Review

Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review

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Abstract

Objective: The assessment of supportive care needs is a crucial step in the development of appropriate interventions that may improve the quality of life of cancer patients. This review describes and analyzes the prevalence and predictors of the unmet supportive care needs of breast cancer (BC) patients and survivors and suggests paths for further research.

Method: Multiple databases were searched, considering only quantitative studies using validated needs assessment instruments and focusing uniquely on women diagnosed with BC.

Results: Out of 761 hits, 23 studies answered to all eligibility criteria. Nineteen were cross-sectional, and the remaining four were longitudinal. Most included patients at different moments along the BC trajectory, from diagnosis to decades into survivorship, with the major proportion of patients under treatment. Only five concentrated on the posttreatment phase into extended survivorship. The concerns of women diagnosed with BC clustered around psychological and information needs, with the top concern being 'fear of the cancer returning'. Predictors of higher levels of needs included advanced disease stage, greater symptom burden, shorter time since diagnosis, higher levels of distress, and younger age. Prevalence differed between cultures with Asian women reporting greater information needs and lower psychological needs compared with Western women.

Conclusions: Revealing which needs BC patients consider most urgent and the factors related to greater needs will permit the development of improved and targeted supportive care. Future research should comprise longitudinal designs concentrating on women at specific moments along the BC trajectory for a dynamic understanding of these needs.
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Introduction

Breast cancer (BC) is the most commonly diagnosed cancer in women, with an estimated 226,870 new cases expected in 2012 in the USA alone [1]. In France, 100 per every 100,000 women develop BC each year [2]. Survival after 5 years for early, localized BC is now above 96%, and 82% of all women diagnosed with BC can expect to survive 10 years [3]. BC survivors are the largest group of cancer survivors among women in the western world. Although the majority return to a level of quality of life (QOL) similar to those reported in the general population one or more years after the end of treatment, a significant proportion of these women continue to experience physical and emotional sequelae many years later [4–7].

The goal of supportive care is to improve the QOL of patients with a serious or life-threatening disease by treating the symptoms and side effects caused by the illness and its treatment. This entails prompt attention to physical difficulties, pain management, and psychological, social, and spiritual problems [8]. It demands treating the patient as an individual, taking into account their fears and worries, going beyond symptoms management. Numerous studies and reviews examine the QOL of women diagnosed with BC at different phases of the disease, assessing physical, psychological, and social difficulties from diagnosis well into survivorship [9–13], but to date, we do not have a precise or overall picture of what help women actually need or expect to manage the symptoms and problems they face [9,14,15].

'Unmet needs' refers to the gap between a person's experience of services and the actual services required or desired [16]. In health care, both QOL and needs assessments cover multidimensional domains such as physical

function, and psychological and social issues, but quantitative studies comparing the scores of QOL and needs on parallel items have revealed a mismatch, underscoring the highly subjective nature of needs [14,15,17]. In other words, two women who report the same symptom may express a different level of need for help. This discordance may be due to disease factors, socio-demographic factors, psychological and social variables, or expectations based on previous health care experiences [15–19]. It is the direct assessment of needs that allows us to gauge a woman's perception of what concerns must be addressed in order to improve the quality if not the quantity of her life.

In the past decade, there has been increased interest in needs assessment in cancer care, to which the abundance of tools available bears witness [20]. Most cancer needs assessment studies have examined the needs of mixed cancer populations, including all stages at various times since diagnosis; the majority of these are cross-sectional in design [21–26] although there are a few large longitudinal studies [18,27]. These studies also vary in their examination of other crucial factors, such as QOL and distress in relation to needs. Previous systematic reviews examining the unmet supportive care needs of BC populations have focused primarily on information needs [28,29], comparing patient and caregiver needs [28,30], or urban and rural populations [32], and have included studies using various designs [31,32]. Although one review addressed BC patients [30], the goal was to compare the needs of BC patients to those of their relatives. None concentrated specifically on studies examining the needs of BC patients that employ validated quantitative measures.

Breast cancer patients are different from other cancer groups in many ways. Unlike colorectal cancer, which is uncommon under the age of 45, or bone cancer, which is most often detected in young adults, BC is diagnosed across a wide age group, between the ages of 35 and 84 with a mean age of 61. Between the ages of 20 and 44, 11.7% of cases are detected, and another 70% is evenly dispersed between the ages of 45 and 74 (approximately 23% per every 10 years of age) [33]. This means that a significant proportion of diagnoses hit women during childbearing age. Supportive care needs change as a function of age as large-scale studies on mixed cancer populations have shown. Specifically, being younger or female is related to reporting greater unmet needs in at least one domain [18,19,22,24,26]. But BC and its treatment also have direct bearing on a woman's femininity and body image. Therefore, in this review, we concentrate on studies that examine the supportive care needs specific to women who have been diagnosed with BC, and include new studies not contained in previous reviews. We only considered studies using validated quantitative instruments to present concrete estimates and analyses of the number, frequency, and intensity of the supportive

care needs specific to this population that may in turn enable the prediction of who is more likely to express greater need.

This review attempts to answer the following questions:

(1) What are the supportive care needs of women who have been diagnosed with BC? What are the domains and specific items of need most frequently reported as unmet by BC patients, and what is the intensity of these needs?
(2) What are the factors (socio-demographic, clinical, psychosocial) that amplify or diminish the intensity of these needs?

Our goal is not only to summarize what is presently known, but also in teasing out the associations between socio-demographic, physical, emotional, and psychosocial factors, we hope to aid in identifying who may be at risk for greater needs, and highlight gaps in the literature that require further investigation.

Method

Search strategy

A systematic search of the following databases was conducted: CINHAL, PubMed/Medline, and PsycInfo. Papers published between January 2000 and December 2012 assessing the supportive care needs of BC patients were identified entering key words in combination with BC (breast cancer, breast neoplasm*) and supportive care needs (supportive care, psychosocial care, need*, unmet need*, needs assessment) and validated need assessment instruments ('Cancer Patient Needs Survey', CARES, 'Cancer Rehabilitation Evaluation System', 'Concerns Checklist', 'Needs Evaluation Questionnaire', 'Patient Needs Assessment Tool', PNAT, 'Psychosocial Needs Inventory', SCNS, 'supportive care needs survey'). Reference lists of major articles on the subject were examined for any additional titles. The search returned a total of 761 hits.

Inclusion and exclusion criteria

Quantitative studies employing validated needs assessment instruments focusing uniquely on BC patients or survivors were considered for review. All stages of BC including advanced and recurring disease at any point along the cancer trajectory (post diagnosis, in treatment, and post treatment) were included. A validated instrument was operationally defined as a self-report measure either previously or concurrently demonstrating basic psychometric properties (construct validity and internal consistency) in a peer-reviewed journal. Papers were considered only if they were in English.

We excluded studies reporting data on mixed cancer types except if they reported data for BC separately, participants who were at pre-diagnosis, genetic screening of healthy women at risk, needs of relatives/partners, health care provider training studies, and commentaries.

Data extraction and analysis

Two authors (CF and AB) discussed the criteria for including papers and describing needs within selected studies. We extracted the prevalence of needs (the number of patients that expressed individual need items) and/or the intensity of needs (the mean scores in domains of need). To present the most commonly endorsed needs assessed with the same questionnaire in different studies, we calculated weighted frequencies for each item. We identified predictors as all factors and variables that presented a relationship to needs within each study. Using an established PRISMA checklist, we assessed the quality of the final 23 studies [34]. Checklist items include 'subject characteristics sufficiently described?' and 'conclusions supported by results?' Studies were scored to what extent they met each applicable criterion: 2 (yes), 1 (partial), or 0 (no). Of the 14 checklist items, three were excluded, as they are not relevant to observational studies. The summary score for each paper was then divided by the highest possible score of 22 (i.e., scoring 2 on each of the 11 applicable criteria) and graded high (>0.75), moderate ($0.55–0.75$), or low (<0.55). All studies scored moderate or high; a grade of low would have earned exclusion from this review.

The database search returned 761 hits. After removing duplicates, 439 remained. All of these titles and abstracts were inspected for relevance. Dissertations, book chapters, reviews, and those using qualitative designs were rejected, reducing the number of papers to 87. The method and instruments used in these 87 studies were inspected leading to the exclusion of an additional 30. The remaining 57 were read in entirety, and an additional 34 were rejected, as they did not employ validated instruments or did not report concrete data regarding frequencies or mean scores. Twenty-three responded to all criteria and are reviewed in this paper (Figure 1).

Results

Table 1 summarizes the characteristics of 23 studies examining the prevalence and intensity of unmet needs of BC patients. Nearly all are cross-sectional in design except for four, which are longitudinal [35–38].

Samples

Six of these studies recruited patients diagnosed at different stages and undergoing various treatments, including recurring cancers and metastatic forms [39–44], three papers concentrate on those with recurrent and progressive disease [45–47], two specify the exclusion of patients with
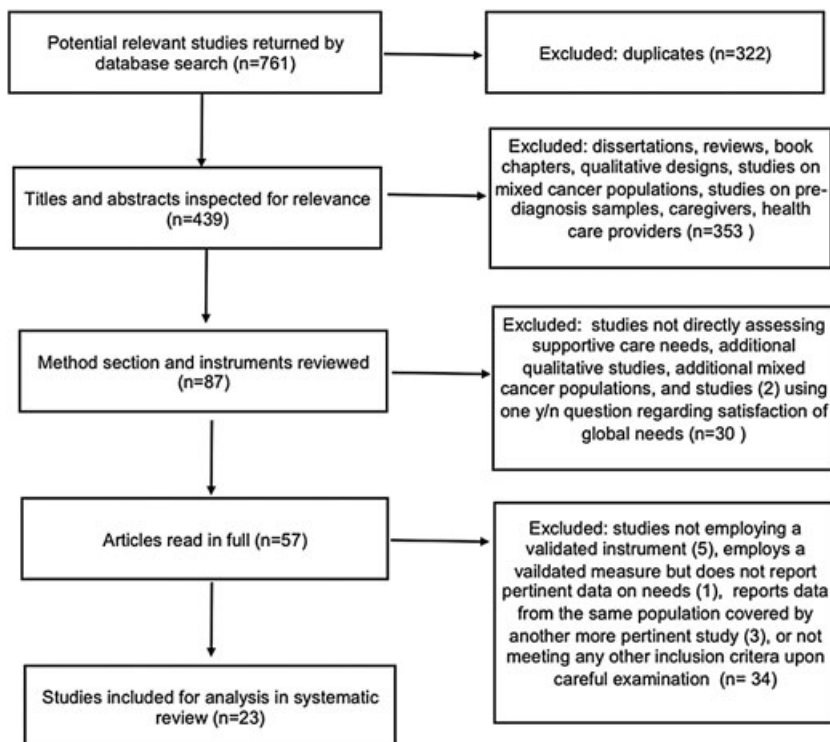

Figure 1. Flowchart showing selection procedure

Table I. Study characteristics

Author (year) country	Design	Sample	Time since diagnosis (DX)	Supportive care needs measure	Other measures	Data and analyses	Quality rating
Akechi *et al.*, 2011 (Japan) [39]	Cross-sectional	N=408 mean age=56 stage 0–IV, recurrence	6 months–4 years post DX (mean =3years)	SCNS-SF34 % rated low, mod, or high	HADS, QLQ-C30	Mean number of unmet needs per domain, 10 most prevalent unmet needs, multiple regression analyses of predictors of need	High
Aranda *et al.*, 2000 (Australia) [45]	Cross-sectional	N=105 mean age=57 advanced, recurred, progressed	DX in past 12 months	SCNQ-59 % rated mod or high	QLQ-C30	Mean scores per domain (0–100), prevalence per domain, prevalence per item, hierarchical cluster analyses identifying women with different need profiles	High
Au *et al.*, 2011 (China) [40]	Cross-sectional/ psychometric	N=348 all stages, metastases recurrence	<1 year–29 years post DX	SCNS-SF34 % rated low, mod, or high	CHQ-12, HADS, C-LOT-R, MASAS PANAS, ChPSQ	Mean scores per domain (0–100), prevalence for all 33 items, psychometric analyses	High
Au *et al.*, 2012 (China) [46]	Cross-sectional	N=198 mean age=53 SIII, SIV first and recurred	Mean time since DX: 4 months 76% pre-CT	SCNS-SF33 % rated low, mod or high	HADS MSAS-SF PSQ	Mean scores per domain (0–100), prevalence for all 33 items, multiple regression analyses of predictors of need	High
Avis *et al.*, 2004 (USA) [57]	Cross-sectional	N=204 age < 50 years old SI, II, and III	DX between 3 months–3 years	CARES with two extra questions (pregnancy/menopause)	None	Mean scores (0–4), prevalence for need items above 40% reported, multiple regressions analyses of predictors of need, quantitative and qualitative analyses	High
Brédart, Kop *et al.*, 2013 (France, Switzerland) [41]	Cross-sectional	N=384 mean age=54 all stages, metastases	Post surgery or in treatment	SCNS-34, SCNS-BR8 % rated low, mod, high	EORTC QLQ-C30, IN PATSAT32/ OUT-PATSAT35 HADS	Mean scores per domain (0–100), 10 most prevalent unmet needs, multiple regression analyses with needs scales and regression residuals as dependent variables to explain discordance between needs and difficulties	High
Erci & Karabulut 2007 (Turkey) [48]	Cross-sectional	N=143 SII	Time since DX < 3 years	Self Assessed Support Needs	None	Mean scores for seven categories, cluster analyses by demographic factors	High
Girgis, Boyes *et al.*, 2000 (Australia) [50]	Cross-sectional	N=229 (rural = 129, urban =100) stage n/a	Time since DX between 6 months–5 years (most 3–5 years post DX)	CPNQ + BRCPN % rated mod or high	None	Fifteen most prevalent needs, prevalence for all eight BC specific items, regression analyses of predictors of need	High
Girgis, Stacey *et al.*, 2011 (Australia) [51]	Cross-sectional	N=237 complete data on 195 stage n/a	Time since DX=3–5 years	LNQ-BC (based on SCNS, with lymphedema specific questions added) % rated mod or high	None	Ten most prevalent needs, logistic regression analyses to explore predictors of need	High
Griesser *et al.*, 2010 Switzer-land) [42]	Cross-sectional	N=274 M age= 57.2 all stages, mostly SI	Newly diagnosed and under treatment	SCNS-SF34 % rated mod or high	None	Top five moderate or high needs, top five low, moderate, or high needs, multivariate analyses of patient socio-demographic factors predicting needs	High
Halkett *et al.*, 2012 (Australia) [35]	Longitudinal	N=123 stage n/a	T1 = first consultation T2 = planning appointments	RT Concerns, RT Information needs, Patient Information	HADS	Radiotherapy concerns mean scores, RT information needs at each time	High

Study	Design	Sample	Timing	Need measure	Other measures	Analysis	Rating
Hodgkinson, et al., 2007a (Australia) [43]	Cross-sectional	N=117 M age=61 all stages	T3 = first week of treatment; T4 = end of treatment; 3.9 years post DX (2–10 years)	Preference % rated very important; CaSUN % rated met and unmet	SFI2, HADS	point and index for items with significant change over time; Mean total of met needs, 10 most prevalent unmet needs, mean total unmet met needs, 10 most prevalent met needs, 10 most prevalent unmet needs, one-way ANOVA to assess differences between groups	High
Hwang & Park, 2006 (Korea) [56]	Cross-sectional	N=459 M age n/a S0–SIII	3 months–15 years post surgery	SCNS-59 % rated mod or high	None	Frequency by domain, 10 most prevalent needs, forward regression analyses of predictors of need	High
Lam et al., 2011 (Germany, China) [44]	Cross-sectional/ cultural	Ch N=369; Gr N=292 all stages, recurrence, metastases	Half still under active treatment	SCNS-34 % rated low, mod, or high	HADS, MSAS-SF	Mean scores per domain per country, prevalence for all 34 items per country; multiple regression of associated factors with unmet needs	High
Lee et al., 2004 (China) [36]	Longitudinal/ cultural	BC=51; combination of treatments; 50% were between 40–50 years of age	T1 = beginning CT; T2 = half way through CT	TINQ-BR (Toronto Informational Needs)	None	Mean scores, 10 most important information needs by rank, t-tests to compare time points	Mod
Li et al., 2012 (China) [56]	Cross-sectional	N=97 S 0=II	DX > 2 years	SCNS-SF34 % rated low, mod, or high	HADS, MSAS, PSQ	Mean scores per domain (0–100), 10 most prevalent needs, multiple regression analyses	High
Liao et al., 2012 (Taiwan) [37]	Longitudinal	N: T1=124 (DX) T2=119 (1m) T3=115 (2m) T4=114 (4m) M age=49.37 S I,II	DX to 4 months post DX	SCNS-SF34 % rated mod or high	STAIT, SSS-m, SDS-mbc	Mean scores per domain per time point, 10 most prevalent needs per time point, repeated measures analysis of variance to analyze changes over time and predictors of change	High
Mahapatro & Parkar, 2005 (India) [52]	Cross-sectional	N=75 (mastectomy=50 lumpectomy=25) age=18–50 M age=42.7	6 months–1 year post surgery	Coping & Concerns Checklist by Devlen	HADS	Means and predominant concerns by group: lumpectomy versus mastectomy	Mod
Minstrell et al., 2008 (Australia) [38]	Longitudinal (partial)	N T1=74; N T2=83; participants in both=63; rural sample	T1 = 1 month post DX; T2 = 3 months post DX	SCNS-59 % rated mod or high (T1 > T2)	None	Mean unmet needs compared at two time points, prevalence of top needs compared to earlier study [53]	Mod
Park & Hwang 2012 (Korea) [49]	Cross-sectional	N=1084 M age=n/a S I, II, III no metastases no recurrence	Four cohorts post DX <1 year, 1–3 years, 3–5 years, >5 years	SCNS-59 % rated mod, or high (but also labeled as 3 or more on Likert scale, ie, low, mod, high)	BDI, FACT-G/B, ECOG-PS	Ten most prevalent needs, regression analyses of depression and needs, analysis of covariance for comparing four groups and needs	High
Schmid-Büchi et al., 2011 (Germany) [53]	Cross-sectional	N=72 (patients and 72 relatives) stage n/a	1–22 months post treatment	SCNS-SF34 % rated low, mod, or high	PNI, CTSS, HADS, DT, PRISM	Means needs per domain (1–5), 12 most prevalent needs, backward regression analyses for factors associated with needs	High
Schmid-Büchi et al., 2012 (Germany) [54]	Cross-sectional	N=175 M age=57.5 stage n/a	4.2 months post DX, under treatment	SCNS-SF34 % rated low, mod, or high	CTSS, IPRI, HADS, DT	Mean needs per domain (1–5), four examples of prevalent needs, backward regression analyses predicting needs	High
Uchida et al., 2011 (Japan) [47]	Cross-sectional	N=85 advanced (SIV) recurrence (80%)	70 months post DX	SCNS-SF34 % rated mod or high (but also labeled as 3 or more on Likert scale, ie, low, mod, high)	HADS, QLQ-C30	Mean needs per domain, correlations between needs and other measures	High

recurrence or metastases [48,49], and two comprise mostly stages I and II [41,42]. Seven studies do not specify stage inclusion criteria [36,38,50–54]. The studies vary in time since diagnosis, ranging from the newly diagnosed [37,42] to those with recurrent disease [47], to 15 years into remission [55]. Only one study reports data separately for different groups according to time since diagnosis [49], one concentrates on the posttreatment phase [53] and three on women at least 2–10 years post diagnosis [43,51,56]. Two studies concentrate on younger women [52,57], whereas the rest report mean ages between 53 [46] and 61 [43]. Sample sizes range from 51 [36] to 1084 [49].

Several cultures and languages are represented, nearly half Asian: Chinese [40,44,46,56], English [35,38,43,45,50,51,57], French [41,42], German [44,53,54], Japanese [39,47], Korean [49,55], Taiwanese [37], and Turkish [48].

Measures

The instrument of choice for 18 of these studies is the SCNS, short form 34 [58] or the earlier version 59 (based on the CNQ) [59,60], a survivor's version (CaSUN) [61], and a version adapted specifically to needs related to lymphedema (LNQ-BC) [51]. The most commonly used version, the SCNS-SF34 [61] comprises five domains: psychological, health system and information, physical and daily living, patient care and support, and sexuality. Participants rate the importance of need items in each domain from 1 to 5 as follows: (1) no need/not applicable, (2) no need/satisfied, (3) low need, (4) moderate need, and (5) high need. Scoring and reporting of needs vary between studies. Nine studies [39–41,43,46,49,53,54,56] report frequency of needs scored low, moderate, or high (3 and above on the 5-point Likert scale), seven others report frequency or proportion of needs scored medium or high (4 or 5) [37,38,45,47,51,55]. Five studies also reported standardized mean scores for each domain [40,41,44,46,56], whereas six presented the mean or number of unmet needs per domain [38,39,43,53,54,47].

Other instruments employed are the CARES, Devlen's Coping and Concerns Checklist, Radiotherapy (RT) Concerns and Information Needs, Self Assessed Support Needs, and Toronto Informational Needs. The CARES [62,63] asks patients to rate multidimensional problem statements from 1 (a little) to 4 (very much). The Coping and Concerns Checklist [64,65] examines both supportive care needs and how patients cope with their concerns. Similar to the SCNS, patients rate whether each item on the checklist is of concern or not and to what level of severity (mild, moderate, and severe). Patients are also asked how they cope with each concern. The Self Assessed Support Needs of women with BC questionnaire [66] consists of seven categories (diagnosis, treatment, support, femininity and body image, family and friends, information, and after care) rated from 1 (no importance)

to 5 (extremely important). The RT Concerns and Information Scales [67] and the Toronto Informational Needs [68] are geared to measuring information needs specific to BC patients in the areas of disease, treatment, side effects, physical, and psychosocial concerns. Each of these instruments is scored differently, with mean scores and/or the percentage of the sample expressing each need reported in the results.

The relative importance of needs can be judged by comparing parallel domains and items across these surveys.

Prevalence of needs

Table 2 lists the most common items reported as unmet per instrument, taking into account sample sizes by calculating weighted average frequencies. Across these studies, the highest needs were in the health system/information and psychological domains, with dealing with fear of the cancer recurring or spreading as the one most prevalent need. A significant proportion of women report at least one high or moderate unmet supportive care need, ranging from 20% [38] reporting at least one need across all domains, to 70% expressing unmet needs [42] specifically in the health information domain.

Intensity of needs

Intensity of needs is reported as mean scores on each domain, reflecting the mean severity of needs on that scale; however, not all studies report mean scores. These scores are used to compare severity of needs across different samples, or the same sample at different time points, and to examine factors associated to needs. Appendix 1 shows prevalence and intensity data for each study.

Predictors of needs

Several factors were examined in relation to the number and intensity of needs and are summarized per study in Table 3 and per predictor in Table 4. Appendix 2 shows detailed data per study.

Discussion

The purpose of this review was to summarize what is currently known about the prevalence and severity of the supportive care needs of BC patients and tease out the predictors of greater needs so as to shed light on directions for research and clinical applications. Results indicate that a substantial proportion of women who have been diagnosed with BC perceive significant unmet needs throughout the cancer trajectory which cluster around several domains, with information and psychological needs being the most prevalent and most intense.

Most studies employing instruments that assess a wide range of needs demonstrate that 'fear that the cancer is

Table 2. Prevalence of supportive care needs

	(Top five needs, or needs rated 30% and above)		
Measure	% Prevalence	# Samples	Reference
Supportive Care Needs Survey (SCNS-SF34, SCNS-SF33)		N = 10	[39–42,44,53,54,56]
% Rated low, moderate, high			
Fears about the cancer spreading[a]	39	9	
Being informed about things you can do to get well[b]	72	8	
Uncertainty about the future[a]	33	8	
Worried that the results of the treatment are beyond your control[a]	35	7	
Anxiety[a]	30	7	
Concerns about the worries of those close to you[a]	30	7	
Having one staff member you can talk to[b]	61	6	
Being informed about remission[b]	53	6	
Having access to professional counseling[b]	37	6	
Being given information about managing your illness at home[b]	37	6	
Being informed about test results as soon as feasible[b]	50	5	
Being given written information about important aspects of care[b]	46	5	
Supportive Care Needs Survey (SCNS-SF34, SCNS-SF33)		N = 4	[37,42,47]
% Rated moderate, high			
Being informed about test results as soon as feasible[b]	62	4	
Being informed about things you can do to get well[b]	59	3	
Worried that the results of the treatment are beyond your control[a]	57	3	
Fear of the cancer spreading or returning[a]	52	3	
Having one staff member you can talk to[b]	51	3	
Uncertainty about the future[a]	50	3	
Concerns about the worries of those close to you[a]	67	2	
Being informed about the benefits and side effects of treatments[b]	63	2	
Being treated in a hospital or clinic that is physically pleasant[b]	56	2	
Not being able to do the things you used to do[c]	39	2	
Supportive Care Needs Survey (CNQ, CPNQ, SCNS-59)		N = 6	[38,45,49,50,55]
% Rated moderate, high			
Being informed about test results as soon as feasible[b]	43	6	
Being informed about things you can do to get well[b]	43	5	
Fears of the cancer spreading[a]	42	5	
Being informed about the benefits and side effects of treatments[b]	72	4	
Being informed about remission[b]	53	4	
Fears of cancer returning[a]	46	4	
Being given information about managing your illness at home[b]	49	3	
Having access to professional counseling[b]	43	3	
Concerns about the worries of those close to you[a]	34	3	
Uncertainty about the future[a]	30	3	
Cancer Survivors' Unmet Needs Measure (CaSUN)		N = 1	[43]
% Rated unmet			
I need help to manage my concerns about the cancer coming back[a]	33		
I need up-to-date information[b]	30		
I need information provided in a way that I can understand[b]	26		
I need an ongoing case manager to whom I can go to[b]	23		
I need access to complementary therapy services[b]	22		
Lymphedema Needs Questionnaire-Breast Cancer (LNQ-BC)		N = 1	[51]
% Rated moderate or high			
Having doctor acknowledge that lymphedema is a serious problem[b]	34		
Having doctor fully informed about lymphedema and its associated problems[b]	34		
Having doctor willing to treat lymphedema[b]	32		
Non-recognition or coverage of lymphedema by health insurance[f]	30		
To be informed about alternative treatments for lymphedema[b c]	30		
Having doctor/health care professionals willing to follow-up with lymphedema treatment[b]	30		
Cancer Assessment & Rehabilitation Survey (CARES)		N = 1	[57]
Concerns about premature menopause	57		

(Continues)

Table 2. (Continued)

| | (Top five needs, or needs rated 30% and above) | | |
Measure	% Prevalence	# Samples	Reference
Communication with partner (talking about death)	53		
Worried whether pregnancy would affect breast cancer	48		
Body Image	47		
Concerns about body image	47		
Worried whether could become pregnant	43		
Sexual interest	42		
Lubrication during sex	41		
Coping and Concerns Checklist		N = 2	[52]
% Rated across two surgical groups			
Worries about recurrence or relapse	75		
Current Illness	63		
The future	40		
Feeling upset or distressed	39		
Body image or disfigurement (mastectomy group only)	78		
RT Concerns and Information Needs		N = 4	[35]
% Rated as 'very important' across four time points			
How to take care of my skin	48		
Whether my lungs will be damaged	47		
Whether the radiation will affect my heart	46		
What side effects I may experience	45		
Why I need to receive radiation therapy	43		
How much of my breast will be treated	41		
What will radiation therapy involve	40		
What will happen after treatment is finished	39		
The radiation oncologist who will be treating me	37		
The cost of treatment	30		
Self Assessed Support Needs		N = 1	[48]
% Highest rated clusters of need items			
Family and friends	79		
After care	78		
Treatment	63		
Support	59		
Information	54		
Femininity and body image	47		
Diagnosis	43		
Toronto Informational Needs Questionnaire—Breast Cancer (TINQ-BR)		N = 2	[36]
Most important by rank across two time points			
What side effects I should report to the doctor/nurse			
If the breast cancer will come back			
How to tell if the cancer has come back			
If there is cancer anywhere else in my body			
The possible side effects of my treatment			
How the treatment works against the cancer			
If I have side effects, how to deal with them			

[a]Psychological needs.
[b]Healthy system and information needs.
[c]Physical and daily living needs.
[d]Care and support needs.
[e]Sexual needs.
[f]Financial needs.

spreading or returning' is the most prevalent need among BC samples and therefore requires urgent attention. The studies reviewed here that assessed anxiety and depression found higher scores were related to higher psychological needs. But only needs assessments can pinpoint what fear patients actually need help with.

When the sample includes women with advanced, recurring, or metastatic disease, the primary concerns shift

Table 3. Predictors of supportive care needs

Study		Predictors
Akechi et al., 2011 (Japan) [39]	Demographic	Employment related to lower total, PSY, HS/INFO, PHY/DL, CARE needs
		Younger age (<55) related to greater sexuality needs
	Clinical	Time since DX (<6 months), advanced BC, lower physical performance each related to higher total, PSY, HS/INFO, PHY/DL, Care needs
	QOL	Higher Global QOL related lower PHYT/DL & SEX needs
	Distress	Higher HADS total & each (A/D) scores related to higher PSY needs, higher D related to greater SEX needs
Aranda et al., 2005 (Australia) [45]	QOL	No correlation made
Au et al., 2011 (China) [40]	Demographic	Younger age related to greater SEX, SPY, HS/INFO/CARE needs
	Clinical	Not being under treatment related to lower PSY, HS/INFO, PHY/DL needs
		Advanced BC have higher PSY, PHY/DL needs
	QOL	Global distress, physical, psychological, and number of symptoms correlated with all five SCNS domains
	Distress	Higher HADS total and each (A/D) scores related to higher PSY, HS/INFO, PHY/DL, Care; D to SEX needs
	Patient Satisfaction	Weakly correlated with HS/INFO
	Affect	Negative affect correlated to greater needs on all five SCNS domains and greater symptoms distress
Au et al., 2012 (China) [46]	Demographic	Being single related to greater PHY/DL needs
		Being married related to greater SEX needs
	Clinical	Active CT related to lower HS/INFO needs and higher PSY needs
		Breast reconstruction related to lower total needs
	QOL	Greater symptom distress related to more unmet HS/INFO/CARE, PSY needs
	Distress	HADS/A positively correlated to PSY needs
	Patient Satisfaction	Dissatisfaction related to unmet HS/INFO/CARE needs
Avis et al., 2004 (USA) [57]	Demographic	Missed work or activities (>90 days) related to sexual interest and sexual dysfunction, body images, and premature menopause concerns
		Women with children reported more difficulties with partner
	Clinical	Mastectomy related to sexual interest, body image, premature menopause concerns
		CT related to sexual dysfunction, pregnancy, premature menopause concerns
Brédart, Kop et al., 2013 (France, Switerland) [41]	Demographic & QOL	Greater PSY needs than expected from QOL corresponding scales predicted by having children, lower education, hospital service, anxiety, or depression
	Clinical & Patient Satisfaction	Discrepancies between HS/INFO needs and patient satisfaction scores explained by previous BC medical history to less information needs
		Anxiety and depression to greater information needs relative to patient satisfaction
Erci & Karabulut 2007 (Turkey) [48]	Demographic	Age (25–45) report greater femininity, body image, family/friends needs
		Education (university) correlated with greater information needs
Girgis, Boyes et al., 2000 (Australia) [50]	Demographic	Age (30–49) report greater PSY & communication needs
	Clinical	Cancer spread related to greater HS/INFO
		RT/CT reported greater CARE needs
		CT greater PHY/DL
		RT greater communication needs
Girgis, Stacey et al., 2011 (Australia) [51]	Demographic	Age (<50) have greater body image needs
	Clinical	Shoulder stiffness/dominant side related to greater HS/INFO/SUPPORT, body image, self esteem needs
Griesser et al., 2010 (France, Switzerland) [45]	Demographic	Age (<63) related to higher needs in PHY/DL, PSY, SEX
		Having partner & children <20 years report higher PHY/DL, PSY needs
		Having partner/no children have higher total and CARE needs
		Women born outside of Switzerland report higher needs in Phy/DL and HS/INFO
Halkett et al., 2012 (English) [35]	Distress	No significant changes in anxiety or depression over time
	Time	Significant decline in information needs from T3 to T4
Hodgkinson, et al., 2007a (Australia) [43]	Demographic	No significant correlations with age, employment, relationship status
	Clinical	Greater number of treatments related to total met needs; no correlation with time since DX
	QOL	Within USA population norms
	Distress	HADS/A/D related to total unmet needs
Hwang & Park, 2006 (Korea) [55]	Demographic	Age (<50) related to greater SEX, HS/INFO
		Being married related to greater SEX
		Living alone report greater CARE
		Education (<9 years) associated to greater CARE
		Income (<2 million won/month) associated to greater PHY/DL
	Clinical	More recent DX have greater HS/INFO
		Tumor size (>2) related to greater PSY, HS/INFO
		Node metastases related to greater PHY/DL
		Recurrence related to greater HS/INFO

(Continues)

Table 3. (Continued)

Study		Predictors
Lam *et al.*, 2011 (Germany & China) [44]	Demographic	Surgery (<3 years)related to greater PHY/DL
		CT related to greater PHY/DL
		Younger age or married related to greater SEX
		Higher education related to greater PSY, HS/INFO, CARE, SEX
		Being Chinese related to greater HS/INFO, CARE
		Being German related to greater PHY/DL, SEX
	Clinical	CT related to greater PSY
		Recurrence related to greater PHY/DL
		Not receiving hormone therapy related lower CARE
		Completed surgery related to greater SEX
	QOL	Greater symptom burden related to greater unmet needs in all 5 domains
	Distress	HADS/A related to greater needs in all but PHY/DL domains
		HADS/D related to greater PSY & PHY/DL
		HADS scores and interactions with PSY needs greater for German sample
Lee *et al.*, 2004 (China) [36]	Demographic	Being married related to greater disease information need
Li *et al.*, 2012 (China) [56]	Demographic	Younger age report lower HS/INFO
	QOL	Global symptom distress related to greater needs in all but SEX domain
		Total symptoms correlated to greater PHY/DL
	Distress	HADS/A positively correlated with total symptom distress
		HADS/D positively correlated with PHY/DL, negatively correlated with HS/INFO
Liao *et al.*, 2012 (Taiwan) [37]	Demographic	Age (<50) and higher education report greater needs
		Sexuality needs may be underestimated due to culture
	Clinical	Closer to DX related to greater needs
		Surgery only, related to lower needs
	QOL	Severe symptom distress correlated with greater need
		Symptoms increased from T1–T2, decreased at T3, increased again T4
	Distress	High STAI/ST related to greater need; state anxiety decreased over time
	Social Support	Family/provider support peaked at T2 then decreased (no correlation reported with needs)
	Time	Supportive care needs decreased over time; PHY/DL showed greatest increase at T4
Mahapatro & Parkar, 2005 (India) [52]	Clinical	Mastectomy (vs Lumpectomy) was related to greater concern regarding sexual role and body image
Minstrell *et al.*, 2008 (Australia) [38]	Time	Significant decreases in needs over 3m in PSY, HS/INFO, with increase in SEX
Park & Hwang 2012 (Korea) [49]	Clinical	Surgery <1 year versus >5 years related to greater needs in all domains except SEX
		Surgery 1–3 years versus >5 years related to greater PSY & HS/INFO
		No significant difference between 3–5 years versus 5 years groups
	QOL	Lower QOL significantly related to greater SCNS scores
	Distress	Greater SCNS scores significantly predicted depression
Schmid-Büchi *et al.*, 2011 (Germany) [53]	Clinical	Being premenopausal related to greater PHY/DL
	QOL	PHY/SOCIAL impairment related to greater PSY needs
	Body Image	Greater BI problems related to PHY/DL
Schmid-Büchi *et al.*, 2012 (Germany) [54]	Demographic	Younger age related to greater SEX
		Higher education related to greater PSY
	Clinical	Closer to DX related to greater PSY
		CT + RT related to greater CARE
	QOL	Gastro symptoms related to SEX
		PSY/SOCIAL impairment related to PSY, CARE, HS/INFO
	Distress	HADS positively correlated to PHY/DL, SEX; HADS/A to HS/INFO; HADS/D to CARE
	Social Support	Perceived support related to lower SEX
	Body Image	BI problems related to PHY/DL, PSY, SEX
Uchida *et al.*, 2011 (Japan) [47]	QOL	Better global health related lower total needs, and to each subscale
	Distress	HADS positively related to total needs, and to each domain of need

PSY, psychological; HS/INFO, health system and information; PHY/DL, physical daily living; CARE, patient care and support; SEX, sexual; BR8, breast cancer specific module; BDI, Beck Depression Index; CHQ-12, Chinese Health Questionnaire; ChPSQ, Chinese Patient Satisfaction Questionnaire; C-LOT-R, Chinese Life Orientation Test-revised; CTSS, Cancer Treatment Symptom Scale; DT, Distress Thermometer; FACT-G/B, Functional Assessment of Cancer Therapy—General/Breast; ECOG-PS, Eastern Cooperative Oncology Group-Performance Status; EORTC QLQ-C30, core quality of life questionnaire; HADS, Hospital Anxiety and Depression Scale; EORTC IN-PATSAT32/OUT-PATSAT35, the cancer In Patient or Out Patient Satisfaction Questionnaire; IPRI, Interpersonal Relationship Inventory; MASAS, PANAS, PRISM Pictorial Representation of Illness and Self-Measure; PSQ, Patient Satisfaction Questionnaire; SDS-mbc, Symptom Distress Scale-modified for breast cancer; SSS-m, Social Support Scale-modified; STAI, State-Trait Anxiety Inventory.

toward 'worries about those close to you', that 'results are beyond control', and 'uncertainty about the future' [45–47], but 'having one staff member to talk to' remains prominent. The latter is the top need in Japanese and Chinese populations, with at least 70% of Chinese women noting this as their primary need [40,46,56], and at least 55% in Japanese samples

Table 4. Greater needs by predictor

Predictor	PSY	HS/INFO	PHY/DL	CARE	SEX
Demographics	Younger age, lower education (one study: higher education), having children, being unemployed	Younger age, higher education, being unemployed	Younger age (pre-menopause), being single, being unemployed	Living alone, lower education (one study: higher education), being unemployed	Younger age, living with partner, higher education
Culture	Western compared to Asian culture	Some Asian cultures			Western compared to Asian culture
Clinical & Treatment	Higher stage, chemotherapy, surgery more recent	Higher stage, recurrence, surgery more recent	Higher stage, recurrence, node metastases, surgery more recent, chemotherapy	Higher stage, chemotherapy, radiotherapy	Mastectomy, chemotherapy
Time since DX	Closer to DX	Closer to DX	Closer to DX		
Psychological and emotional	Anxiety, depression, negative body image	Anxiety, depression	Anxiety, depression, negative body image	Depression, psychological or social impairment	Depression, negative body image
Quality of Life	Lower QOL	Lower QOL	Lower QOL	Lower QOL	
Patient satisfaction		Lower satisfaction		Lower satisfaction	
Social support					Less perceived support
Change over time	Decreases over time	Decreases over time	Increases over time		Increases over time

PSY, psychological; HS/INFO, health system and information; PHY/DL, physical daily living; CARE, patient care and support; SEX, sexual.

[39,37]. The difference between Chinese and German populations is highlighted in Lam [44] where 39.1% German versus 69% Chinese women reported this need. Looking closer, we see that Chinese women report more information needs and less psychological needs compared with their German counterparts; even so, 'having one staff member to talk to' is reported nearly twice as frequently in Chinese samples. These disparities may reflect differences in health system and patient care or in expectations from care providers specific to each culture or country [69].

Culture may play a significant part in the expression of sexuality needs as well. It is unlikely that the significantly lower sexual needs reported across Asian populations is due to sexuality not being a concern for these women. Rather, the subject may be more private, or expectations for help may be lower [37]. This review suggests that Asian health care providers should broach the subject with sensitivity in order to offer the help these women may need.

The present review underscores other factors that influence needs. Younger age is systematically related to greater needs, particularly sexuality needs and body image concerns, and is compounded when living with a partner. Living alone predicts other unmet needs in the domain of patient care. Different types of surgery and treatments engender different supportive care needs. Needs increase from having surgery only, surgery and RT, to surgery, RT, and CT. More advanced stage and a more recent diagnosis are also related to greater needs in several domains. However, having more symptoms and more treatments were related to more met needs in long term survivors [43] perhaps because these attract more clinical attention. Some factors require further examination, such as education and employment. Financial difficulties and crucial psychosocial factors are overlooked. For example, social support is known to be an essential factor influencing the

well-being of BC patients and may even have bearing on survival [70–73]. Yet, only two studies [37,54] assessed social support, and only one [54] examined its relationship to needs.

Few health care systems have the resources to implement needs screening for every patient at multiple time points, along with the interpretation of results this entails. A better understanding of the prevalence and intensity of the needs of specific groups of BC patients and survivors at different moments along the disease trajectory would help care providers predict early on which women are at risk for particular needs and guide the development of supportive care interventions that actually work.

This review is limited by the designs of the studies included, which are primarily cross-sectional, hampering our understanding of how needs evolve over time and identifying causal predictors of needs. Furthermore, they employ different measures, or the same measure scored in different ways (i.e., whether needs are defined from low or from moderate), making comparison between studies problematic. Comparing the relative importance of needs across different instruments is yet a greater struggle, even when instruments assess parallel items or similar domains, as no quantitative comparison is possible. This may also be confusing to clinicians and hinder their application in clinical practice. At the same time, instruments that are designed to gather detailed information regarding a specific condition (such as lymphedema [51]) or a specific treatment (such as RT [35]) remain useful for care management and have therefore been presented in this review alongside broader instruments. It is unfortunate that few studies exploit the BC module (BR-8) of the SCNS, which could highlight other specific needs. Another limitation is the inclusion of psychometric studies in this review. Needs assessment is a relatively new area of research, and many studies focus on the development of

instruments. Although psychometric studies are designed for this particular objective, the scarcity of studies assessing the needs of BC patients led to our decision to include them. In spite of these limitations, it should be noted that there is agreement across instruments focusing on similar domains.

Furthermore, the paucity of crucial psychosocial factors assessed in relation to needs, the wide range in sample sizes, and different inclusion criteria, thwart our ability to compare results. Finally, although different languages and cultures are represented here, most survey Asian and Australian populations, with only one study actively comparing Western (German) and Asian (Chinese) samples [44], putting generalizability into question.

If the goal of supportive care is to improve the QOL of patients suffering from a serious illness by helping them manage pain and symptoms, functional problems, fears, and worries, if it means treating each person as an individual and satisfying their unique concerns, then what we know at present is not good enough. Longitudinal studies with large samples assessing specific moments along the cancer trajectory, with standardized scoring and reporting procedures examining the pertinent factors highlighted in this review, would allow for a dynamic understanding of these needs.

Conclusion

The supportive care needs of BC patients and survivors touch upon many domains, clustering around psychological and information needs, but are influenced by individual characteristics, be they clinical, demographic, emotional, psychological, or psychosocial. Studies so far confirm what we may expect: that overall younger patients have more problems, specifically in the domains of sexuality and body image, that patients with advanced stage or recurrence have greater needs. In showcasing what we know so far about the needs of women who have been diagnosed with BC, we can move forward and design research protocols to refine our understanding in order to predict who is at risk for greater needs and how needs are likely to change over time. Specifically, this review directs future research to delve deeper into individual factors that may influence needs and to design longitudinal studies, with unambiguous scoring and reporting of needs. In this way, we will learn what we need to know to allocate scarce resources to those who need it most and at the right time.

Acknowledgements

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