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REVIEW

The Information Needs of Breast Cancer Patients at All Stages of Their Journey: A Scoping Review

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Background: Breast cancer is the most commonly diagnosed cancer and the leading cause of cancer-related mortality among women worldwide. Adequate and timely information is essential to reduce anxiety, uncertainty, and psychological distress among breast cancer patients. However, many women report dissatisfaction with the information they receive, and evidence addressing patients' information needs across the entire disease continuum remains limited.

Purpose: This scoping review aimed to synthesize evidence of the information needs among breast cancer patients across different phases of the cancer continuum, from diagnosis to post-treatment survivorship.

Methods: A scoping review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). Studies were identified through systematic searches of EBSCOhost, PubMed, Scopus, ScienceDirect, and Taylor & Francis, supplemented by Google Scholar searches, reference list screening, and expert network recommendations. Study selection followed the Population–Concept–Context (PCC) framework, focusing on women with breast cancer, information needs, and stages of the cancer continuum.

Results: Forty eligible studies were included. Four major themes of informational needs were identified across the disease trajectory. In the diagnostic phase, patients primarily sought information on disease characteristics, prognosis, treatment options, and emotional support. During treatment, information needs focused on treatment management, self-care, lifestyle modification, and psychosocial support. In the post-treatment and survivorship phase, patients emphasized long-term follow-up, recurrence prevention, and quality-of-life issues. Across all phases, patients preferred trusted healthcare professionals and multimodal information delivery formats.

Conclusion: Breast cancer patients have diverse and evolving information needs throughout the cancer continuum. Addressing these needs through structured, culturally sensitive, and patient-centered information strategies is essential to reduce anxiety, support informed decision-making, and improve quality of care.

Keywords: breast cancer patients, health information, the information needs

Introduction

Breast cancer is the most commonly diagnosed cancer and the leading cause of cancer-related death among women in most countries worldwide.[1] In 2022, an estimated 2.3 million women worldwide diagnosed with breast cancer, resulting in 670,000 deaths.[1] Women diagnosed with breast cancer usually experience a grieving process such as fear, denial, vulnerability, and uncomfortable psychosocial status.[2] Providing adequate information needed by patients can reduce anxiety and feelings of insecurity.[3] However, 96% of women with breast cancer stated that the information obtained was unsatisfactory.[4] In general, oncology patient dissatisfaction is related to communication problems with doctors and lack of information received about their disease.[5]

Currently, the standard of care for breast cancer varies based on the stage of the disease, classified as early, advanced, or metastatic. For patients with early-stage breast cancer, surgery is usually recommended, which may involve breast-conserving surgery or mastectomy. This choice depends on factors such as tumor size, breast size, and patient

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preference.[6] Early postoperative complications can include wound infection, bleeding, seroma formation, hematoma, and flap necrosis.[7,8] Late-stage complications include shoulder stiffness, brachial plexopathy, and psychosocial problems.[8]

Basic information about breast cancer stages and clinical manifestations is essential. In addition to understanding the cancer itself, knowing the advantages and disadvantages of recommended treatment options plays an important role in decision-making and treatment adherence.[9] It is important for nurses to understand these needs to help patients manage their illness, treatment, and side effects, thereby improving their quality of life and helping reduce levels of depression and anxiety.[10]

Specific information needs for breast cancer patients have been studied using the framework proposed by Galloway et al (1997), which includes five main domains: disease, diagnosis, treatment, physical aspects, and psychosocial aspects.[11] Furthermore, the literature indicates that information provision to women with breast cancer has primarily been examined within specific clinical contexts, such as adjuvant therapy,[6] chemotherapy,[10] and outpatient follow-up.[12] However, there remains limited research addressing comprehensive information needs across all stages of the breast cancer trajectory. Scoping review of studies is needed to map the breadth of available knowledge regarding information needs of women with breast cancer at all stages. This review aims to understand the breadth of existing literature, identify the comprehensive information needs of breast cancer patients related to bio, psycho, socio and spiritual at all stages of the disease's journey from diagnosis, treatment, post-treatment (survivorship), to palliative care, and highlight gaps in current research as consideration studies for further research.

Materials and Methods

Study Design

This scoping review followed framework of Arksey and O'Malley (2005), which consists of six stages: (1) defining the research question; (2) identifying relevant literature; (3) selecting studies based on inclusion and exclusion criteria; (4) mapping the data; (5) collecting, summarizing, and reporting the results; and (6) providing consultation exercises. The review process is reported using the Optional Reporting Items for Systematic Reviews and Scoping Reviews of Meta-Analyses (PRISMA-ScR) checklist.[13] This scoping review protocol has been published previously.[14]

Defining the Research Question

The scoping review question was developed to address the review objectives using the Population/Concept/Context (PCC) framework. The population was patients with breast cancer and the concept was information needs in the context of the disease course across stages. The review questions included the following: (1) what information do breast cancer patients need? (2) What factors influence information needs? (3) sources or educational techniques to meet the information needs of breast cancer patients.

Identifying the Relevant Literature

A research assistant assisted in the development of the search strategy to ensure the completeness of the literature search. The results of the literature search were downloaded and imported into the Mandeley data management system. Key terms were identified according to PCC and the Boolean operating system was used with the following terms:

> "breast cancer*" OR "breast tumor*" OR "breast neoplasm*" OR "breast carcinoma*" OR "breast oncology*" OR "mammary cancer*" OR "mammary tumor*" OR "mammary neoplasm*" OR "mammary carcinoma*" OR "mammary oncology*" OR "breast cancer patients" OR "breast cancer survivors" AND "information need*" OR "education need*" OR "knowledge need*" OR "supportive care need*" OR "health service need*" OR "health system need*" OR "psychological need" OR "physical need*" OR "sexuality need*" OR "daily need*" OR "living need*" OR "patient care need*" AND "cancer continuum" OR diagnosis OR treatment OR "post-treatment" OR survivorship OR recurrence OR "palliative care".

Wildcards are also used to expand the search. The databases searched were PubMed, Scopus, Taylor & Francis, EBSCOhost, and ScienceDirect. The literature search was conducted from 2010 to 2025.

Selecting Studies

The first and second authors independently screened the abstract titles. In case of disagreement, both authors discussed the articles and if agreement could not be reached, the third author acted as a mediator and reviewed the articles. Inclusion criteria included articles that addressed the information needs of breast cancer patients. Exclusion criteria included articles without full text available, books/book chapters, and publications in languages other than English, articles that only explore the perspectives of health workers or caregivers without directly involving patients, studies that do not include a discussion of information needs, and articles in the form of study protocols, conference abstracts, or editorials without empirical data. An initial search of five databases with additional searches from other sources yielded 1.779 articles. After excluding duplicate articles, 1.467 articles remained. Screening of titles and abstracts yielded 80 articles. Finally, 40 full-text articles were included in the analysis (Figure 1).

Thematic analysis will be used to identify key findings in the literature. The first and second authors will critically review the selected articles and report the results independently. Consensus will be reached for all reviewed articles and key themes will be identified. Next, the third author will evaluate the summary of the data selection process based on PRISMA-ScR.

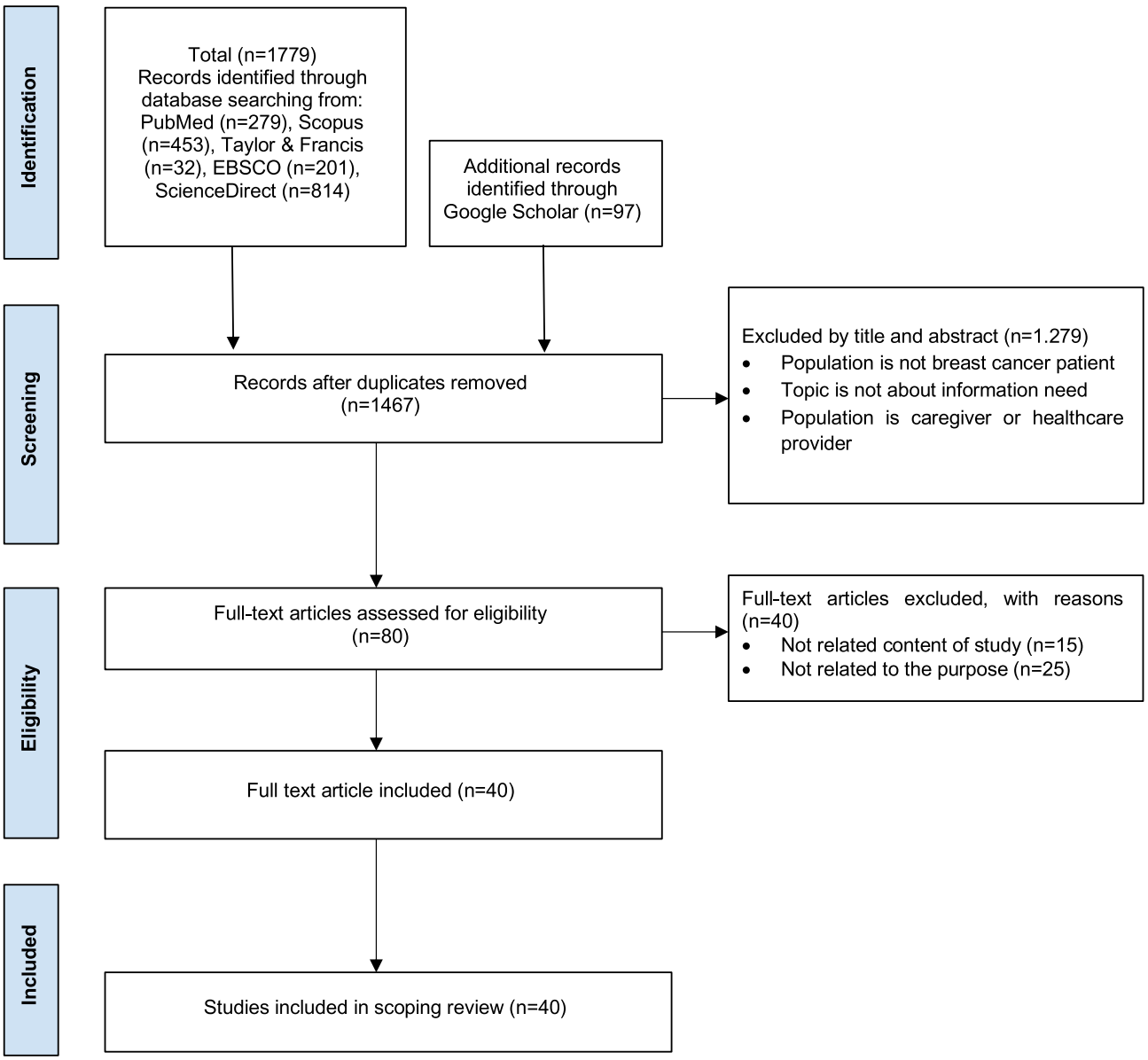

Figure 1 PRISMA Flowchart.

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Charting, Summarizing, and Reporting Data

Data charting was conducted comprehensively by two reviewers using a predefined extraction framework. The process involved a structured mapping of evidence to ensure that all relevant aspects of each included study were systematically captured and comparable across sources. Two complementary data extraction tables were developed to support this process. The first table summarized the characteristics of the included studies, encompassing information on the author, year, and country of publication, research design, sample size, target population, assessment instruments, and the main findings. This step provided an overview of methodological diversity and contextual distribution across studies from various geographical regions and healthcare systems. The second table presented the core findings related to the information needs of breast cancer patients, arranged according to the stage of disease progression and patients' preferences for information sources and formats. Through this mapping, the reviewers identified patterns and variations in information needs across the diagnostic, treatment, survivorship, and post-treatment phases.

All extracted data were then synthesized narratively and thematically to provide a comprehensive interpretation of the findings. The synthesis highlighted recurring trends, contextual nuances, and cross-stage relationships that reflected how patients' information needs evolve throughout their cancer journey. This process ensured that data reporting was consistent, transparent, and aligned with the methodological principles of scoping review frameworks.

Expert Consultation and Validation

To enhance the rigor and applicability of the review findings, a consultation exercise was conducted with two critical care nurse specialists. These experts were invited to critically review and validate the synthesized results. Their input focused on ensuring clarity, relevance, and practical value of the findings from both clinical and educational perspectives. Specifically, the consultation aimed to (1) refine the structure and presentation of the results, including titles, subheadings, and thematic organization; (2) assess the comprehensiveness and coherence of the identified categories; and (3) ensure that the interpretation accurately reflects current clinical realities and patient-centered perspectives. Feedback from the consultation was incorporated into the final framework to strengthen the credibility, clarity, and transferability of the review outcomes.

Results

Study Selection

A total of 1.779 records were identified through database searching, consisting of PubMed (n = 279), Scopus (n = 453), Taylor & Francis (n = 32), EBSCO (n = 201), and ScienceDirect (n = 814). An additional 97 records were retrieved through Google Scholar. After removing duplicates, 1.467 unique records remained for screening (see Figure 1). During the title and abstract screening phase, 1.279 records were excluded for the following reasons: (i) the population was not breast cancer patients, (ii) the topic was unrelated to information needs, and (iii) the population consisted of caregivers or healthcare providers. This process resulted in 80 full-text articles assessed for eligibility. Subsequently, 40 full-text articles were excluded due to irrelevance 15 did not align with the content focus of the study, and 25 were not related to the study purpose. Finally, 40 studies met the inclusion criteria and were incorporated into the final scoping review.

Characteristics of Studies

A total of 40 studies were analyzed in this scoping review (see Table 1). These studies originated from diverse geographical regions, including Asia (eg, China, South Korea, Iran, Japan, Taiwan, India), Europe (eg, the United Kingdom, the Netherlands, Germany, Sweden, Spain, Ireland), North America (the United States and Canada), Australia, Africa (Ethiopia), and the Middle East. Methodologically, the majority of studies employed quantitative approaches (n = 28), followed by qualitative studies (n = 11) and mixed methods (n = 3). A total of 40 studies were distributed across five continents. The largest proportion originated from Asia (n = 13) and Europe (n = 11), followed by America (n = 9), Africa (n = 4), and Australia (n = 3) (see Figure 2). Five studies were secondary in nature, consisting of systematic reviews (n = 2), a meta-synthesis (n = 1), and an umbrella review (n = 1). This diversity in study design demonstrates a

Table 1 Characteristics of Studies

No.	Author (Year) and Origin	Design	Sample	Assessment Tools	Intervention (Strategy, Topic, Duration, Students/Group)	Major Findings
1	Gaynor et al, 2025[15] Ireland	Cross-sectional	Metastatic breast cancer (MBC) (n=246), Mean age 52.5 (range 30–82 y/o)	Custom-developed 76-item questionnaire co-produced by MBC patients and interdisciplinary team	• Patient-led online survey; questionnaire co-designed by 41 MBC patients and a multidisciplinary team; promoted via national media platforms • Information and communication needs	• Most patients were satisfied with the manner of disclosure of their diagnosis but 77% wanted more prognostic information. • Only 35.1% currently have access to their medical records, of those with no access 99.4% of patients wanted access. • The majority (83%) of patients were amenable to earlier palliative care referral. • The symptom burden of respondents was high, 87% experienced mental health issues and 68% of those with menopausal symptoms were dissatisfied with the support. These burdens were compounded by financial stress with 20% of patient unable to meet monthly expenses and by time toxicity with 25% attending emergency departments in the previous 6 months.
2	Schmidt et al, 2016[16] Germany	Multi-center Prospective Cohort Study + mixed-methods (qualitative preliminary phase)	1.248 breast cancer patients from 60 German centers (87% follow-up rate)	• Structured questionnaire (12 specific "yes/no" items on information needs) developed through qualitative preliminary work • Health literacy assessed via a validated measure	• Strategy: Mixed-methods survey; qualitative phase informed questionnaire, followed by quantitative data collection. • Topic: Information needs post-primary treatment, health literacy, and the role of healthcare workers. • Duration: 10 weeks after initial surgery	• The results show that information needs of breast cancer outpatients are mainly in "follow-up after acute Treatment" (55.8%), "coping with long-term side effects" (65.7%), and "heredity of breast cancer" (44.9%). • Better health literacy and perceived helpful contact with healthcare professionals reduced unmet information needs.
3	Kuruppu et al, 2020a[12] Srilanka	Cross-sectional	Female BC patients (n=400), Mean age 56.35 (range 27–76 y/o)	Sri Lankan Information Needs Assessment Questionnaire - BC (SINAQ-BC)	• Interview-based administration • Patients' informational needs across disease, treatment, psychosocial care domains	All patients indicated a strong need for information. The most prominent findings of the study showed that breast cancer (BC) patients placed the highest importance on the following informational domains: treatment (Mean = 60.7, SD = 6.3), psychosocial services (Mean = 58.7, SD = 6.7), disease (Mean = 55.8, SD = 7.0), diagnosis (Mean = 31.0, SD = 5.9), and physical care (Mean = 20.2, SD = 3.2).

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Table 1 (Continued).

No.	Author (Year) and Origin	Design	Sample	Assessment Tools	Intervention (Strategy, Topic, Duration, Students/Group)	Major Findings
4	Ko et al, 2023b[17] USA	Mixed methods	Invasive breast cancer (n=53), Median age was 54 years old.	Focus group guide, structured survey (QoL, healthcare experience, education needs)	• Strategy: focus groups followed by survey • Topic: survivorship needs, education preferences • Duration: within 5 years post-treatment • Participant/ Group: 53 black women in focus group, 43 completed survey	• Participants identified the importance of relationships with health care providers, gaps in survivorship care, experiences with cancer-related symptoms, challenges with mental health, worry about recurrence, body image, cancer financial toxicity, and coping through religion and spirituality. • Unmet information needs: preparation for cancer-related symptoms and long term effects, clarifying healthy lifestyle, tangible resources for survivorship, understanding recurrence risk, need for information support, addressing emotional needs, preferred type of educational materials and timing, some preference for videos, information needed before and after treatment.
5	Levesque et al, 2020[18] Australia	Qualitative study	Women with breast cancer (n=24)	Semi-structured interview	Strategy: Conduct focus groups/ interviews in native language to elicit culturally-specific insights Topic: Cultural appropriateness of information and communication with healthcare providers Duration: Single-phase qualitative data collection Group: 24 Chinese-Australian breast cancer patients	Five core themes emerged, focusing on information needs, communication barriers, psychological impact, challenges, and social support. This paper highlights the first two themes. Participants actively sought information but were often unsure what to ask due to limited medical understanding, relying instead on peers for guidance and practical advice about disease management and treatment options.
6	Groß et al, 2020a[19] Germany	Quasi-experimental (non-randomized intervention)	Breast cancer centres (n = 86), female breast cancer patients (n=4626), median age 61 years (range 18 - older)	Annual breast cancer patient survey (University of Cologne) with nutrition-related information need questions.	**Strategy**: Distribution of a one-page fact sheet with basic nutrition information. **Topic**: Nutrition guidance for breast cancer patients. **Duration**: Implemented in 2017 during routine care; evaluated within that year's survey. **Group**: Patients passing through intervention sites (21 breast care centres), compared against those at non-intervention sites.	Unmet information needs are experienced more by younger and non-native German-speaking patients. With regard to education, patients without a graduation and a high grade of education express more unmet information needs. The multilevel analysis showed that patients who were treated at an intervention site and therefore possibly received the fact sheet have a significantly higher chance of their information needs being met (OR = 1.45; $p \leq 0.05$).

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7	Mazzi et al, 2020a[20] Italy	Cross-sectional	Early-stage non-metastatic breast cancer patients (n=377; ages 18–75) Employed = 164 Non-employed = 103 Retired = 110	Audio-recorded and transcribed first oncology consultations Quantified number/types of patient questions Linear regression models considering age, education, employment status, etc.	**Strategy**: Audio-recording consultations → Analyze question frequency and content **Topic**: Early information needs (disease, prognosis, prevention, management, social functioning) **Duration**: Single consultation per patient **Group**: 377 women categorized by employment status (employed, non-employed, retired)	• Employed patients asked more questions overall (mean 17) than non-employed (13) and retired (14); significance lost after adjusting for age and education. • Employed women asked more about: • Prognosis Prevention • Illness management • Social functioning
8	Abbas et al, 2018[21] Iran	Cross-sectional	Women with breast cancer (n-120)	A researcher-designed questionnaire covering 7 domains—disease, treatment, daily activities, sexual health, family/private life impact, disease acceptance/ self-image, and other educational content—rated on 5-point scales via SPSS.	**Strategy**: Survey distribution among internet-using breast cancer patients **Topic**: Online information needs across seven thematic areas **Duration**: Single administration **Group**: 120 female breast cancer patients with internet familiarity	The information content needed by patients on the internet, was in seven areas: Treatment (mean= 4.62 out of 5), daily activity (mean= 4.51 out of 5), disease (mean= 4.42 out of 5), disease acceptance and self-image (mean= 4.37 out of 5), the effect of disease on private life (mean= 4.21 out of 5),sexual health (mean= 4.2 out of 5) and other educational content (mean=4.55 out of 5).
9	Meer et al, 2017[22] Canada	Cross-sectional	Breast cancer survivors (n=132; ages 30- ≥70)	Paper-based questionnaire	**Strategy**: Mail-out survey **Topic**: Lifestyle information needs (diet and exercise) **Duration**: Single cross-sectional assessment **Group**: 132 breast cancer survivors in Northern BC	• The most commonly reported need was diet and physical activity (58%) to decrease risk of recurrence or improve survival. • The most frequently identified sources of lifestyle information included physicians, family or friends, the internet, and magazines. • A majority of breast cancer survivors (64%) pre-frres face-to-face interactions when considering potential lifestyle-related programs or services; dis-tance-based formats (eg video conferencing) were least preferred (11%).
10	Sparidaens et al, 2022[23] Netherlands	Phenomenological qualitative study	Breast cancer survivors (n=18)	Semi-structured interview guides	**Strategy**: Four-phase qualitative approach, culminating in co-developed online information **Topic**: Fertility preservation, risk of early menopause/infertility, long-term menopause consequences **Duration**: 23 to 44 min **Group**: Input from professionals and young breast cancer survivors; output delivered via nationwide online platform	Professionals indicated that there are no guidelines regarding the provision of fertility related information during cancer survivorship. Survivors reported unmet information needs. Women identified the following as most important information needs (a) fertility preservation options, (b) the risk of menopause or infertility, and (c) long term consequences of early menopause.

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Table 1 (Continued).

No.	Author (Year) and Origin	Design	Sample	Assessment Tools	Intervention (Strategy, Topic, Duration, Students/Group)	Major Findings
11	Bei et al, 2015[24] China	Cross-sectional	Female breast cancer patients (n=275), Mean age 54.5	Information Needs Questionnaire (INQ)	**Strategy**: Administer INQ and structured survey to assess priority levels of information needs. **Topic**: Prioritization of information about cure likelihood, disease extent, treatment options, and family risk. **Duration**: Single cross-sectional survey. **Participants/Group**: 275 Hong Kong Chinese breast cancer patients.	• Most participants ranked as their top four needs information about the likelihood of a cure (79%), extent of the disease (76%), treatment options (55%), and family risk of developing breast cancer (51%). • Prioritization influenced by: religious beliefs, living alone, household income, education level, and time since diagnosis.
12	Kaur et al, 2014[25] India	Cross-sectional	Breast cancer survivors (n=154)	Functional assessment of cancer therapy-breast (FACT-B): assessed overall and subscale QoL Semi-structured interviews: explore unmet information and rehabilitation needs	**Strategy**: Cross-sectional evaluation via interviews + questionnaire **Topic**: QoL, information deficits, physical rehabilitation needs **Duration**: Single assessment per participant post-treatment **Group**: 154 breast cancer survivors divided into 3 treatment-completion cohorts	• Common issues: pain, fatigue, fear of progression, body-image concerns; these negatively impacted QoL • Unmet information needs: treatment side effects, long-term care, body image, sexual dysfunction • Rehabilitation needs: physical symptom management, counseling/support services, and better access to clinical and social support during long-term follow-up
13	Rattanakanlaya et al, 2024[26] Thailand	Cross-sectional	Post-mastectomy breast cancer patient (n=123)	Sri Lankan Information Needs Assessment Questionnaire - BC (SINAQ-BC)	**Strategy**: Conduct cross-sectional survey during initial treatment phase **Topic**: Assessment of physical care, treatment, diagnosis, disease specifics, psychosocial care information needs **Duration**: Single time-point during early treatment **Participants/Group**: 123 Thai post-mastectomy breast cancer patients	• The findings revealed that patients exhibited high overall information needs (224.7/260.0). • The greatest demand focused on physical care, treatment and diagnosis. In contrast, needs related to disease specifics and psychosocial care were less prominent. • A total of 94 respondents (76.4%) expressed a particularly high demand for information regarding physical care. • Education level was identified as an influencing factor, accounting for 7.7% of the variance in information needs among women with breast cancer.

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14	Valero-Aguilera et al, 2014[27] Spain	Cross-sectional	Breast cancer patients (n=100) Urological cancer patients (n-169)	The questions about sources of health information and patients' information needs were taken from Finney's systematic review	**Strategy**: On-site questionnaire interviews during routine care **Topic**: Information needs and Internet use **Duration**: Single cross-sectional session per patient **Group**: 100 breast cancer and 169 urological cancer patients	• Breast cancer patients are more concerned with long-term results and the effects on their family, personal life and peer support experience. • The information needs of patients with urological cancer are linked to short-term alternative treatments, their sex life, keeping healthy, and exercise. • More clinical aspects, such as tests and experiments linked to their treatment, are not a frequent information need. • Internet use was more likely among younger, higher-educated patients who took an active role in decisions and received aggressive treatment.
15	Boadi et al, 2021[28] Ghana	Cross-sectional	Breast cancer patients (n=75)	Questionnaire using the survey design.	**Strategy**: Questionnaire survey during clinic visits **Topic**: Patients' information needs across five thematic domains (diagnosis, physical care, treatment, psychosocial support, and disease-specific information) **Duration**: Single cross-sectional assessment **Group**: 75 breast cancer patients at two hospital sites	• The patients also ranked diagnostic information as their highest need, followed by physical care information, treatment information, psychosocial information and disease-specific information in that order. • Patients with higher educational levels reported greater information needs across all domains compared to those with lower education.
16	(Legese et al, 2021[10] Ethiopia	Cross-sectional	Breast cancer patients (n=375) Median age 40 (range 20–51 y/o)	Toronto informational need questionnaire for breast cancer (TINQ-BC)	**Strategy**: Interviewer-administered TINQ-BC + semi-structured interviews **Topic**: Domains of information needs (disease, treatment, tests, physical care, psychosocial) **Duration**: Single cross-sectional assessment (Mar–May 2017) **Group**: 375 breast cancer patients; data collectors included trained nurses	Among the five subscales information on disease and information on treatment were the most highly needed areas with a mean percentage of 94.8 and 93.7, respectively; and 254 (67%) of them preferred the information to come from health professionals.
17	(Legese et al, 2021[29] Italy	Cross-sectional	Breast cancer patients (n=70), Mean age 58 (range 31–75 y/0)	Audio recordings transcribed to quantify and categorize patient questions Pre-/post-consultation scales: STAI-X1 (anxiety), PHQ-9 (depression), GHQ-12, CPS (control preferences), DSES, PEI (physician empathy), SDM-Q (shared decision making), SWD (satisfaction with doctor)	**Strategy**: Real-time observation of first consultations **Topic**: Types and number of information-seeking questions **Duration**: One consultation per patient **Group**: 70 Italian breast cancer patients (first oncologist visit)	Patients asked an average of 18 questions, mainly about illness management: patients who were prescribed chemo-therapy asked more questions (t 1/4 3.17, dof 1/4 23.45, $p < 0.01$). The topics were mostly related to illness management, particularly treatment, and administrative procedures. In contrast, patients asked fewer questions about prognosis, prevention and etiology.

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Table 1 (Continued).

No.	Author (Year) and Origin	Design	Sample	Assessment Tools	Intervention (Strategy, Topic, Duration, Students/Group)	Major Findings
18	Wang et al, 2017[30] US	Cross-sectional	Early-stage breast cancer patients aged ≥ 65 years (n=83), Mean age 72,5 years, range 65–93 y/0	Custom survey listing 24 potential information items	**Strategy**: Cross-sectional structured questionnaire **Topic**: Information needed for informed radiotherapy decision-making **Duration**: Single-time survey during radiotherapy decision phase **Group**: 93 women aged ≥ 65 with early-stage breast cancer	• More than 96% of participants indicated they were the main decision-maker on receiving radiotherapy. • There was wide variation in information needs regarding radiotherapy decision-making. Participants rated a mean of 18 (range: 3–24) items as "essential." • Participants rated items related to benefits highest, followed by side effects.
19	Recio-Saucedo et al, 2016[31] UK	Systematic review	Breast cancer patients (n=2.487)	Varied across studies; commonly included surveys, interviews, focus groups.	**Strategy**: Synthesis of existing literature **Topic**: Information about surgical options, side effects, body image, sexuality, fertility, family risk **Duration**: Throughout treatment continuum **Group**: Young women (<50 y) deciding between mastectomy or breast-conserving surgery	• Findings indicate that young women prefer greater and more detailed information regarding treatment side effects, sexuality, and body image. • Younger age of diagnosis leads to an increased risk perception of developing a second breast cancer. • Young women's choices are influenced by factors associated with family and career. • Information is required in a continuum throughout the treatment experience and not only at diagnosis when treatment decisions are made. • Young women show differing levels of participation preferences.
20	Son et al, 2023[32] Vietnam	Cross-sectional	Women undergoing chemotherapy for breast cancer patients (n=130), Mean age 47.06, range 22–70 y/o	Toronto Informational Needs Questionnaire- Breast Cancer (TINQ-BC) and the European Organization for Research and Treatment of Cancer -specific quality of life questionnaire module (EORTC QLQ-BR23)	**Strategy**: Cross-sectional survey among chemotherapy patients **Topic**: Self-perceived informational needs focusing on recurrence, test interpretation, side effects, and diet **Duration**: Single assessment during ongoing chemotherapy **Group**: 130 Vietnamese female breast cancer patients receiving chemotherapy	• The results revealed participants had high information needs and a negative future perspective. • The highest information needs related to potential for recurrence, interpretation of blood test results, treatment side effects, and diet. • Future perspective, income level, and educational level were identified as determinants of information needs, explaining 28.2% of the variance in the need for breast cancer information.

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21	Sayed et al, 2017[33] Egypt	Cross-sectional	Female breast cancer patients (n=100), Mean age 51.23, range 18–65 y/o	An interview questionnaire and Toronto informational needs questionnaire of breast cancer (TINQ-BC)	**Strategy**: Interview-based administration of TINQ-BC and guideline development **Topic**: Illness, treatment, tests, and care-related information needs **Duration**: Single administration during outpatient visit(s) over six months **Group**: 100 newly diagnosed breast cancer patients	• The present study revealed that about (83%) of the studied patients had unsatisfactory level of knowledge regarding breast cancer. • Women with breast cancer lack information especially about their disease, treatments and examinations they are undergoing.
22	Lei et al, 2011[34] Malaysia	Descriptive longitudinal observational study	Breast cancer patients (n-169), oncology nurses (n=39)	Toronto Informational Needs Questionnaires-Breast Cancer (TINQ-BC)	**Strategy**: Repeated cross-sectional survey at two chemo cycles **Topic**: Informational needs across disease, treatment, physical care, investigative tests, psychosocial domains **Duration**: Two time-points (cycle 1 and cycle 4) **Group**: Patients (n = 169) and nurses (n = 39)	• The overall mean scores at first and fourth cycle of chemotherapy were 3.91 and 3.85 respectively: ie, between 3 (or important) and 4 (or very important), which indicated a high level of informational needs. • There was no significant difference in information needed by the breast cancer patients between the two cycles of chemotherapy (p=0.402). • The most important information was from the subscale of disease, followed closely by treatment, physical care, investigative tests and psychosocial needs. • Nurses had different views on the important information needed by breast cancer patients at both time points (p = 0.023).
23	Lei et al, 2011[35] USA	Descriptive observational study	Metastatic breast cancer patients (n=59)	Patient-prepared question lists categorizing inquiry themes Post-consultation summaries Frequencies of topics counted and matched to physician responses	**Strategy**: Analysis of pre-visit question lists vs physician response **Topic**: Common concerns (prognosis, symptom management, clinical trials, quality of life) **Duration**: Single consultation per patient **Group**: 59 metastatic breast cancer patients engaged with Decision Support Services	• Of the 59 patients whose documents we reviewed, patients most often asked about prognosis (38), symptom management (31), clinical trials (43), and quality of life (38). • Physicians answered questions about prognosis infrequently (37% of the time); other questions that were answered more than commonly are the following: symptom management (81%), clinical trials (79%), and quality of life (66%). • Breast cancer patients have many questions regarding their disease, its treatment, and symptoms, which were facilitated in this setting by Decision Support Services.

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Table 1 (Continued).

No.	Author (Year) and Origin	Design	Sample	Assessment Tools	Intervention (Strategy, Topic, Duration, Students/Group)	Major Findings
24	Nader et al, 2016)[36] Lebanon	Cross-sectional	Female breast cancer patients receiving chemotherapy (n=84)	21 questions was inspired from the Supportive Needs Screening Tool (SNST) and the Supportive Care Needs Survey (SCNS)	**Strategy**: Self-administered satisfaction survey during chemo visits **Topic**: Satisfaction with information about disease, treatment steps, lymphedema, and familial risk **Duration**: Single administration during ongoing chemotherapy **Group**: 84 female chemotherapy patients	• The major information needs were related to the risk of cancer in sisters/daughters, the risk of recurrence and metastasis, the follow-up after chemotherapy and managing lymphedema. • Primary information sources: Oncologists (most), followed by TV and radio
25	Halkett et al, 2010[37] Australia	Qualitative	Early breast cancer patients (n=34) Radiotherapy healthcare professionals (n=14)	Semi-structured interview guide	**Strategy**: Two-phase interview process (during RT and post-RT) **Topic**: Patients' evolving informational needs over their RT journey **Timing**: Highest need identified at: First appointment with radiation oncologist Radiotherapy planning appointment **Group**: 34 patients and 14 professionals	Breast cancer patient's specific information needs during radiotherapy and shows that patients' information needs are highest during their first appointment with their radiation oncologist and at the time of their planning appointment. The findings presented will enable health professionals to develop and refine their approaches to patient education in radiotherapy.
26	Carr et al, 2019[38] Canada	Qualitative Meta-Synthesis	Breast cancer survivors (n=2.077)	Open-ended survey question: "What needs to change so that women have a better experience?"	**Strategy**: Analyze free-text patient comments to extract themes **Topic**: Information needs around reconstruction options, expectations, recovery, and sources **Duration**: Comments captured post-reconstruction or decision-making **Group**: Breast cancer survivors reflecting on their BR decision process (n > 2,000)	Women did not feel adequately informed about the outcomes of surgery and the recovery process. In general, women's desire for normality and effective emotional coping shapes their information needs.
27	Kwok & White, 2014[39] Australia	Qualitative	Chinese-Australian female breast cancer survivors (n=23) Mean age 56	Semi-structured focus group guide	**Strategy**: Native-language focus groups to elicit culturally-specific needs **Topic**: Linguistically and culturally appropriate information needs, and support mechanisms **Duration**: Single engagement per participant via focus groups **Group**: 23 Chinese-Australian survivors	Themes for information needs were identified as (1) using linguistically appropriate information, (2) the need for culturally sensitive information for the management of expected side effect and promotion of recovery and (3) the need for information on signs and symptoms of recurrence. Families were described as a primary source of multifaceted social support, although it was challenging to obtain. Support groups were also an important support source, but health care professionals were not identified as a source of support.

28	Kwok & White, 2014[40] Iran	Qualitative	Women post-mastectomy (n=17)	Semi-structured interview	**Strategy**: In-depth interviews to elicit needs and motives **Topic**: Health information needs post-mastectomy and underlying personal/social motives **Duration**: Single interview session per participant (Winter 2014) **Group**: 17 postmastectomy women across two hospitals	• Three basic contents were extracted including information needs related to mental health, physical health related to disease and personal daily activities along with their subcategories, and representing common experience and perception of mastectomized women seeking for health information. • Furthermore, hope, self-esteem, return to life, and available social support resources were expressed as the main information-seeking motives.
29	Kwok & White, 2014[6] Ethiopia	Cross-sectional	Women with breast cancer on adjuvant therapy (n=121)	Toronto information needs questionnaire for breast cancer (TINQ-BC)	**Strategy**: Administering TINQ-BC via trained nurses in interviews **Topic**: Information needs related to disease, treatment, investigations, physical and psychosocial care **Duration**: Single cross-sectional assessment during adjuvant therapy **Group**: 121 women with breast cancer	• The total mean score for overall information needs in the current study was 194.30 (±28.01), with a range scale of 142–260 and a standardized mean score of 3.74 (±0.54). • The disease and treatment domains had the highest information needs, with standardized mean scores (standard deviation) of 4.00 (±0.54) and 3.77 (±0.59), respectively. 95% of the participants sought information from healthcare professionals, and 67.7% of the women needed the information before beginning the treatments. • Predictors of information needs were following a single treatment option (β=12.68; 95% CI (0.68, 24.68); P=0.039) and joining higher education and above (β=17.1; 95% CI (1.47, 34.14); P=0.033).
30	Kwok & White, 2014[41] New York	Cross-sectional	Female breast cancer patients treated at 50 breast centres in North Rhine Westphalia (n=4.166)	The Cologne patient questionnaire for breast cancer 2.0 (KPK-BF 2.0)	**Strategy**: Mailing CPQ-BC 2.0 to patients post-discharge **Topic**: Unmet psychosocial information requirements across multiple domains **Duration**: Data collected during one annual postal survey **Group**: 4.166 breast cancer patients, stratified by presence of comorbidity	• In general, it transpired that BPs had relatively low unfulfilled information requirements regarding work (20.7%), everyday life (26.8%), illness (27.4%) and treatment (35.7%), though such requirements were higher when it came to health-related behaviour (54.2%). • Multimorbid BPs had significantly lower unfulfilled information requirements regarding work and significantly larger ones regarding treatment in comparison to BPs without concomitant illnesses. • Renal diseases and concomitant mental illnesses were associated with particularly high information requirements ($p < 0.05$).

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Table 1 (Continued).

No.	Author (Year) and Origin	Design	Sample	Assessment Tools	Intervention (Strategy, Topic, Duration, Students/Group)	Major Findings
31	Xiao et al, 2023[42] China	Qualitative	Breast cancer patients (n=18), range 27–36 y/o	Semi-structured interviews	**Strategy**: Conduct individual in-depth interviews **Topic**: Fertility information anxiety, reproductive concerns, and family support **Duration**: One interview per participant during treatment period (mid-2022) **Group**: 18 young breast cancer patients	Three themes and 10 subthemes were summarized from the interview data: Information anxiety (strong information demand, insufficient information support, information explosion, and information security); reproductive concerns (desire for fertility, anxiety about their children's health, denial of one's health, multiple burdens of emotional interweaving); and family support (the importance of good family relations, the need for a positive marital relationship).
32	Crowley et al, 2016)[43] USA	Cross-sectional	Breast cancer survivors (n=58), prostate cancer survivors (n=56)	Information on Sexual Health: Your Needs after Cancer (InSYNC)	**Strategy**: Single-time administration of InSYNC **Topic**: Sexual health concerns and unmet information needs **Duration**: Cross-sectional survey **Group**: Cancer survivors (breast and prostate)	Results of the InSYNC questionnaire showed high levels of sexual concern among cancer survivors. Areas of concern differed by cancer type. Prostate cancer survivors were most concerned about being able to satisfy their partners (57%) while breast cancer survivors were most concerned with changes in how their bodies worked sexually (46%). Approximately 35% of all cancer survivors wanted more information about sexual health. Sexual health concerns and unmet information needs are common among breast and prostate cancer survivors,
33	Crowley et al, 2016)[44] Netherlands	Cross-sectional	Breast cancer survivors (n=173), mean age 60.1, range 29–91 y/o)	The questionnaires were developed by the author	**Strategy**: Online/post-visit survey distribution **Topic**: Sexual health information needs/preferences **Duration**: Single point during or around treatment **Group**: 173 patients, 76 partners	The majority of respondents (80.4%, n 1/4135) stated to not have received any information about effect of their breast cancer on sexuality. A quarter (24.9%, n 1/4 42) reported a need for information regarding sexuality; of them, 62.0% (n 1/4 26) did not receive any information.
34	Crowley et al, 2016)[45] US	Qualitative	38 focus group participant, Mean age 61	Semi-structured focus group	**Strategy**: Multilingual focus groups in safety-net settings **Topic**: Required survivorship information, provider communication, SCP content preferences **Duration**: Single focus group session per linguistic group **Group**: Underserved breast cancer survivors across six racial/ethnic groups	Analysis of focus group data identified three themes: 1) the need for information and education on the transition between "active treatment" and "survivorship"; 2) information needed (and often not obtained) from providers; and 3) perspectives on SCP content and delivery.

35	Schmidt et al, 2015[46] Germany	Prospective Multicenter Cohort Study	Female breast cancer patients (n=1.344)	Modified version of the Cancer Patients Informations Needs Scale	**Strategy**: Administered postoperative survey to assess unmet information needs **Topic**: Information needs across multiple domains (eg, naturopathy, nutrition, work-related guidance) **Duration**: Single time point after surgery in early treatment trajectory **Group**: Women of working age with recent breast cancer diagnosis	The most frequently reported unmet information needs among newly diagnosed breast cancer patients were related to supplementary naturopathy, followed by nutrition, physical burden, exercise and sport, health promotion, work during breast cancer, tax relief, and vacation/travel, in descending order. These topics reflect areas where patients desired more information beyond what was provided.
36	Sheehy et al, 2018[47] Ireland	Cross-sectional	Breast cancer survivors (n=105)	Toronto Information Needs Questionnaire for Breast Cancer (TINQ-BC).	**Strategy**: Single-time administration of TINQ-BC to different cohorts **Topic**: Ongoing informational needs across long-term survivorship **Duration**: Cross-sectional assessment at 1, 3, and 5 years post-diagnosis **Group**: 105 breast cancer survivors grouped by follow-up time	Over time, the information needs of breast cancer patients shifted. • At 1 year, the top-ranked needs were related to the disease process, treatments, and investigative tests. • At 3 years, treatment information became the top priority, while interest in the disease process remained high, followed by physical concerns. • At 5 years, the most needed information was still about treatments, with growing interest in physical effects and a consistent need for information on investigative tests and psychosocial aspects across all time points.
37	Miyashita et al, 2015[48] Japan	Cross-sectional	Breast cancer survivors (n=163) Mean age 44.8, range 21–64 y/o	Information needs questionnaire containing 26 items, the World Health Organization Quality of Life InstrumentYShort Form (WHOQOL-BREF)	**Strategy**: Single-time survey capturing unmet informational needs and correlating with QOL **Topic**: Key domains—overall communication, follow-up tests, recurrence treatment, communication strategies, nutrition, secondary menopause **Duration**: Cross-sectional; single time-point data collection **Group**: Young breast cancer survivors in Japan, mostly premenopausal at diagnosis	• Participants generally received adequate information on diagnostic results (77.9%) and follow-up tests (95.1%), yet over one-fourth remained dissatisfied with details on post-discharge symptoms and lymphedema. • Approximately 70% obtained information about recurrence treatment and communication with medical staff, but around one-third expressed dissatisfaction. Information on nutrition, exercise, genetics, and complementary therapy was received by fewer than half of participants, with high dissatisfaction rates (34–56%). Although most received fertility- and menopause-related information, fewer than 25% were unsatisfied, indicating moderate gaps in reproductive health education.

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Table 1 (Continued).

No.	Author (Year) and Origin	Design	Sample	Assessment Tools	Intervention (Strategy, Topic, Duration, Students/Group)	Major Findings
38	Obeidat & Khrais, 2015[49] Jordan	Descriptive comparative	Women with breast cancer (n=156)	Information Needs Questionnaire (INQ)	**Strategy**: Single-time self-report survey measuring top information priorities and preferences for honest disclosure **Topic**: Preferences around knowing cancer diagnosis, stage, spread, cure chances, and side effects **Duration**: One-time survey during the first 18 months of treatment **Group**: 156 Jordanian women with a confirmed breast cancer diagnosis	The vast majority of patients wanted to know whether the diagnosis was breast cancer (92%) and the stage of the disease (78%). Information about spread of the disease and chances of cure was of highest importance for the majority of the patients (88% and 85% respectively). Younger patients and those with higher education were more likely to express a preference for truthful disclosure of breast cancer diagnosis. The majority of Jordanian women wanted information about breast cancer diagnosis, chances of cure, and treatment side effects.
39	Villarreal-Garza et al, 2019[50] Mexico	Qualitative	Women with breast cancer (n=29)	Semi-structured Focus group	**Strategy**: Conducted one-time, in-person focus groups **Topic**: Understanding of diagnosis/ treatment, side effects, communication preferences—especially around fertility, menopause, sexuality **Duration**: Sessions held once per group during 6–12 months post-diagnosis **Group**: 29 young breast cancer patients in Mexico City	Expressed needs were classified into the following categories: (a) understanding diagnosis and treatment; (b) treatment side effects; and (c) time, source and communication means. Patients felt their medical team did not provide enough information regarding diagnosis, treatment and relevant side effects related to fertility, menopause and sexuality. Lack of information fuelled uncertainty, distress, anxiety and fear, and could negatively influence treatment decisions.
40	Villarreal-Garza et al, 2019[51] Turkey	Descriptive cross-sectional	Breast cancer patient (n=55)	Patient Information Needs Scale (PINS)	**Strategy**: Distribution of PIN scale and personal form once post-surgery **Topic**: Post-surgical information needs across multiple domains, including medication, wound care, physical recovery **Duration**: Single-time assessment during post-operative follow-up **Group**: Women post breast cancer surgery at university hospital	Among the different subscales evaluated, information relating to medication was the most needed, and the information needs pertaining to this subscale were met to a greater degree ($p<0.05$) than the remaining subscales. The results showed that the information needs, primarily the medication-related information needs, of the patients were high, but that the level of meeting these needs was low.

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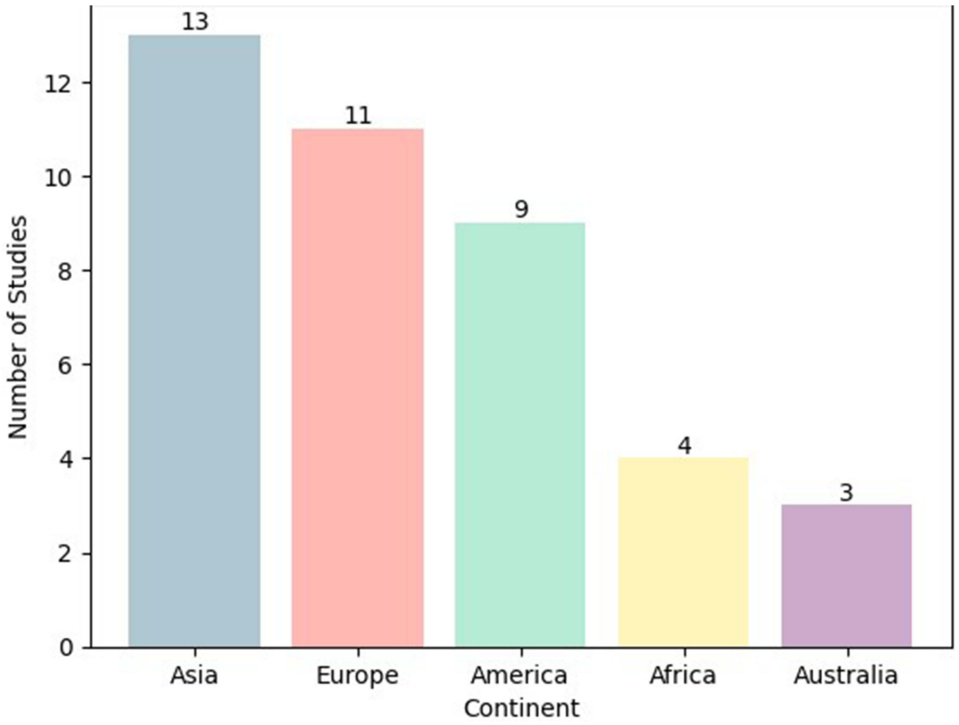

Figure 2 Geographical Distribution of Included Studies by Continent.

multidimensional approach in exploring the informational needs of breast cancer patients across various stages of their disease trajectory.

Qualitative studies explored patients lived experiences of information needs across the breast cancer trajectory, providing in-depth insights into emotional, psychosocial, and contextual concerns such as diagnostic uncertainty, fertility issues, coping during treatment, and survivorship challenges.[27,40,42] In contrast, quantitative studies measured the type and magnitude of information needs using structured questionnaires, including the Toronto Informational Needs Questionnaire for Breast Cancer (TINQ-BC), the Information Needs Questionnaire (INQ), the Sri Lankan Information Needs Assessment Questionnaire for Breast Cancer (SINAQ-BC), and researcher-developed tools. These studies quantified unmet needs across disease-related, treatment-related, physical, and psychosocial domains and examined associated demographic and clinical factors. Mixed-methods studies combined qualitative and quantitative approaches, enabling triangulation of experiential insights with standardized measurements to provide a more comprehensive understanding of information needs.

The participants in the reviewed studies were breast cancer patients, most of whom were women, with some studies also including male patients. The reviewed studies included adult and older adult breast cancer patients aged 18 to over 90 years, with most participants between 30 and 70 years. Studies focusing on younger adults (20–40 years) primarily addressed fertility-related concerns, whereas studies involving older adults (≥65 years) examined decision-making and survivorship-related information needs.[23,30,42,50] In terms of the disease trajectory, participants were represented across various phases, including newly diagnosed, undergoing treatment, post-treatment, and survivorship stages.

Informational Needs Among Breast Cancer

This scoping review identified four major themes: information needs in the early phase of breast cancer diagnosis, information needs throughout the treatment phase, information needs in the post-treatment and survivorship phase, preferences regarding sources and formats of information. Details of Breast Cancer Patient Information Needs Based on Disease Progress Phase and Source/Format Preferences are depicted in Figure 3.

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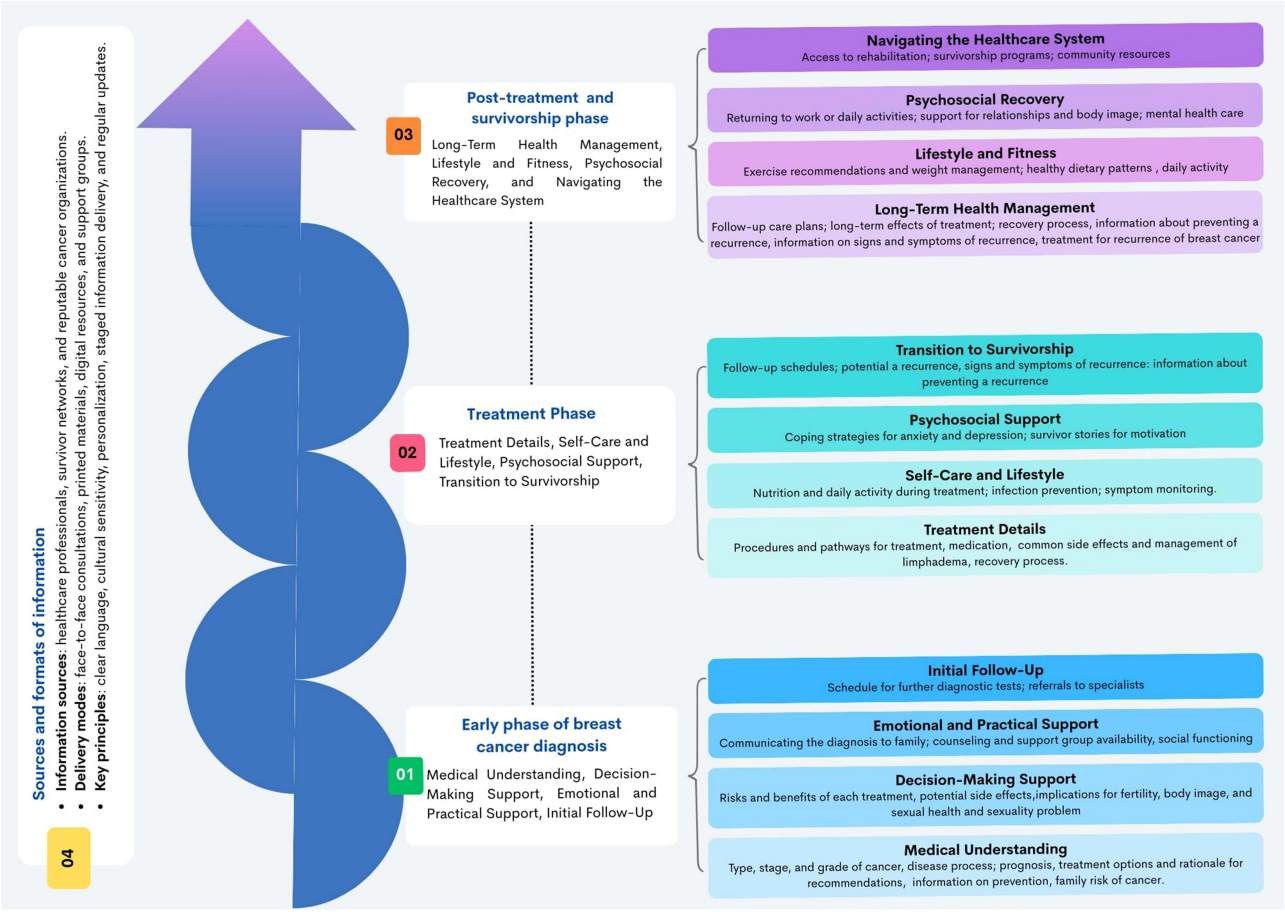

Figure 3 Thematic Analysis of Informational Needs among Breast Cancer Patients.

Category I: Early Phase of Diagnosis

In the early diagnostic phase, breast cancer patients consistently expressed a strong need for fundamental medical information to understand their condition. Across studies conducted in Ethiopia, Ghana, Jordan, Italy, China, Sri Lanka, Turkey, Vietnam, and Hong Kong, patients prioritized information regarding cancer type, stage, grade, disease process,[10,28,29,33,47,49,52,53] and prognosis.[41] Information about prevention, including effectiveness of breast self-examination,[3,6,20,50] family risk of cancer,[24,54] tre atment options and the rationale underlying clinical recommendations was also highly valued during this phase.[10,12,15,20,24,26,27,29,49,52,55]

Decision-making–related information emerged as a central need, particularly concerning the benefits and risks of treatment,[30,38,55] expected side effects, and long-term consequences.[27,30,49] Younger women, especially those aged 20–40 years in studies from China, Mexico, and the Netherlands, emphasized fertility preservation, reproductive health, and early menopause risks as critical informational priorities.[23,42,48] Older patients (≥65 years), particularly in the United States, sought information to support informed decision-making regarding radiotherapy and other treatment modalities.[30] Apart from that, patients also mentioned the need for information regarding body image, sexual health and sexuality problems.[6,27,44,50,56]

Beyond biomedical information, emotional and practical information needs were prominent. Patients reported the need for guidance on coping with the diagnosis, communicating with family members, accessing counseling services, and navigating initial care pathways, as documented in studies from Ireland and Australia.[20,27,44,54] These findings indicate that the diagnostic phase is characterized by multidimensional information needs encompassing biomedical, decisional, emotional, and practical domains.

Category II: Treatment Phase

During active treatment, information needs shifted toward managing treatment-related demands and maintaining daily functioning. Studies from Sri Lanka, Vietnam, Turkey, Ethiopia, Thailand, Malaysia, and Australia consistently reported high demand for detailed information on chemotherapy, radiotherapy, surgery, hormonal therapy, and medication use.[10,12,28,37,48] Patients sought clear explanations of recovery process,[38] treatment procedures, anticipated side effects, and strategies for managing symptoms such as fatigue, pain, nausea, infection risk, and lymphedema.[3,6,27,32,34,39,40,47,50,51]

Self-care and lifestyle-related information represented another major domain during treatment. Patients requested guidance on nutrition, physical activity, daily activities, and symptom monitoring, as reported in studies from Germany, India, Canada, and Iran.[19,22,25,32,40,48,52,56] These informational needs supported patients' efforts to maintain physical well-being and adhere to treatment. Psychosocial information needs remained substantial throughout treatment. Patients expressed a need for emotional support, coping strategies, reassurance, and survivor narratives to help manage anxiety, depression, body image concerns, and disruptions to social roles.[12,27,28] As treatment progressed, information about follow-up schedules and recurrence risk also became increasingly salient.[32,54]

Category III: Post-Treatment and Survivorship Phase

Following completion of active treatment, information needs persisted and evolved toward long-term survivorship concerns. Breast cancer survivors in the United States, Germany, Ireland, Canada, Japan, and Australia reported strong needs for information related to follow-up care, long-term and late effects of treatment, and survivorship care planning.[17,27,38,45,54] Information on recurrence prevention and recognition of recurrence symptoms was consistently identified as a priority, reflecting ongoing uncertainty and fear of recurrence among survivors.[3,39,40,45,47,48,50–52,57] Survivors also sought guidance on lifestyle modification, including exercise, weight management, and healthy dietary practices, to support recovery and improve quality of life.[3,17,19,22,40,45,58]

Psychosocial recovery needs were prominent during survivorship. Studies from Spain, India, Iran, and Canada reported unmet informational needs related to returning to work, managing long-term emotional distress, body image, sexuality, and rebuilding social relationships.[3,25,27,38,40] Survivors also required information to navigate healthcare systems, access rehabilitation services, and connect with community-based resources.[27]

Category IV: Preferences for Sources and Delivery Formats

Across all phases of the breast cancer continuum, patients consistently identified healthcare professionals—particularly oncologists, breast care nurses, and other clinical specialists—as their most trusted sources of information.[3,6,10,12,49,53] Survivor networks and reputable cancer organizations were also valued as complementary sources, particularly for experiential and emotional support.[27,45,47,52]

Preferences for information delivery formats varied by age and context. Younger adult patients, typically aged 20–49 years, in studies from Australia, South Korea, Iran, Spain, and Ireland demonstrated a strong preference for digital resources, including websites, videos, mobile applications, webinars, and online platforms.[15,17,27,37,56] In contrast, older adults more frequently preferred face-to-face communication and printed materials, as reported in studies from Ethiopia and Sri Lanka.[10,12] Across populations, patients emphasized the importance of information that is clear, culturally sensitive,[17] personalized, staged according to readiness, and updated over time.[15,17,37,50] These preferences highlight the need for blended, multimodal information strategies that integrate professional guidance with accessible digital and printed resources.

Discussion

This review was designed to provide a comprehensive understanding of the information needs of breast cancer patients across all stages of their disease trajectory from diagnosis, treatment, and survivorship to post-treatment and palliative care. By systematically mapping and synthesizing existing evidence, the review aimed to identify the scope, characteristics, and variations of patients' information needs, as well as the factors influencing these needs and the sources or educational strategies most effective in addressing them. The findings of this review extend existing evidence by demonstrating that breast cancer patients' information needs evolve dynamically across the cancer continuum, reflecting shifting clinical,

emotional, and practical challenges. Rather than representing static demands, these needs appear closely aligned with patients' changing roles, decision-making responsibilities, and psychosocial adjustment at different stages of care.

Information Needs in the Early Phase of Breast Cancer Diagnosis

The findings related to Theme 1 indicate that the early diagnostic phase represents a period of heightened uncertainty, during which patients require extensive information to make sense of their diagnosis and impending treatment decisions. The strong emphasis on disease-related information and prognosis reflects patients' need to regain a sense of control and predictability following the initial shock of diagnosis. Previous studies similarly describe the diagnostic phase as one of the most psychologically distressing points in the cancer trajectory, where inadequate information may exacerbate anxiety, fear, and decisional conflict.[29,58]

The prominence of decision-making–related information, particularly regarding treatment options and potential side effects, underscores the growing expectation for shared decision-making in contemporary breast cancer care. This finding aligns with earlier research demonstrating that timely and transparent information provision enhances patients' participation in treatment decisions and reduces decisional regret.[27,50] Moreover, the heightened information needs observed among younger women, especially concerning fertility and reproductive health, highlight the necessity of age-sensitive and life-stage–specific communication strategies during diagnosis.[23,42]

Overall, the findings reinforce previous evidence that the early diagnostic phase of breast cancer is characterized by multidimensional information needs encompassing biomedical, decisional, emotional, and practical domains. The consistency of these needs across cultural and healthcare contexts suggests a largely universal pattern, albeit with variation according to age, education, and sociocultural factors. This review further highlights that timely, structured, and patient-centered information provision at diagnosis is integral to high-quality breast cancer care, as it reduces anxiety, supports shared decision-making, and improves patients' overall care experience.[59]

Information Needs Throughout the Treatment Phase

Throughout active treatment, information needs appear to shift from understanding the disease to managing its consequences. The emphasis on treatment procedures, side-effect management, and self-care suggests that information serves as a practical coping resource that enables patients to navigate the physical and emotional burden of therapy. This is consistent with previous studies indicating that symptom-related information is critical for maintaining treatment adherence, reducing distress, and supporting QoL during chemotherapy and radiotherapy.[12,32,51]

The persistence of psychosocial information needs during treatment further reflects the multidimensional impact of breast cancer therapy. Prior research has shown that inadequate psychosocial information may intensify emotional distress and feelings of isolation, particularly when patients face changes in body image, daily functioning, and social roles.[25,27] These findings reinforce the importance of integrating psychosocial education and supportive resources into routine treatment-related communication, rather than focusing solely on biomedical information.

Information Needs in the Post-Treatment and Survivorship Phase

Findings related to Theme 3 suggest that the completion of active treatment does not signal the end of information needs but rather marks a transition toward survivorship-oriented concerns. Persistent needs related to follow-up care, recurrence prevention, and long-term health management reflect ongoing uncertainty and fear of recurrence commonly reported among breast cancer survivors.[45,47] This underscores the importance of structured survivorship care planning to support long-term self-management and psychological reassurance.

The continued demand for lifestyle and health-promotion information highlights survivors' desire to actively reduce recurrence risk and regain a sense of agency over their health. Previous studies similarly emphasize that guidance on physical activity, diet, and weight management is perceived as integral to recovery and quality of life, yet often remains insufficiently addressed in routine follow-up care.[19,22] In addition, unmet psychosocial information needs related to work reintegration, relationships, and body image further illustrate that survivorship encompasses complex social and emotional adjustments beyond clinical surveillance.[27,40]

The review highlights that post-treatment information needs are long-term and multidimensional, encompassing follow-up and late-effects management, recurrence prevention, lifestyle guidance, psychosocial recovery, and healthcare navigation.[17,45,47] Addressing these needs through individualized and survivorship-oriented information strategies is essential to reduce uncertainty and support long-term quality of care.

Preferences Regarding Sources and Formats of Information

The preferences identified in Theme 4 highlight that the effectiveness of information provision is strongly influenced by the source and format through which information is delivered. The continued preference for healthcare professionals as primary information sources underscores the central role of trust, credibility, and continuity in patient–provider communication. This finding is consistent with previous research demonstrating that patients are more likely to rely on and act upon information received from trusted clinicians.[10,49]

At the same time, the increasing use of digital information resources,[60] particularly among younger patients, reflects broader trends in health information–seeking behavior and digital health engagement. Prior studies suggest that digital formats can enhance accessibility and flexibility, especially when combined with face-to-face consultations, but should complement rather than replace professional guidance.[17,37,61,62] The preference for clear, culturally sensitive, and staged information delivery further emphasizes that patient-centered communication must be responsive to individual readiness, sociocultural context, and evolving needs across the cancer continuum.[15,23] The patients want information to be refreshed over time, reflecting the dynamic and continuous nature of informational needs across the cancer trajectory.[15] This finding, emphasizing that information provision should be viewed as a longitudinal process rather than a one-time intervention, particularly during survivorship and long-term follow-up.[47,57]

Taken together, these findings reinforce the view that breast cancer–related information needs are dynamic, multidimensional, and closely aligned with patients' clinical trajectories and life contexts. Addressing these needs requires information strategies that are not only comprehensive but also adaptive, individualized, and integrated across phases of care. Consistent with previous literature, embedding stage-appropriate, patient-centered information provision into routine breast cancer care may play a critical role in reducing distress, supporting shared decision-making, and improving long-term outcomes.[27,58]

Strengths and Limitations of the Study

This review offers several strengths that enhance its rigor and relevance. First, it provides a comprehensive synthesis of the available evidence on the information needs of breast cancer patients across all stages of the cancer continuum, from diagnosis to survivorship and post-treatment. By employing the Arksey and O'Malley framework and adhering to the PRISMA-ScR guidelines, this review ensures methodological transparency and replicability. The inclusion of diverse study designs quantitative, qualitative, and mixed methods further strengthens the interpretive depth and captures the multidimensional nature of patients' experiences. In addition, the consultation exercise with critical care nursing specialists adds practical value by validating the relevance, clarity, and applicability of the synthesized themes to real-world nursing practice and patient education.

This review has limitations that should be acknowledged. First, heterogeneity in study designs and assessment tools may have introduced variability in the measurement of information needs, limiting the ability to make direct comparisons across studies. Second, the predominance of cross-sectional designs constrains understanding of how information needs evolve longitudinally across the breast cancer continuum, from diagnosis to survivorship and palliative care. Finally, the review was limited to English-language publications, which may have excluded relevant studies published in other languages and thus reduced the inclusivity of culturally specific evidence.

Conclusion

This scoping review synthesizes breast cancer patients' information needs into four clearly defined themes across the cancer continuum. In the diagnostic phase, patients require information on disease characteristics, prognosis, treatment options, and emotional support. During the treatment phase, information needs focus on treatment management, side-effect control, self-care, lifestyle modification, and psychosocial support. In the post-treatment and survivorship phase,

patients emphasize long-term follow-up, recurrence prevention, management of late effects, and quality-of-life issues. The fourth theme highlights preferences for information sources and delivery formats, with patients favoring trusted healthcare professionals and multimodal, culturally sensitive information delivery. These findings demonstrate that information needs evolve systematically across disease stages and underscore the importance of phase-specific, patient-centered informational strategies. Healthcare professionals should provide phase-specific, patient-centered information that aligns with breast cancer patients' evolving needs across the cancer continuum. Delivering information through trusted professionals and multimodal formats may enhance understanding and support informed decision-making. Future research should develop and evaluate tailored, phase-specific informational interventions and assess their effectiveness across diverse sociocultural contexts.

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Disclosure

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