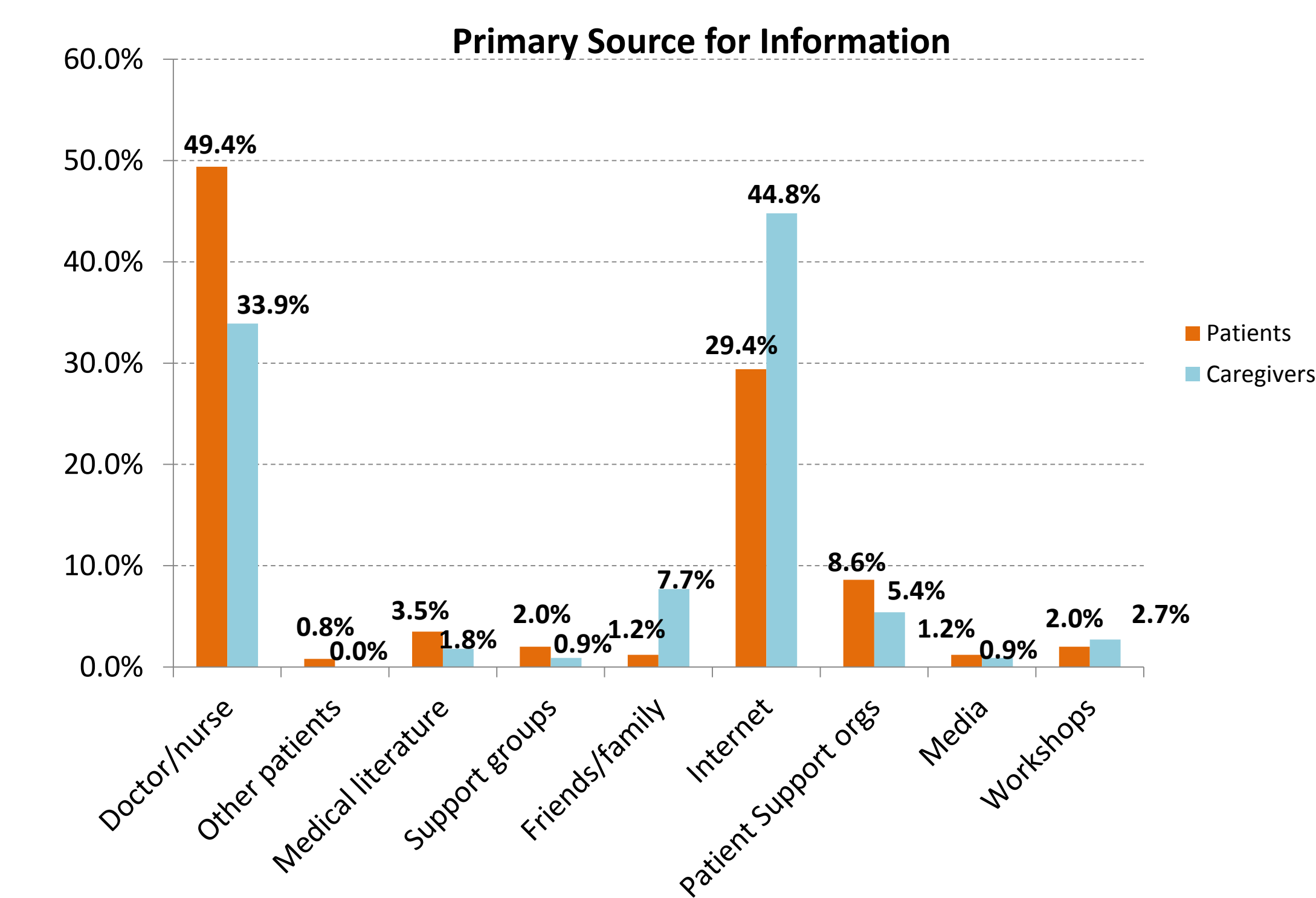
Information-Seeking: Caregivers v. Lung Cancer Patients



In general, most respondents seek out information from health care team and the Internet, which is similar to findings across all FSAC programs.

Patients were more likely to seek information from their health care team and other patients ($\chi^2 = 25.8, p < .01$; $\chi^2 = 10.5, p < .01$, respectively), compared with caregivers.

Caregivers were more likely than patients to seek information from the internet and family/ friends ($\chi^2 = 3.6, p < .05$; $\chi^2 = 21.2, p < .01$, respectively).



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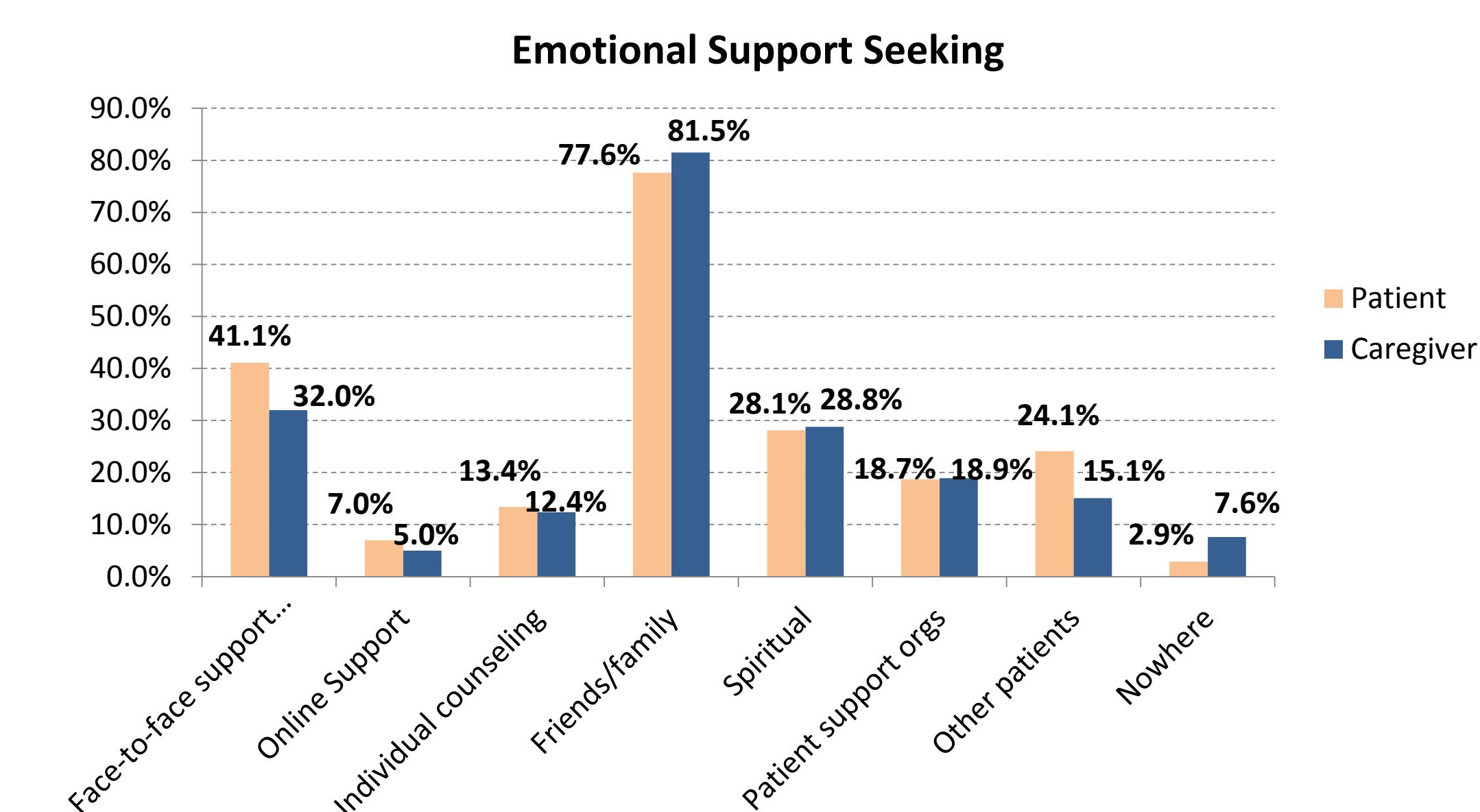
Psychosocial Support Utilization

Previous utilization of formal support services were as follows:

More patients than caregivers had previously attended a psychoeducational workshop ($\chi^2 = 14.0, p < .01$).

Nearly half (42.9%) of patients currently participated in a support group, versus 17.5% of caregivers ($\chi^2 = 48.2, p < .01$).

Emotional Support-Seeking: Caregivers v. Lung Cancer Patients



Most respondents seek out some form of emotional support.

Patients and caregivers were equally likely to seek emotional support via patient support organizations, spirituality, online, and individual counseling.

Few differences between groups emerged in terms of emotional support, though patients were more likely than caregivers to receive support from other patients ($\chi^2 = 7.1, p < .01$) and face-to-face support groups ($\chi^2 = 3.9, p < .01$).

Summary

Overall most respondents sought cancer information from their HCP, followed by online sources

Several notable differences in typical sources of information were observed between patients and caregivers:

- Patients were more likely to seek information from their health care team and other patients
- Caregivers were more likely than patients to seek information from the internet and family/ friends
- "First source" was overwhelmingly health care team or Internet, with reported patterns similar to those for "typical source" of information

Overall, friends and family were the most commonly utilized resource for emotional support.

Fewer differences between groups emerged in terms of emotional support, though patients were more likely to receive support from other patients

More patients than caregivers currently participated in a support group and had previously attended a psychoeducational workshop

Discussion

Whether patient or caregiver, all who are affected by lung cancer have significant informational and emotional needs and are actively seeking out support.

The reasons for differences in informational support utilization patterns may simply be an issue of access; Patients may, in general, have more access to health care providers for their care and perhaps less physical resources to research information online than caregivers. Regardless of the reasons, these findings are significant for understanding how to best target the needs of these populations.

Increased understanding about how services are being utilized can inform current and new services and interventions for lung cancer patients and caregivers.