Review Article



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

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ARTICLE INFO

Article history:

Received 05-02-2025 Revised 15-03-2025 Accepted 03-04-2025

Keyword:

Breast Cancer Patients, Health Information, Information Needs

Other information:

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https://jurnal.unpad.ac.id/ pacnj/

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E-ISSN: 2715-6060

ABSTRACT

Breast cancer is the most commonly diagnosed cancer and the leading cause of cancer death in women, therefore breast cancer is the most common cancer in women in most countries. Providing adequate information needed by patients can reduce anxiety and feelings of insecurity. Most of women with breast cancer stated that the information obtained was unsatisfactory. However, few studies have comprehensively addressed the information needs of women with breast cancer across all stages of the disease. This scoping review aimed to fully understand the unique information needs of breast cancer patients at various stages of the cancer continuum. A scoping review will be conducted following PRISMA guidelines. Relevant studies will be identified from databases such as PubMed, Scopus, and Taylor & Francis, EBSCOhost, and ScienceDirect. In addition, searches interpersonal via Google Scholar, recommendations, and reference chains will also be conducted. Studies will be selected based on PCC criteria, focusing on breast cancer patients as the population, information needs as content, and at various stages of the cancer continuum as the context. Data extraction and risk of bias assessment will be performed using Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist. This review is expected to provide comprehensive information needs of breast cancer patients at various stages of the cancer continuum. The findings will be valuable for educational institutions, healthcare facilities, in designing innovative, technology-based educating programs that enhance knowledge retention, practical skills, and psychological preparedness.

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Introduction

Breast cancer is the most commonly diagnosed cancer and the leading cause of cancer death in women, therefore breast cancer is the most common cancer in women in most countries (World Health Organization 2024). In 2022, an estimated 2.3 million women worldwide diagnosed with breast cancer, resulting in 670,000 deaths (World Health Organization 2024). Women diagnosed with breast cancer usually experience a grieving process such as fear, denial, vulnerability, and uncomfortable psychosocial status (Stephens et al. 2008). Providing adequate information needed by patients can reduce anxiety and feelings of insecurity (Abi Nader et al. 2016). However, 96% of women with breast cancer stated that the information obtained was unsatisfactory (Erci 2021). In general, oncology dissatisfaction patient related communication problems with doctors and lack of information received about their disease (Iconomou et al. 2002).

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 preference (Tilahun, Kitaw, and Yusuf 2023). Early postoperative complications can include wound infection, bleeding, seroma formation, hematoma, and flap necrosis (Jafari Nedooshan et al. 2022; Rizvi et al. 2020). Late-stage complications include shoulder stiffness, brachial plexopathy, and psychosocial problems (Rizvi et al. 2020).

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 (Freedman et al. 2022). 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 (Legese et al. 2021).

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. Furthermore, according to the literature, information provision to women with breast cancer occurs in various situations—such as receiving adjuvant therapy (Tilahun, Kitaw, and Yusuf 2023), undergoing chemotherapy (Legese et al. 2021a), or attending outpatient follow-up (Kuruppu et al. 2020)—there is little is known study on the comprehensive information needs of women with breast cancer that includes all stages of the disease. 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, and highlight gaps in current research consideration studies for further research.

Method

Research design

This study is based on the scoping review 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 Preferred Reporting Items for Systematic Reviews and Scoping Reviews of Meta-Analyses (PRISMA-ScR) checklist (Tricco et al. 2018).

Determining 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 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 Mendeley 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*" "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.

Study selection

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. An initial search of five databases with additional searches from other sources yielded 1779 articles. After excluding duplicate articles, 1467 articles remained. Screening of titles and abstracts yielded 80 articles. Finally, 51 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.

Charting, summarizing, and reporting data

Data mapping was performed by two authors using a pre-defined data extraction sheet. A chart (Table 1) was developed to extract key data from the articles, including authors, year and origin of publication, objectives, source type, study design, target population, study assessment tools, and key findings.

Consultation exercise

Two critical care nursing specialists were invited to critically review the results of the review. These reviewers were consulted to provide advice on the presentation of the results, including titles, headings, and organization of the content.

Acknowledgments

All authors thank to Universitas Padjadjaran, Bandung, West Java, Indonesia, who has facilitated the database for us in this study.

Conflict of Interests

The authors had no conflict of interest in this research.

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