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Breast cancer survivors—supportive care needs: systematic review

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ABSTRACT

Objectives To achieve optimal survival care outcomes, all healthcare services must be tailored to patients' specific needs, preferences and concerns throughout the survival period. This study aimed to identify supportive care needs from the point of view of breast cancer survivors.

Methods Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines for reporting systematic reviews, a comprehensive search of PubMed, Web of Science and Scopus was performed. The inclusion criteria were studies published from inception to the end of January 2022, covering all stages of breast cancer. The exclusion criteria were mixed-type studies relating to cancer, such as case reports, commentaries, editorials and systematic reviews, as well as studies that assessed patients' needs during cancer treatment. Two quality assessment tools were used for the qualitative and quantitative studies.

Results Of the 13 095 records retrieved, 40 studies, including 20 qualitative and 20 quantitative studies, were retained for this review. Survivors' supportive care needs were classified into 10 dimensions and 40 subdimensions. The most frequently mentioned supportive care needs of survivors were psychological/emotional needs (N=32), health system/informational needs (N=30), physical and daily activities (N=19), and interpersonal/intimacy needs (N=19).

Conclusions This systematic review highlights several essential needs for breast cancer survivors. Supportive programmes should be designed in order to take into consideration all aspects of these needs, particularly psychological, emotional and informational needs.

INTRODUCTION

In 2020, there were estimated to be 19.3 million new cancer cases worldwide and almost 10 million cancer-related deaths. Female breast cancer was the most commonly diagnosed cancer, with

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Several original studies have investigated the different dimensions of the supportive care needs of breast cancer survivors. Each of these studies achieved different results. However, to date, no systematic study has combined these results in order to achieve a general and reliable conclusion.

WHAT THIS STUDY ADDS

⇒ In this systematic study, we identified the most important supportive care needs of breast cancer survivors through an extensive search with no time limit. This study classified the needs of breast cancer survivors into main dimensions (10) and subdimensions (40). They are provided with supporting details.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Survivorship care programmes for breast cancer survivors could be designed based on the supportive care needs derived from this study. Researchers could test the implementation of survivorship care programmes based on these needs in clinical trials. Policymakers could also use these results to prevent secondary cancer and improve survivors' quality of life.

2.3 million new cases (11.7%), surpassing lung cancer.¹ Thanks to early diagnosis and improved treatment, the survival rate in patients with breast cancer has improved.² Almost 88% of patients with breast cancer survive for 5 years or more.³ According to the National Institutes of Health, 'an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life'.⁴ Increased survival rates in patients with breast cancer have led to a growth in the number of survivors with disease-related problems that require ongoing post-treatment care.⁵ The growing population of breast cancer survivors (BCSs) is a challenge for the healthcare providers

and policymakers who are expected to meet the multifaceted needs of this group of patients.⁶

Needs arise when a person does not have the capacity to deal with their problems and requires external resources to achieve well-being.⁷ Ten years after a breast cancer diagnosis, most patients continue to have many medical, psychological and social care needs, and should be helped to deal with these problems^{8,9}; they will have many unmet needs of all kinds after completing breast cancer treatment.¹⁰ These problems can include fatigue, pain, cognitive impairment, osteoporosis, traumatic stress, fear of recurrence and sexual problems.^{11–13} The Institute of Medicine has listed five main areas in survivorship care: (1) monitoring the recurrence of cancer or new cancers; (2) managing the remaining symptoms after the end of treatment; (3) risk assessment for preventing late effects from treatment; (4) assessment of the psychosocial needs and providing appropriate support; and (5) advising patients on lifestyle modifications.¹⁴ Supportive care is defined as rendering essential services that satisfy the physical, psychological, social, informational and spiritual needs of patients with cancer throughout the entire illness trajectory.¹⁵ Planning supportive care services for patients with cancer starts with an identification of their needs.¹⁶

The supportive care framework for cancer care was first introduced in 1994.¹⁷ The framework provides a tool for cancer care professionals and programme managers, allowing them to design services based on the type of assistance that patients with cancer may need.¹⁸ Based on the current literature, individual supportive care needs are classified into 11 aspects, including psychosocial/emotional, physical, health system/information, family-related, social, interpersonal/intimacy, practical, daily living activity, spiritual/existential, patient–health professional communication and cognitive needs.¹⁹ The current trend in modern medicine is changing from a disease-based model to a patient-centred model in which patients are active and their preferences and care needs are considered.²⁰ The important factor in providing quality care is identifying and satisfying the needs of this group of patients.^{6,20} In order to achieve optimal survival care outcomes, all healthcare services must be tailored to the patient's needs, preferences and concerns.²¹ Therefore, the present study aimed to identify the supportive care needs of BCSs.

METHODS

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.²²

Eligibility criteria

Based on the PICOS (Population, Intervention, Comparison, Outcomes and Study) framework, the inclusion criteria were as follows: studies on BCSs

according to the definition of the National Cancer Institute's Office of Cancer Survivorship, irrespective of disease stage, time since diagnosis or treatment modality (P); studies without intervention or control groups (I, C); studies reporting the needs of BCSs (O); and various types of qualitative and quantitative studies published in English language from inception until the end of January 2022 (S). The exclusion criteria were mixed-type studies related to cancer, case reports, commentaries, editorials, systematic review studies and studies that assessed patients' needs during cancer treatment.

Search strategy and study selection

Three electronic databases—Medline (using PubMed), ISI Web of Science and Scopus—were searched from inception until the end of January 2022. Keywords were selected based on their relation to “breast cancer survivors” and “needs”, in three steps. The first keyword search was performed using the Medical Subject Heading and Emtree. Additional keywords were then instigated using the titles and abstracts of the related articles. Finally, a list of keywords was created based on the opinions of cancer research experts. A manual search was also performed, using the keywords “breast cancer survivors” and “needs”, in the Google and Google Scholar search engines. The search strategy focused on three concepts (supportive care needs, breast cancer survivors and needs assessment). Additionally, a combination of search terms and phrases relating to BCSs and supportive care needs such as “breast cancer survivors”, “cancer survivors”, “healthcare needs”, “educational needs”, “needs assessment” and “self-care needs” was also included in the search strategy. The search queries are presented in [table 1](#).

Data extraction

Articles obtained from manual and systematic searches were entered into EndNote (Thomson Reuters, EndNote V.20.2.1.Build, Toronto, Ontario, Canada) and duplicate articles were excluded. Two independent reviewers screened the titles and abstracts of the articles and selected the potentially relevant studies. The full text of the articles was then studied and the final articles were selected based on the inclusion and exclusion criteria. All steps were performed by the two independent reviewers, with any disagreements resolved through discussion and a third reviewer. The following data were extracted from a predefined form of articles: author, purpose, context, setting, country, sample size, sampling, response rate, design, data collection, demographic characteristics, cancer stage, time since diagnosis, treatment and outcome.

Quality assessment

Quality assessment of the studies was conducted using two quality appraisal tools: quantitative and

Table 1 Search strategy: 27 January 2022

Search term	Results
PubMed	4698
1 (Breast Cancer Survivors[tiab] OR "Cancer Survivors"[mh] OR Cancer Survivors[tiab] OR Cancer Survivor[tiab] OR Survivors Cancer[tiab] OR Cancer Survivor[tiab] OR Cancer Survivorship[tiab] OR Survivorship Cancer[tiab] OR Long Term Cancer Survivors[tiab] OR Cancer Survivor Long-Term[tiab] OR Cancer Survivors Long-Term[tiab] OR Long Term Cancer Survivors[tiab] OR Long-Term Cancer Survivor[tiab] OR Survivor Long-Term Cancer[tiab] OR Survivors Long-Term Cancer[tiab] OR "Breast Neoplasms"[mh] OR Breast Neoplasms[tiab] OR Breast Cancer[tiab] OR Cancer Breast[tiab] OR long-term breast cancer survivors[tiab] OR Breast Tumors[tiab] OR Breast Tumor[tiab]) AND ("Self Care"[mh] OR Self Care[tiab] OR Care Self[tiab] OR Self-Care[tiab] OR "Needs Assessment"[mh] Needs Assessment[tiab] OR Needs Assessments[tiab] OR Educational Needs Assessment[tiab] OR supportive care needs[tiab] OR Assessment Educational Needs[tiab] OR Needs Assessment Educational[tiab] OR Needs Assessments Educational[tiab] OR Determination of Health Care Needs[tiab] OR Determination of Healthcare Needs[tiab] OR Assessment of Healthcare Needs[tiab] OR Needs Assessment Healthcare[tiab] OR Needs Assessments Healthcare[tiab] OR Assessment of Health Care Needs[tiab] OR "Learning"[mh] OR Learning[tiab] OR "Teaching"[mh] OR primary healthcare[tiab] OR learning needs)	
Scopus	1150
((TITLE-ABS-KEY ("Breast Cancer Survivors") OR TITLE-ABS-KEY ("Survivors Long-Term Cancer") OR TITLE-ABS-KEY ("Breast Neoplasms") OR TITLE-ABS-KEY ("Breast Cancer") OR TITLE-ABS-KEY ("long-term breast cancer survivors") OR TITLE-ABS-KEY ("Breast Tumor")) AND ((TITLE-ABS-KEY ("Self Care") OR TITLE-ABS-KEY ("Needs Assessments Educational") OR TITLE-ABS-KEY ("Needs Assessment Healthcare") OR TITLE-ABS-KEY ("learning needs"))))	
Web of Science	7247
TS=("Breast Cancer Survivors" OR "Cancer Survivors" OR "Cancer Survivor" OR "Survivors Cancer" OR "Cancer Survivor" OR "Cancer Survivorship" OR "Survivorship Cancer" OR "Long Term Cancer Survivors" OR "Cancer Survivor Long-Term" OR "Cancer Survivors Long-Term" OR "Long Term Cancer Survivors" OR "Long-Term Cancer Survivor" OR "Survivor Long-Term Cancer" OR "Survivors Long-Term Cancer" OR "Breast Neoplasms" OR "Breast Cancer" OR "Cancer Breast" OR "long-term breast cancer survivors" OR "Breast Tumors" OR "Breast Tumor") TS=("Self Care" OR "Care Self" OR "Self-Care" OR "Needs Assessment" OR "Needs Assessments" OR "Educational Needs Assessment" OR "Assessment Educational Needs" OR "Needs Assessment Educational" OR "Needs Assessments Educational" OR "supportive care needs" OR "Determination of Health Care Needs" OR "Determination of Healthcare Needs" OR "Assessment of Healthcare Needs" OR "Needs Assessment Healthcare" OR "Needs Assessments Healthcare" OR "Assessment of Health Care Needs" OR "Learning" OR "primary healthcare" OR "learning needs")	

qualitative. This method had previously been used in a similar systematic review.¹⁹ The quantitative appraisal tool consisted of 17 items, evaluated a range of designs including observational study, randomised controlled trial (RCT), non-RCT, cohort and case study, and classified them into the three levels: 'good' (2), 'fair' (1) and 'poor' (0). The qualitative appraisal tool, meanwhile, had 15 items and 3 levels from 0 to 2.²³ All steps of the quality assessment were performed by two independent reviewers (see tables 2 and 3).

Analysis and synthesis of the results

In this study, the dimensions of the supportive care needs of BCSs were based on the supportive care needs framework proposed by Fitch.¹⁸ The review used narrative synthesis and tabulation of primary research studies to generate broad findings and conclusions. The narrative synthesis undertook the following steps: data reduction (subgroup classification based on the levels of evidence and the review questions), narrative data comparison (the iterative process of making comparisons and identifying relationships), and conclusion and verification (checking primary data sources for accuracy and confirmability).²⁴

RESULTS

Search results

The database searches retrieved 13 095 original studies, of which 8845 remained after deduplication (figure 1). After reviewing titles and abstracts, 243

studies were included in the full-text review. Based on the predefined eligibility criteria, 34 studies from the databases and a further 6 studies from manual searching were included in the review. The PRISMA flow chart in figure 1 illustrates the selection process.

Characteristics of the included studies

Among the 40 studies selected for inclusion, 20 qualitative studies and 20 quantitative studies were included. The publication period ranged from inception until the end of January 2022. Fifteen studies (37.5%) were conducted in the USA and four (10%) in Korea. The sources of data were tumour registries or hospital databases in 12 (52.2%) of the included studies and self-reported surveys or interviews in 9 (39.1%) of the studies, while 2 studies (8.7%) used both sources (online supplemental table 1). Methodological quality assessment of the studies was performed in parallel with data extraction.

Evidence of unmet supportive care needs by domain

Psychological/emotional needs

Thirty-two studies described the psychological and emotional needs of BCSs.^{3 6 12 13 20 21 25–50} The most frequently reported psychological and emotional needs were depression, anxiety and stress (N=15),^{3 21 25 28 32 36 41–45 47–49} as well as fears about cancer spread and recurrence (N=13).^{6 21 26 32 35 37 41 42 44 45 47–49} In a study conducted by Bu *et al*, fear of recurrence was identified as the most important need in BCSs; it

Table 2 Quality appraisal of primary studies

Qualitative studies	Item number checklist														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Gray <i>et al</i> ³⁵	1	2	2	2	2	2	0	2	2	1	1	1	0	1	1
Buki <i>et al</i> ⁴⁰	2	1	2	1	0	0	1	2	2	2	2	2	1	1	1
Ankersmid <i>et al</i> ²	2	2	2	2	1	2	0	2	2	1	1	1	0	0	2
Gisiger-Camata <i>et al</i> ²⁵	2	2	2	1	1	1	0	2	2	1	1	1	1	0	2
Pembroke <i>et al</i> ²⁶	2	1	0	2	1	2	2	2	1	2	2	2	1	0	2
Dsouza <i>et al</i> ¹¹	2	1	2	2	1	1	0	2	2	1	1	1	0	1	1
Wilson <i>et al</i> ³¹	2	2	2	2	2		0	2	2	1	1	1	1	0	2
Galván <i>et al</i> ³⁹	2	2	2	1	1	2	0	2	2	2	2	2	1	1	1
Cappiello <i>et al</i> ³⁶	2	2	2	2	1	2	1	1	1	2	1	0	0	0	1
Black <i>et al</i> ⁵¹	2	2	2	2	1	2	1	2	2	2	2	2	2	2	1
Tanjasiri <i>et al</i> ⁴⁴	2	2	2	2	1	1	0	2	2	2	2	2	1	1	2
Adams <i>et al</i> ⁴³	2	2	2	1	1	1	0	0	2	2	2	2	1	1	2
Hubbeling <i>et al</i> ¹³	2	2	2	2	2	2	2	2	2	2	2	2	1	1	2
Kim <i>et al</i> ²⁹	2	2	2	2	1	2	0	2	2	2	2	2	1	1	2
Lee <i>et al</i> ³	2	1	2	2	1	1	0	1	1	2	1	1	1	0	1
Thewes <i>et al</i> ⁹	2	1	2	2	1	2	1	2	2	2	2	2	1	1	2
Kwok and White ⁵³	2	2	2	1	2	2	0	2	2	2	2	2	1	1	2
Wells <i>et al</i>	1	2	2	2	2	2	1	2	2	2	2	2	2	1	2
Shaw and Coggin ³⁸	2	2	1	2	2	2	1	2	2	2	2	2	1	1	2
Ridner <i>et al</i> ⁵⁵	2	2	2	1	2	2	2	2	2	2	2	2	2	1	2

Item number checklist key: (1) research question clearly described, (2) qualitative method appropriate, (3) setting/context clearly described, (4) sampling strategy clearly described, (5) sampling method likely to recruit all relevant cases, (6) characteristics of the sample provided, (7) rationale of sample size given, (8) methods of data collection clearly described, (9) method of data collection appropriate for research question and paradigm, (10) researcher has verified data (eg, by triangulation), (11) data analysis methods clearly described, (12) data analysis methods appropriate, (13) competing accounts/deviant data taken into account, (14) extent to which the researcher is reflective, (15) interpretations and conclusions supported by the data. Three levels of quality assessment of scores: ■ low risk of bias (2), ■ unclear risk of bias (1), ■ high risk of bias (0).

was reported by 69% of patients.⁴² Furthermore, in a study conducted by So *et al*, fear of cancer spreading was identified as the most important unmet psychological need.⁴⁵ Fear of disclosure,^{11 13 20 25 26 33 36 43} feelings about death and dying,^{6 35 44 45} and uncertainty about the future^{6 35 41 45} were the next highest-ranked needs. Other psychological and emotional needs included stigma associated with cancer,^{3 13} frustration,²⁸ low mood and isolated needs,²⁸ and feelings of sadness.⁴⁵ In a study by Autade and Chauhan, all BCSs reported emotional needs, including worry, anxiety, depression, anger, frustration, low mood and isolation.²⁸

Health system/information needs

Health system/information needs were reported by 30 studies.^{2 6 11 12 20 21 25–27 30–35 37–39 41–47 51–55} Receiving easy-to-understand and accurate information about the side effects of medication and treatment was the most common information need reported by BCSs (N=13).^{21 26 27 32 35 38 41 45 46 52–54} In a study by Pembroke *et al*, almost half of the participants reported unmet needs associated with treatment-related side effects.²⁶ Eight studies also reported information needs relating to improved self-control of the situation, lifestyle advice and self-management.^{6 12 21 27 29 35 45 54} There was a need to obtain information about self-management skills associated with exercise, proper diet and regular

breast self-examination. Participants were keen to achieve and maintain well-being and a healthy lifestyle that would prevent breast cancer recurrence.⁶ The study conducted by Cappiello *et al* showed that almost all participants wanted more detailed information. A number of women suggested that information should be provided during a separate visit, not at the end of treatment.³⁶ On the other hand, there were some needs that were rarely reported by survivors: the need for a linguistically and culturally appropriate programme³; providing information to family and partners⁴⁷; information on a case-by-case basis⁵² and complementary therapy.⁵² Other needs are listed in table 4.

Physical and daily living needs

Nineteen studies described the physical needs of BCSs. The most common symptoms reported were fatigue (N=8)^{25 28 33 36 42–45} and pain (N=7).^{25 28 33 36 38 42 45} The largest sample population (n=1210) reported fatigue in 40.7% of the subjects and pain in 37.2%.⁴² In a qualitative study conducted by Cappiello *et al*, patients reported fatigue as a persistent physical symptom.³⁶ Other physical needs are listed in table 4. The least common physical needs mentioned in the studies included hot flashes,^{25 28 36} shortness of breath,^{28 32} change in appetite or eating pattern,^{28 36} and digestive problems.^{28 32} Survivors also reported a lack of energy

Table 3 Quality appraisal of primary studies

Quantitative studies	Item number checklist																
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Befort <i>et al</i> ⁸¹	2	2	1	0	N/A	N/A	N/A	N/A	2	N/A	1	2	1	1	N/A	N/A	1
Sleight <i>et al</i> ²⁷	2	2	2	2	N/A	N/A	N/A	N/A	1	N/A	1	2	2	1	N/A	N/A	2
Autade and Chauhan ²⁸	2	2	1	1	N/A	N/A	N/A	N/A	1	N/A	1	1	0	1	N/A	N/A	1
Chae <i>et al</i> ²⁰	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	2	2	2	2	N/A	N/A	2
Cheng <i>et al</i> ⁶	2	2	1	1	N/A	N/A	N/A	N/A	2	N/A	1	2	2	0	N/A	N/A	2
Lee <i>et al</i> ³²	2	2	1	1	N/A	N/A	N/A	N/A	2	N/A	2	2	2	1	N/A	N/A	2
Pauwels <i>et al</i> ³⁰	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	1	2	2	1	N/A	N/A	2
Vuksanovic <i>et al</i> ²¹	2	1	2	1	N/A	N/A	N/A	N/A	2	N/A	1	2	2	1	N/A	N/A	2
Fong and Cheah ¹²	2	2	1	1	N/A	N/A	N/A	N/A	2	N/A	1	2	1	2	N/A	N/A	2
Chou <i>et al</i> ³⁴	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	1	2	2	1	N/A	N/A	2
Cheng <i>et al</i> ¹⁰	2	2	2	1	N/A	N/A	N/A	N/A	2	N/A	2	2	2	1	N/A	N/A	2
Ellegaard <i>et al</i> ³⁷	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	1	2	2	1	N/A	N/A	2
Brennan <i>et al</i> ⁴¹	2	2	1	1	N/A	N/A	N/A	N/A	2	N/A	0	2	2	1	N/A	N/A	2
Bu <i>et al</i> ⁴²	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	1	2	2	2	N/A	N/A	2
Fang <i>et al</i> ⁴⁶	2	2	2	1	N/A	N/A	N/A	N/A	2	N/A	0	2	2	2	N/A	N/A	2
So <i>et al</i> ⁴⁵	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	0	2	2	2	N/A	N/A	2
Miyashita <i>et al</i> ⁵²	2	2	2	1	N/A	N/A	N/A	N/A	2	N/A	1	2	2	1	N/A	N/A	2
Hodgkinson <i>et al</i> ⁴⁷	2	2	1	1	N/A	N/A	N/A	N/A	2	N/A	0	2	2	2	N/A	N/A	2
Martinez Arroyo <i>et al</i> ⁴⁸	2	2	1	2	N/A	N/A	N/A	N/A	2	N/A	0	2	2	1	N/A	N/A	2
Park and Hwang ⁵⁴	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	2	2	2	2	N/A	N/A	2

Item number checklist key: (1) hypothesis/aim/objective clearly described, (2) study design well described and appropriate, (3) method of patient/control group selection clearly described, (4) characteristics of the patient/control group clearly described, (5) patients randomised to the intervention group, (6) randomisation/allocation concealed, (7) characteristics of patients lost to follow-up clearly described, (8) intervention clearly described, (9) main outcome measures clearly described, (10) attempt made to blind those measuring the primary outcome of the intervention, (11) population characteristics adequately described and controlled, (12) main findings clearly described, (13) methods of analysis appropriately and clearly described, (14) estimates of variance reported for main results, (15) analyses adjusted for different lengths of follow-up, (16) data analysed according to intention-to-treat principle, (17) conclusions supported by the results. Three levels of quality assessment of scores: ■ low risk of bias (2), ■ unclear risk of bias (1), ■ high risk of bias (0).

and tiredness relating to daily activities; they needed help with housekeeping, childcare, bathing, dressing and cooking.^{11 28 32 44 45}

Interpersonal needs/intimacy concerns

Nineteen studies reported BCSs' concerns about interpersonal/intimacy needs,^{13 25 26 28–30 32 33 35 36 39 41–45 48 49 51} including body image, femininity, altered physical appearance and self-confidence, all of which affected interpersonal/intimate relationships.^{13 25 26 28–30 32 39 41–45 48 49 51} Needs relating to sexual function^{26 28 30 33 35 36 44 45} and relationship with a partner^{30 32 44} were also reported in a number of studies. In a study conducted by Kim *et al*, survivors stated that self-confidence played an essential role in adjusting to different changes following cancer treatment.²⁹ A study by Cappiello *et al* showed that changes in sexuality and sexual function were usually reported in the post-treatment phase and were mostly attributed to decreased libido.³⁶

Social needs

Eighteen studies reported social needs among BCSs.^{3 13 28 30–33 38 43 44 47–49 53} The top-ranking social need was support from friends and social networks/support groups.^{31 33 38 43 44 49 53} The next highest

ranked was the need to return to work or re-employment.^{3 13 30 32 42} The other social needs of BCSs are listed in table 4. Galván *et al* stated that their participants who had received good social support reported less psychological distress and better adjustment to breast cancer.³⁹ Fassier *et al* found that women had different motivations for returning to work after breast cancer. This challenge relates to social relationships, financial issues, perceived utility in society and the meaning of life.⁵⁰ Despite the fact that survivors had problems communicating with others,^{28 31 49} they were willing to communicate with their partners, healthcare providers and other people with cancer.^{13 31 47 48}

Family-related needs

Thirteen articles reported that survivors needed support from their family.^{31 33 38 43 44 49 53} Wilson *et al* reported that support from friends and family was a positive coping strategy.³¹ Additionally, in a study by Lee *et al*, family members, including adult children and spouses, were the main source of support for all participants.³ On the other hand, a number of survivors reported that they did not want to be a burden to their family.^{3 13 44 49} They preferred to be the family caretaker rather than

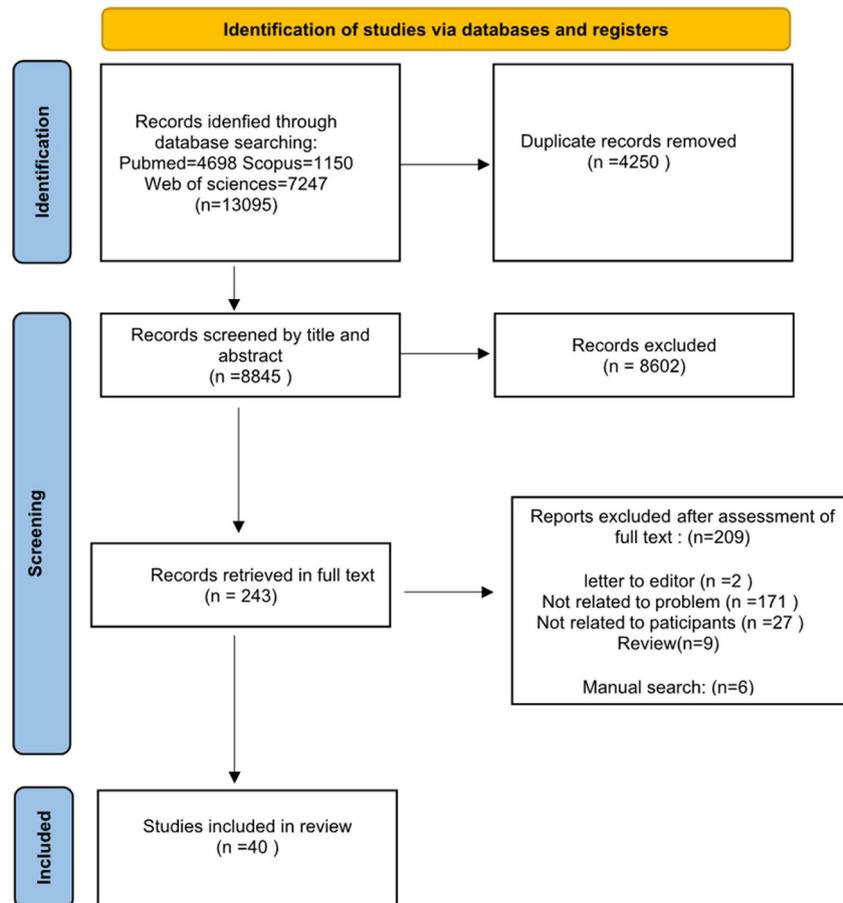


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram.

a care receiver.⁴⁴ In two studies, survivors stated that family members, primarily the male partner, emerged as the primary source of emotional support following treatment.^{39 53} Other needs reported by BCSs included help with difficulties that arose in family relationships following cancer diagnosis³² and concerns relating to managing family and everyday living.³⁶

Practical needs

Thirteen articles reported practical needs for BCSs, including financial distress, healthcare costs, life insurance, and dealing with problems at work or in education.^{11 28 31 32 38 40–42 44–46 48 49} In a study by Autade and Chauhan, the majority of participants reported problems at work or in education. Thirty-three per cent said they had problems with making plans for activities, 19% said that they sometimes had problems with dressing and bathing, and 53% reported having trouble preparing food. All the BCSs reported problems with finance.²⁸

Spiritual/existential needs

Overall, there were 12 studies that covered the spiritual needs of BCSs.^{3 11 25 28 38 40 44 48 49} Religion and/or spirituality was an important source of emotional support for them.^{40 43 44} Some survivors reported experiencing frustration and loss of meaning and purpose

in life^{28 38}; they needed strong faith and a sincere relationship with God.^{38 44} In a study by Autade and Chauhan, loss of hope or other spiritual concerns were expressed by 50% of BCS respondents. About 5.8% of respondents felt that they had lost their sense³¹ of meaning or purpose in life.²⁸

Patient–clinician communication needs

Five studies discussed patient–clinician communication needs.^{2 29 31 41 51 52} Patients were generally satisfied with the decision-making and surveillance of the organisations.² Participants reported a high level of satisfaction with the quality of medical care and the care coordination.⁴¹ In a study by Miyashita *et al*, 68% of participants were satisfied with their strategies for communicating with medical staff.⁵² There was some discord in relation to fertility preservation options and cancer treatment decision-making with providers.⁵¹ Survivors stated that they had many unanswered questions and were not receiving a response from healthcare providers. In their view, both survivors and healthcare providers needed more effective communication skills.²⁹ Participants reported poor interactions with healthcare providers, which led to them feeling ignored.³¹

Table 4 Supportive care needs of breast cancer survivors

Domain of need	Type of need	No of studies reporting this need	Studies
Psychological/emotional needs	Overall	32	3 6 9 11–13 20 21 25–32 34–49
	Needing help with depression, anxiety and stress	15	3 13 21 25 28 32 36 41–45 47–49
	Needing help to cope with fears about cancer spread and recurrence	13	6 21 26 32 35 37 41 42 44–46 48 49
	Fear of disclosure	8	11 13 20 25 26 33 36 43
	Feelings about death and dying	4	10 35 44 45
	Uncertainty about the future	4	6 35 41 45
	Others	8	3 13 25 28 29 31 41 45
Health system/informational needs	Overall	30	2 6 9 11 12 20 21 25–27 29–32 34 35 37–39 41–47 51–53 61
	Needing an easy and accurate explanation about benefits, side effects, medication and treatment sequelae	13	12 20 21 26 27 32 35 38 41 45 52 53 61
	Needing information about tests and treatments	7	12 20 26 32 45 52 54
	Needing up-to-date and ongoing information that could be understood	7	21 29 37 41 45–47
	Being informed about things to do to help oneself get well: control of situation, lifestyle advice and self-management	9	6 12 20 21 27 29 35 45 61
	Needing information regarding sexuality, fertility, coping with new body image, relationship with partner and relationship with others	5	30 39 45 51 52
	Needing information about symptoms requiring a hospital visit and possible symptoms after hospital discharge	4	20 32 45 52
	Needing information about correct diet (food to eat, food to avoid)	4	20 26 32 52
	Others	10	3 11 20 26 32 35 45 47 52 61
Physical and daily living needs	Overall	18	6 11 25 28–33 36–38 40 42–46
	Fatigue	8	25 28 33 36 42–45
	Pain	7	10 25 28 33 38 42 45
	Needing someone to help with housekeeping, childcare, bathing, dressing and preparing food	5	11 28 32 44 45
	Needing help with sleeping trouble or oversleeping	4	28 32 36 42
	Managing side effects and complaints about treatments	4	11 31 37 46
	Needing help with loss of hair	4	25 32 36 44
	Managing lymphoedema	4	25 33 40 43
	Weight control needs	3	28 36 43
Interpersonal/intimacy needs	Overall	6	25 28 29 32 36 43
	Overall	19	9 13 25 26 28–30 32 35 36 41–45 48 49 51 52
	Adjusting to concerns relating to body image, femininity, altered physical appearance and self-confidence	16	13 25 26 28–30 32 39 41–45 48 49 51
Social needs	Sexual function	8	9 26 28 30 35 36 44 45
	Relationship with partner	3	30 32 44
	Overall	18	3 9 13 28 30–32 40 42–44 47–50 53 55
	Return to work or re-employment	5	3 13 30 32 42
	Support from family, friends and social networks/support groups	7	9 31 38 43 44 49 53
Family-related needs	Relationship with partner/others/healthcare provider; talking to others who have had cancer	4	13 31 47 48
	Trouble communicating with others	3	28 31 49
	Overall	13	3 9 11 13 23 31 32 36 39 43 44 49 53
	Support from family, friends and social networks/support groups	7	9 31 38 43 44 49 53
	Burden to the family	4	3 13 44 49
Family-related needs	Family members, primarily the male partner, emerging as the primary source of emotional support after treatment	2	39 53
	Others	2	32 36

Continued

Table 4 Continued

Domain of need	Type of need	No of studies reporting this need	Studies
Practical needs	Overall	13	11 28 31 32 38 40–42 44–46 48 49
	Financial distress/healthcare costs/life insurance	12	11 28 31 32 38 40–42 44–46 48 49
	Problems at work or in education	3	28 44 48
Spiritual needs	Overall	12	3 25 28 31 38 40 41 43 44 47–49
	Religious and spiritual needs	5	25 31 44 48 49
	Religion and/or spirituality as a source of emotional support	3	40 43 44
	Loss of hope and sense of meaning or purpose in life	2	28 38
	Need for a strong faith and an intimate relationship with God	2	38 44
	Others	2	3 11
Patient–clinician communication needs	Overall	5	2 29 31 41 51 52
	Satisfaction with decision-making and surveillance of the organisation	3	2 51 52
	Needing to acquire effective communication skills	2	29 31
	Satisfaction with the quality of medical care	1	41
Cognitive needs	Overall	4	25 28 36 42
	Memory problems/paying attention	4	25 28 36 42

Cognitive needs

Four articles reported the cognitive needs of BCSs.^{25 28 36 42} In a study by Autade and Chauhan, 53% of BCSs stated that they had trouble remembering things.²⁸ Cappiello *et al* stated that difficulties in remembering things and concentrating were reported by 60%–80% of participants and persisted during the first year of treatment.³⁶

DISCUSSION

This systematic review aimed to determine a comprehensive set of domains for the supportive care needs of BCSs. Therefore, we decided not to limit the research to studies with the title and/or purpose of supportive care needs, as we wanted to analyse all studies that evaluated the needs of BCSs. Owing to the different tools and qualitative methods used for needs assessment, it was relatively difficult to compare the studies. We integrated the studies' results through a deductive approach based on classes of supportive care needs. This review analysed 40 studies that evaluated the supportive care needs of BCSs. It showed that BCSs have a wide range of supportive care needs; this extracted evidence was categorised into 10 dimensions including psychological, informational, physical, social, spiritual, interpersonal, family-related, practical, patient–clinician communication and cognitive needs.

The most prevalent needs were mainly psychological/emotional needs, followed by health system/information needs. There have been no similar studies on the supportive care needs of BCSs. However, similar to this study, a systematic review by Fiszer *et al* covered the supportive care needs of women with breast cancer. The most important supportive care needs for these patients were information and psychological needs.^{15 36}

In the psychological/emotional domain, three of the most common supportive care needs were 'needing help with depression, anxiety and stress', 'needing help to cope with fears about cancer spread and recurrence', and 'fear of disclosure'.^{47 57} A study by Ahmadi Gharaei *et al* in Iran showed that the prevalence of depression in patients with breast cancer was 46.8%, which is higher than the prevalence of postpartum depression, depression among infertile couples and depression among Iranian adolescents.⁵⁸ A study by Saeedi *et al* indicated that high levels of anxiety and stress in patients with breast cancer were considered to be the first and most important psychological consequences of breast cancer.⁵⁹ These symptoms of depression and anxiety may be related to some stressors such as breast cancer perception, long-term treatment-related side effects and fear of cancer recurrence.⁶⁰ Fear of cancer recurrence is recognised as one of the most common—and destructive—problems in cancer survivors; in some studies, it has been reported by up to 70% of survivors.^{61–64} Since fear of cancer recurrence is a common concern in cancer survivors and can negatively affect health behaviour and quality of life, it should be considered an important issue for intervention.⁶¹

In the health system/informational domain, three of the most common supportive care needs were 'needing an easy and accurate explanation about side effects and treatment sequelae', 'needing information about tests and treatments', and 'needing up-to-date and ongoing information'. These results are consistent with those of other studies that have measured the information needs of patients with breast cancer.⁶⁵ In the survivorship stage, patients focused on information about side effects and management of side effects. In addition,

they wanted information that would help prevent recurrence during this stage.⁶⁵ Information needs in patients with breast cancer change with time, and patients at different stages of the disease have different information needs. Generally, information on the chances of cure is more important to women at diagnosis and information about self-care is more significant to move further away from diagnosis.⁶⁶

Within the physical and daily living needs, three of the most common supportive care needs were 'fatigue', 'pain' and 'needing someone to help with usual activities'. Fatigue and pain are common physical symptoms in patients with breast cancer.⁶⁷ Bu *et al* (N=1210) reported that 41.8% of patients had symptoms of fatigue and 37.2% had pain.⁴² A systematic review indicated that in most studies, about 30% of patients reported fatigue after completing treatment; this figure was higher in obese younger women with diabetes.⁶⁸ In summary, as treatment following diagnosis progresses, fatigue decreases and most survivors recover; however, fatigue is complex and persistent among a small percentage of patients.⁶⁸ Given the growing population of survivors, this is a worrying problem and requires appropriate interventions in the field. Chronic pain is one of the most common symptoms experienced by cancer survivors. Forsythe *et al* reported that almost 30% of BCSs suffer above-average pain 10 years after the end of treatment.⁶⁹ Leysen *et al*, in a systematic study, identified several risk factors for chronic pain in BCSs, including body mass index >30, lymphoedema, axillary lymph node dissection, chemotherapy and radiotherapy.⁷⁰ Most studies have reported that the most common physical symptom in women is breast/arm pain.⁷¹⁻⁷³ Lymphoedema monitoring can be performed using basic circumferential measurements of the limb girth (www.armvolume.com). In general, ongoing support should be provided in order to manage the symptoms of fatigue and pain in these patients.⁷⁴

Another significant set of needs for BCSs is interpersonal/intimacy needs; these include 'adjusting to concerns relating to body image', 'sexual function' and 'relationship with partner'. Paterson *et al*, in a systematic review, stated that body image disturbance is an important issue of survival after breast cancer treatment, and that this issue is often associated with other types of distressing psychological, physical and interpersonal concerns.⁷⁵ In another study, various interventions were proposed to improve body image, including an exercise intervention programme, a sexual life reframing programme, and a combination of couple and sex therapy interventions.⁷⁶⁻⁷⁹ The majority of BCSs experience sexual problems during their survival, often with vaginal and vulvar dryness. There is significant evidence that encourages the regular use of vaginal moisturisers to improve dryness, dyspareunia and sexual satisfaction. Educational and counselling interventions, especially those targeting sexual dysfunction, can improve various aspects of sexual health.⁸⁰

CONCLUSION

This systematic review has highlighted several essential needs for BCSs. A comprehensive knowledge of the needs and experiences of survivors during the survival period is essential for providing them with patient-centred and family-centred care. In this study, psychosocial/emotional needs were at the top, followed by informational and physical needs. These results are consistent with those of other studies on supportive care for chronic diseases. Supportive programmes that provide support for BCSs should consider all physical, psychological, informational, social and spiritual aspects. Future studies are needed in order to determine how to tailor supportive care according to patients' needs and thus improve their quality of life.

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