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FEASIBILITY STUDY

Psychological experiences of family caregivers of patients with breast cancer: Protocol for a meta-synthesis

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Abstract

Aim: The number of breast cancer patients is increasing, but there are insufficient sources of information for their family caregivers. The purpose of this systematic review was to elaborate the psychologically realistic experiences and corresponding needs of family members of patients with breast cancer in the course of their experience in the disease which may provide them with effective, targeted intervention strategies to improve their quality of life.

Design: Protocol for a meta-synthesis.

Methods: We will search the Chinese databases (i.e., China National Knowledge Infrastructure, VIP Database and Wanfang Database) and the English databases (i.e., PubMed, Embase, Web of Science, the Cochrane Library, CINAHL and PsycINFO). Qualitative studies from the above databases, studying the psychological experiences of family members of patients with breast cancer, will be searched comprehensively. The quality of the study will be evaluated by two reviewers independently using the Joanna Briggs Institute (JBI) critical appraisal tools for qualitative study, and any disagreements will be discussed and judged by the third reviewer. Data will be extracted using JBI standardized data extraction tool. Then, the literature will be compared and analysed, and the raw results summarized using the JBI meta-aggregation tool. The reliability and credibility of the overall quality of the included studies will be assessed by using the JBI ConQual approach.

Results: N/A.

No Patient or Public Contribution.

PROSPERO registration number: REDACTED.

KEYWORDS
breast cancer, caregivers, family, meta-synthesis, protocol, psychological experiences

1 | INTRODUCTION

Breast cancer is the most common malignancy among women's cancers worldwide and the leading cause of cancer deaths among women (International Agency for Research on Cancer, 2022). It is estimated that there are 2.3 million new cases in 2020, accounting for 11.7% of all cancer cases (Sung et al., 2021), with 685,000 women dying from breast cancer (Anderson et al., 2021). By 2050, it will be an estimated 3.2 million new cases per year (Youlden et al., 2012; Zaidi & Hamdi Cherif, 2015). Although the overall 5-year survival rate for breast patients with breast cancer is improving (Scott et al., 2020), the diagnosis and treatments of breast cancer have posed statistically significant challenges for patients and their caregivers (Kusi, Boamah Mensah, Boamah Mensah, Dzomeku, Apiribu, Duodu, Adamu, et al., 2020). Previous studies have even suggested that the cancer diagnosis and treatment affect family members more than the patient (Girgis et al., 2013). Once a patient is confirmed with a diagnosis of breast cancer, the care of the family caregiver becomes a long-term task (LeSeure & Chongkham-Ang, 2015). It is exhaustive for the caregiver with many repercussions.

A family caregiver, including a relative, a partner or a friend, is a non-paid person who provides ongoing care and assistance to a family member who needs external support due to poor physical, cognitive or mental health (Ruibo Wang et al., 2021). The burdens of breast cancer caregivers primarily include physical stress, psychological problems, financial worries and social relations disruption. First, multiple studies showed moderate to severe declines in caregivers' physical condition (Hashemi-Ghasemabadi et al., 2016; Khanjari et al., 2014; Wulandari et al., 2017; Zhu et al., 2014). Sleep pattern changes and hypertension were the most reported physical problems (Hashemi-Ghasemabadi et al., 2016; Khanjari et al., 2014; Wulandari et al., 2017). Second, psychological problems are another major stressor for caregivers. More than 70% of family caregivers experienced severe psychological effects in the 6 months following a breast cancer diagnosis and assumption of a caregiving role (Khanjari et al., 2014). The most reported psychological symptoms among caregivers included depression, anxiety and fear of recurrence (Heidari Gorji et al., 2012; Khanjari et al., 2014; Mahadevan et al., 2013; Moreno et al., 2019; Nik Jaafar et al., 2014; Selamat Din et al., 2017; Wulandari et al., 2017; Yeung et al., 2018; Zhu et al., 2014). Additionally, caregivers frequently reported financial worries as the role of the caregiver often results in the caregiver working fewer hours or losing paid employment (Nik Jaafar et al., 2014; Wulandari et al., 2017). Even when caregivers are still employed, the high cost of treatment poses a high financial burden on family caregivers (Gabriel, 2019; Nik Jaafar et al., 2014; Wulandari et al., 2017). Lastly, caregivers experienced a loss of normalcy in their lives, particularly the social relations disruption. Caregivers often indicated that they felt isolated and lacked support from other family members and friends, further increasing the burden associated with the caregiving role (Hashemi-Ghasemabadi et al., 2016). Therefore, family caregivers of patients with breast cancer experience multilevel burdens, which may lead to wore health outcomes for patients and their caregivers.

Although caregivers of patients with breast cancer experienced an array of adverse outcomes, these outcomes are often not well addressed (Cheng et al., 2022; Ussher et al., 2009). Breast cancer family caregivers may have no access to supportive structures and systems (Kusi, Boamah Mensah, Boamah Mensah, Dzomeku, Apiribu, & Duodu, 2020). In the current healthcare system, caregivers' needs for information and support are far from being reached (Sklenarova et al., 2015). Until now, we do not have solid evidence and information about the psychological experience of family caregivers while caring for a patient with breast cancer. The psychological situation of relatives of patients with breast cancer is currently understudied by clinical professionals and healthcare providers. Furthermore, it is worth noting that we have placed the majority of our attention on the treatment and symptom management of breast cancer rather than caregivers (Doumit et al., 2010; Holst-Hansson et al., 2017; Vahidi et al., 2016; Wagner et al., 2006). There is an urgent need to address the adverse psychological experience of family caregivers of patients with breast cancer. There are multilevel biopsychosocial pathways of interaction between families and individuals according to the Biobehavioral Family Model (BBFM) (Wood, 2017). The model posits that family relationships can buffer or enhance the emotional and physical functioning of individuals (Wood et al., 2000, 2008). This study will use the BBFM model to analyse the psychological effects between patients with breast cancer and family caregivers.

This qualitative review aims to elucidate the psychological experiences of family caregivers in supporting people with breast cancer during their disease and to explore how their needs and caregiving confidence have been evolved. A comprehensive qualitative review can provide targeted and appropriate care strategies to improve the quality of life of patients with breast cancer and their family members.

2 | METHODS AND ANALYSIS

The BBFM model will be used in this protocol. This is a qualitative systematic review protocol that follows the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISRMA) to ensure that the research plan is rigorous. We used the PRISMA-Reporting guidelines (Appendix S1) (Moher et al., 2015).

2.1 | Inclusion criteria

2.1.1 | Participants

This systematic review will consider studies that include family caregivers of patients with breast cancer without limiting the age of patients with breast cancer, and subtype or stage of breast cancer. Caregivers of patients with breast cancer are limited to a non-paid person who provides ongoing care and assistance to the patients, such as a relative, a spouse or a friend.

2.1.2 | Phenomenon of interest

This review will include studies that describe the psychological experience of family members of patients with breast cancer involved in the disease process, including psychological status, information and support needs.

2.1.3 | Context

The context will consider the psychological experience of the caregiver of a patient with breast cancer throughout the patient's life experience during hospitalization or home rehabilitation.

2.2 | Types of studies

This study will consider qualitative research on the experience of family members of patients with breast cancer as they aid in the disease process, including but not limited to phenomenological, personal narrative, rooted theory, ethnographic and feminist studies. English and Chinese articles will be included, with no restrictions on year of publication.

2.3 | Patient and public involvement

No patients or families will be involved in the design, planning and conception of this study.

2.4 | Search strategy

We start with a pre-search using the development of a pre-program. The purpose of the search strategy was to find published articles related to the psychological experience of family caregivers of patients with breast cancer. Different search strategies were developed to fit this study and to be searchable in each database based on the subject headings of the different databases. The developed search terms will be searched in the following databases: China National Knowledge Infrastructure, VIP Database, Wanfang Database, PubMed, Embase, Web of Science, the Cochrane Library, CINAHL and PsycINFO. Our search terms are: "Breast cancer," "family," "spouse," "social," "psychosocial," "social," "psycholog*," "qualitative study," the search strategy will be applied to the above database. We will use Mesh terms in combination with free words and then supplement them with manual search. Customized search strategies for use in PubMed are shown in the Appendix S2. An additional search of the grey literature was performed using OpenGrey, and PROQUEST Thesis& Dissertations will also be performed.

2.5 | Study selection

The EndNote 20 will be used for literature management. First, we will conduct automatic and manual duplicate. Then, two independent researchers (QZ and JC) will screen titles and abstracts according to the inclusion and exclusion criteria. Full texts will be read in detail if studies meet the eligibility criteria will be selected while articles that do not meet the inclusion criteria will be excluded. To maintain the credibility of the screening process, all included studies will be screened according to a rigorous process and any disagreements will be judged by the third researcher (CZ).

2.6 | Assessment of methodological quality

All literature to be included was screened and quality assessed by two independent researchers (QZ and JC) through a 10-item checklist using the Joanna Briggs Institute (JBI) critical appraisal tool (Appendix S3) for qualitative study (Lockwood et al., 2015). The checklist consists of items in 10 different aspects, including research methodology, philosophical underpinnings, data collection, analytical methods and validity of results (Online Appendix S3). Each project will be judged by 'yes', 'no' and 'unclear'. The results will be determined by the number of projects that meet the criteria for the research area (10 in total), ≤6 is weak, 7–8 is moderate and 9–10 is high quality. Any disagreements that arise between the two researchers will be judged by the third researcher (CZ) until the three researchers reach agreement. We will extract and integrate data from studies evaluated as moderate and above.

2.7 | Data collection

The Joanna Briggs Institute (JBI) Qualitative Assessment and Review Tool Qualitative Research Data Extraction Tool will be used to conduct data extraction for qualitative research (Lockwood et al., 2015) (Appendix S4). Two researchers (QZ and JC) independently performed data extraction and performed checks. Relevant information was extracted from the included studies: author, year, geographic location, study methodology, study population, phenomenon of interest and time and space of the interview. All extracted information will be coded and tabulated one by one.

2.8 | Data synthesis

Data will be collected and analysed and synthesized using JBI meta-integration methods (Lockwood et al., 2020). Prior to integration, two independent reviewers (QZ and JC) will read the articles carefully to understand the full texts. They then classify the quality of the extracted findings into three levels: clear, ambiguous and unsupported. These results will be coded one by one and further classified to obtain meaningful concepts consistent with the meaning of the original context. Researchers will derive new themes and integrate them based on the similarity of research implications and thematic categories to produce a comprehensive set of results that can improve the quality of the psychological experience of family members of patients with breast cancer in the disease process. In addition, two reviewers (QZ and JC) will discuss to resolve disagreements in the data integration process and develop the subject catalogues.

2.9 | Assessing the accuracy of results

The final study results accuracy will be assessed based on the JBI ConQual control method. The result will be categorized as high, medium, low and very low (Appendix S5). The process will be completed by two independent reviewers (QZ and JC) and any disagreements will be resolved through discussion. The entire protocol process is shown in Figure 1.

2.10 | Reporting of protocol

The results of the qualitative meta-integrated synthesis of this study will be reported following the guidelines for improving the transparency of reporting of qualitative research synthesis statements to ensure the rigour of the study (Tong et al., 2012) (Appendix S6).

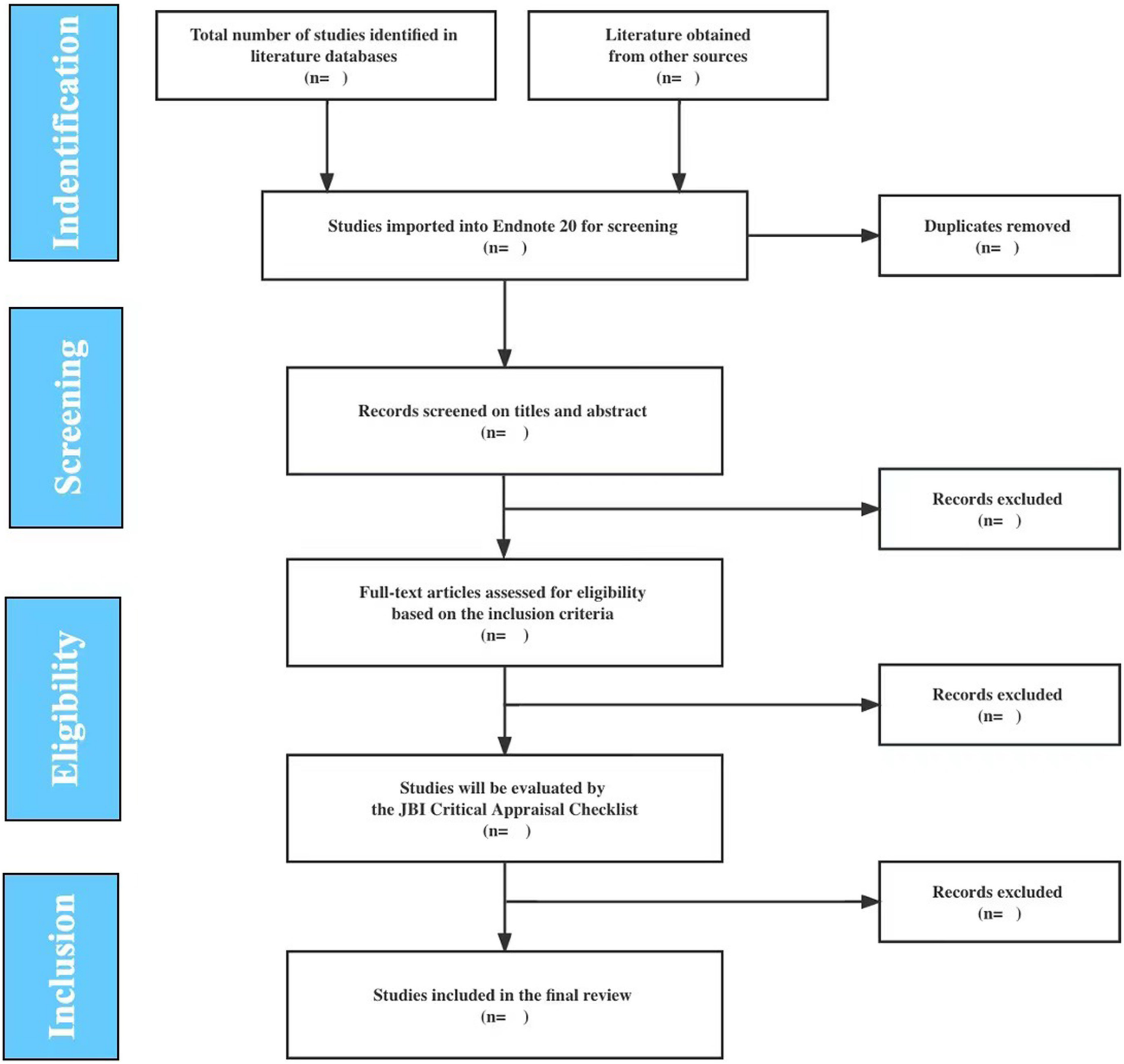

FIGURE 1 PRISMA flow diagram of the study process.

2.11 | Ethics and dissemination

This systematic review does not require formal ethical consideration as the original published literature requires ethical review. This systematic review will identify and integrate the psychological experience of family members of patients with breast cancer to provide targeted care to improve the quality of life of families and patients. If possible, our findings will be published in peer-reviewed journals or presented at scientific meetings.

2.12 | Relevance for clinical practice

Currently, to our best knowledge, there is no meta-synthesis focus on breast cancer caregivers' experiences. This protocol and subsequent systematic review can help nurses to better understand the caregiver's psychological experiences and needs, and to present targeted nursing interventions.

AUTHOR CONTRIBUTIONS

QZ and JC contributed equally to this study. QZ and JC contributed to the design of the study. The introduction was written by QZ and JC. The methods, including literature retrieval, data extraction and appraisal, risk offset assessment and data synthesis, were drafted by PZ, QL and KF. In addition, JB and CZ assisted in quality control and revised the article. All authors contributed to the final manuscript and agreed with its publication.

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CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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