Needs of breast cancer survivors: a systematic review of quantitative data

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ABSTRACT

This systematic review aimed to update the perceived needs of individuals with breast cancer (BC). Databases were searched for studies reporting quantitative data collected through validated assessment tools. Needs of adults with BC were reported by survivorship phase. The post-diagnosis and the post-surgery phases revealed the most needs; health system and information needs represented the greatest concern, with average Supportive Care Needs Survey-Short Form (SCNS-SF34) scores ranging from 62.0 to 75.8 post-diagnosis and from 45.0 to 67.8 post-surgery. Needs then seemed to decrease or remain stable up to within one year from diagnosis, when needs in all domains increased again; health system and information needs remained a priority. Younger age, side effects, type of treatment, and advanced stage were associated with the occurrence of unmet needs. The needs of BC survivors vary over the course of their cancer experience. This knowledge can assist the planning of appropriate assessments.

1. Introduction

Breast cancer (BC) represents a public health burden worldwide, with increasing prevalence in Western countries. Its high incidence, accounting for 12.1 % of the four million new cancer diagnoses registered in Europe (EU-28) in 2020, and its survival rate (85 %) contributes to the extremely high prevalence of this health condition in the female population (Cancer Today, 2020; Allemani et al., 2018). Of note, approximately 50 % of new BC diagnoses affect working age females (Cancer Today, 2020).

While screening strategies and effective treatments offer individuals with BC a longer lifespan, current multimodal therapeutic approaches usually last a long time, leading to a range of side effects, namely cognitive and physical dysfunctions, fatigue, neuropathy, lymphedema, upper limb impairment, and pain. These side effects affect individuals' health and quality of life (Hamer et al., 2017), hindering participation in activities of daily living (Loubani et al., 2022; Zomkowski et al., 2018).

Therefore, individuals with BC may perceive the need for support in one or more of these areas, for instance physical, psychological, or social support, in order to improve their health outcomes and regain normalcy. According to the European research agenda, the models of cancer care targeted to cancer survivors should be comprehensive and encompass multiple disciplines (i.e., medical, rehabilitation, psychosocial) to address the health-related needs of individuals with cancer at all the stages of the disease (Lagergren et al., 2019). Nevertheless, individuals' needs are not always exhaustively addressed by these models. These needs therefore remain unmet, denoting a gap of a person's experience with the services provided (Carr and Wolfe, 1976).

Unmet needs have been studied in mixed cancer or tumor-specific populations and categorized into the following domains: activities of daily living, communication, financial, informational, physical, psychological, psychosocial, supportive care, sexuality, spiritual, and transportation (Harrison et al., 2009). While most needs during active treatments are perceived in the activities of daily living, psychosocial,

and supportive care areas, during survivorship, physical needs also arise; in the end-stage of disease, economic, physical, and spiritual needs become prevalent (Harrison et al., 2009).

A general perspective on the unmet needs of all cancer survivors is pivotal to guiding the implementation of survivorship care for this population, since some needs, such as the need for information (Miroševič et al., 2019; Sutherland et al., 2009 Nov), are a priority regardless of the specific diagnosis. Nonetheless, investigating the unmet needs of a specific cancer population facilitates the provision of timely and person-centered survivorship care plans. The unmet needs of individuals with BC were systematically reviewed ten years ago, finding that, while needs in the physical daily living domain increased from diagnosis onwards, information needs, and psychological needs seemed to decrease over time in this population (Fiszer et al., 2014). Moreover, sociodemographic, psychosocial, and cultural traits influenced the perception of unmet needs in BC, since young age, anxiety, and being employed at the time of diagnosis acted as risk factors for higher levels of unmet needs (Fiszer et al., 2014; Akechi et al., 2011; Cardoso et al., 2016; Mazzi et al., 2020).

Building on the previous systematic review (Fiszer et al., 2014), this review aimed to update the knowledge of the perceived needs of individuals with BC and to support the implementation of evidence-based models of care for this target population.

Therefore, this systematic review searched the most recent literature that i) investigated the extent of needs in individuals with BC, ii) identify the most frequent unmet needs in the target population, and iii) explore the factors associated with the perception of unmet needs.

2. Methods

2.1. Search strategy and selection criteria

This systematic review is reported according to the PRISMA guidelines (supplementary material A) and has been registered on PROSPERO (CRD42022320396).

Studies were included if they had recruited adults with BC and had reported quantitative data on the needs of this population collected through validated assessment tools. In order not to exclude potential studies that investigated the needs of the population of interest, we decided to include all types of primary studies.

The literature search was conducted by an information specialist (M. C.B.) assisted by two rehabilitation healthcare professionals experts in the field (S. Co and S.P.), who searched the electronic databases of MEDLINE, Embase, CINAHL, and PsycInfo for records from January 2012 to February 2024, with no language restrictions. The strategy used to search records is reported as supplementary material B. A Web search was conducted to retrieve further eligible records.

Records were screened for eligibility by two independent reviewers (S.P. and A.C.), and disagreements were resolved through consensus with a third researcher (S. Co). Rayyan was used to manage the screening process (Ouzzani et al., 2016). The methodological quality of the included records was judged independently by two reviewers (S.P. and S. Co), and any disagreement was resolved through consensus.

Appraisal was performed by using the Joanna Briggs Institute Critical Appraisal Checklist for Prevalence Studies (Munn et al., 2020), the Joanna Briggs Institute Critical Appraisal Checklist for Randomized Controlled Trials (Barker et al., 2023), or the Joanna Briggs Institute Critical Appraisal Checklist for Quasi-Experimental Studies (Joanna Briggs Institute, 2017a), as appropriate. These appraisal checklists assess the domains of study design, participant selection strategies, exposure, outcome measurement, data analysis, and reporting. Since none of these tools provides a minimum score for quality, we used them to understand the overall strengths and weaknesses of included reports.

2.2. Methodological quality assessment

The results of the quality assessment are presented in supplementary material C. True randomization was used for most experimental studies, and the similarity of the groups at baseline was tested. Although blinding of participants and researchers was difficult to obtain, outcomes were measured unbiased, and intention-to-treat analysis was performed. In the quasi-experimental studies, cause–effect relationships were clearly discernable, and outcomes were assessed before and after the intervention in all studies. However, the reliability of measurements often remained unclear. Finally, the internal validity of observational studies was judged good, as sample frame, participants, and settings were described in depth for almost all the studies. Furthermore, valid assessment tools were used to collect the outcomes of interest.

2.3. Data extraction and analysis

A standardized data extraction form was used in accordance with three authors (S.P., S. Co and S. Ca) to collect information on report details, study design, data collection period, setting information, sample characteristics, employment status, stage of tumor, treatments, time since diagnosis/surgery/completion of active treatment, assessment tool used to collect needs, extent of needs, most frequently reported unmet needs, and factors associated with the perception of unmet needs. The data collection period was categorized according to the survivorship phase when needs were assessed, namely post-diagnosis, post-surgery, during active treatment, after completion of active treatment, within one year from diagnosis, or ≥1 year from diagnosis.

Regarding the first aim of this review, i.e., investigating the extent of needs in the target population, we report both the overall average value of needs and the average value of needs by domain as reported in the original studies. We then report both the absolute percentage of unmet needs in the target population and the percentage of unmet needs by domain as reported in the original studies. Moreover, we report the percentages of unmet needs by item, which vary according to the assessment tool used, and used bar charts to represent the most frequently reported item. As for the third aim, we labelled the factors associated with the perception of unmet needs into five categories: demographic, general health status, time since diagnosis, cancer-related factors, and BC care services. We report the factors by the overall risk of perceiving unmet needs and by the risk of predicting unmet needs in the specific domains in the assessment tools used. Since the original studies used different assessment tools to collect needs, the items, domains, and scoring modalities varied according to the tool used, making it impossible to extract homogeneous data from the reports included in this review.

3. Results

We retrieved 6284 records from the selected databases. After removal of duplicates, 4167 titles and abstracts were screened, of which 387 reports were sought in full-text. Four additional reports were identified through a Web search. Overall, 227 full-text reports were assessed for eligibility, of which 174 were excluded. The latter are referenced in supplementary material D together with the reasons for their exclusion.

This systematic review includes 53 studies (Fig. 1) with an experimental, quasi-experimental, or observational design.

3.1. Characteristics of study designs included

Table 1 summarizes data collected from the 53 studies included, which were conducted in Australia (Ahern et al., 2016; Barr et al., 2020; Brennan et al., 2015; Eggins et al., 2022; Ettridge et al., 2021 Feb; Kemp et al., 2018; Vuksanovic et al., 2021; White et al., 2018), Canada (Kwan et al., 2019), China (Au et al., 2013; Bu et al., 2022; Lyu et al., 2023; So
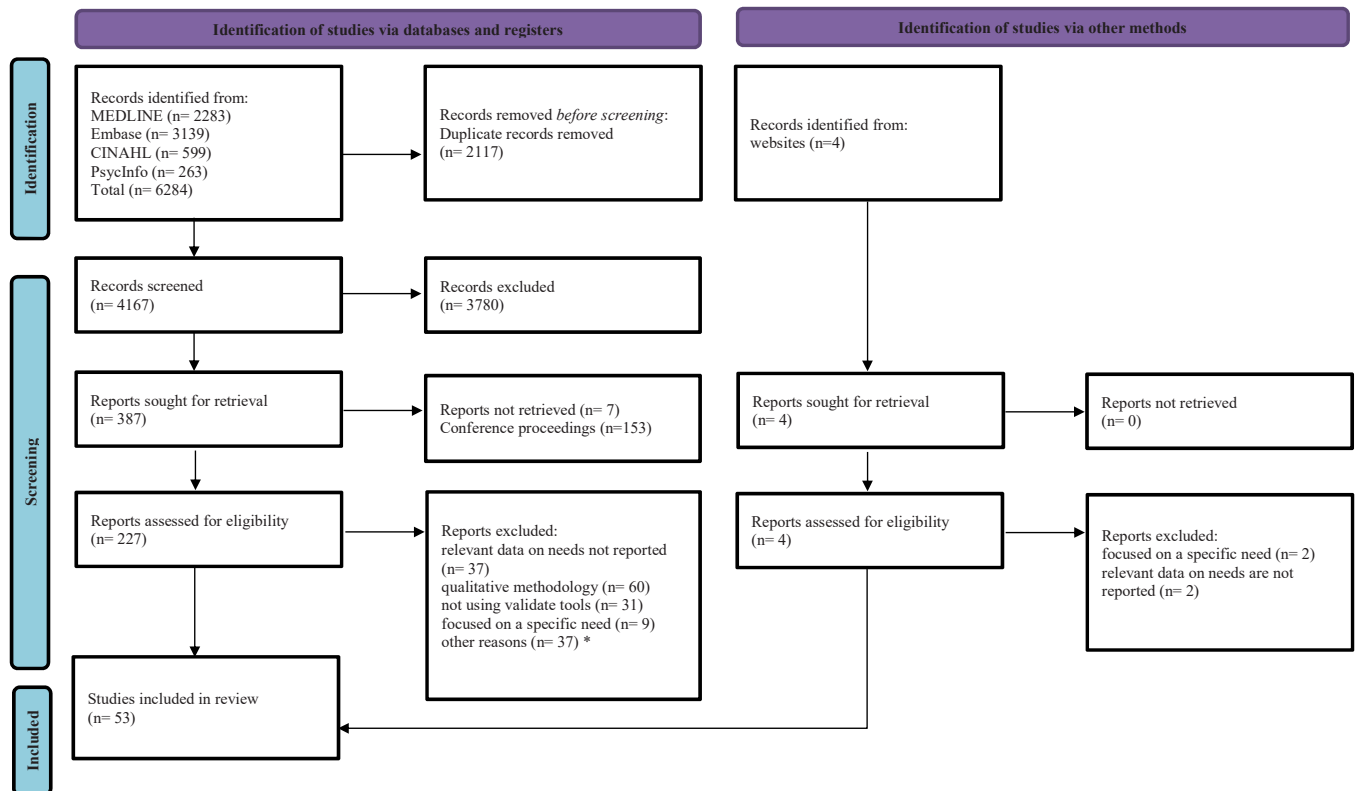
Fig. 1. PRISMA flow diagram. * Full text is not in English (n= 5), duplicate full text (n= 3), development/ validation of a tool (n= 7), mixed populations (e.g., breast cancer patients and caregivers were interviewed together, n= 8), overlapped cohort (n= 8), data request to authors (n= 5), included BC of all ages (n= 1).

et al., 2014; Wang et al., 2018, 2023; Zhou et al., 2020), France (Brédart et al., 2013, 2016; Cariou et al., 2018), Ghana (Akuoko et al., 2022), Iran (Abdollahzadeh et al., 2014; Mirzaei et al., 2018; Mohammadzadeh Nimekari et al., 2019; Okati-Aliabad et al., 2022), Japan (Akechi et al., 2015, 2021, 2023; Momino et al., 2017), Kenya (Shaikh et al., 2022), Korea (Park and Hwang, 2012; Kim and Lee, 2023), Malaysia (Fong and Cheah, 2017), Mexico (Pérez-Fortis et al., 2018), Oman (Al-Azri et al., 2022), Palestine (Elsous et al., 2023), Singapore (Cheng et al., 2016), Slovenia (Mirošević et al., 2022), Switzerland (Schmid-Büchi et al., 2013), Taiwan (Fang et al., 2018, 2020; Liao et al., 2012, 2014; Shih et al., 2020), the Netherlands (Jansen et al., 2023; Lo-Fo-Wong et al., 2020), Turkey (Temiz et al., 2024), the United Kingdom (Capelan et al., 2017; Hubbard et al., 2015), and the United States of America (Burris et al., 2015; Im et al., 2021, 2023; Oswald et al., 2021; Sleight et al., 2018). Participants were recruited mainly from cancer registries, electronic databases, and inpatient or outpatient settings. Data collection occurred from 2005 to 2022.

Forty-two of the studies were observational, with a cross-sectional design (Ahern et al., 2016; Kemp et al., 2018; Vuksanovic et al., 2021; Kwan et al., 2019; Au et al., 2013; Bu et al., 2022; Lyu et al., 2023; So et al., 2014; Wang et al., 2018; Zhou et al., 2020; Brédart et al., 2013; Akuoko et al., 2022; Abdollahzadeh et al., 2014; Mirzaei et al., 2018; Mohammadzadeh Nimekari et al., 2019; Okati-Aliabad et al., 2022; Akechi et al., 2015; Shaikh et al., 2022; Park and Hwang, 2012; Kim and Lee, 2023; Fong and Cheah, 2017; Al-Azri et al., 2022; Elsous et al., 2023; Cheng et al., 2016; Mirošević et al., 2022; Schmid-Büchi et al., 2013; Fang et al., 2018; Shih et al., 2020; Jansen et al., 2023; Capelan et al., 2017; Hubbard et al., 2015; Oswald et al., 2021; Sleight et al., 2018), or longitudinal prospective design (Brennan et al., 2015; Eggins et al., 2022; Wang et al., 2023; Brédart et al., 2016; Cariou et al., 2018; Pérez-Fortis et al., 2018; Liao et al., 2012; Lo-Fo-Wong et al., 2020; Burris et al., 2015). Among the former, four studies were actually a mixed methods design (Elsous et al., 2023; Jansen et al., 2023; Hubbard

et al., 2015; Oswald et al., 2021), since they also included qualitative data collection. Eleven studies were randomized controlled trials (Barr et al., 2020; Ettridge et al., 2021 Feb; White et al., 2018; Akechi et al., 2021, 2023; Im et al., 2021, 2023) or quasi-experimental studies (Momino et al., 2017; Fang et al., 2020; Liao et al., 2014; Temiz et al., 2024).

Regarding the 33 cross-sectional studies, data were collected post-surgery (Au et al., 2013; Zhou et al., 2020), during active treatment (Kemp et al., 2018; Brédart et al., 2013; Akuoko et al., 2022; Mirzaei et al., 2018; Mohammadzadeh Nimekari et al., 2019; Shaikh et al., 2022; Elsous et al., 2023; Schmid-Büchi et al., 2013; Oswald et al., 2021), after completion of active treatments (Ahern et al., 2016; Kemp et al., 2018; Kwan et al., 2019; Bu et al., 2022; So et al., 2014; Abdollahzadeh et al., 2014; Cheng et al., 2016; Capelan et al., 2017), within one year from diagnosis (Okati-Aliabad et al., 2022; Akechi et al., 2015; Park and Hwang, 2012; Jansen et al., 2023), or ≥ 1 year from diagnosis (Vuksanovic et al., 2021; Lyu et al., 2023; Wang et al., 2018; Akechi et al., 2015; Park and Hwang, 2012; Kim and Lee, 2023; Fong and Cheah, 2017; Al-Azri et al., 2022; Cheng et al., 2016; Mirošević et al., 2022; Fang et al., 2018; Shih et al., 2020; Hubbard et al., 2015; Sleight et al., 2018).

Regarding the nine longitudinal observational studies, this review reports the needs collected at each assessment of the cohorts, which were post diagnosis (Wang et al., 2023; Pérez-Fortis et al., 2018; Liao et al., 2012), post-surgery (Wang et al., 2023; Cariou et al., 2018; Pérez-Fortis et al., 2018; Liao et al., 2012), during active treatment (Brédart et al., 2016; Liao et al., 2012; Burris et al., 2015), after completion of active treatment (Brennan et al., 2015; Cariou et al., 2018; Pérez-Fortis et al., 2018; Burris et al., 2015), within one year from diagnosis (Eggins et al., 2022; Pérez-Fortis et al., 2018; Lo-Fo-Wong et al., 2020), and ≥ 1 year from diagnosis (Eggins et al., 2022; Cariou et al., 2018; Pérez-Fortis et al., 2018; Lo-Fo-Wong et al., 2020). Regarding experimental or quasi-experimental studies, we report the

Table 1
Study characteristics.

First author (year)	Country	Study design	Data collection period	Recruitment setting	Inclusion criteria	Exclusion criteria	Assessment tools
(Ahern et al., 2016)	Australia	cross-sectional	NR	national databases of women diagnosed with BC Register4 and the BCNA Review and Survey Group	completion of active treatment at least 6 months prior to participation	NR	SCNS-SF34
(Barr et al., 2020)	Australia	randomized controlled trial	NR	Victorian Cancer Registry	stage I or II; cancer registry registration within 5 months since diagnosis	previous cancer diagnosis	SCNS-BC40
(Brennan et al., 2015)	Australia	prospective observational	NR	multidisciplinary BC team in a metropolitan breast center that provides specialist cancer care in public and private health settings	stage I-III; completion of treatment, (S, CT, HER2-targeted therapy and/or RT); ongoing HT	NR	CaSUN
(Eggins et al., 2022)	Australia	prospective observational	NR	Queensland Cancer Registry	20–79 years	NR	SCNS-SF34
(Ettridge et al., 2021 Feb)	Australia	randomized controlled trial	June - September 2018	online survey disseminated national BC and cancer organizations and support groups	within 5 years since diagnosis	NR	SCNS-ST9
(Kemp et al., 2018)	Australia	cross-sectional	NR	during appointments with clinicians, survivorship database of BC patients no longer receiving treatments, South Australian-based members of Breast Cancer Network Australia's Review & Survey Group	NR	treatment completed more than 24 months ago	SCNS-SF34SCNS-BC40SCNS-Access to services needs17
(Vuksanovic et al., 2021)	Australia	cross-sectional	NR	outpatient clinics of two regional public hospitals that comprise the Gold Coast Breast Service	BC diagnosis at least one year prior to participation	primary cancer treatments not yet completed; terminal stage	CaSUN
(White et al., 2018)	Australia	randomized controlled trial	NR	Victorian Cancer Registry	stage I or II; cancer registry registration within 5 months since diagnosis	previous cancer diagnosis; prognosis less than 18 months	SCNS-BC54
(Kwan et al., 2019)	Canada	cross-sectional	August 2012 - May 2013	radiation oncology clinics of a large academic cancer center in Toronto	diagnosed with a pT1–2N0 estrogen receptor–positive or progesterone receptor-positive (or both) and her2-negative bca; completed radiation treatment; undergoing follow-up care	higher-risk survivor populations (i.e., hormone receptor–negative and her2-positive); did not complete primary treatment; had already been discharged from the cancer centre	CaSUN
(Au et al., 2013)	China	cross-sectional	Sept 2008 - Oct 2010	six Hong Kong public hospital oncology/ breast center outpatient clinics	new diagnosis; stage III – IV; awaiting/ receiving CT	NR	SCNS-SF33-C
(Bu et al., 2022)	China	cross-sectional	May 2020 - November 2022	cancer hospitals in China (two hospitals for each region)	completion of the primary therapy (S, CT, and/or RT)	NR	Cancer Survivor Profile-Breast Cancer (CSPro-BC)
(Lyu et al., 2023)	China	cross-sectional	July-November 2021	outpatient clinic and two breast surgery departments of a university-affiliated hospital situated in Henan	stage 0–III; completion of the primary therapy (S, RT and/or CT) within the past 10 years; having a mobile phone with internet access	mental or cognitive disorders; distant metastases, secondary cancer, or cancer recurrence	SCNS-SF34
(So et al., 2014)	China	cross-sectional	2010–2011	outpatient oncology department in a teaching hospital in Hong Kong	completion of treatment (S, CT and RT) within a year	recurrence;brain localization of metastases;had received additional treatment within one year of the main treatment	SCNS-SF34
(Wang et al., 2018)	China	cross-sectional	July 2015 - January 2016	tertiary-care hospital in Weifang	awareness of diagnosis	secondary BC; terminal diseases	SCNS-SF34

Table 1 (*continued*)

(Wang et al., 2023)	China	prospective observational	September 2021- February 2022	Ruijin Hospital Breast Centre, Shanghai Jiaotong University School of Medicine	≥ 65 years old; underwent S	BC with other malignant tumors or failure of vital organs, those with visual, auditory or cognitive disorders, mental disability	SCNS-SF34
(Zhou et al., 2020)	China	cross-sectional	March - October 2018	two hospitals in Xi'an	within 6 months after S	NR	Needs Self-Rating Questionnaire for Breast Cancer (NSQ-BC)
(Brédart et al., 2013)	France and Switzerland	cross-sectional	April 2010 - March 2011	CT day hospital and RT service of Institute Curie and University Hospital CHUV, and BC S Unit of the CHUV	NR	NR	SCNS-SF34
(Brédart et al., 2016)	France	prospective observational	March 2012 - February 2013	Curie Institute	local or loco-regional non-metastatic tumorS followed by RT (with or without CT)	NR	SCNS-SF34
(Cariou et al., 2018)	France	prospective observational	December 2014 - March 2016	Eight nonprofit hospitals: 3 teaching hospitals, 4 general hospitals and 1 comprehensive cancer center	previously untreatedfirst BC	metastatic cancerlocally advancedinflammatory BCprevious BC diagnosis	SCNS-SF34SCNS-BR8
(Akuoko et al., 2022)	Ghana	cross-sectional	May - August 2019	outpatient oncology clinics in one public hospital and a private health institution in Kumasi	stage III – IV; had commenced treatment	NR	SCNS-LF59
(Abdollahzadeh et al., 2014)	Iran	cross-sectional	June - September 2012	Inpatient wards and an outpatient clinic at the Ghazi Tabatabay Hospital and the Breast Cancer Support Center in Tabriz	in curative or palliative treatment; awareness of diagnosis	NR	SCNS-SF34
(Mirzaei et al., 2018)	Iran	cross-sectional	June - July 2017	public and private oncology centers in Arak for CT or RT	undergoing CT or RT	diagnosed in less than a month	SCNS-SF34
(Mohammadzadeh Nimekari et al., 2019)	Iran	cross-sectional	September 2017 - June 2018	Omid CT and RT Center affiliated with Hormozgan University of Medical Sciences, Bandar Abbas	all stages; diagnosed at least 3 months prior to participation	NR	SCNS-SF34
(Okati-Aliabad et al., 2022)	Iran	cross-sectional	February-August 2020	Clinical Oncology Department of Khatam-Al-Anbia Hospital and the Radiotherapy Department of Ali ibn Abi Talib Hospital	confirmed BC diagnosis	NR	SCNS-SF34
(Akechi et al., 2015)	Japan	cross-sectional	February 2006 - February 2007	outpatient clinic for Oncology, Immunology and S at the Nagoya City University Hospital	all stagesawareness of diagnosisFour groups of BC patients (grouped by time since cancer diagnosis): group 1= within 1 ygroup 2= 1–3 ygroup 3= > 3 y group 4= cancer recurrence, irrespective of time since cancer diagnosis	NR	SCNS-SF34
(Akechi et al., 2021)	Japan	randomized controlled trial	October 2010 - March 2013	outpatient clinic for Oncology, Immunology and Surgery at Nagoya City University Hospital	awareness of diagnosis3–6 months after breast S, currently disease-free	NR	SCNS-SF34
(Akechi et al., 2023)	Japan	quasi-experimental	April 2018-July 2020	NR	20–49 years; 1 year after S; currently disease-free	having physical disease, history of cancer other than BC; being followed by a psychiatrist; having previously received problem-solving therapy or similar	SCNS-SF34
(Momino et al., 2017)	Japan	feasibility	NR	outpatient clinic of Nagoya City University Hospital	invasive breast cancer 3–6 months after S; received adjuvant CT	NR	SCNS-SF34

Table 1 (*continued*)

					or HT after S; currently disease-free		
(Shaikh et al., 2022)	Kenya	cross-sectional	July 2018 - July 2019	Kenya Metastatic Breast Cancer Network	stage IV	NR	SCNS-SF34
(Park and Hwang, 2012)	Korea	cross-sectional	NR	Severance Hospital Breast Cancer Clinic, Seoul	stage I-III; no recurrenceFour groups of BC patients (grouped by the time since S): group 1= less than 1 y from surgerygroup 2= 1–3 ygroup 3= 3–5 ygroup 4= more than 5 years	NR	SCNS-LF59
(Kim and Lee, 2023)	Korea	cross-sectional	February-March 2022	NR	females; > 19 years; stages I-III; within 5 years of completing major treatments (i.e., S, CT and RT)	secondary cancers, BC recurrence, stage IV	SCNS-SF34
(Fong and Cheah, 2017)	Malaysia	cross-sectional	January 2014 - June 2014	community based nongovernmental organization (NGO) Sarawak Breast Cancer Support Group (SBCSG) in Kuching, Sarawak	all stages	NR	SCNS-SF34
(Pérez-Fortis et al., 2018)	Mexico	prospective observational	May 2014 - July 2015	public hospital in Mexico City	first BC diagnosis	recurrence;already undergone to S for BC; male sex	SCNS-SF34
(Al-Azri et al., 2022)	Oman	cross-sectional	November 2020-February 2021	Sultan Qaboos University Hospital (SQUH), Muscat	BC diagnosis over the past five years; all stages	NR	SCNS-SF34
(Elsous et al., 2023)	Palestine	mixed method	September-December 2021	Al Rantisi specialised hospital and Al-Amal hospital	BC diagnosis regardless of stage, time since diagnosis, or status of treatment, had visited a hospital for cancer treatment within the past 12 months	physical or psychological problems resulted from other diseases	SCNS-SF34
(Cheng et al., 2016)	Singapore	cross-sectional	2007–2011	hospital online record system: potential subjects were approached and invited by telephone call to participate in the study. Those who expressed interest in participation were face-to-face recruited for the study at a follow-up appointment	completion of cancer treatment (S, CT) 6 months to 5 years prior to participation	NR	SCNS-SF34
(Mirošević et al., 2022)	Slovenia	cross-sectional	September 2021-January 2022	Institute of Oncology Ljubljana	1–5 years post-primary treatment (S, RT, or CT); no recurrence; no cognitive disorders	NR	CaSUN
(Schmid-Büchi et al., 2013)	Switzerland	cross-sectional	October 2005 - February 2007	two hospitals in the Zurich area of Switzerland	completion of treatment (CT and/or RT) within 1–12 months (mean 4·2 months)	NR	SCNS-SF34
(Fang et al., 2018)	Taiwan	cross-sectional	NR	medical records and cancer registry to screen eligibility and outpatient clinic	diagnosis at least 5 years prior to participation; no recurrence	NR	CaSUN
(Fang et al., 2020)	Taiwan	quasi-experimental	NR	single medical center in Southern Taiwan	diagnosis within the last 5 years; completion of the primary treatment; no recurrence	NR	CaSUN-C (adapted version)
(Liao et al., 2012)	Taiwan	prospective observational	September 2008 - November 2009	general surgical oncology outpatient department in northern Taiwan	new diagnosis; awareness of cancer diagnosis	NR	SCNS-SF34
(Liao et al., 2014)	Taiwan	quasi-experimental	February - September 2011	Omid CT and RT Center affiliated with Hormozgan University of Medical Sciences, Bandar Abbas	all stages; diagnosed at least 3 months prior to the start of the study	NR	SCNS-SF34

Table 1 (*continued*)

(Shih et al., 2020)	Taiwan	cross-sectional	group 1= October 2015 - September 2016group 2= September 2014 - July 2015	NR	stage 0-III; completion of active treatments; currently disease-freegroup 1= with a survival duration between two and five years group 2= with a survival duration of more than five years	recurrence;stage IV	CaSUN-C (adapted version)
(Jansen et al., 2023)	The Netherlands	mixed method	NR	St. Antonius Hospital	newly diagnosed with BC in 2019 and 2020	unknown email address, history of BC, deceased by time of follow-up, no surgical treatment, treatment in another hospital, distant metastasis poor prognosis	CaSUN-NL
(Lo-Fo-Wong et al., 2020)	The Netherlands	prospective observational	November 2009	six academic hospitals, two community hospitals and one comprehensive cancer center	primary BC diagnosed up to 6 months earlier		SCNS-SF34SCNS-BR8
(Temiz et al., 2024)	Turkey	quasi-experimental	November 2021-April 2022	Radiation Oncology Clinic of the Department of internal medicine, Marmara University Faculty of Medicine	receiving radiotherapy	over the age of 75; psychiatric illness; brain localization of metastases	SCNS-SF34
(Capelan et al., 2017)	UK	cross-sectional	January - December 2015	Royal Marsden Hospital NHS Foundation Trust	stages I-III; completion of primary treatment (S, CT, RT)	ductal carcinoma;invasive breast cancer; male sex	Holistic Needs Assessment (HNA) Electronic patient record (EPR)
(Hubbard et al., 2015)	UK	mixed method	NR	electronic database of women with BC living and cured in a rural area of Scotland	NR	NR	SCNS-SF34
(Burris et al., 2015)	USA	longitudinal (pilot randomized controlled trial)	July 2011 - March 2012	two South Carolina cancer centers	first cancer diagnosis; stage I–III; undergoing RT	NR	CaSUN (adapted version)
(Im et al., 2021)	USA	randomized controlled trial	NR	online and offline communities/groups for Asian Americans, which included primary care clinics, churches, community centers/organizations, professional groups, social media sites, and online forum groups	diagnosed within 5 years	NR	SCNS-SF34
(Im et al., 2023)	USA	randomized controlled trial	NR	online and offline communities/groups among Asian Americans (e.g., social media sites, health care clinics/centers, churches, markets, etc.).	Asian American women from 3 ethnic sub-groups; access the internet using computers or mobile devices	NR	SCNS-SF34
(Oswald et al., 2021)	USA	mixed method	Apr - May 2020	Cancer Center's Breast Oncology Clinic	diagnosed with HR+/HER2−; stage IV; prescribed a CDK4/6 inhibitor for ≥4 weeks; expected to survive ≥3 months	NR	Needs Evaluation Questionnaire (NEQ)
(Sleight et al., 2018)	USA	cross-sectional	NR	flyers distributed in the waiting room of the Los Angeles County and USC Medical Center (LAC+USC) Oncology Clinic	completion of cancer treatment (S, CT, and RT), undergoing HT or reconstructive S	metastatic cancerundergoing CT or radiation	SCNS-SF34

S= surgery, MT= mastectomy, AD= axillary dissection, CT= chemotherapy, RT: radiotherapy, HT= hormone therapy, TT= TT/trastuzumab

data on needs assessed at baseline; according to study designs, this was post-surgery (Liao et al., 2014), after completion of active treatment (Fang et al., 2020; Temiz et al., 2024), within one year from diagnosis (Barr et al., 2020; Akechi et al., 2021; Momino et al., 2017), or ≥ 1 year from diagnosis (Ettridge et al., 2021 Feb; White et al., 2018; Akechi et al., 2023; Im et al., 2021, 2023). Of note, while the cohorts of Barr et al. and White et al (Barr et al., 2020; White et al., 2018). overlapped, the data did not fully; thus they were extracted from both the reports.

3.2. Assessment tools used to collect needs

Most studies included in this review collected needs using the Supportive Care Needs Survey-Short Form 34 (SCNS-SF34) by Boyes et al. (2009) (Ahern et al., 2016; Barr et al., 2020; Eggins et al., 2022; Ettridge et al., 2021 Feb; Kemp et al., 2018; White et al., 2018; Au et al., 2013; Lyu et al., 2023; So et al., 2014; Wang et al., 2018, 2023; Brédart et al., 2013, 2016; Cariou et al., 2018; Akuoko et al., 2022; Abdollahzadeh et al., 2014; Mirzaei et al., 2018; Mohammadzadeh Nimekari et al., 2019; Okati-Aliabad et al., 2022; Akechi et al., 2015, 2021, 2023; Momino et al., 2017; Shaikh et al., 2022; Park and Hwang, 2012; Kim and Lee, 2023; Fong and Cheah, 2017; Pérez-Fortis et al., 2018; Al-Azri et al., 2022; Elsous et al., 2023; Cheng et al., 2016; Schmid-Büchi et al., 2013; Liao et al., 2012, 2014; Lo-Fo-Wong et al., 2020; Temiz et al., 2024; Hubbard et al., 2015; Im et al., 2021, 2023; Sleight et al., 2018) or the Cancer Survivors Unmet Needs measure (CaSUN) by Hodgkinson et al. (2007) (Brennan et al., 2015; Vuksanovic et al., 2021; Kwan et al., 2019; Miroševič et al., 2022; Fang et al., 2018, 2020; Shih et al., 2020; Jansen et al., 2023; Burris et al., 2015). Few other studies collected needs using the Needs Evaluation Questionnaire (NEQ) by Annunziata et al. (2009) and Tamburini et al. (2000) (Oswald et al., 2021), the Cancer Survivor Profile-Breast Cancer (CSPro-BC) by Cheng et al. (2019) and Todd et al. (2015) (Bu et al., 2022), the Holistic Needs Assessment (HNA) (Capelan et al., 2017), and the Needs Self-Rating Questionnaire for Breast Cancer (NSQ-BC) by Zhou et al. (2019), (Zhou et al. 2020). These validated assessment tools are described in supplementary material E.

Twenty studies did not report the average values of needs through a standardized Likert summated score between 0 and 100, nor the percentages of unmet needs (Brennan et al., 2015; Eggins et al., 2022; Kemp et al., 2018; Wang et al., 2023; Cariou et al., 2018; Mirzaei et al., 2018; Akechi et al., 2015, 2021, 2023; Momino et al., 2017; Park and Hwang, 2012; Fong and Cheah, 2017; Al-Azri et al., 2022; Elsous et al., 2023; Schmid-Büchi et al., 2013; Fang et al., 2020; Lo-Fo-Wong et al., 2020; Temiz et al., 2024; Im et al., 2021, 2023). These studies are described in Table 1 but were excluded from further analyses, since the comparability of their results with those of the other studies would have not been possible.

3.3. Participants in included studies

Table 2 summarizes the data on the cohorts who participated in the studies included in this review, according to the survivorship phase when needs were assessed. Overall, there were 8690 adults, mostly female, with BC. Only Shaikh et al. (2022) included four males with BC (Shaikh et al., 2022). Twenty-two studies described the employment status of 5497 participants, of whom 2201 (40 %) were employed during the study (Barr et al., 2020; Ettridge et al., 2021 Feb; White et al., 2018; Kwan et al., 2019; Au et al., 2013; Bu et al., 2022; So et al., 2014; Zhou et al., 2020; Brédart et al., 2016; Akuoko et al., 2022; Abdollahzadeh et al., 2014; Shaikh et al., 2022; Kim and Lee, 2023; Pérez-Fortis et al., 2018; Miroševič et al., 2022; Fang et al., 2018; Shih et al., 2020; Jansen et al., 2023; Capelan et al., 2017; Hubbard et al., 2015; Burris et al., 2015).

Great variability was observed in the treatments received: between 9.9 % (Kim and Lee, 2023) and 100 % of participants (White et al., 2018; Kwan et al., 2019) underwent surgery. In particular, from 21.1 %

(Brédart et al., 2013) to 78.1 % (Shih et al., 2020) underwent mastectomy, and from 3.1 % (Jansen et al., 2023) to 41.4 % (Brédart et al., 2013) of participants underwent axillary dissection. From 2 % (Liao et al., 2012) to 99 % (Zhou et al., 2020) of participants underwent chemotherapy, from 6.3 % (Akuoko et al., 2022) to 100 % (Kwan et al., 2019) underwent radiotherapy, and from 3.6 % (Au et al., 2013) to 89.4 % (Shih et al., 2020) of participants underwent hormone therapy. When reported, time from diagnosis was from 4.4 months (Au et al., 2013) up to 8.9 years (Fang et al., 2018) on average, or between 2 (Au et al., 2013) to 24 (Akuoko et al., 2022) months (median). Few studies reported time from treatment completion (Ahern et al., 2016; Vuksanovic et al., 2021; Kim and Lee, 2023; Cheng et al., 2016; Miroševič et al., 2022), surgery (Jansen et al., 2023) or since first follow-up (Kwan et al., 2019).

3.4. Extent of needs by domains

Table 3 reports data concerning the extent of needs based on the survivorship phase of reporting (post-diagnosis, post-surgery, during active treatment, after completion of active treatment, within one year from diagnosis, or ≥ 1 year from diagnosis). The average needs score was reported for all the survivorship phases investigated, while the percentages of unmet needs were not reported for two of those phases, namely post-diagnosis and post-surgery.

Two studies assessed the needs of BC survivors post-diagnosis (Pérez-Fortis et al., 2018; Liao et al., 2012); the average needs score was 55.6 (Liao et al., 2012). Needs in the domain of health system and information were the highest, with the average score ranging from 62 to 75.8 (Pérez-Fortis et al., 2018; Liao et al., 2012). These two were followed by the needs in the psychological domain and in the patient care and supports domain, which ranged from 33.8 (Pérez-Fortis et al., 2018) to 63.5 (Liao et al., 2012) and from 28.8 (Pérez-Fortis et al., 2018) to 47.9 (Liao et al., 2012), respectively. Needs in the sexuality and physical and daily living domains were perceived as less pressing, since they ranged from 14.6 (Pérez-Fortis et al., 2018) to 31.1 (Liao et al., 2012) and from 14.9 (Pérez-Fortis et al., 2018) to 19.8 (Liao et al., 2012), respectively.

Five studies assessed the post-surgery needs of BC survivors (Au et al., 2013; Zhou et al., 2020; Pérez-Fortis et al., 2018; Liao et al., 2012, 2014) with the average needs score ranging from 41.4 (Liao et al., 2014) to 52.9 (Liao et al., 2014). Again, the needs in the domain of health system and information represented a major priority (from 45 (Pérez-Fortis et al., 2018) to 67.8 (Liao et al., 2014)), followed by needs in the psychological domain and those in patient care and supports domain (22 (Au et al., 2013) –58.4 (Zhou et al., 2020) and 28.4 (Pérez-Fortis et al., 2018) – 47.4 (Liao et al., 2014), respectively). Compared to the post-diagnosis phase, the extent of needs in the physical and daily living domain increased after surgery, with the average score ranging from 20.1 (Au et al., 2013) to 38.8 (Liao et al., 2014), while needs in the sexuality domain fluctuated from between 3.2 (Au et al., 2013) and 25.6 (Liao et al., 2014). One study specifically detected needs in the rehabilitation domain, with an average score ranging from 59.3 to 73.6 (Zhou et al., 2020).

Eight studies assessed the needs of BC survivors during active treatment (Brédart et al., 2013, 2016; Akuoko et al., 2022; Mohammadzadeh Nimekari et al., 2019; Shaikh et al., 2022; Liao et al., 2012; Burris et al., 2015; Oswald et al., 2021). The average needs score ranged from 31.6 (Liao et al., 2012) to 33.5 (Liao et al., 2012). Needs related to the health system and information domain and to the physical and daily living domain were the highest, and their ranges were similar (30.7 (Mohammadzadeh Nimekari et al., 2019) to 41.6 (Liao et al., 2012) and 31.1 (Liao et al., 2012) to 40.6 (Mohammadzadeh Nimekari et al., 2019), respectively). These were followed by needs in the psychological domain (28.9 (Mohammadzadeh Nimekari et al., 2019)–38.5 (Brédart et al., 2013)), needs in patient care and supports domain (26.2 (Brédart et al., 2013) – 37.9 (Mohammadzadeh Nimekari et al., 2019)), and those

Table 2
Participant characteristics.

First author (year)	Participants for whom data on needs are reported n.	Time of needs assessment	Age mean (±SD), median (range), categories (%)	Employed n (%)	Stage of tumor %	Treatment %	Time from diagnosis, completion of active treatment, surgery, or first follow-up mean (±SD) median (range) categories (%)
POST-DIAGNOSIS							
(Pérez-Fortis et al., 2018)	group 1= 29 (only S) group 2= 70 (S + adjuvant treatment) group 3= 56 (neoadjuvant treatment + S + adjuvant treatment)	after diagnosis but before S	group 1= 54.4 (9.8) group 2= 53.3 (10.6) group 3= 50.9 (11.1)	group 1= 8 (27.6) group 2= 26 (37.7) group 3= 20 (35.7)	By group 1,2,3 I= 17.2, 12.9, 5.4, II= 51.7, 52.9, 8.9 III/IV= 13.8, 17.1, 73.2 Unknown= 17.2, 17.1, 12.5	S= 18.7 S and adjuvant= 45.2 neoadjuvant, S and adjuvant= 36.1	NR
(Liao et al., 2012)	T1= 124	T1= after cancer diagnosis	49.4 (0.8)	NR	I= 26.0 II= 35.0	S and CT= 65.0 only S= 12.0 S and chemoradiation= 10.0 S and RT= 8.0 S and HT= 4.0 only CT= 2.0	NR
POST-SURGERY							
(Au et al., 2013)	111	after surgery and receiving/awaiting CT	52.5 (9.44)	39 (35.1)	NR	S= 52.2 CT= 21.6 RT= 0.0 TT= 5.4 HT= 3.6	time from diagnosis: 4. (11.1) monthsmedian= 2 months (range NR)
(Zhou et al., 2020)	406	within 6 months after surgery	49.8 (9.6)	152 (37.4)	I= 18.2 II= 52.0 III= 23.4 IV= 6.4	modified radical MT= 63.5 MT= 24.4 lumpectomy with AD= 9.1 breast conserving S= 3 CT= 99.0 RT= 11.3 HT= 8.4	NR
(Pérez-Fortis et al., 2018)	group 1= 29 (only S) group 2= 70 (S + adjuvant treatment) group 3= 56 (neoadjuvant treatment + S + adjuvant treatment)	after S and before adjuvant treatment	group 1= 54.4 (9.8) group 2= 53.3 (10.6) group 3= 50.9 (11.1)	group 1= 8 (27.6) group 2= 26 (37.7) group 3= 20 (35.7)	By group 1,2,3 I= 17.2, 12.9, 5.4, II= 51.7, 52.9, 8.9 III/IV= 13.8, 17.1, 73.2 Unknown= 17.2, 17.1, 12.5	S= 18.7 S and adjuvant= 45.2 neoadjuvant, S and adjuvant= 36.1	NR
(Liao et al., 2012)	T2= 119	T2= one month after diagnosis (while receiving surgery)	49.4 (0.8)	NR	I= 26.0 II= 35.0	S and CT= 65.0 only S= 12.0 S and chemoradiation= 10.0 S and RT= 8.0 S and HT= 4.0 only CT= 2.0	NR
(Liao et al., 2014)	CG= 40 IG= 40	first post-operative visit	By group CG, IG≤ 50= 45.0, 50.0 >50= 55.0, 50.0	NR	By group CG, IG I= 42.5, 37.5 II= 40.0, 42.5 III= 17.5, 20.0	By group CG, IG conserving S, CT= 27.5, 37.5 MT, CT= 72.5, 62.5	NR
DURING ACTIVE TREATMENT							
(Brédart et al., 2013)	384	during CT, RT or after S	54 (11.3)	NR	loco/regional / localized or regional= 80.7 metastatic / distant= 19.3	CT= 46.6 RT= 41.2 only S= 12.2	time from diagnosis and questionnaire completion: 6.3 months (0.5–284.4)
(Brédart et al., 2016)	360	the last week of radiotherapy	55.2 (12.4)	79 (22.0)	0, I= 57.1 II= 33.0 III= 9.9	MT= 21.1 AD= 41.4 CT= 45.6 HT= 73.0	NR
(Akuoko et al., 2022)	176	during CT, HT, RT, other treatment or no treatment	50.8 (11.8)	80 (45.5)	III= 38.0 IV= 48.3 Unknown= 13.6	CT= 56.8 HT= 28.4 RT= 6.3 other treatment= 5.1 no treatment= 3.4	time from diagnosis: 24 months (3–120)

Table 2 (*continued*)

First author (year)	Participants for whom data on needs are reported n.	Time of needs assessment	Age mean (±SD), median (range), categories (%)	Employed n (%)	Stage of tumor %	Treatment %	Time from diagnosis, completion of active treatment, surgery, or first follow-up mean (±SD) median (range) categories (%)
(Mohammadzadeh Nimekari et al., 2019)	150	during treatment	45.8 (10.4)	NR	I, II= 46.3III, IV= 53.7	NR	time from diagnosis: 16.4 months (9.3)
(Shaikh et al., 2022)	114	during systemic treatment	On 114 respondents51.4 (12.7)	On 110 respondents41 (37.3)	IV= 100.0	On 93 respondentssystemic= 64.5 oral/hormone=35.5	NR
(Liao et al., 2012)	T3= 115T4= 114	T3= two months after diagnosisT4= four months after diagnosis	49.4 (0.8)	NR	I= 26.0II= 35.0	S and CT= 65.0 only S= 12.0 S and chemoradiation= 10.0 S and RT= 8.0 S and HT= 4.0 only CT= 2.0	NR
(Burris et al., 2015)	90	2–3 weeks prior the completion of RT	55.3 (9.2)	41 (45.6)	I= 52.2II= 32.2III= 15.6	MT= 24.4 CT= 54.4 HT= 75.6	NR
(Oswald et al., 2021)	20	during treatment	59 (12.3)	NR	IV= 100.0	CDK4/6 inhibitor= 100.0	time from diagnosis: 4.3 years (6.4)
AFTER COMPLETION OF ACTIVE TREATMENT							
(Abdollahzadeh et al., 2014)	136	completion of the initial phase of treatment (4–6 month after diagnosis)	46.8 (10.1)	25 (18.4)	NR	S= 88.9 CT= 93.3 RT= 46.3 other= 3.7	time from diagnosis: 35.8 months (11.2)
(Ahern et al., 2016)	839	completion of active treatment at least 6 months ago	56 (28−82)	NR	NR	S= 99.7 CT= 63.2RT= 71.3 HT= 71.4	completion of active treatment: ≥ 6 months
(Kwan et al., 2019)	187	after completion of RT	63 (10.0)	79 (42.0)	NR	S= 100.0 RT= 100.0 CT= 21.0	time from first follow-up: median= 21 months
(Bu et al., 2022)	1192	after completion of primary treatment (S, CT and RT)	< 40= 19.7 % 40–49= 38.1 % 50–59= 33.6 %≥ 60= 8.6 %	297 (24.9)	I= 21.3II= 47.6III= 23.4IV= 7.7	S= 9.2 S and CT= 32.3 S and RT= 1.2 S, CT and RT= 17.7 S, CT, RT and HT= 15.0 S and TT= 3.4	time from diagnosis: ≤ 12 months= 22.9 %13–24 months= 48.9 % 25–60= 23.2 %≥ 61= 5 %
(So et al., 2014)	163	completion of primary treatment (S, CT and RT) within a year	51 (9.2)	59 (36.2)	II= 79.1III= 20.9	1 cancer treatment= 5.5≥ 2 cancer treatments= 94.5HT= 69.8	time from diagnosis: 14 months (11−19)
(Pérez-Fortis et al., 2018)	group 2= 70 (S + adjuvant treatment)group 3= 56 (neoadjuvant treatment + S + adjuvant treatment)	at the end of adjuvant	group 2= 53.3 (10.6)group 3= 50.9 (11.1)	group 2= 26 (37.7)group 3= 20 (35.7)	By group 2,3I= 12.9, 5.4,II= 52.9, 8.9III/IV= 17.1, 73.2Unknown= 17.1, 12.5	S and adjuvant= 45.2 neoadjuvant, S and adjuvant= 36.1	NR
(Cheng et al., 2016)	group1= 113	group 1= <2 years after completion of treatment (S and CT)	53 (8.4)	NR	0= 12.5I, II= 66.1III, IV= 21.4	MT= 61.1 CT= 13.3 RT= 24.8 TT= 22.1 HT= 46.0	time from completion of active treatment: 28.9 months (17.8) group 1= 45 %
(Capelan et al., 2017)	625	after completion of primary treatment (S, CT and RT)	median 59 (range 27–97)	263 (42)	I= 35.0 II= 56.0 III= 9.0	MT= 31.0 AD= 22.0CT= 42.0 HT= 81.0	time from diagnosis: < 12 months= 68 %≥ 12 months= 32 % median= 8.9 months

Table 2 (*continued*)

First author (year)	Participants for whom data on needs are reported n.	Time of needs assessment	Age mean (±SD), median (range), categories (%)	Employed n (%)	Stage of tumor %	Treatment %	Time from diagnosis, completion of active treatment, surgery, or first follow-up mean (±SD) median (range) categories (%)
(Burris et al., 2015)	90	10 weeks after completion of RT	55.3 (9.2)	41 (45.6)	I= 52.2II= 32.2III= 15.6	MT= 24.4 CT= 54.4 HT= 75.6	NR
WITHIN ONE YEAR FROM DIAGNOSIS							
(Barr et al., 2020)	IG= 202	7 months post-diagnosis	43.5 (5.0)	152 (75.0)	NR	S= 99.0 CT= 63.0 RT= 57.0 TT= 20.0 HT= 57.0	time from diagnosis: 7.1 months (2.1)
(Jansen et al., 2023)	225	NR	58.1 (28−87)	125 (55.5)	NR	S= 100 AD= 3.1 CT= 45.3 RT= 72.9 HT= 49.8	time from surgery: 8.6 months (0−18)
(Pérez-Fortis et al., 2018)	group 1= 29 (only S)	first post-treatment FU appointment	group 1= 54.4 (9.8)	group 1= 8 (27.6)	By group 1I= 17.2II= 51.7III/IV= 13.8Unknown= 17.2	S= 18.7	NR
(Okati-Aliabad et al., 2022)	total= 120 group 1= 65 group 2= 35 group 3= 20	group 1= within 12 months from diagnosis group 2= 12–48 months from diagnosis group 3= > 48 months from diagnosis	47.3 (10.6)	NR	I-II= 25 III= 40.8 IV= 34.2	MT= 53.3 CT= 94.2 RT= 64.2	time from diagnosis: < 12 months= 54.2 % 12–48= 29.2 % > 48= 16.7 %
≥ 1 YEAR FROM DIAGNOSIS							
(Ettridge et al., 2021 Feb)	77	within 5 years from diagnosis	< 50= 33 % 50–59= 38 %≥ 60= 29 %	45 (59.0)	Invasive cancer/ in situ= 77.0spread to lymph nodes/ regional= 47.0metastatic/ distant= 8.0	MT= 68.2	time from diagnosis: ≤ 12 months= 24 %1–2 years= 17 %2–5 years= 59 %
(Vuksanovic et al., 2021)	130	diagnosis at least 1 year prior to study participation	< 46= 11.4 % 46–65= 54.6 %≥ 60= 33.8 %	NR	NR	HT= 70.0	time from diagnosis: 37.3 months (27.1) time from completion of active treatment: 27.4 months (22.7)
(White et al., 2018)	CG= 142	13 months after diagnosis	on 177 respondents 43.9 (5.3)	on 177 respondents 142 (82.0)	on 177 respondents I= 47.0II= 52.0III= <1	on 177 respondents S= 100.0 CT= 64.0 RT= 58.0TT= 22.0 HT= 55.0	NR
(Wang et al., 2018)	264	one year or more after diagnosis	49.5 (9.7)	NR	0/I= 28.4II= 40.2III= 21.6IV= 9.8	lumpectomy= 26.9 MT= 76.1 RT= 28CT= 72.3	time from diagnosis: ≤ 1 years= 42.8 %1–5 years= 39 %>5 years= 18.2 %
(Pérez-Fortis et al., 2018)	group 2= 70 (S + adjuvant treatment)group 3= 56 (neoadjuvant treatment + S + adjuvant treatment)	first post-treatment FU appointment	group 2= 53.3 (10.6)group 3= 50.9 (11.1)	group 2= 26 (37.7)group 3= 20 (35.7)	By group 2,3I= 12.9, 5.4,II= 52.9, 8.9III/IV= 17.1, 73.2Unknown= 17.1, 12.5	S and adjuvant= 45.2 neoadjuvant, S and adjuvant= 36.1	NR
(Fang et al., 2018)	192	diagnosis at least 5 years earlier	57.3 (9.7)	62 (32.3)	0, I= 38.5II, III= 58.9	MT= 35.0 CT= 63.5 RT= 44.3 HT= 62.0	time from diagnosis: 8.9 years (3.2)
(Shih et al., 2020)	total= 349group 1= 157group 2= 192	group 1= survival duration from 2	total= 56.4 (10.1) group 1= 55.2	total= 144 (41.3)group 1=	By group 1,2, total0, I= 47.8, 38.5, 42.6II= 38.2,	By group 1,2, totalBC conserving S= 33.8, 21.9, 27.2MT= 66.2, 78.1,	time from diagnosis: total= 6.5 years

(continued on next page)

Table 2 (*continued*)

First author (year)	Participants for whom data on needs are reported n.	Time of needs assessment	Age mean (±SD), median (range), categories (%)	Employed n (%)	Stage of tumor %	Treatment %	Time from diagnosis, completion of active treatment, surgery, or first follow-up mean (±SD) median (range) categories (%)
		to 5 years group 2= survival duration > 5 years	(10.6)group 2= 57.3 (9.6)	73 (46.5)group 2= 71 (37.0)	46.9, 43.5III= 13.4, 13.5, 13.4	72.8RT= 51.4, 3, 47.3HT= 89.4, 21.8, 54.7CT= 63.1, 63.5, 63.3TT= 4.4, 1.6, 2.9	(3.6) group 1= 3.7 years (0.9) group 2= 8.9 years (3.2)
(Hubbard et al., 2015)	44	diagnosis at least 18 months prior	59.1 (10.0)	19 (43.2)	NR	CT= 29.1 HT= 60.0	time from diagnosis: ≤ 18 months= 11.4 %18 moths-5 years= 36.4 %> 5 years= 52.3 %
(Sleight et al., 2018)	99	after completion of primary treatment (S, CT and RT)	54 (8.6)	NR	On 80 respondentsI= 36.3II= 23.8III= 2.5IV= 1.3Unknown= 36.3	S, RT and CT= 49.5 S and RT= 19.2 S and CT= 13.1 S= 13.1 RT= 4.0 CT= 1.0	time from diagnosis: 4.5 years (2.61)
(Cheng et al., 2016)	group 2= 137	group 2= 2–5 years after completion of treatment (S and CT)	56.1 (7.8)	NR	0= 15.3I, II= 73.7III, IV= 10.9	MT= 53.3 CT= 10.2 RT= 24.8 TT= 12.4 HT= 52.6	time from completion of active treatment: 28.9 months (17.8) group 2= 55 %
(Miroševič et al., 2022)	430	1–5 years post-primary treatment	55.5 (12.4)	257 (59.7)	0–1= 20.9 II= 58.6 III=20.5	S= 100.0 CT= 11.6 RT= 39.3 CT+RT=37.9 None= 11.6	time from completion of active treatment: 29.9 months (18.2)
(Lyu et al., 2023)	385	having completed primary treatments within the past 10 years	47.9 (9.9)	NR	0= 6.8 I= 27.5 II= 40.3 III= 25.5	S= 95.6 CT= 87.5 RT= 49.6 HT= 51.7	time from diagnosis: < 2 years= 50.9 % 2–5= 28.3 % >5= 19 %
(Kim and Lee, 2023)	121	within 5 years from completion of the major treatments	46 (7.57)	46 (38)	I= 38.0 II= 43.8 III= 18.2	HT= 65.3 S= 9.9 S+CT=9.1 S+RT= 19.8 S+CT+RT= 61.2	time from completion of active treatment: < 24 months= 73.6 % ≥ 24–60= 26.4 %

S= surgery, MT= mastectomy, AD= axillary dissection, CT= chemotherapy, RT: radiotherapy, HT= hormone therapy, TT= trastuzumab, MTD= molecular targeted drug, FU= follow-up

in the sexuality domain (16.1 (Liao et al., 2012) – 30.2 (Brédart et al., 2013)) Four studies described the prevalence of unmet needs, ranging from 70 % (Oswald et al., 2021) to 95.7 % (Shaikh et al., 2022). Unmet needs in the domains of health system and information (55.5 % (Shaikh et al., 2022) – 93.8 % (Akuoko et al., 2022)), psychological (63 % (Shaikh et al., 2022) – 68.8 % (Akuoko et al., 2022)), and physical and daily living (60.1 % (Shaikh et al., 2022) – 61.9 % (Akuoko et al., 2022)) were the most frequent.

Nine studies assessed the needs of BC survivors after the completion of active treatment (Ahern et al., 2016; Kwan et al., 2019; Bu et al., 2022; So et al., 2014; Abdollahzadeh et al., 2014; Pérez-Fortis et al., 2018; Cheng et al., 2016; Capelan et al., 2017; Burris et al., 2015). On average, needs attributable to the health system and information and to the psychological domains were the highest during this survivorship phase, ranging from 22.9 (Cheng et al., 2016) to 44.4 (Pérez-Fortis et al., 2018) and from 11.9 (Cheng et al., 2016) to 30.3 (Pérez-Fortis et al., 2018) respectively. This was followed by needs in the patient care and support domain (14.8 (Cheng et al., 2016) – 28.5 (Pérez-Fortis et al., 2018)), in the physical and daily living domain (7.7 (Cheng et al., 2016)–24.3 (Pérez-Fortis et al., 2018)), and in the sexuality domain (2.6 (Cheng et al., 2016)–14.3 (Pérez-Fortis et al., 2018)). Seven studies

described the prevalence of unmet needs after treatment completion, ranging from 27.1 % (So et al., 2014) to 69.3 % (Burris et al., 2015). Unmet needs in the domains of sexuality (9.2 % (So et al., 2014) – 72.6 % (Ahern et al., 2016)), healthcare system and information (38.6 % (Ahern et al., 2016) – 70.7 % (Abdollahzadeh et al., 2014)), and physical and daily living (16.9 % (So et al., 2014) – 67.8 % (Abdollahzadeh et al., 2014)) were the most frequent.

Four studies assessed the needs of BC survivors within one year from diagnosis (Barr et al., 2020; Okati-Aliabad et al., 2022; Pérez-Fortis et al., 2018; Jansen et al., 2023). On average, the needs in the health system and information domain ranged from 44.2 (Pérez-Fortis et al., 2018) to 62.7 (Okati-Aliabad et al., 2022), those in the psychological domain ranged from 25 (Pérez-Fortis et al., 2018) to 51 (Okati-Aliabad et al., 2022), those in the patient care and support domain ranged from 26.7 (Pérez-Fortis et al., 2018) to 46.9 (Okati-Aliabad et al., 2022), those in the physical and daily living domain ranged from 24.6 (Pérez-Fortis et al., 2018) to 33.6 (Okati-Aliabad et al., 2022), and those in the sexuality domain ranged from 8.7 (Okati-Aliabad et al., 2022) to 18.6 (Pérez-Fortis et al., 2018). Two studies described the prevalence of unmet needs, ranging from 48.4 % (Jansen et al., 2023) to 88 % (Barr et al., 2020). In the latter study, 68 % of unmet needs were recorded in

Table 3
Extent of needs.

First author (year)	Participants n.	Unmet needs reported as %	Needs reported as mean (±SD) or median (range)	Unmet needs by domains reported as %	Needs by domains reported as mean (±SD) or median (range)
POST-DIAGNOSIS					
(Pérez-Fortis et al., 2018)	group 1= 29 group 2= 70 group 3= 56	NR	NR	NR	**Mean score of needs by groups 1, 2, 3** *standardized Likert summated score (range 0–100)* P 33.8 (29.1), 35.7 (27.6), 34.6 (29.1) HSI 62.1 (32.9), 62.5 (33.4), 62.0 (29.2) PCS 28.8 (23.0), 38.1 (29.4), 47.4 (29.1) PDL 15.5 (22.5), 14.9 (20.6), 19.8 (22.3) Sex 19.0 (27.1), 18.0 (24.7), 14.6 (24.0) additional 40.4 (28.1), 40.6 (30.1), 38.8 (31.4)
(Liao et al., 2012)	T1= 124	NR	**Mean score of needs** *standardized Likert summated score (range 0–100)* Total needs 55.6 (21.7)	NR	**Mean score of needs** *standardized Likert summated score (range 0–100)* P 63.5 (31.5) HSI 75.8 (25.1) PCS 47.9 (27.4) PDL 17.7 (27.1) Sex 31.1 (35.4)
POST-SURGERY					
(Au et al., 2013)	111	NR	NR	NR	**Mean score of unmet needs** *standardized Likert summated score (range 0–100)*P 22.0 (21.5)HSI and PCS 47.9 (24.9) PDL 20.1 (19.43)Sex 3.2 (11.1)
(Zhou et al., 2020)	406	NR	NR	NR	**Mean score of needs importance, needs satisfaction***standardized Likert summated score (range 0–100)*respect/self-esteem needs 76.4 (12.4), 69.7 (12.5)rehabilitation needs 73.6 (13.6), 59.3 (16.1)information needs 71.5 (13.7), 52.6 (16.8)physical needs 65.8 (17.8), 55.9 (17.2)P needs 58.4 (19.6), 51.4 (18.2)
(Pérez-Fortis et al., 2018)	group 1= 29 group 2= 70 group 3= 56	NR	NR	NR	**Mean score of needs by groups 1, 2, 3** *standardized Likert summated score (range 0–100)* P 34.8 (36.0), 31.8 (26.1), 22.1 (23.1) HSI 57.8 (29.9), 60.2 (27.4), 45.0 (28.5) PCS 33.8 (28.9), 32.8 (27.7), 28.4 (23.9) PDL 31.5 (30.1), 35.1 (28.9), 24.1 (21.8) Sex 15.2 (27.5), 20.4 (27.8), 12.3 (20.8) additional 40.7 (27.6), 37.8 (25.7), 28.1 (25.0)
(Liao et al., 2012)	T2= 119	NR	**Mean score of needs by T2** *standardized Likert summated score (range 0–100)* Total needs 43.7 (21.9)	NR	**Mean score of needs at T2** *standardized Likert summated score (range 0–100)* P 46.0 (30.0) HSI 56.8 (29.0) PCS 33.3 (24.0) PDL 34.3 (25.3) Sex 21.1 (25.0)
(Liao et al., 2014)	CG= 40 IG= 40	NR	**Mean score of needs by CG, IG***standardized Likert summated score (range 0–100)*Total needs 52.90 (22.1), 41.4 (19.2)	NR	**Mean score of needs by CG, IG***standardized Likert summated score (range 0–100)*P 54.5 (29), 43.2 (30.4)HSI 67.8 (27.0), 54.5 (23.6) PCS 47.4 (26.9), 29.5 (18.3)PDL 38.8 (27.3), 35.4 (24.5)Sex 25.6 (29.1), 17.5 (22.6)
DURING ACTIVE TREATMENT					
(Brédart et al., 2013)	384	NR	NR	NR	**Mean score of needs**standardized Likert summated score (range 0–100) P 38.5 (24.2), HSI 33.4 (19.2), PCS 26.2 (17.4), PDL 34.5 (23.3), Sex 30.2 (32.4)
(Brédart et al., 2016)	360	NR	NR	NR	**Mean score of needs**standardized Likert summated score (range 0–100) P 36.2 (24.5), HSI 35.0 (18.2), PCS 27.8 (16.6), PDL 31.2 (23.0), Sex 28.0 (31.7)
(Akuoko et al., 2022)	176	84.1	NR	P 68.8 %, HSI 93.8 %, PCS 64.2 %, PDL 61.9 %, Sex 35.2 %	NR
(Mohammadzadeh Nimekari et al., 2019)	150	NR	NR	NR	**Mean score of needs** standardized Likert summated score (range 0–100)P 28.9 (17.3), HSI 30.7 (18.4), PCS 37.9 (32.6), PDL 40.6 (23.5), Sex 23.1 (30.4)
(Shaikh et al., 2022)	total 114	95.7	NR	**(moderate or high unmet needs)**	NR

Table 3 (*continued*)

First author (year)	Participants n.	Unmet needs reported as %	Needs reported as mean (±SD) or median (range)	Unmet needs by domains reported as %	Needs by domains reported as mean (±SD) or median (range)
(Liao et al., 2012)	T3= 115T4= 114	NR	**Mean score of needs by T3, T4** *standardized Likert summated score (range 0–100)* Total needs 33.5 (21.0), 31.6 (21.2)	P 63.0 %, HSI 55.5 %, PDL 60.1 % NR	**Mean score of needs at T3, T4** *standardized Likert summated score (range 0–100)* P 33.9 (27.6), 27.4 (25.5) HSI 41.6 (25.4), 38.3 (25.5) PCS 27.1 (19.4), 29.3 (23.4) PDL 31.1 (27.6), 36.8 (27.2) Sex 17.3 (21.6), 16.1 (24.7)
(Burris et al., 2015)	90	80	**Mean number of needs** *(score range 0–30)* UNMET needs 6.49 (6.70), 4.68 (5.97)	NR	NR
(Oswald et al., 2021)	20	70	**Mean score of unmet needs** Total score was obtained by summing the domain scores (range 0–23)Total mean score 2.8 (3.5)	NR	**Mean number of unmet needs by domains**Domain scores were obtained by summing the individual items for each domaininformation 1.6 (2.2) score range 0–7social 0.3 (0.7) score range 0–2psychological and emotional 0.3 (0.6) score range 0–2material/economic 0.6 (0.8) score range 0–2
AFTER COMPLETION OF ACTIVE TREATMENT					
(Abdollahzadeh et al., 2014)	136	NR	NR	P 62.7 %, HSI 70.7 %, PCS 60.5 %, PDL 67.8 %, Sex 59.1 %	NR
(Ahern et al., 2016)	839	54.5	NR	P 67.5 %, HSI 38.6 %, PCS 41.0 %, PDL 65.5 %, Sex 72.6 %	NR
(Kwan et al., 2019)	187	47	NR	NR	NR
(Bu et al., 2022)	1192	NR	NR	symptom burden 47.7 %, function domain 46.5 %, financial strain 48.5 %health behavior domain 42.8 %, health care-seeking skills domain 55.4 % *	NR
(So et al., 2014)	163	27.1	NR	P 14.8 %, HSI 45.5 %, PCS 32 %, PDL 16.9 %, Sex 9.2 % *	NR
(Pérez-Fortis et al., 2018)	group 2= 70group 3= 56	NR	NR	NR	**Mean score of needs by groups 2, 3** *standardized Likert summated score (range 0–100)* P 30.3 (29.7), 22.7 (22.2) HSI 44.4 (29), 37.3 (21.9) PCS 28.5 (24.5), 24 (19.2) PDL 24.3 (27.4), 22.0 (21.1) Sex 14.3 (24.5), 9.8 (1.8) additional 30.4 (27.0), 22.8 (20.8)
(Cheng et al., 2016)	group 1= 113	52 %	**Mean number of needs** (range 0–23) UNMET needs 3.1 (5.3) **Total mean score of unmet needs** *(range 0–34)* 3.14 (5.3)	NR	**Mean score of needs**standardized Likert summated score (range 0–100)P 15.1 (16.8), HSI 26.1 (15.8), PCS 15.1 (12.8), PDL 9.2 (13.8), Sex 2.1 (5.9)
(Capelan et al., 2017)	625	61	NR	physical 55.0 %, emotional 24.0 %, practical 6.0 %, family 5.0 %, spiritual 4.0 %, loss of faith or other spiritual concern 1.0 %	NR
(Burris et al., 2015)	90	69.3	**Mean number of needs** *(score range 0–30)* UNMET needs 4.68 (5.97)	NR	NR
WITHIN ONE YEAR FROM DIAGNOSIS					
(Barr et al., 2020)	IG= 202	88 (moderate or high)	NR	**(moderate or high unmet needs)** *P 68.0 %, health system 68.0 %, information 61.0 %, PCS 42 %, PDL 63.0 %, peer contacts 64.0 %	NR
(Jansen et al., 2023)	225	48.4 (at least one unmet need)	NR	NR	NR
(Pérez-Fortis et al., 2018)	group 1= 29	NR	NR	NR	**Mean score of needs** *standardized Likert summated score (range 0–100)*

Table 3 (*continued*)

First author (year)	Participants n.	Unmet needs reported as %	Needs reported as mean (±SD) or median (range)	Unmet needs by domains reported as %	Needs by domains reported as mean (±SD) or median (range)
					P 25.0 (27.0) HSI 44.2 (30.1) PCS 26.7 (20.8) PDL 24.6 (24.4) Sex 18.6 (26.3) additional 26.5 (28.9)
(Okati-Aliabad et al., 2022)	group 1= 65	NR	NR	NR	**Mean score of needs** *standardized Likert summated score (range 0–100)* P 51.0 (25.2) HSI 62.7 (21.5) PCS 46.9 (19.2) PDL 33.6 (22.9) Sex 8.7 (23.3)
≥ 1 YEAR FROM DIAGNOSIS					
(Ettridge et al., 2021 Feb)	77	NR	**Mean number of needs** standardized Likert summated score (score range 0–100) 34.9 (26.2)	NR	NR
(Vuksanovic et al., 2021)	130	66.9	**Mean number of needs** (score range 0–35) No need 18.5 (10.4)MET needs 3.4 (4.5)UNMET needs 4.4 (6.3)	NR	NR
(White et al., 2018)	CG= 142	88	NR	NR	NR
(Wang et al., 2018)	264	86.7	NR	NR	**Mean score of needs** standardized Likert summated score (range 0–100)P 37.9 (19.1), HSI 57.0 (28.4), PCS 37.7 (29.8), PDL 28.7 (15.1), Sex 19.3 (18.2)
(Pérez-Fortis et al., 2018)	group 2= 70group 3= 56	NR	NR	NR	**Mean score of needs by groups 2, 3** *standardized Likert summated score (range 0–100)* P 22.6 (21.5), 21.0 (22.9) HSI 40.7 (24.3), 48.7 (34.4) PCS 22.2 (19), 28.0 (23.1) PDL 19.1 (21.4), 19.7 (20.8) Sex 16.9 (25.4), 9.7 (16.8) additional 28.2 (24.2), 25.8 (22.5)
(Cheng et al., 2016)	group 2= 137	47	**Mean number of needs** (range 0–25) UNMET needs 2.2 (4.1) **Total mean score of unmet needs** *(range 0–34)* 2.24 (4.1)	NR	**Mean score of needs** *standardized Likert summated score (range 0–100)*P 9.3 (11.5), HSI 20.3 (15.5), PCS 14.5 (13.9), PDL 6.5 (10.5), Sex 3.0 (9.3)
(Fang et al., 2018)	192	88	**Mean number of needs** (range 0–35) UNMET needs 5.62 (5.1) **Total mean score of needs** (range 0–34) 13.2	NR	**Mean score of unmet needs**ES 1.49 score range 0–13CCC 1.34 score range 0–6Inf 0.90 score range 0–3QoL 0.29 score range 0–2 R 0.21 score range 0–2
(Shih et al., 2020)	total= 349group 1= 157group 2= 192	group 1= 35.5 group 2=30.9	**Mean score of needs** (score range 0–3) unmet needs 0.57 (0.45) (total) unmet needs 0.49 (0.36) (group 1)unmet needs 0.63 (0.50) (group 2)	**By total and group 1, 2**Inf 51.0 %, 53.3 %, 9.1 %, C 46.7 %, 42 %, 50.5 %PPE 20.6 %, 27.6 %, 14.9 %MC 16.2 %, 14.4 %, 17.7 %	**Mean score of unmet needs by total and groups 1, 2**Inf 0.88 (0.69), 0.72 (0.51), 1.01 (0.79) PPE 0.32 (0.42), 0.36 (0.40), 0.28 (0.44) MC 0.28 (0.56), 0.20 (0.46), 0.35 (0.63)C 0.88 (0.84), 0.66 (0.59), 1.06 (0.97)
(Hubbard et al., 2015)	44	68.2	NR	**(moderate or high unmet needs)**P 43.2 %, HSI 43.2 %, PCS 25.0 %, PDL 29.5 %, Sex 9.1 %	NR
(Sleight et al., 2018)	99	93	NR	P 39.2 %, HSI 46.6 %, PCS 38.6 %, PDL 42.0 %, Sex 21.5 %	**Mean score of needs**Domain scores were obtained by summing the individual items for each domain; mean scores (sd) were also calculated for each of the five SCNS SF34 domains by calculating each participant's raw score for each domain and then averaging those scores P 22.1 (10.5) score range 10–50HSI 28.4 (14.8) score range 11–55PCS 11.1 (5.8) score range 5–25PDL 11.5 (6.2) score range 5–25Sex 5.1 (3.3) score range 3–15
(Kim and Lee, 2023)	121	NR	**Mean score of needs** *standardized Likert summated*	NR	**Mean score of unmet needs** *standardized Likert summated score (range*

Table 3 (*continued*)

First author (year)	Participants n.	Unmet needs reported as %	Needs reported as mean (±SD) or median (range)	Unmet needs by domains reported as %	Needs by domains reported as mean (±SD) or median (range)
			score (range 0–100) Total needs 44.2 (19.1)		*0–100)* P 36.4 (23.4) HSI 57.6(24.6) PCS 46.4 (24.7) PDL 33.7 (20.2) Sex 34.7 (28.4)
(Okati-Aliabad et al., 2022)	group 2= 35 group 3= 20	NR	NR	NR	**Mean score of needs by group 2,3** *standardized Likert summated score (range 0–100)* P 53.0 (26.3), 50.2 (27.9) HSI 63.2 (20.1), 65.1 (20.5) PCS 36.3 (19.1), 44.7 (20) PDL 31.8 (21.4), 36.0 (20.5) Sex 5.9 (16.6), 1.6 (7.4)
(Miroševič et al., 2022)	430	67	**Mean number of needs** (range 0–33) MET needs 14.3 (9.6) UNMET needs 4.3 (6.0)	**(high unmet needs)** ES 24.7 %, CCC 44.0 %, P and emotional support 35.3 %, R 13.0 %, Inf 21.2 %	**Mean score of unmet needs** ES 0.61 (1.3) score range 0–7 CCC 1.2 (1.8) score range 0–7 P and emotional support 1.04 (1.9) score range 0–7 R 0.2 (0.6) score range 0–3 Inf 0.4 (0.8) score range 0–3
(Lyu et al., 2023)	385	81.3	NR	**(moderate or high unmet needs)** P 50.9 %, HSI 44.9 %, PCS 39.7 %, PDL 36.8 %, Sex 14.8 %	NR

SCNS-SF34 and compatible versions= HSI: health system and information, P: psychological, PCS: patient care and support, PDL: physical and daily living, Sex: Sexuality

CaSUN= ES: Existential Survivorship, CCC: Comprehensive Cancer Care, Inf: Information, QoL: Quality of Life, R: Relationship

NR= not reported in the study

* the domain Health system and information of the SCNS-SF34 was reported by two separated domains

the psychological and health system domains, followed by the physical and daily living domain (63 %), information domain (61 %), and patient care and support domain (42 %).

Fourteen studies assessed the needs of BC survivors one year or more from diagnosis (Cheng et al., 2016; Ettridge et al., 2021; Fang et al., 2018; Hubbard et al., 2015; Kim and Lee, 2023; Lyu et al., 2023; Miroševič et al., 2022; Okati-Aliabad et al., 2022; Pérez-Fortis et al., 2018; Shih et al., 2020; Sleight et al., 2018; Vuksanovic et al., 2021; Wang et al., 2018; White et al., 2018). The average needs score was 44.2 (Kim and Lee, 2023). On average, needs in the healthcare system and information domain remained of priority, averaging from 20.3 (Cheng et al., 2016) to 65.1 (Okati-Aliabad et al., 2022). Needs in the
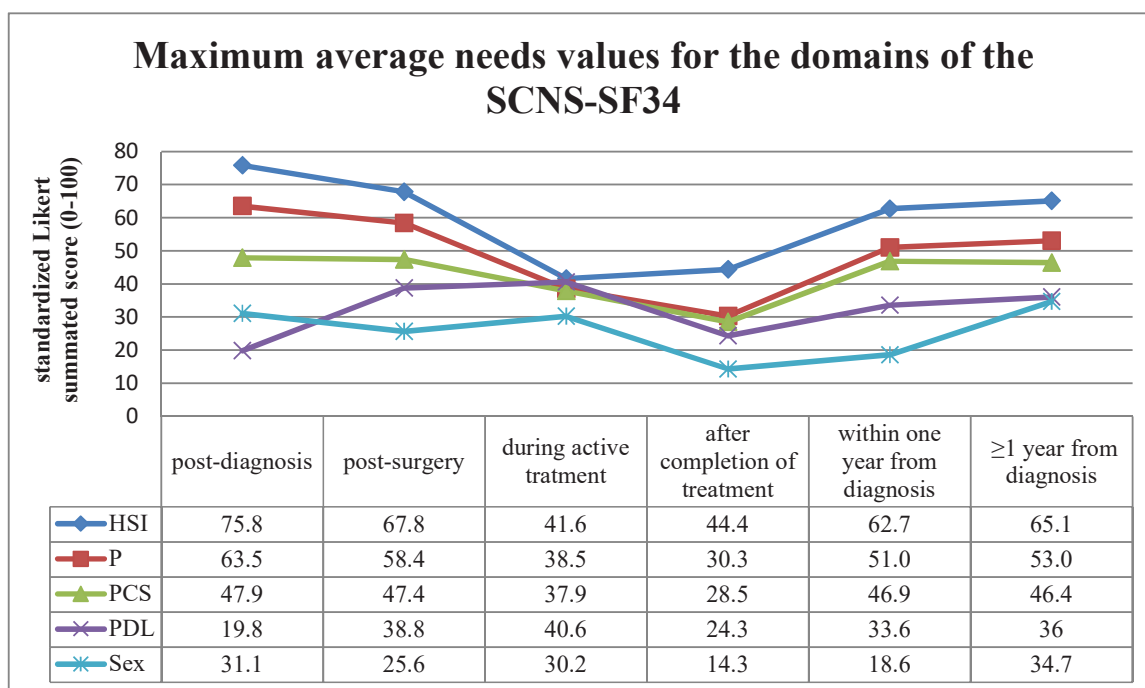

Fig. 2. Maximum average needs values for the domains of the SCNS-SF34 throughout the survivorship phases. HSI: health system and informatio, P: psychological, PCS: patient care and support, PDL: physical and daily living, Sex: Sexuality.
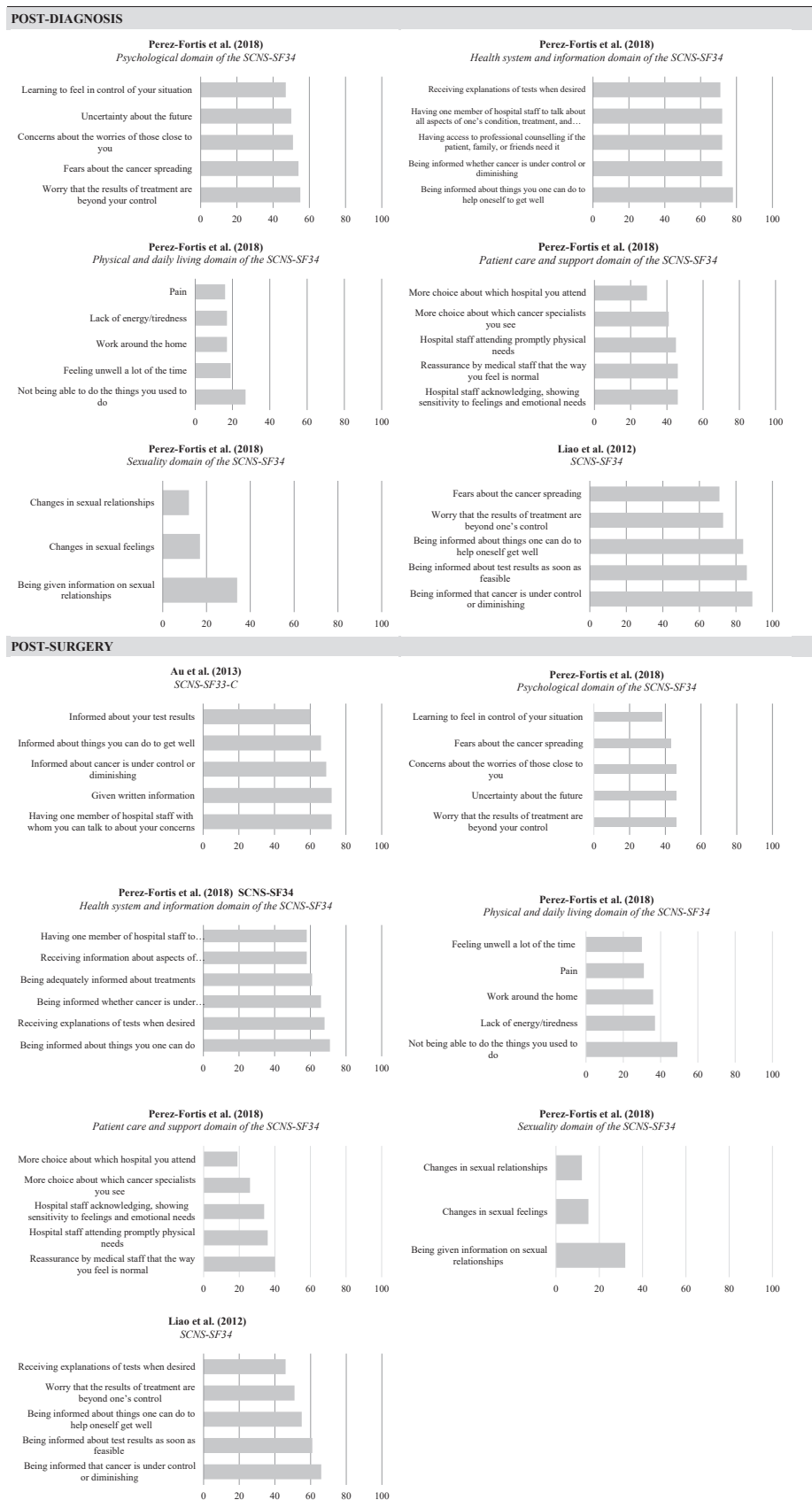
Fig. 3. Percentages of the top five unmet needs reported by survivorship care phases.
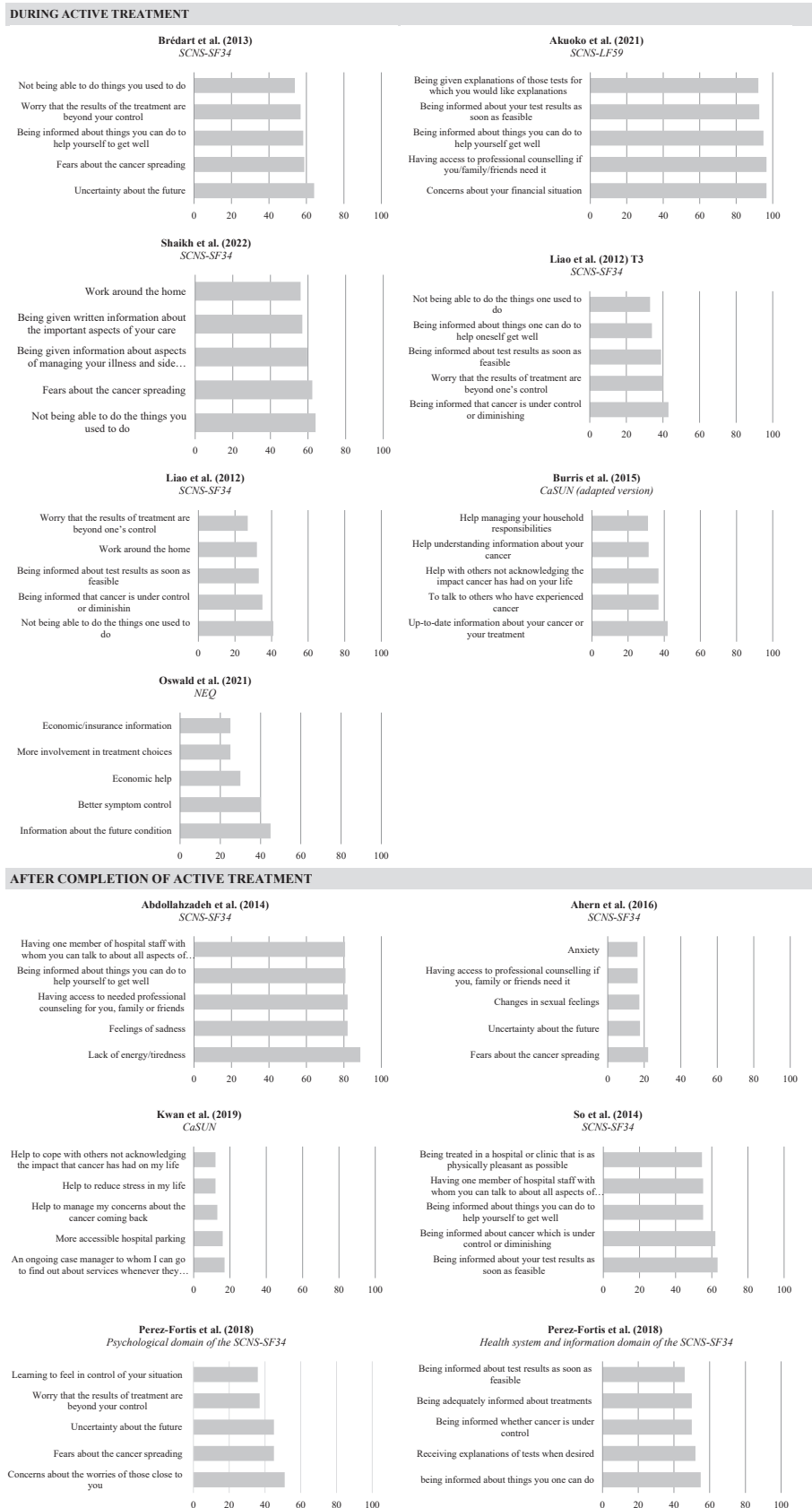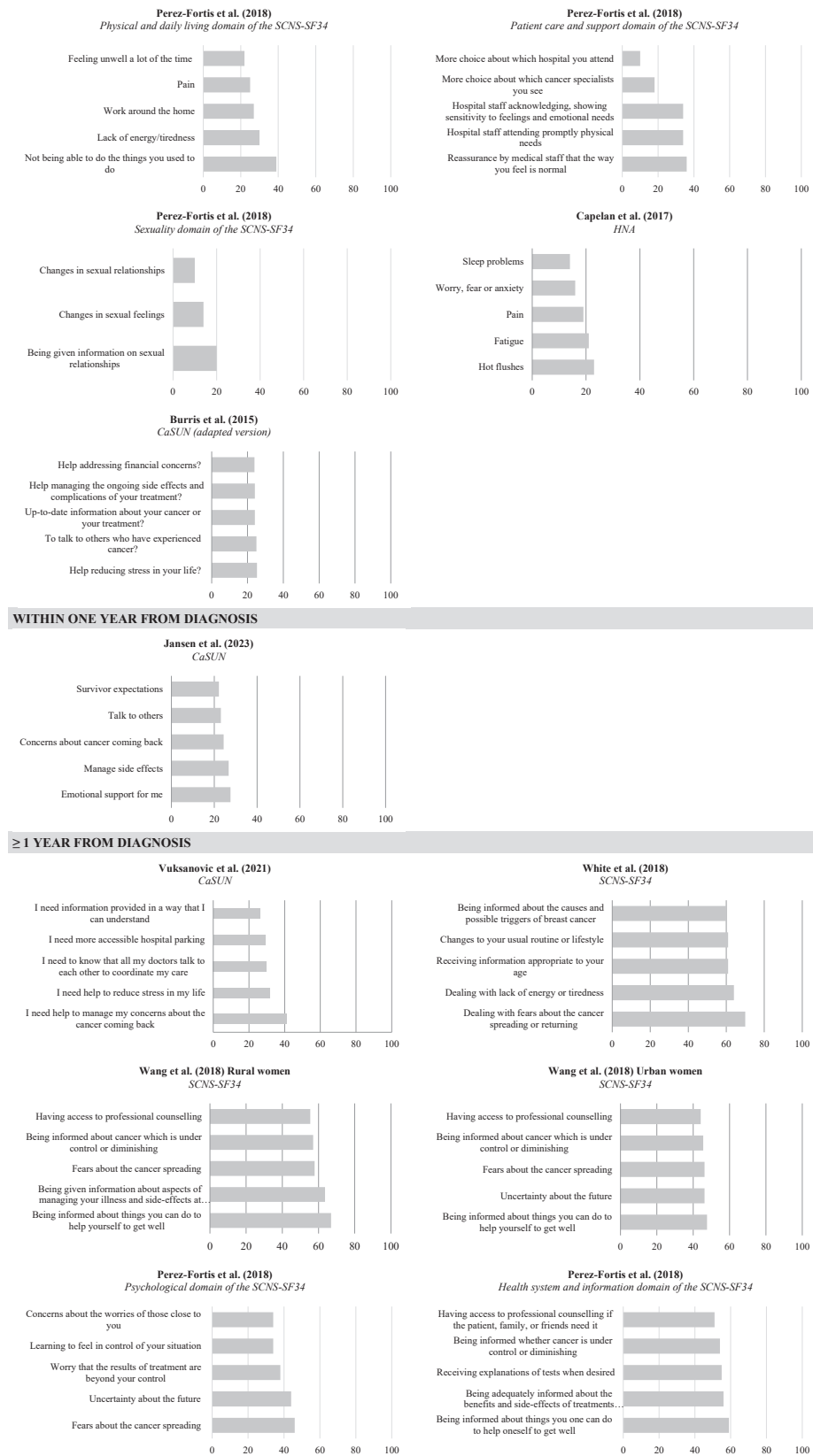
DURING ACTIVE TREATMENT

AFTER COMPLETION OF ACTIVE TREATMENT

Fig. 3. (*continued*).

Perez-Fortis et al. (2018)
Physical and daily living domain of the SCNS-SF34

Perez-Fortis et al. (2018)
Patient care and support domain of the SCNS-SF34

Perez-Fortis et al. (2018)
Sexuality domain of the SCNS-SF34

Capelan et al. (2017)
HNA

Burris et al. (2015)
CaSUN (adapted version)

WITHIN ONE YEAR FROM DIAGNOSIS

Jansen et al. (2023)
CaSUN

≥ 1 YEAR FROM DIAGNOSIS

Vuksanovic et al. (2021)
CaSUN

White et al. (2018)
SCNS-SF34

Wang et al. (2018) Rural women
SCNS-SF34

Wang et al. (2018) Urban women
SCNS-SF34

Perez-Fortis et al. (2018)
Psychological domain of the SCNS-SF34

Perez-Fortis et al. (2018)
Health system and information domain of the SCNS-SF34

Fig. 3. (*continued*).

psychological and patient care and support domains ranged from 9.3 (Cheng et al., 2016) to 53 (Okati-Aliabad et al., 2022) and from 14.5 (Cheng et al., 2016) to 46.4 (Kim and Lee, 2023), respectively. These were followed by needs in the physical and daily living domain (6.5 (Cheng et al., 2016) - 36 (Okati-Aliabad et al., 2022)) and in the sexuality domain (3.0 (Cheng et al., 2016) - 34.7 (Kim and Lee, 2023)). Ten
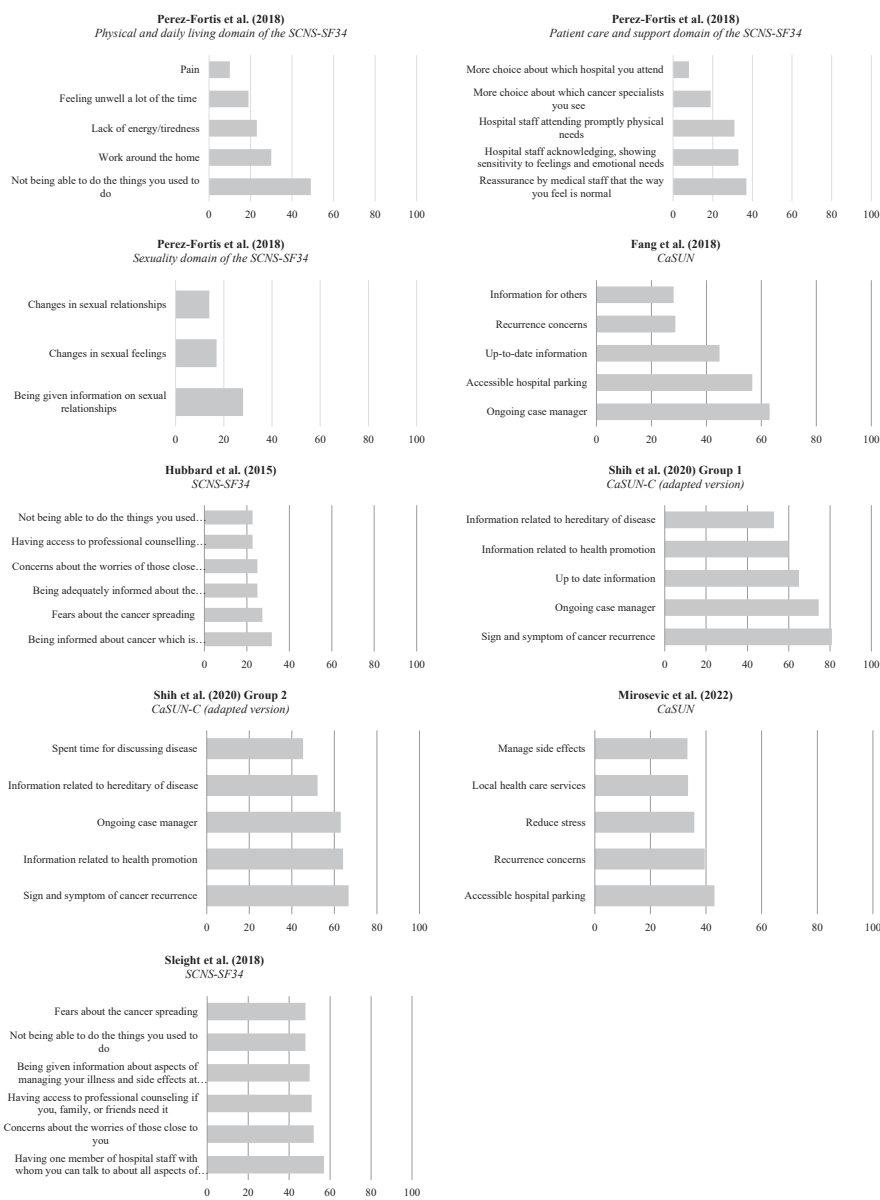
Fig. 3. (*continued*).

of these studies described the prevalence of unmet needs, which ranged from 30.9 % (Shih et al., 2020) to 93 % (Sleight et al., 2018), where the psychological domain was 50.9 (Lyu et al., 2023), healthcare system and information domain was 46.6 % (Sleight et al., 2018), followed by the physical and daily living domain (42 %) (Sleight et al., 2018), the patient care and support domain (39.7 %) (Lyu et al., 2023), and the sexuality domain (21.5 %) (Sleight et al., 2018).

Fig. 2 shows the maximum average needs values for the domains of the SCNS-SF34 throughout the survivorship care phases. After diagnosis, needs in the health system and information domain were higher than needs expressed in the other domains. The trends of the former decreased up to the active treatment phase, then increased again slightly through the completion of treatment and onwards. A similar trend was found in the needs in the psychological and the patient care and support domains, while needs in the sexuality and in the physical and daily living domains were expressed to a lesser extent at diagnosis and peaked during active treatment. Of note, compared to the previous survivorship phase, there was an increase in the needs perceived in all domains of the SCNS-SF34 one year or more after diagnosis.

3.5. Top five unmet needs by survivorship phase

Fig. 3 illustrates the top five unmet needs as described by 22 studies, while the complete list of items defined as unmet needs are reported in supplementary material F, with percentages (Ahern et al., 2016; Vuksanovic et al., 2021; White et al., 2018; Kwan et al., 2019; Au et al., 2013; So et al., 2014; Wang et al., 2018; Brédart et al., 2013; Akuoko et al., 2022; Abdollahzadeh et al., 2014; Shaikh et al., 2022; Pérez-Fortis et al., 2018; Miroševič et al., 2022; Fang et al., 2018; Liao et al., 2012; Shih et al., 2020; Jansen et al., 2023; Capelan et al., 2017; Hubbard et al., 2015; Burris et al., 2015; Oswald et al., 2021; Sleight et al., 2018). Post-diagnosis, unmet needs mainly concerned "being informed that cancer is under control or diminishing" (Liao et al., 2012), "being informed about test results as soon as feasible" (Liao et al., 2012), and "being informed about things one can do to help oneself to get well" (Liao et al., 2012). Post-surgery, unmet needs mainly concerned "having one member of hospital staff with whom you can talk to about your concerns" (Au et al., 2013), "given written information" (Au et al., 2013), and "being informed about things one can do to help oneself to

get well" (Pérez-Fortis et al., 2018). During active treatment, unmet needs mainly involved "concerns about your financial situation" (Akuoko et al., 2022), "having access to professional counselling if you/family/friends need it" (Akuoko et al., 2022), and "being informed about things one can do to help oneself to get well" (Akuoko et al., 2022). After completion of active treatment, unmet needs mainly concerned "lack of energy" (Abdollahzadeh et al., 2014), "feelings of sadness" (Abdollahzadeh et al., 2014), and "having access to needed professional counseling for you, family or friends" (Abdollahzadeh et al., 2014). Within one year from diagnosis, unmet needs mainly concerned "emotional support", "manage side effects", and "concerns about cancer coming back" (Jansen et al., 2023). One year or later, unmet needs mainly concerned "sign and symptoms of cancer recurrence" (Shih et al., 2020), "ongoing case manager" (Fang et al., 2018; Shih et al., 2020), "up to date information/information related to health promotion" (Shih et al., 2020), "dealing with fears of cancer spreading" (White et al., 2018), "dealing with lack of energy" (White et al., 2018), "up-to-date information" (Shih et al., 2020), and "being informed about things one can do to help oneself to get well" (Wang et al., 2018).

3.6. Factors associated with the perception of unmet needs

Table 4 reports the factors associated with the perception of unmet needs as reported by 17 studies (Ahern et al., 2016; Vuksanovic et al., 2021; Bu et al., 2022; Wang et al., 2018; Abdollahzadeh et al., 2014; Okati-Aliabad et al., 2022; Shaikh et al., 2022; Kim and Lee, 2023; Fong and Cheah, 2017; Miroševič et al., 2022; Fang et al., 2018; Liao et al., 2012; Shih et al., 2020; Capelan et al., 2017; Hubbard et al., 2015; Burris et al., 2015; Sleight et al., 2018). Among personal factors, younger age seemed to be positively associated with the occurrence of unmet needs in a wide range of domains (Abdollahzadeh et al., 2014; Liao et al., 2012; Burris et al., 2015), including those of existential survivorship and quality of life (Vuksanovic et al., 2021) and symptom burden and financial strain (Bu et al., 2022). Regarding factors related to health status, the physical and psychological side effects of treatments (Kim and Lee, 2023; Miroševič et al., 2022; Liao et al., 2012; Shih et al., 2020; Burris et al., 2015), the number of comorbidities (Sleight et al., 2018), and the fear of cancer recurrence (Fang et al., 2018; Shih et al., 2020) were positively associated with the occurrence of unmet needs. Moreover, an early phase of cancer survivorship (≤12 months from diagnosis) seemed to be associated with the onset of unmet needs in the symptom burden domain (Bu et al., 2022), while the recurrence of disease seemed to be associated with the onset of unmet needs in the domain of patient care and support (Hubbard et al., 2015).

As for cancer-related factors, receiving hormone therapy and/or chemotherapy and having advanced stage disease seemed to be associated with the occurrence of overall unmet needs (Wang et al., 2018; Capelan et al., 2017). The worsening of the disease affected all the domains of the SCNS-SF34 (Shaikh et al., 2022). Finally, among environmental factors, the lack of BC care services seemed to be associated with the occurrence of having unmet needs in the health system and information, psychological, and patient care and support domains of the SCNS-SF34 (Ahern et al., 2016).

4. Discussion

This systematic review provides an updated understanding of the needs BC survivors perceive and describes the extent of needs, the prevalence of unmet needs, and the factors associated with the perception of unmet needs throughout the phases of survivorship. Of note, most BC survivors in the studies included had completed their primary treatment. This updated evidence suggests that needs in the health system and information domain and in the psychological domain are paramount, particularly after diagnosis, and needs in the domain of physical and daily living increase during active treatment. In the previous systematic review, conducted a decade ago by Fiszer et al (Fiszer

et al., 2014)., although the needs examined were collected on BC survivors in different survivorship phases, most were collected during active treatment. Most of the reported needs involved the information and psychological domains, with the fear of cancer recurrence being a primary concern. As regards their trends, the needs in these two domains seemed to decrease over time, while needs in the domain of physical and daily living seemed to increase. Similarly to the updated review, advanced stage disease, greater symptom burden, shorter time from diagnosis, higher levels of distress, and younger age seemed to be factors associated with higher levels of perceived needs.

Our results indicate that the extent of BC survivors' needs changes from diagnosis onwards. Consistently with previous findings (Fiszer et al., 2014), our results indicate that there were higher levels of perceived needs in the health system and information and psychological domains for BC survivors post-diagnosis (Pérez-Fortis et al., 2018; Liao et al., 2012), when it is likely that the most prominent worries and necessities of individuals regard information about prognosis, future treatments, and the consequences of cancer. Conversely, the needs in the domain of physical and daily living, which are not a major concern after diagnosis, peak during the active treatment phase, probably due to the side effects of cancer treatment (i.e., pain, fatigue), which pose several limitations on performing activities of daily living (Loubani et al., 2022) and, consequently, worsen general health and quality of life (Hamer et al., 2017). The needs in the domain of sexuality represented a minor concern throughout the survivorship phases. This result is difficult to interpret, as it may depend on the willingness of individuals to discuss this topic with a healthcare professional, and vice versa. As a matter of fact, in The Netherlands, 41.2 % of BC survivors do not seek information regarding sexuality (Den Ouden et al., 2019). Of note, this systematic review highlights that a specific need for rehabilitation was reported only by one study, which included Chinese BC survivors within six months after surgery and undergoing chemotherapy (Zhou et al., 2020). These rehabilitation needs extended far beyond the comorbidities which affect the upper limb after BC surgery (Levy et al., 2012; Doege et al., 2022) (lymphedema, axillary web syndrome, mobility limitations) and pertained to the individuals coping with the disease and the whole recovery process. Thus, a broader perspective on rehabilitation needs, which encompasses the physical, mental and social consequences that might arise in this population, should be adopted, as described in a recent scoping review on BC survivorship care (Pinto et al., 2022). Our updated systematic review shows that the needs in all domains increased during the long-term survivorship phase (≥ 1 year from diagnosis). This finding is slightly different from that of Harrison et al., who stated that most cancer survivors reported unmet needs in the early post-treatment phase. Our results show that the needs of BC survivors were not as intense in the early post-treatment phase as in the following phases; this may emphasize that the type of cancer diagnosis can pose some differences in the perception of needs. If the increasing trend of needs one year or more after diagnosis can be explained by the progressive separation from the hospital setting and from healthcare professionals, which could lead to BC survivors' feelings of abandonment (Tompkins et al., 2016), it must be acknowledged that this population often undergoes treatments that last several years, such as hormone therapy, whose side effects may impact the ability to perform activities of daily living, employment, and social roles (Rosenberg et al., 2022). Furthermore, the increasing trend occurring approximately within one year from diagnosis may also be driven by the availability of data, as only two studies categorized as regarding this phase described the needs of BC survivors by reporting their average values (Okati-Aliabad et al., 2022; Pérez-Fortis et al., 2018). In addition, the highest average values in the long-term survivorship phase (≥ 1 year from diagnosis) in the psychological, healthcare system and information, and physical and daily living domains of the SCNS-SF34 were retrieved in the Iranian study by Okati-Aliabad (Okati-Aliabad et al., 2022). Thus, the latter study could have influenced the trajectory of needs in these specific segments of survivorship.

Information needs were frequently reported by BC survivors, not

Table 4
Factors associated with the perception of unmet needs by type of assessment tool and unmet needs (overall risk of having unmet needs or having unmet needs in specific domains).

SCNS-SF34 or compatible versionsDomains= HSI: health system and information, P: psychological, PCS: patient care and support, PDL: physical and daily living, Sex: sexuality

Type of factors	Total unmet needs*	HSI	P	PCS	PDL	Sex
demographic	younger age (Liao et al., 2012; Burris et al., 2015) higher education level (Liao et al., 2012) lower education level and living in rural areas (Wang et al., 2018)	living in major cities, specific item "being treated in a hospital or clinic that was as physically pleasant as possible" (Ahern et al., 2016) younger age (Abdollahzadeh et al., 2014)	younger age (Abdollahzadeh et al., 2014) lower education level and living in rural areas (Shaikh et al., 2022)	living in remote areas, specific item "which healthcare service/ hospital they attended" (Ahern et al., 2016) younger age and number of children (Abdollahzadeh et al., 2014)	younger age (Abdollahzadeh et al., 2014) lower education level (Okati-Aliabad et al., 2022; Shaikh et al., 2022) living in rural areas and having no internet access (Shaikh et al., 2022)	Younger age and being married (Abdollahzadeh et al., 2014) lower education level and being in perimenopause (Shaikh et al., 2022) being married (Shaikh et al., 2022)
general health condition	higher anxiety and severe symptoms distress (Liao et al., 2012) (*changes in Supportive Care Needs*) greater symptoms severity and interference (Burris et al., 2015) higher number of comorbidities (Sleight et al., 2018) physical and depressive symptoms (Shih et al., 2020) fear of cancer recurrence (Shih et al., 2020) physical symptoms and anxiety (Kim and Lee, 2023) (*Supportive care needs*)					
time from diagnosis	shorter time (Liao et al., 2012) (*changes in Supportive Care Needs*)	≤5 years (Hubbard et al., 2015)		Recurrence (Hubbard et al., 2015)		
Cancer-related	hormone therapy (Capelan et al., 2017) chemotherapy (Capelan et al., 2017) advanced stage of disease (Wang et al., 2018)	metastatic disease (Shaikh et al., 2022) worsening disease (Shaikh et al., 2022) chemotherapy (Shaikh et al., 2022) life expectancy ≥ of 6 months (Shaikh et al., 2022)	worsening disease (Shaikh et al., 2022) chemotherapy (Shaikh et al., 2022) life expectancy ≥ of 6 months (Shaikh et al., 2022)	worsening disease (Shaikh et al., 2022) life expectancy ≥ of 6 months (Shaikh et al., 2022; Fong and Cheah, 2017)	worsening disease (Shaikh et al., 2022) life expectancy ≥ of 6 months (Shaikh et al., 2022)	stable disease (Shaikh et al., 2022) stage I-II (Okati-Aliabad et al., 2022)
BC care services		(not using) breast cancer care services (Ahern et al., 2016)	(not using) breast cancer care services (Ahern et al., 2016)	(not using) breast cancer care services (Ahern et al., 2016)		

CSPro-BC
Domains= SB: Symptom burden, HC: Health care–seeking skills, F: function, HB: Health behavior, FS: financial strain

Type of factors	Total unmet needs*	SB	HC	F	HB	FS
demographic		younger age lower income heavy physical activities having a master's degree city group being a worker or farmer being employed and not receiving treatment (Bu et al., 2022)	lower income heavy physical activities having a master's degree city group being employed and not receiving treatment (Bu et al., 2022)	younger age lower income heavy physical activities high school/ technical-secondary school being employed and not receiving treatment (Bu et al., 2022)	younger age lower income heavy physical activities high school/ technical-secondary school city group being a worker or farmer being employed and not receiving treatment (Bu et al., 2022)	younger age lower income heavy physical activities high school/ technical-secondary school being unemployed and had rural cooperative medical insurance (Bu et al., 2022)
general health condition		having severe pain (Bu et al., 2022)	having severe pain (Bu et al., 2022)	having severe pain (Bu et al., 2022)	having severe pain (Bu et al., 2022)	having severe pain (Bu et al., 2022)
time from diagnosis		≤12 months (Bu et al., 2022)	> 61 months (Bu et al., 2022)	≤12 months (Bu et al., 2022)	≤12 months (Bu et al., 2022)	> 61 months (Bu et al., 2022)

(*continued on next page*)

Table 4 (*continued*)

| Cancer-related | | | stage IV and family history of cancer received multimodal treatment (surgery, chemotherapy, radiation therapy, and hormone therapy) Bu et al., (2022) | stage IV and family history of cancer(Bu et al., 2022) | stage IV and family history of cancer received multimodal treatment (surgery, chemotherapy, radiation therapy, and hormone therapy) (Bu et al., 2022) | | | | | stage IV and family history of cancer received multimodal treatment (surgery, chemotherapy, radiation therapy, and hormone therapy) (Bu et al., 2022) |

BC care services

CaSUN

Domains= ES: Existential Survivorship, CCC: Comprehensive Cancer Care, Inf: Information, QoL: Quality of Life, R: Relationship

CaSUN-C adapted version

Domains= Inf: Information, PPE: Physical/Psychological effect, MC: Medical Care, C: Communication

Type of factors	Total unmet needs*	ES	CCC	Inf	QoL	Rel.	Inf	PPE	MC	C
demographic	single or divorced (Mirošević et al., 2022) half time employed (Mirošević et al., 2022)	younger age, specific items "stress", "employment" and "decision making" (Bu et al., 2022)	disabled retired (Mirošević et al., 2022)		younger age, specific item "quality of life" (Vuksanovic et al., 2021)					
general health condition	higher number of symptoms (Fang et al., 2018) anxiety and depression (Mirošević et al., 2022) higher fear of cancer recurrence (Mirošević et al., 2022; Fang et al., 2018)	higher number of symptoms, higher fear of cancer recurrence, higher depression (Fang et al., 2018)	higher number of symptoms, anxiety and depression (Mirošević et al., 2022) higher fear of cancer recurrence, higher depression (Mirošević et al., 2022; Fang et al., 2018)	higher number of symptoms, higher fear of cancer recurrence, higher depression (Fang et al., 2018)	higher number of symptoms, higher fear of cancer recurrence (Fang et al., 2018)	higher fear of cancer recurrence, higher depression (Fang et al., 2018)	physical symptoms depressive symptoms fear of cancer recurrence (Shih et al., 2020)	physical symptoms depressive symptoms fear of cancer recurrence (Shih et al., 2020)	physical symptoms depressive symptoms fear of cancer recurrence (Shih et al., 2020)	physical symptoms depressive symptoms (not significant in the survival stage class < 5 years) fear of cancer recurrence (Shih et al., 2020)
time from diagnosis										
Cancer-related			hormone therapy (Mirošević et al., 2022)	hormone therapy (Fang et al., 2018)						
BC care services										

SCNS-SF34 or compatible versions

Domains= HSI: health system and information, P: psychological, PCS: patient care and support, PDL: physical and daily living, Sex: sexuality

* overall risk of having unmet needs (total needs, more unmet needs, changes in supportive care needs)

* overall risk of having unmet needs (total needs, more unmet needs, changes in supportive care needs)

only after surgery (Pérez-Fortis et al., 2018; Liao et al., 2012) or during active treatment (Brédart et al., 2013; Akuoko et al., 2022), but also 1 year or more after diagnosis (Wang et al., 2018; Pérez-Fortis et al., 2018). This suggests that BC survivors need to receive tailored information and professional counselling throughout the recovery pathway, even years after diagnosis, regarding available health services and/or self-management techniques that may help to deal with the long-term and late side effects of treatment. Therefore, data may reflect that BC survivors perceive a gap in the provision of care, regardless of the country of origin, healthcare systems, and the survivorship care plan adopted, as confirmed by other studies (León-Salas et al., 2022).

As for factors associated with the perception of unmet needs, this review confirms that these factors are younger age, having treatment-related physical or psychological side effects, and advanced stage disease (Fiszer et al., 2014). With regards to age, younger BC survivors may perceive more unmet needs than do older cancer survivor as their daily lives may be more affected following diagnosis; younger individuals are more likely to be employed, may have children to care for, and there may therefore be more severe psychological and physical repercussions (Burg et al., 2015). The influence of physical and psychological side effects was also detected by Penedo et al., who found that higher levels of anxiety and depression and poorer physical function were related to a

greater perception of unmet needs (Penedo et al., 2023).

Our results also show that cancer treatment can result in the perception of unmet needs, since chemotherapy and hormone therapy seemed to be associated with the highest level of perceived unmet needs (Capelan et al., 2017). As for chemotherapy, despite its side effects, this treatment forces individuals to have frequent contacts with healthcare professionals, which allows for the timely management of the most urgent needs, such as symptom control. As for hormone therapy, its side effects may arise later in the care pathway; they may be unexpected and may require more care and support (Yamamoto et al., 2016). Finally, this review found that advanced stage disease is associated with a high frequency of unmet needs, an association confirmed by previous findings (Fiszer et al., 2014).

As for practical suggestions, our findings suggest that healthcare providers should acknowledge the complexity of BC survivors' needs, which may involve coping with the disease and its long-term consequences as well as returning to a normal life, participating in social activities, discussing financial matters, taking care of family members, and addressing end-of-life issues. Furthermore, specific needs may be more pressing at specific times of the care pathway. Therefore, healthcare providers could pose needs-related questions based on the survivorship phase. For example, based on the findings of this review, psychological aspects should be systematically investigated early after diagnosis, while physical and daily living needs should be examined mainly during active treatment. Instead, information needs should be continuously investigated. Considering the factors associated with the perception of unmet needs, healthcare providers should pay attention to needs when they care for vulnerable individuals (e.g., those who are in an advanced stage of disease). However, this approach should be carefully evaluated in each context as the investigation of needs could lead patients to ask in-depth questions about their own as well as how to satisfy them. It is therefore advisable to promptly map the services available at the hospital and in the local area, in order to provide a suitable answer.

As for research, future studies should aim to implement evidence based-models of care for BC survivors by describing not only the type of needs of this population but also the methods and timing of collection of needs as well as how to address each need. Engaging patients in this process is also recommend (Womack et al., 2022). Furthermore, primary studies should be promoted in those countries that have not yet produced evidence regarding BC survivors' needs. Finally, in order to facilitate the comparison of data, we suggest that future research use the classification of the survivorship phase applied in this systematic review or other classifications that also consider the long-term survivorship phases to collect data on the needs of BC survivors.

This study presents both some strengths and limitations. One limitation was that, because of the considerable heterogeneity of the assessment tools used in the included primary studies to collect the needs of BC survivors and the scoring system they used, we were not able to analyze the data from these primary studies. However, we included studies that assessed needs through validated tools (Contri et al., 2023) and, thanks to the inclusion of longitudinal study designs, a prospective description of the trends of those needs over time was possible. Furthermore, we included studies regardless of the country of origin, the time from diagnosis, the stage of disease, and type of treatment to broaden the understanding of the needs of BC survivors, which would in turn support the implementation of evidence-based models of care for this target population. Thus, this systematic review presents an updated description of the perceived needs of BC survivors. This is in line with the ESMO expert consensus statements on cancer survivorship, which suggest reaching a better understanding of cancer survivors' needs by paying particular attention also to the management of the physical, psychological, social, work-related, and financial side effects of cancer in order to provide good quality survivorship care (Vaz-Luis et al., 2022).

To summarize our major findings, health system and information needs were a major concern post-diagnosis, while physical and daily living needs were particularly pressing during active treatment, and needs in all domains increased in the late survivorship phase. In all phases, the most represented one concerned information and professional advice on how to feel better.

Information needs are explicitly cited in the ASCO Breast Cancer Survivorship guidelines (Runowicz et al., 2016), which provide recommendations regarding the management of surveillance and BC recurrence, physical and psychosocial side effects, health promotion, and care coordination. However, the ASCO Breast Cancer Survivorship guidelines do not specify the timing of needs assessment nor the type of support that should be provided. This review describes the extent of needs of BC survivors during all the phases of survivorship; our findings may therefore contribute to the implementation of survivorship care plans for BC survivors. Since perceived needs change over the course of the cancer experience, knowing when to assess what is crucial.

Author contributions

SP: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing-original draft; S. Ca: Formal analysis, Writing-review & editing; AC: Investigation; MCB: Investigation; FB: Supervision, Writing-review & editing; MS: Writing-review & editing; SF: Writing-review & editing; MG: Writing-review & editing; S. Co: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Supervision, Writing-review & editing.

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Declaration of Competing Interest

All authors declare no conflict of interest.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.critrevonc.2024.104432.

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