

ASSESSING THE EDUCATIONAL AND PSYCHOSOCIAL NEEDS OF WOMEN WITH OVARIAN CANCER

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Survey Background

Women with ovarian cancer often experience a range of psychosocial and informational needs. In 2011, the Cancer Support Community conducted an online survey to investigate their needs and how they are being met. The goal of this survey is to inform future programing needs for those affected by ovarian cancer by best understanding the educational and psychosocial needs of women with Ovarian Cancer.

Ninety-five women with ovarian cancer responded to a variety of questions assessing cancer history, treatment, informational needs, psychosocial concerns, and demographic characteristics. Survey results point to the continued need for further education and support for those affected by ovarian cancer.

Education & Support Program Series

This survey was developed as part of the Frankly Speaking About Cancer (FSAC) series of programs developed by the Cancer Support Community.

FSAC programs provides in-depth coverage of topics of relevance to those affected by cancer that are often not otherwise available in a comprehensive format. FSAC program materials, representing the most up-to-date content, include:

- Web-based written materials
- Webinars
- Print booklets
- Online radio series and podcasts
- Professionally-led workshops held across the country
- Interactive program formats include professionally-facilitated support component

Survey Methods

Online Survey assessed:

- Demographics
- Cancer history and treatment
- Informational needs regarding Ovarian Cancer
- Ease of locating information
- Psychosocial Concerns

Participant Characteristics:
(n=95)

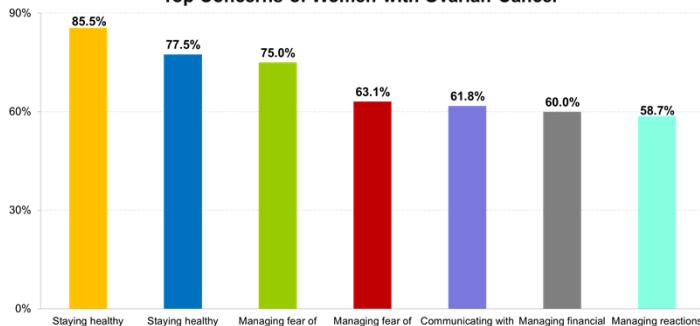
- 93.2% were Caucasian
- Most participants (72.6%) were aged 46 or older
- 44.7% were diagnosed within the past year
- 17.9% had been diagnosed at least 5 years ago
- 29.5% experienced a recurrence of ovarian cancer
- 93.5% had health insurance
- 63.4% are currently married
- 33.3% currently work full time; 51.1% report no change in employment status since diagnosis

Psychosocial and Health Concerns

Respondents expressed concern about a wide variety of issues throughout their treatment such as:

- Communicating with their healthcare team
- Managing fear of recurrence and fear of dying
- Staying healthy during and after treatment
- Managing the financial burden of their treatment
- Communicating with family members about their cancer and managing their reactions

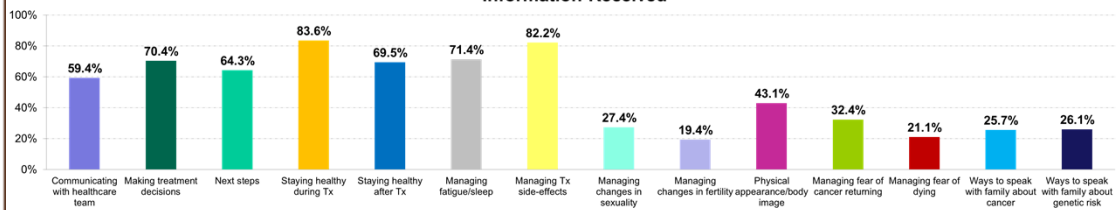
Top Concerns of Women with Ovarian Cancer



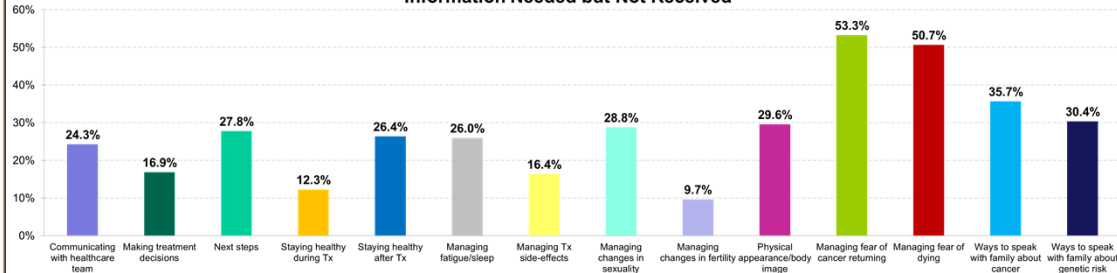
Informational Needs

Over two-thirds of women have received information from their healthcare team about staying healthy during and after treatment, managing fatigue and sleep disruptions, and managing treatment side effects. Other information relevant to the needs of women affected by ovarian cancer have been provided less frequently, such as managing fears, and communicating with others.

Information Received



Information Needed but Not Received



In spite of the psychosocial needs of women with ovarian cancer, many psychosocial and informational needs are not being met. Nearly one quarter of respondents (24.3%) reported they were not given any information about how to communicate with their healthcare team though they would have benefited from it. 53.3% would have benefited from receiving information about managing fear of cancer recurrence, though they did not receive it and 50.7% wanted information on managing fear of death. One-third would have liked information about communicating with family members about their disease (35.7%) and about genetic risk (30.4%)

Demand for Resources

- In spite of respondents' stated need for such informational materials, approximately half of respondents rated **resources for both financial aspects of cancer care (55.3%) and sexuality and relationship issues (46.8%)** as difficult to obtain.
- 64.7% of respondents would be interested in an online support group with other ovarian cancer survivors.
- 66.7% of respondents would be interested in an online educational group to learn more about cancer related issues

Summary

- Women with ovarian cancer commonly experience a variety of concerns after diagnosis and throughout treatment.
- Data indicate while many treatment-related informational needs of women with ovarian cancer are effectively being met, other psychosocial concerns, especially those that are more sensitive, though significant nonetheless, are often not addressed by their healthcare team.
- Similarly, resources on assisting with many topics relevant to this population have been rated as difficult to obtain.
- There is a significant demand for additional education and support services relevant to women with ovarian cancer, particularly in an online format

Future Directions

- Survey results clearly point to the continued need for education and support for those affected by ovarian cancer.
- Particular attention should be given to meeting the currently unmet and under-met psychosocial and informational needs, especially those related to cancer-related fears and concerns around communication with loved ones.
- These results will inform the development of future CSC programming, including Fact Sheets and Webinars, for those affected by ovarian cancer.

For More Information Contact CSC at 1-888-793-9355 or www.cancersupportcommunity.org

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Background

Women with ovarian cancer often experience a range of psychosocial and informational needs. In 2011, the Cancer Support Community conducted an online survey to investigate their needs and how they are being met.

Ninety-five women with ovarian cancer responded to a variety of questions assessing cancer history, treatment, informational needs, psychosocial concerns, and demographic characteristics. Most participants (72.6%) were aged 46 or older, and 93.2% were Caucasian. 44.7% were diagnosed with ovarian cancer within the past year.

Respondents expressed a great deal of concern about the following issues throughout their treatment such as: communicating with healthcare team (41.3%); managing fear of recurrence (48.0%); and staying healthy during (56.0%) and after (51.4%) treatment. That said, nearly one quarter of respondents (24.3%) reported they were not given any information about how to communicate with their healthcare team though they would have benefited from it, and 52.9% would have benefited from receiving information about managing fear of cancer recurrence, though they did not receive it. Similarly, 51.4% wanted information on managing fear of death, and one-third would have liked information about communicating with family members about their disease and about genetic risk.

Approximately half of respondents rated resources for both financial aspects of cancer care (55.3%) and sexuality and relationship issues (46.8%) as difficult to obtain. Notably, 64.7% of respondents reported they would be interested in an online support group with other ovarian cancer survivors. Survey results point to the continued need for further education and support for those affected by ovarian cancer.