

WHICH QUALITY OF LIFE ISSUES ARE RATED BY PATIENTS AS BEING THE MOST IMPORTANT?: RESULTS OF A SURVEY OF 3860 PATIENTS WITH BREAST, LUNG AND PROSTATE CANCER

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Abstract

Background: Identifying issues of importance for patients with cancer is central to assessing health-related quality of life (QL) and patient reported outcomes. These data are critical for patients to be able to communicate effectively with oncology nurses. Validated QL instruments aid in evaluating the effectiveness of interventions and in assuring that appropriate goals are met.

Purpose: To determine among the many issues, which are considered to be the most important, and whether the ratings differ by cancer type, gender, age group or other key factors, as assessed with the patient-rated: Lung Cancer Symptom Scale (LCSS), Prostate Cancer Symptom Scale (PCSS), and Breast Cancer Symptom Scale (BCSS).
Conceptual or Clinical Model/Philosophic or Theoretical Framework: The underpinning framework of these instruments is based on a published conceptual model. This model indicates that areas of change are captured in detail, while those dimensions less likely to vary are captured more globally. (Hollen, Supp Care Ca 1994, and Cancer 1994).

Methods and Analysis: We utilized the established web-based patient information resource, NexCura, to electronically survey registered patients with lung (660 patients), prostate (2128 patients), or breast cancer (1072 patients). Surveys were completed anonymously online. Characteristics included disease stage, age, gender, and treatment history. Patients ranked issues (20-lung, 18-prostate, 21-breast) on 5-point scales assessing the importance of each item.

Findings and Implications: For all three malignancies, the two highest-rated items in the top-ranked category were: 1) good QL (79%-82%), and 2) maintaining independence (71%-75%). The order remained constant across all diseases, genders, and stages. Other issues rated most highly were: able to perform normal activities, ability to sleep, fatigue, and depression (all in the 40-64% range). These results represent one of the largest surveys of patient concerns in these cancers. This study provides support for the content validity of the LCSS, BCSS and PCSS QL and indicates that these items should be part of any QL instrument in these malignancies and warrants testing in patients with other cancers.

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Background

- Identifying issues of importance for patients with cancer is central to assessing health related quality of life (QL) and patient reported outcomes (PRO) during all points of the illness trajectory.
- Validated QL instruments aid in evaluating the effectiveness of interventions and in assuring that appropriate goals are met.
- Patient input is essential to the development of disease specific programs and establishing valid QL instruments.

Content Validity Survey – Objectives -

- To determine which quality of life issues are of greatest importance to patients with breast cancer
- To establish a large data set to support content validity for quality of life and patient reported outcomes ("PROs") questionnaires in breast, lung and prostate cancer
- 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 cancer type, gender, age group or other key factors

Content Validity Survey – Methods -

- 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, lung cancer and prostate cancer. Patients who had previously visited this site (www.nexcura.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.
 - Selection criteria: patients with either active disease or with a history of breast, lung or prostate cancer. Caregivers were excluded. Demographic stratifications included age, gender, educational level, stage of disease, and treatment history.
 - For this comparison study it was required that similar items were present in at least 2 of the 3 disease-specific surveys.

Content Validity Survey – Methods: Items per Disease-Specific Survey, and Number of Similar Items in Each Survey -

	Breast Cancer	Lung Cancer	Prostate Cancer
Number of Items tested in total	21	20	18
Number of Items common to all 3 surveys	11	11	11
Number of Items common in at least 2 surveys	14	15	14

Content Validity Survey – Methods -

Instruments.

A questionnaire with 18 to 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 for lung cancer was based on the content validity process for the well-validated Lung Cancer Symptom Scale (LCSS). The Prostate Cancer (PCSS-QL) and Breast Cancer (BCSS-QL) are based on the LCSS theoretical framework model*.

* Hollen et al, *Supp Care Cancer* 1994, and *Cancer* 1994

Content Validity Survey – Scoring -

Patients were asked to rank each issues 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") or in the two highest categories.

Demographic stratifications included:
 - disease extent - age
 - hormonal status - time since diagnosis
 - prior or current treatment (surgery, RT, chemotherapy, hormonal, targeted, and CAM approaches)

Results

Comparison of Highest Rated items for BCSS, LCSS and PCSS Items Ranked the Highest as "Very Important" (Percent of Patients and Rank Order)

	Breast Cancer Patients (n=1072)	Lung Cancer Patients (n=660)	Prostate Cancer Patients (n=2128)
Quality of Life	82% (1)	80% (1)	78% (1)
Maintaining Independence	75% (2)	71% (2)	74% (2)
Ability to perform normal activities	62% (5)	64% (4)	66% (3)
Ability to sleep	69% (3)	63% (5)	51% (6)
Fatigue	61% (6)	58% (7)	40% (7)

Comparison of Highest Rated items for BCSS, LCSS and PCSS Items Ranked the Highest as "Very Important" + "Important" (Percent of Patients and Rank Order)

	Breast Cancer Patients (n=1072)	Lung Cancer Patients (n=660)	Prostate Cancer Patients (n=2128)
Quality of Life	99% (1)	98% (1)	98% (1)
Maintaining Independence	97% (2)	97% (2)	97% (2)
Ability to perform normal activities	97% (5)	96% (3)	97% (3)
Ability to sleep	97% (3)	94% (4)	94% (4)
Fatigue	95% (6)	93% (5)	89% (7)

Ranking of Disease Specific Items: Items ranked mid-range

- Disease-Specific symptoms tended to be ranked in the mid-range of importance of the 18 – 21 items per malignancy:
 - Prostate Cancer Symptoms were ranked from the 7th to the 11th most important (Pain, Urinary Issues, Items regarding Sexuality)
 - Breast Cancer Symptoms were ranked from the 9th to the 21th most important (Pain, Hot flashes, Vaginal dryness, Breast swelling)
 - Lung Cancer Symptoms were ranked from the 6th to the 15th most important (Pain, Dyspnea, Hemoptysis, Cough, Hoarseness)
- Of these multiple disease-related symptoms, pain was more highly ranked (generally from the 6th to the 11th most important item) across all 3 cancers, and as expected was ranked higher by patients with metastatic disease

Comparison of Lowest Rated items for BCSS, LCSS and PCSS Items Ranked the Lowest as Very Important + Important (Percent of Patients and Rank Order)

	Breast Cancer Patients (n=1072)	Lung Cancer Patients (n=660)	Prostate Cancer Patients (n=2128)
Anxiety	47% / 85% (8)	40% / 78% (14)	35% / 78% (13)
Cough	31% / 68% (14)	28% / 65% (17)	NA*
Sexual Difficulties	27% / 60% (17)	20% / 48% (20)	41% / 79% (14)
Problems with urination	NA*	27% / 65% (18)	35% / 81% (12)
Hot Flashes	24% / 57% (19)	NA*	10% / 35% (18)
Appetite	20% / 63% (20)	33% / 60% (15)	13% / 64% (17)

* % ranked "very important" / % ranked "very important" + "important" (rank)
 NA= not assessed in this malignancy

Content Validity Survey 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

Conclusions and Implications

- For all three malignancies, the two highest-rated items were the same:
 - Having good Quality of Life
 - Maintaining Independence
 This was true whether rating by the "most important" category or by "most important" + "important"
- The order of the highest ranked items remained essentially the same across all 3 diseases. This was true also by stage of disease and by gender
- Other highly rated items included ability to perform normal activities, ability to sleep, fatigue and depression (all in 40-64% range)
- The results are useful in supporting the content validity of the BCSS, LCSS, PCSS-QL, as well as other disease-specific QL and PRO questionnaires.
- General items (such as QL) were typically more highly ranked by patients than disease-specific symptoms
- This web-based survey method provides a rapid way of obtaining a large sample assessing the views of patients
- The results represent one of the largest surveys of patient concerns in these cancers
- Evidence supporting use of these items and this method indicates that assessments in patients with all malignancies are warranted.

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For more information on the LCSS, please go to www.lcss-ql.com.
 For more information on this poster, please contact jhorgan@nshs.edu.