

HOW DO WOMEN WITH BREAST CANCER RATE COGNITIVE FUNCTION? THE IMPORTANCE AND IMPLICATIONS AS REPORTED BY 1072 PATIENTS IN A WEB-BASED SURVEY

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Abstract

Background: Difficulties in cognitive function, as evaluated in terms of memory or the ability to concentrate, have been the subject of research and controversy. Cognitive difficulties have been associated with chemotherapy and other treatments for breast cancer. While many causes of these problems have been proposed, including biological and psychological factors, strong evidence is lacking. As part of this survey, we sought the opinions of women with breast cancer to ascertain how these women rated the ability to concentrate among 21 major issues.

Methods: We used the established patient base of the web-based NexCura information resource to survey registered patients with breast cancer. Demographic stratifications included disease stage, age, menopausal status, time since diagnosis, prior treatment with surgery, RT, chemotherapy, hormonal, targeted, and CAM approaches. 1072 women (median age 53, 65% stage I, 43% > 2 years since diagnosis) completed the anonymous web-conducted survey. Patients ranked the importance of 21 issues on a 5-point scale. Issues included general, physical, functional, psychosocial and summative items.

Results: Of all 21 items, the 1072 women ranked the ability to concentrate as one of the four most important factors, as determined by those who rated it in the top category (very important, 65%) and the top 2 importance categories (97%). It followed only overall quality of life in the "very important" category, and was tied with maintaining independence and the ability to sleep in the sum of the top 2 importance categories. Analysis is being conducted to determine if ratings by breast cancer subsets (newly diagnosed, on treatment, NED, hormonal or non-hormonal treatment, metastatic disease, survivors) will differ compared with the whole group.

Conclusions: These results from one of the largest groups of breast cancer patients surveyed to date support the belief that women value the ability to concentrate most highly. Interference with concentration can affect nearly every aspect of functioning and quality of life, and can have an impact on quality decision making. Regardless of whether causes of cognitive impairment have supporting evidence, oncology nurses should be aware of the level of importance of concentration to patients with breast cancer and report symptoms related to executive function.

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Background

- Difficulties in cognitive function, as evaluated in terms of memory or the ability to concentrate, have been the subject of research and controversy.
- Cognitive difficulties have been associated with chemotherapy and other treatments for breast cancer.
- While many causes of these problems have been proposed, including biological and psychological factors, strong evidence is lacking.
- As part of this survey, we sought the opinions of women with breast cancer to ascertain how these women rated the ability to concentrate among 21 major issues.

Objectives

- To determine how women with breast cancer rate cognitive function among quality of life issues of greatest importance.
- To obtain information from a sufficient sample of patients to permit PRO analyses of various patient subgroups.
- To determine which issues are considered to be the most important and whether ratings differ by demographic or treatment-related factors.
- To establish a large data set to support content validity for quality of life and patient-reported outcomes ("PROs") questionnaires in breast cancer.

Design and Patient Recruitment

- This methodological study used an online survey approach.
- The established patient base of the web-based NexCura patient information resource was used to electronically survey patients with breast cancer. Patients who had previously visited this site (www.nexcure.com), and had registered are routinely asked if it is agreeable to contact them in the future. Such patients were sent an invitation to participate anonymously in this survey, and if agreed, an electronic survey was sent. No patient identifier was used at any time.
- Patients with active disease or a history of disease; caregivers were excluded.

Sample

- 1072 women (median age 53, 65% stage I, 43% > 2 years since diagnosis) completed the anonymous web-conducted survey.
- Other stratifications included:
 - hormonal status
 - prior or current treatment* (surgery, RT, chemotherapy, hormonal, targeted, and CAM approaches)

Methods

Instruments:

A questionnaire with 21 items in a categorical format, encompassing physical, functional, psychological, social and spiritual domains was completed by each patient. The content was based on:

- an expert panel of oncology health care professionals
- review of existing quality of life instruments

The questions varied from disease-specific to general items. The initial content was based on the content validity process for the well-validated Lung Cancer Symptom Scale (LCSS) theoretical framework model*

* Hollen et al. *Supp Care Cancer* 1994; *Cancer* 1994

Scoring

Patients were asked to rank each issue on a 5-point categorical scale assessing the importance of each item. The scale ranged from:

"Very Important" to "Not Important at All"

The results are given by the percent rating the item in the highest category ("very important").

Results

Top 5 of 21 Items Rated "Very Important"

	Breast Cancer Patients (N=1072)
Quality of life	82%
Maintaining Independence	75%
Ability to sleep	69%
Ability to concentrate	65%
Ability to perform normal activities	62%

Top 5 of 10 Disease-Specific Symptoms Rated "Very Important"

	Breast Cancer Patients (N=1072)
Ability to concentrate	65%
Pain	46%
Breast swelling	24%
Hot flashes	24%
Vaginal dryness	20%

Ranking by Age Group

Percent Rating "Very Important" (and rank)

	25-44 (n=131)	45-64 (n=641)	65 or older (n=104)
Quality of life	85% (1)	81% (1)	72% (1)
Maintaining Independence	75% (2)	75% (2)	76% (2)
Ability to perform normal activities	76% (3)	67% (3)	66% (3)
Ability to concentrate	63% (5)	65% (4)	61% (4)
Ability to sleep	70% (4)	61% (5)	50% (5)

Ranking by Stage

Percent Rating "Very Important" (and rank)

	Localized (n=577)	Lymph Node Involvement (n=273)	Metastatic (n = 24)
Quality of life	82% (1)	80% (1)	96% (1)
Maintaining Independence	76% (2)	71% (2)	92% (2)
Ability to perform normal activities	69% (3)	66% (3)	92% (2)
Ability to concentrate	67% (4)	59% (4)	84% (3)
Ability to sleep	63% (5)	58% (5)	72% (4)

Ranking by Time Since Diagnosis

Percent Rating "Very Important" (and rank)

	0-12 Months (n=228)	1-4 years (n=549)	4-7+ years (n=99)
Quality of life	80% (1)	83% (1)	84% (1)
Maintaining Independence	78% (2)	78% (2)	71% (2)
Ability to perform normal activities	64% (4)	71% (3)	65% (3)
Ability to concentrate	65% (3)	66% (4)	62% (4)
Ability to sleep	65% (3)	62% (5)	60% (5)

Ranking by Treatment Type

Percent Rating "Very Important" (and rank)

	All Patients (N=1072)	Hormonal Therapy (n=598)	Chemotherapy (n=559)
Quality of life	83% (1)	81% (1)	82% (1)
Maintaining Independence	76% (2)	73% (2)	73% (2)
Ability to perform normal activities	69% (3)	69% (3)	67% (3)
Ability to concentrate	66% (4)	65% (4)	64% (4)
Ability to sleep	63% (5)	61% (5)	60% (5)

Limitations of this Web-Based Methodology

- Patients had to have access to a computer and have some degree of computer literacy
- Patients had to have enough interest in their disease and treatment to:
 - Go online to seek additional information
 - Complete a survey form
- As with all methods, patients who were very ill are less able to participate
- However, those who participated:
 - Are similar to the overall population of patients with these malignancies in the U.S.
 - Information from large subgroups of importance was obtained

Resulting Newly Developed Quality of Life Instrument: Breast Cancer Symptom Scale (BCSS)

BCSS Instrument:



Sample questions and answers:

How good is your appetite?



How much difficulty do you have with concentrating?



How much difficulty do you have with one-sided swelling of the breast?



Conclusions and Implications

- These results from one of the largest groups of breast cancer patients surveyed demonstrate that women value the ability to concentrate most highly.
- Of the 10 disease-specific symptoms surveyed (as opposed to global items), the **ability to concentrate** was the most highly ranked of all (as "most important"), rated even higher than such symptoms as pain.
- This cognitive item, ability to concentrate, was consistently ranked highly among all subgroups analyzed (age, stage of disease, time since diagnosis, and type of treatment).
- Interference with concentration affects every aspect of functioning and quality of life, and can have an impact on quality decision making.
- Many factors potentially can affect cognitive functioning. These include treatment, psychological, and pre-existing factors. Regardless of the cause, oncology nurses need to be aware of the level of importance that patients place on concentration and symptoms related to executive functioning.
- These results are also useful in supporting the content validity of the newly developed BCSS, as well as for other disease-specific quality of life and PRO questionnaires.
- This web-based survey method provides a rapid way of obtaining a large sample assessing the views of patients, which can be applied to single areas of interest as well as to new questionnaires or instruments.

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