#### REVIEW



# Experience of women with breast cancer undergoing chemotherapy: a systematic review of qualitative research

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# Abstract

**Purpose** Chemotherapy exerts adverse effects on physical, psychological and social functioning in women with breast cancer, which may trigger adaptive activities. For a better understanding of the experience of symptoms associated with chemotherapy and the development of targeted interventions, this study aimed to (a) explore the patient experience of chemotherapy, (b) identify patients' strategies to cope with the side effects and distress and (c) explore the link between their experience and coping strategies.

**Methods** Qualitative studies were included if they explored the experience or coping strategies of women with breast cancer receiving chemotherapy. Instruments from the Joanna Briggs Institute were used to critically appraise the methodological quality, extract data and aggregate findings from the included studies.

**Results** Twelve studies presenting findings from 184 women with breast cancer who had received chemotherapy were included in this review. Three synthesized findings were identified from 8 categories based on 91 original findings: (1) Women living with chemotherapy experienced various stressful side effects, and their lives were changed. (2) Supportive care to address needs is essential to help women get through this difficult time. (3) They engaged in numerous types of coping strategies to deal with side effects and adapt to this difficult journey. Moreover, the link between experience of chemotherapy and coping strategies is based on the Lazarus' stress and coping theory.

**Conclusions** Although the experience of women with breast cancer undergoing chemotherapy is individualized, we concluded that the distressing experience related to chemotherapy as a stimulus was viewed as a stressor that demands coping or adaptation. Based on the Lazarus stress and coping theory, the ability of a woman to appraise how chemotherapy changed her life and how she appraises her resources to cope with chemotherapy are essential. The results highlight that pre-chemotherapy care programmes, information support systems, social support groups and individual effective coping strategies are helpful in reducing treatment-related distress levels and enhance self-care effects at home.

Keywords Breast neoplasms · Drug therapy · Support · Coping strategies · Review

#### Abbreviations

JBI-QARIJohanna Briggs Institute Qualitative<br/>Assessment and Review InstrumentJBI-SUMARIJoanna Briggs Institute System for the<br/>Unified Management Assessment and<br/>Review of Information

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# Background

# The effects of breast cancer and chemotherapy

Breast cancer has the highest incidence of cancer in women worldwide and is the leading cause of cancer-related death. In 2018, 2,090,000 new cases and 626,000 deaths due to breast cancer occurred in women worldwide, accounting for 11.6% and 0.6% of all cancers, respectively [1]. Organized breast cancer screening and advances in adjuvant therapy have helped decrease breast cancer mortality rates and improve survival rates [2, 3]. Currently, the 5-year survival rate is greater than 90%, and the 10-year survival rate is greater than 80%. Clinically, the first five to ten years after breast cancer treatment represent a vulnerable period, during

which some women face a multitude of physical and psychosocial problems [4].

Over half of patients with breast cancer are treated with chemotherapy that comprises chemical agents for both localized and metastatic cancer. For patients who present with localized cancer, the therapeutic goals are tumour eradication and recurrence prevention, while the therapeutic goals for patients who present with metastatic cancer are the prolongation of survival, maintenance of quality of life and palliation of symptoms [5, 6]. Chemotherapy helps reduce the 10-year mortality rate and achieve the greatest survival potential in the first 5 years for women with breast cancer [6, 7]. However, chemotherapy has some side effects, which can be immediate, short term or long term [8, 9]. Several quantitative studies have indicated that women with breast cancer undergoing chemotherapy experienced a cluster of symptoms associated with toxicity and side effects and experienced substantial changes in their psychological status, quality of life and social function [8-10]. According to most studies, women with breast cancer who received chemotherapy reported a poorer quality of life, physical functioning and psychological functioning (or psychological well-being) than women who did not receive chemotherapy [11, 12].

# Qualitative systematic reviews on the experience of chemotherapy

Recently, researchers in related fields have shown considerable interest in exploring the adverse effects of chemotherapy, quality of life during chemotherapy and related interventions to cope with chemotherapy. However, the use of quantitative instruments to capture the unique features of individual experiences of patients with breast cancer related to chemotherapy is challenging, and this approach may omit important issues that would be analysed in a qualitative research study [13]. The perspective of patients on chemotherapy was much deeper than what an outsider would describe; thus, the best sources of information about their experience are the patients themselves. Qualitative studies are valuable because they enable patients to describe their experiences during chemotherapy treatment, facilitating a deeper understanding of the adaptive experiences that emerge. Some qualitative studies have described the lived experiences, social support and coping strategies of women receiving chemotherapy. These studies focussed on specific issues, such as different cycles of chemotherapy and diverse samples (e.g. patients with different stages of cancer, chemotherapy regimens, ages and cultures) [14–17].

Meta-aggregation is a process that identifies meanings from qualitative studies that may attributed to different methodologies and further abstracts those meanings into categories that are then synthesized [18]. In this review, we chose meta-aggregation as a suitable synthesis methodology to study the experience of chemotherapy among women with breast cancer because it has the advantages listed below [19–21]. First, because its philosophical foundation is pragmatic and influenced by transcendental phenomenology, a review focussing on qualitative research is philosophically congruent. Second, one of the special characteristics of a meta-aggregation is that it tries to provide practical implications for the synthesized findings. Third, meta-aggregation can be used to integrate the results of qualitative studies conducted using different designs (i.e. ethnography, grounded theory and phenomenology).

## Rationale and objective of the review

An understanding of the current experience and coping strategies of women with breast cancer undergoing chemotherapy may help health-care professionals design self-care programmes or interventions to better prepare and manage the adverse effects of chemotherapy. Previous related qualitative reviews focussed on the symptoms experienced during chemotherapy [22], driving and disabling factors for chemotherapy [23, 24], experience and survivorship of patients with breast cancer [25], or the experience of patients with other types of cancer receiving chemotherapy [26]. Although research on the chemotherapy experience during different periods of cancer and treatment with different drugs and across different regions has increased, no qualitative reviews have focussed on the experience and coping strategies of women with breast cancer. By synthesizing the existing evidence, we hope to provide explicit and in-depth evidence of the experience of this population group while undergoing chemotherapy to guide future research. Therefore, we conducted a review focusing on the specific period of breast cancer treatment to understand women's inner thoughts. Specifically, the objectives of this review were to analyse the following questions:

(i) What is the experience of women with breast cancer receiving chemotherapy?

(ii) How do they cope with distress during this process?

(iii) What is the link between their experience and coping strategies?

# Methods

#### Inclusion criteria and exclusion criteria

Studies were included in this review if they were (1) original research, (2) qualitative studies, (3) studies focussed on the perspectives of women with breast cancer reporting their experiences, (4) studies focussed on the experience of chemotherapy and (5) studies written in English. Studies were excluded if they (1) analysed other types of cancer, (2) were

not focussed on chemotherapy or (3) were mixed-method studies or quantitative studies.

# Search strategy

The search strategy (Table 1) aimed to identify published and unpublished qualitative research studies assisted by an evidence-based nursing expert. The search was limited to studies published in the English language. First, an initial unlimited search was performed in PubMed and CINAHL, and an analysis of the title, abstracts and index terms of the resulting articles was then performed. Second, a subsequent search was performed using identified index terms and keywords in the following databases: PubMed (1966-2018), CINAHL (1937–2018), the Cochrane Library (1985–2018), PsycINFO (1887-2018), EBSCO host (1944-2018), Scopus (1823-2018), Embase (1974-2018) and the Web of Science (1900–2018). Third, reference lists of identified articles were searched to find additional studies, including bibliographic searching, reference searching and citation backtracking. Finally, a search for unpublished studies, for example, in OpenSIGLE, Open Grey and the Grey Literature Report by the New York Academy of Medicine Library, was performed

 Table 1
 Search strategy for pubmed

to minimize the influence of publication bias on the findings. The search results and process are illustrated in Fig. 1.

### Assessment of methodological quality

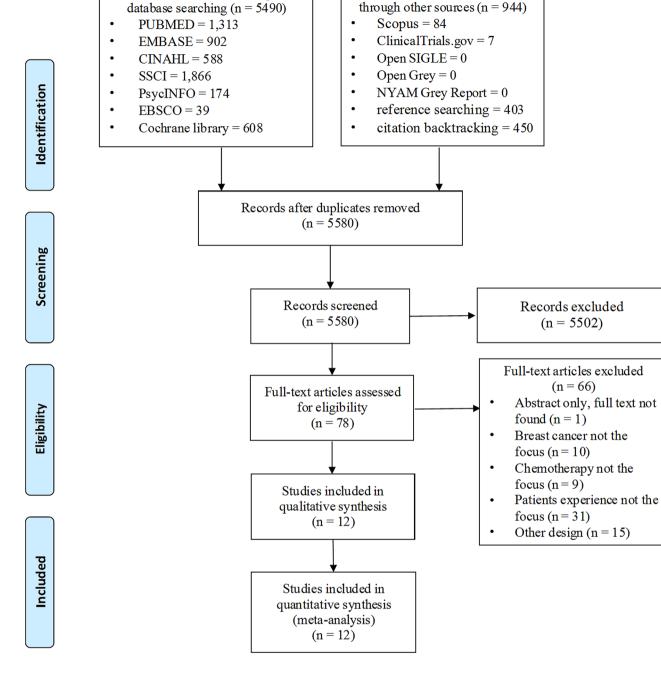
Using the Johanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI), two independent raters (LPL and WLC) read and assessed the full texts of the included studies. A study that answered a minimum of six of ten prompt questions positively was included (or vice versa). Any disagreements that arose between the reviewers were decided through discussion or with the third reviewer. All studies included in the review met the inclusion and study quality criteria.

#### **Data extraction**

Qualitative data were extracted from studies included in the review by two reviewers (YNW and MYH). The extracted information included the bibliographic details, sample age and size, disease stages, numbered findings, data collection methodology, as well as data analysis methodology. Extracted findings together with "Quotations", which form

Search	Query
#1	Search breast neoplasms [MeSH Terms]
#2	Search (breast neoplasm* OR breast malignan* OR breast neoplasm* OR breast cancer* OR breast carcinoma* OR breast adenocarci- noma OR breast tumor* OR breast sarcoma* OR breast lymphedema OR breast dcis OR breast ductal OR breast infiltrating OR breast intraductal OR breast lobular OR breast medullary OR mammary neoplasm* OR mammary malignan* OR mammary neoplasm* OR mammary cancer* OR mammary carcinoma* OR mammary adenocarcinoma OR mammary tumor* OR mammary sarcoma* OR mammary lymphedema or mammary dcis OR mammary ductal OR mammary infiltrating OR mammary intraductal OR mammary lobular OR mammary medullary)
#3	Search (#1) OR #2
#4	Search drug therapy [MeSH Terms]
#5	Search (therap*, drug OR drug therap* OR chemotherap* OR pharmacotherap* OR chemotherapy* protocol* OR antineoplast* agents OR chemotherapy* agents OR antineoplast* protocol*)
#6	Search (#4) OR #5
#7	Search Psychology, Social [MeSH Terms]
#8	Search (social psychology OR psychologies, social OR social psychologies OR need* OR experienc* OR information OR preference OR surviv* OR life OR depression OR anxiety OR distress OR cognitive OR emotion OR feeling OR Loneliness OR fear OR hope)
#9	Search (#7) OR #8
#10	Search qualitative research [MeSH Terms]
#11	Search (qualitative study OR ethnograph* research OR ethnonursing research OR constant comparative method OR observational method OR qualitative validity OR purposive sample OR field study OR phenomenology OR grounded theory OR ethno* OR focus group* OR narrative analys* OR theoretical sampl* OR interview OR content analy* OR field note* OR field note* OR field record* OR field stud* OR semi-structured OR semistructured OR unstructured categor* OR action research OR audiorecord* OR taperecord* OR videorecord* OR qualitative inquiry OR discourse OR methodology* OR life history research)
#12	Search (#10) OR #11
#13	Search (((#3) AND #6) AND #9) AND #12
#14	Search (((#3) AND #6) AND #9) AND #12 Filters: Humans
#15	Search (((#3) AND #6) AND #9) AND #12 Filters: Humans; English

Additional records identified



Records identified through

Fig. 1 Flowchart of the article selection process. (Color figure online)

the first of the three-phased meta-aggregation process, are provided in Online Appendix 1.

# **Data synthesis**

Qualitative research findings were summarized using the standardized data extraction tool from the Joanna Briggs Institute System for the Unified Management, Assessment

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and Review of Information (JBI-SUMARI). Meta-aggregation involves the synthesis or aggregation of findings to generate a set of statements that represent the aggregation through the assembly of the findings rated according to their quality and categorizing these findings based on similarity in meaning. These categories were then subjected to a meta-aggregation procedure to produce a single comprehensive set of synthesized findings that were used as a basis for evidence-based practice. These categories were then mapped according to the principles and framework of Lazarus' Psychological Stress and Coping Theory (Fig. 1).

Two independent reviewers assigned a credibility level to each category based on whether the category was accompanied by a direct quote of a participant and how directly the quote(s) were related to the research question [27]. The credibility level was rated as unequivocal, credible, or not supported (see Table 4 footnotes).

# Results

#### **Study characteristics**

Twelve studies were included in the review [14-17, 28-35]. These included studies were conducted internationally in the USA (n=2), the UK (n=2), Turkey (n=2), Nigeria (n=1), China (n=2), Pakistan (n=1), Sweden (n=1), and Syria (n=1). The sample size ranged from 7 to 30. The total sample of the studies included 184 women aged 22–70 years. The study settings were diverse because of the different countries and varying socioeconomic backgrounds of both the participants and locations. All studies used interviews (n=11) and focus group discussions (n=1) for data collection (Table 2).

The quality ratings of 2 studies were 6/10, of 3 studies were 7/10 and of 7 studies were 8/10 (Table 3). No study was excluded from this review.

# **Results of the synthesis**

We included 12 studies in this review, representing 184 participants. Two independent raters identified 91 themes. These themes were clustered into 8 categories and 3 synthesized findings. A summary of each of these themes and associated studies is provided in Table 2. The three synthesized findings are listed below. (1) Women living with chemotherapy experienced various stressful side effects, and their lives were changed. (2) Supportive care to address needs is essential to help women get through this difficult time. (3) They engaged in numerous types of coping strategies to deal with side effects and adapted to this difficult journey.

In addition, the categories rated as having "unequivocal" credibility included physical problems, psychological discomfort, useful information and decision-making and desired social support. Other categories were rated as having "credible" credibility (Table 4).

# Synthesized finding 1: women living with chemotherapy experienced various stressful side effects, and their lives were changed

A series of painful side effects accompany chemotherapy. Forty-five extracted findings identified that women undergoing chemotherapy experienced various distressful side effects and their lives were impaired. This synthesized finding included four categories: physical changes, emotional distress, cognitive changes and life changes (see Table 4 and Online Appendix 1).

#### **Physical changes**

Although reactions to symptoms and symptom experiences are very individualized, some common symptoms were reported as distressful by most women in this study [15-17, 30-34]. The long duration of the chemotherapy process may cause multiple symptoms, including chemotherapyrelated fatigue, cognitive changes, hair loss, nausea, vomiting, insomnia, bone pain and peripheral neuropathy. Three physical symptoms were predominant in this study: fatigue, cognitive changes and hair loss. Fatigue included a constant sensation of tiredness, a lack of energy, lethargy and weakness that was not alleviated by resting or sleeping. Hair loss was not permanent but constituted a serious detriment to the women's image of themselves. Interestingly, physical symptoms were dynamic; namely, the cycle of illness, recovery and illness as chemotherapy progressed was regarded as having a roller coaster effect.

#### **Emotional distress**

Fourteen findings extracted from eight studies indicated that women with breast cancer experienced a myriad of psychological burdens during the chemotherapy period, such as worry, fear, anxiety, anger, depression, uncertainty and isolation [14, 16, 17, 28, 30, 32, 34, 35]. Four psychological symptoms were predominant: fear, anxiety, depression and sadness. Women feared that the disease would be incurable and that they would be permanently separated from their family. They felt anxious about the changes in their bodies, the loss of independence and the possibility of recurrence in the future. Furthermore, they felt depressed and sad when they blamed themselves for not fulfilling their maternal responsibilities because of the adverse effects of chemotherapy. As they experienced strong psychological strain, they felt powerless and desperate, and some women had suicidal ideation or attempted suicide.

#### Cognitive changes

Although the symptoms were very subtle, the cognitive changes experienced affected their abilities to think clearly. Described as "chemo brain", cognitive changes manifested as (1) difficulty finding words, (2) problems with memory, (3) difficulty in concentrating and paying attention, (4) difficulty organizing and prioritizing problems, (5) fatigue and

<b>Table 2</b> Characteristics of the qualitative studies selected for analysis $(N=12)$	the qualitati	ve studies selected	for analysis $(N=12)$			
First author, Country, Publication date	Sample Age; size	Disease stages Purpose	Purpose	Numbered findings	Data collection methodology	Data analysis methodology
Anarado [28], Nigeria, October 16, 2015	36–66; N=20	Stage II–IV	To explore experiences and nurs- ing support needs of women undergoing outpatient breast cancer chemotherapy in Southeastern Nigeria	Inadequate preparation for chemotherapy Shemotherapy is scary, distress- ing and financially demanding Hope, faith and courage sustained treatment Self-care actions to "weather the storm" Nursing support desired.	Focus Group discussion	Grounded theory approach
Banning [14], Pakistan, January 5, 2009	22-60; N=30	Unclear	To examined the experience and coping strategies used by patients with breast cancer	Family assurance Coping through prayer Feelings of isolation Financial burden of treatment	Semi-structured interviews	Thematic analysis
Beaver [15], the United Kingdom, June 1, 2015	30–67; N=20	Unclear	To explore the experiences of women who received neo-adju- vant chemotherapy for breast cancer	Coping with the rapid transition from "well" to "ill" Information needs Decision-making Needing support and empathy Impact on family Creating a new "normal"	In-depth interviews	Thematic analysis
Boehmke [29], the United States June 20, 2005	32-66; N=20	Stage II–III	To identify symptoms, symp- tom experiences and resulting symptom distress encountered by women with breast cancer receiving current chemotherapy protocols	Symptoms with chemotherapy cycles Severe nausea and hair loss Severe bone pain and peripheral neuropathy Affect on their quality of life and functioning Distressed by the cognitive changes experienced	Taped interviews	Phenomenology
Browall [30], Sweden September 12, 2005	55 to 70; N=8	Unclear	To describe the experience of postmenopausal women with breast cancer who undergo adju- vant chemotherapy treatment	Preconceived notions of the treat- Interview ment Constant worry Physical reminders Psychological reminders Sensory reminders Support from health-care profes- sionals Sharing with others Demands from oneself and others	Interview	Content analysis

Table 2 (continued)						
First author, Country, Publication date	Sample Age; size	Disease stages Purpose		Numbered findings	Data collection methodology	Data analysis methodology
Cebeci [31], Turkey, September 6, 2012	30–47; N=8	Stage II–III	To explores the experience of women living with breast cancer	The need for spouse and family support The need to worship The need to worship information Loss of one's hair Change in ones normal life Change in self-perception Understanding of the value of health Greater appreciation for life	Semi-structured and in-depth individual interviews	Content analysis
Cowley [32], the United Kingdom, May 13, 1999	33-59; N=13	Unclear	To explore women's experiences of adjuvant chemotherapy, and of the risks they faced	Information deficiency about chemotherapy Decision-making on chemo- therapy Uncertainty and fear to chemo- therapy Management strategies Maintain usual roles Concealed their feelings and fears Humour Discount the present The roller coaster effect	Non-standard interview	Grounded theory approach
Gunusen [33], Turkey, May 30, 2013	mean age: 48.84; <i>N</i> =11	Unclear	To identify the experiences of women with breast cancer and the facilitating coping factors while they receive chemo- therapy	Strains factors Coping strategy Social support Positive with treatment Relationships with nurses	Individual semi-structured interviews	Phenomenology
Kanaskie [34], the United States of America, July 20, 2014	42–59; N=7	Unclear	e the meaning and as of cognitive change, pptoms impact roles in and professional lives, women cope with these	Noticing the difference Experiencing cognitive changes Interacting socially Coping Looking forward Lived space Lived body Lived human relationships	Two in-depth semi-structured interviews	Interpretive phenomenology

Table 2 (continued)						
First author, Country, Publication date	Sample Age; size	Disease stages	Purpose	Numbered findings	Data collection methodology	Data analysis methodology
Lai [35], Hongkong (China), March 1, 2017	38–53; N=10	Stage I–III	To understand the experiences of patients with breast cancer and their involvement during outpatient-based chemotherapy in Hong Kong	A sense of uncertainty Information desired Preparation for chemotherapy Lack of confidence Normal life is impaired Behaviour engagement Social engagement Cognitive and emotional strategy Psychological status varied Plan to future Seek solution	Individual interviews	Content analysis
Nizamli [17], Syria, August 31, 2011	N = 17 N = 17	Stage II-IV	To explore the experiences of Syr- ian women with breast cancer regarding their chemotherapy	Negative emotion Body image Depressive symptoms Acute consequences of chemo- therapy General consequences of chemo- therapy Social isolation Lack of marriage opportunities Failure in mother role Failure in sexual relationship	Semi-structured interviews	Content analysis
Chen [16], Taiwan (China) October 13, 2015	N = 20	Stage I–IV	To explore patients' psychological process when receiving initial chemotherapy for breast cancer	Fear of permanent separation from family Fear of chemotherapy Fear of the disease getting worse Physical suffering Mental torment Fight against the disease Adjustment methods Assistance from support systems Relaxation of body and mind Accepting change in their lives	Semi-structured interviews	Grounded theory approach

Table 3Assessment ofmethodological quality usingthe JBI-QARI appraisalinstrument

Studies	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Quality rating
Anarado 2017	N	Y	Y	Y	Y	N	Y	N	Y	Y	7/10
Banning 2009	Ν	Y	Y	Ν	Y	Y	Ν	Ν	Y	Y	6/10
Beaver 2016	Y	Y	Y	Y	Y	Ν	Y	Y	Ν	Y	8/10
Boehmke 2005	Y	Y	Y	Y	Y	Ν	Ν	Y	Ν	Y	7/10
Browall 2006	Y	Y	Y	Y	Y	Ν	Y	Y	Y	Ν	8/10
Cebeci 2012	Y	Y	Y	Y	Y	Ν	Ν	Y	Y	Y	8/10
Cowley 2000	Ν	Y	Y	Y	Y	Ν	Ν	Y	Ν	Y	6/10
Gunusen 2013	Y	Y	Y	Y	Y	Ν	Y	Ν	Y	Y	8/10
Kanaskie 2015	Y	Y	Y	Y	Y	Y	Ν	Y	Ν	Y	8/10
Lai 2017	Y	Y	Y	Y	Y	Ν	Ν	Y	Y	Y	8/10
Nizamli 2011	Y	Y	Y	Y	Y	Ν	Ν	Y	Y	Y	8/10
Chen 2016	Y	Y	Y	Ν	Y	Y	Y	Ν	Y	Ν	7/10

Y yes; N no; U unclear;

Q1. There is congruity between the stated philosophical perspective and the research methodology

Q2. There is congruity between the research methodology and the research question or objectives

Q3. There is congruity between the research methodology and the methods used to collect data

Q4.There is congruity between the research methodology and the representation and analysis of data

Q5. There is congruity between the research methodology and the interpretation of results

Q6.There is a statement locating the researcher culturally or theoretically

Q7. The influence of the researcher on the research, and vice versa, is addressed

Q8.Participants and their voices are adequately represented

Q9.The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body

Q10.Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of data

(6) sensory changes, which created many daily struggles [29–31, 34].

#### Life changes

The symptoms of chemotherapy influence daily life and even the survival of these women [14, 15, 17, 29, 31, 32, 34, 35]. First, the side effects reduced the women's abilities to perform daily activities and their activity levels. Second, as a wife, mother and daughter, women are the keepers of the family and maintain family functioning. Therefore, they experienced role failure when faced with the physical and emotional burdens of treatment. Third, after physical changes in body appearance and self-image, they became extremely sensitive and felt isolated, similar to stigmatization.

# Synthesized finding 2: supportive care to address needs is essential to help women get through this difficult time

As described above, almost all types of patients undergoing chemotherapy face some similar major problems. Studies have focussed on needs for information and social support to assist women in overcoming a list of problems that tend to change and reoccur over time. Twenty-one findings were extracted from six studies that identified that supportive care needs are essential for women to go through this difficult time. This synthesized finding included two categories: the need for information and the need for social support (Table 4 and Online Appendix 1).

#### The need for information

The proactive dissemination of necessary information is important to equip these women with the abilities to better manage their lives, to provide stability and to relieve pressure [15, 28, 31, 32, 35]. The information they indeed needed was related to self-care practices, life-prolonging procedures and disease prognosis and treatment decisions. Most women concluded that the discomfort from chemotherapy was outweighed by the resulting improvement in survival chances, but few of them were allowed to make choices. Moreover, doctors were the major source of information. Other supplementary resources were received from other cancer survivors, books, the internet and friends with similar experiences.

## Table 4 Methodology-meta-aggregation

Synthesized statements	Categories	Study findings	Credibility level <sup>a</sup>
Women living with chemotherapy experi- enced various stressful side effects, and their lives were changed	Physical changes	<ul> <li>16. Symptoms with chemotherapy cycles [29]</li> <li>17. Severe nausea and hair loss [29]</li> <li>18. Severe bone pain and peripheral neuropathy [29]</li> <li>23.Physical reminders [30]</li> <li>34. Loss of one's hair [31]</li> <li>47. The roller coaster effect [32]</li> <li>48. Strains factors [32]</li> <li>59. Lved body [34]</li> <li>74. Body image [17]</li> <li>76. Acute consequences of chemotherapy [17]</li> <li>77. General consequences of chemotherapy [17]</li> <li>85. Physical suffering [18]</li> </ul>	Unequivocal
	Emotional distress	Chemotherapy is scary, distressing, and financially demanding [28] Feelings of isolation [14] 22. Constant worry [30] 24. Psychological reminders [30] 41. Uncertainty and fear to chemotherapy [32] 58. Lived space [34] 62. A sense of uncertainty [35] 70. Psychological status varied [35] 73. Negative emotion [17] 75. Depressive symptoms [17] 82. Fear of permanent separation from family [16] 83. Fear of chemotherapy [16] 84. Fear of the disease getting worse [16] 86. Mental torment [16]	Unequivocal
	Cognitive changes	<ul> <li>20. Distressed by the cognitive changes experienced [29]</li> <li>21. Preconceived notions of the treatment [30]</li> <li>25. Sensory reminders [30]</li> <li>28. Sharing with others [30]</li> <li>36. Change in self-perception [31]</li> <li>53. Noticing the difference [34]</li> <li>54. Experiencing cognitive changes [34]</li> <li>61. Lived human relationships [34]</li> </ul>	Credible
	Life changes	<ul> <li>9. Financial burden of treatment [14]</li> <li>14. Impact on family [15]</li> <li>19. Affect on their quality of life and functioning [29]</li> <li>35. Changes in ones normal life [31]</li> <li>46. Discount the present [32]</li> <li>60. Lived time [34]</li> <li>66. Normal life is impaired [35]</li> <li>78. Social isolation [17]</li> <li>79. Lack of marriage opportunities [17]</li> <li>80. Failure in mother role [17]</li> <li>81. Failure in sexual relationship [17]</li> </ul>	Credible

Synthesized statements	Categories	Study findings	Credibility level <sup>a</sup>
Supportive care to address needs is essential to help women get through this difficult time	The need for information	<ol> <li>Inadequate preparation for chemo- therapy [28]</li> <li>Information needs [15]</li> <li>Decision-making [15]</li> <li>The need to receive and share informa- tion [31]</li> <li>Information deficiency about chemo- therapy [32]</li> <li>Decision-making on chemotherapy [32]</li> <li>Information desired [35]</li> <li>Preparation for chemotherapy [35]</li> <li>Llack of confidence [35]</li> </ol>	Unequivocal
	The need for social support	<ol> <li>5. Nursing support desired [28]</li> <li>6. Family assurance [14]</li> <li>13. Needing support and empathy [15]</li> <li>26. Support from significant others [30]</li> <li>27. Support from health-care professionals [30]</li> <li>30. Demands from oneself and others [30]</li> <li>31. The need for spouse and family support [31]</li> <li>32. The need to worship [31]</li> <li>50. Social support [33]</li> <li>52. Relationships with nurses [33]</li> <li>55. Interacting socially [34]</li> <li>89. Assistance from support systems [16]</li> </ol>	Unequivocal
They engaged in numerous types of coping strategies to deal with side effects and adapt to this difficult journey	Problem- focussed coping strategies	<ol> <li>Coping through prayer [14]</li> <li>Management strategies [32]</li> <li>Humour [32]</li> <li>Coping strategy [33]</li> <li>Coping [34]</li> <li>Cognitive and emotional strategy [35]</li> <li>Adjustment methods [16]</li> </ol>	Credible
	Behaviour coping strategies	<ul> <li>4. Self-care actions to "weather the storm" [28]</li> <li>10. Coping with the rapid transition from "well" to "ill" [15]</li> <li>15. Creating a new "normal" [15]</li> <li>43. Maintain usual roles [32]</li> <li>67. Behaviour engagement [35]</li> <li>68. Social engagement [35]</li> <li>71. Plan to future [35]</li> <li>72. Seek solution [35]</li> <li>87. Fight against the disease [16]</li> </ul>	Credible
	Emotion- focussed coping strategies	<ul> <li>Hope, faith and courage sustained treatment [28]</li> <li>29. Different values [30]</li> <li>37. Understanding of the value of health [31]</li> <li>38. Greater appreciation for life [31]</li> <li>44. Concealed their feelings and fears [32]</li> <li>51. Positive with treatment [33]</li> <li>57. Looking forward [34]</li> <li>90. Relaxation of body and mind [16]</li> <li>91. Accepting change in their lives [16]</li> </ul>	Credible

<sup>a</sup>As defined by Munn ect [26]: Unequivocal—relates to evidence beyond reasonable doubt which may include findings that are matter of fact, directly reported/observed and not open to challenge; Credible—relates to those findings that are, albeit interpretations, plausible in light of the data and theoretical framework. They can be logically inferred from the data. Because the findings are interpretive they can be challenged; Unsupported—is when the findings are not supported by the data

#### The need for social support

Twelve of the extracted findings from five studies indicated that social support, particularly from family members and health-care providers, helped women get through this situation with comfort, safety and happiness [14–16, 28, 30, 31, 33, 34]. First, family, such as parents, children, husbands and siblings, played the most important role in their support systems. Families fulfilled all their needs and boosted their morale to overcome challenges. Furthermore, other support was received from health-care professionals, including preemptive information and health education on chemotherapy, encouragement to face chemotherapy bravely and with a positive attitude and the provision of regular physical care and emotional support. Finally, any source that improved mental energy might be considered a support system, such as encouragement from friends, shared experiences with other patients and spiritual comfort from religion.

# Synthesized finding 3: they engaged in numerous types of coping strategies to deal with side effects and adapt to this difficult journey

Coping strategies often vary from person to person and evolve during chemotherapy. The coping strategies used depend on the patient's personal coping style or nature, personal symptom experience, the need to control symptoms, the way they deal with challenges, how their life was affected by chemotherapy, their knowledge and beliefs, the way they manage their symptoms and their personal goals and different cultural backgrounds. Twenty-eight findings extracted from six studies indicated that women with breast cancer engaged in effective coping strategies to deal with chemotherapy. According to Lazarus' Stress Adaptation Theory, coping is the cognitive and behavioural effort to understand, minimize or endure the inner and outer demands that develop as a result of stressful situations. This synthesized finding included three categories: problem-focussed coping strategies, behavioural coping strategies and emotionfocussed coping strategies. These strategies aimed to reduce distress and increase optimal coping strategies in women with breast cancer undergoing chemotherapy (Table 4 and Online Appendix 1).

#### Problem-focussed coping strategies

Twelve of the extracted findings from five studies indicated that many women with breast cancer engaged in problemfocussed coping strategies to control and address problems related to the side effects of chemotherapy [32–35]. The process may include identifying distressful events, making assessments, finding solutions and solving problems related to a particular scenario. During the chemotherapy process, the women identified strategies to prevent, manage, or eliminate side effects. For example, they adjusted their diet and monitored their nutrition and food intake to solve appetite problems.

#### Behavioural coping strategies

Seven of the extracted findings from six studies identified that behavioural coping strategies were an important part of coping strategies [15, 16, 28, 32, 35]. Behavioural coping strategies aimed to ensure that their mind remained sharp, mobilize them to cope with side effects, and maintain a normal life during the chemotherapy process. First, the abilities to maintain hope and bravely fight the disease helped them accept chemotherapy. Second, religion was an effective selfcare strategy to boost physiological, emotional, social, or spiritual well-being in some cultures. Third, women tried to maintain their usual roles, such as a wife, mother and employee.

#### **Emotion-focussed coping strategies**

Emotion-focussed coping strategies are effective coping strategies aiming to reduce distress and minimize psychological discomfort from chemotherapy. Eleven of the extracted findings from seven studies showed that women with breast cancer described various emotion-focussed coping strategies during chemotherapy, including crying to release all heavy burdens, focusing on the positive, accepting reality, maintaining a sense of humour, being hopeful and faithful, trying to think less, denial, diverting attention to another thing and concealing their feelings, among others [14, 16, 28, 30, 31, 33, 34]. In addition, as the adverse effects of chemotherapy gradually subsided, the patients began to make an effort to maintain a normal and peaceful life, such as understand-ing the value of health, enjoying their life, planning for the future and going back to work.

#### Proposed model: patients' experience of chemotherapy

The proposed model reveals the themes and subthemes arising from the thematic synthesis, as presented in Table 4. The themes that describe the nature of women's experiences during chemotherapy and how these themes are related are shown in Fig. 2. These themes will be elaborated in more detail in the discussion.

# Discussion

This study developed three synthesized findings reflecting the experience and coping strategies of women with breast cancer undergoing chemotherapy. The synthesized

# Experience of women with breast cancer receiving chemotherapy

The first synthesized statement more generally overlapped with the stressful experiences of women with breast cancer receiving chemotherapy. The personal symptom experience was complex and dynamic, and each patient experienced different symptoms daily during the new treatment cycle.

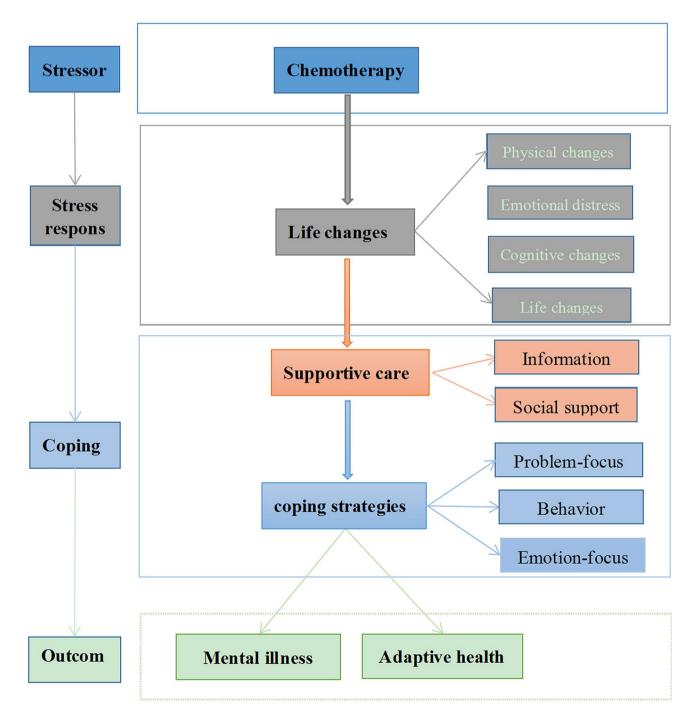


Fig. 2 Principles and framework of Lazrus's pshychological and copying theory. (Color figure online)

However, we identified some common symptoms based on our research. In our review, the common physical symptoms were fatigue, cognitive changes, hair loss, nausea, vomiting, insomnia, bone pain and peripheral neuropathy, which were slightly different from common side effects reported in a previous study conducted in a Southeast Asian setting [36]. In that study, the five most prevalent physical symptoms were fatigue, dry mouth, hair loss, drowsiness and a lack of appetite, and the most distressing symptoms were fatigue, loss of appetite and changes in food taste. However, the differences in the two results may be attributed to the analysis of patients from two countries with different stages of the disease, receiving different types of chemotherapy and different ages. A symptom has a range of physical, psychological, family and social effects. Thus, women with breast cancer may experience a series of physical symptoms resulting from chemotherapy. Any symptom may exert multidimensional effects; namely, a physical manifestation of side effects from chemotherapy may exert profound effects on other aspects of health. In addition, the impact of physical symptoms on daily life is not merely determined by the characteristics of the individual and their beliefs, knowledge and expectations of chemotherapy but also by their identity, roles in family and social networks, future perspectives and the support received in this phase [37].

The second synthesized statement showed that a support network is essential for women to better cope with chemotherapy. In this review, the most important types of support were information and social support. In addition, social support is a type of practical support provided by family, friends, health-care professionals, or anyone in society that makes the individual feel safe and loved. Social support plays an important part in decision-making and survival/ coping strategies, which exerts beneficial effects on social well-being and the quality of life in stressful situations [38, 39]. These findings are consistent with previous studies reporting that patients who undergo chemotherapy tend to emphasize common interpersonal stressors (e.g. providing and caring for family, and distance from family) and social/ structural stressors (e.g. economic problems, and lack of information) [40].

Coping strategies are stated to be effective if they lead to good adaptation and a new pattern of life, while ineffective strategies may lead to health problems. In the present study, problem-focussed coping strategies, behavioural coping strategies and emotion-focussed coping strategies were effective strategies that reduced the severity of symptomrelated distress and enabled the patients to gain control of their lives [41–43]. Problem-focussed coping strategies aim to analyse and explore the causes of stressful events, seek relevant information and social support, eliminate or solve problems, set goals and change personal expectations. Emotion-focussed coping strategy responses are not aimed at solving problems directly but at changing a person's thoughts, such as crying, denial, acceptance, hopeful thinking, a sense of humour, attention diversion and avoidance. Behavioural coping strategies, such as remaining hopeful, understanding and following the instructions for self-care, always checking in with themselves to ensure good health and trying to maintain one's normal role in life, are strategies that may improve patient quality of life and help them cope with adverse symptoms [44].

# The link between experience of chemotherapy and coping strategies

This systematic review has highlighted the link between the chemotherapy experience and coping strategies (see Fig. 2). Chemotherapy is an external stressor for women with breast cancer, which leads to various physiological and psychological side effects (fear, stress, anxiety, and depression). This stress motivates individuals to seek coping strategies that will prevent further psychological disorders and maintain psychological well-being. This finding is consistent with the views of previous studies [41, 43, 45]. A quantitative study by Sari [41] showed that adequate social support and effective coping strategies significantly reduce the symptom-related distress of patients undergoing chemotherapy. In addition, another study by Chirico [46] found an inverse relationship between self-efficacy for coping and distress from chemotherapy and a positive relationship between selfefficacy for coping and quality of life.

Moreover, we found that the results of this review matched the Contextual Model of Lazarus' Stress and Coping Theory, which was helpful in describing and organizing the results. This theory is a system for assessing the process of coping with stressful experiences. Stressful encounters are interpreted as individual-environment transactions, which depend on the impact of the external stressor [47, 48]. All individuals have resources and skills known as coping mechanisms that are used to relieve stress. Anything that causes stress endangers life, unless it is met by adequate adaptive responses; conversely, anything that endangers life causes stress and adaptive responses [49]. The application of this theory would allow nurse practitioners to include a plan to relieve patient stress and to incorporate this plan into short-term goals with the aim of ensuring safety. The ability of patients to successfully complete chemotherapy depends on their coping skills, which will decrease stressors and allow the patient to move towards a more positive outlook and lifestyle.

#### Implications for practice

The synthesized findings from this meta-aggregation the Lazarus stress and coping theory provide some clear recommendations for intervention development and practice for patients to cope with chemotherapy. First, health-care professionals must scientifically and systematically assess real supportive care needs for woman with breast cancer undergoing chemotherapy and proactively provide specific information about the disease prognosis, chemotherapy regimen and potential side effects. Second, information support system and social support groups integrated in the routine procedures offered by nurses and other health-care providers should be established. For example, continuity of care by breast cancer nurses is needed throughout the duration of chemotherapy. Third, the development of pre-chemotherapy care programmes that include specific and focussed preparatory material to reduce the treatment distress level and increase adaptive coping are needed.

### Strengths and limitations of the study

This systematic review and meta-aggregation of qualitative studies is the first to describe the experience and coping strategies of women with breast cancer undergoing chemotherapy. This study developed a comprehensive search strategy and an explicit and clearly reported quality assessment of the included studies and data extraction and synthesis process. The studies included in this review were conducted in eight countries, and these international studies make the results more convincing. In addition, the meta-aggregation also provides valuable insights into the work of nursing researchers and nursing administrators in related areas and identifies many potential areas for the development of further interventions and future research.

However, there are some limitations that should also be noted: First, because of the language limitations, a number of high-quality non-English studies might have been missed. Second, the systematic review protocol used in this study was not registered in Prospero prior to the study. Third, meta-aggregation is an interpretative process in which different teams studying the literature may produce different interpretations. Fourth, the experiences and coping strategies among women of different races and cultures, treated with different chemotherapy regimens and with stages of breast cancer may vary, but we were unable to conduct the analysis separately in this review because of the failure to obtain complete related data from most of the original studies. Therefore, the results from this study are relevant for some but not all patients.

# Conclusions

This review is among the first to synthesize the literature of the experience and coping strategies of women with breast cancer undergoing chemotherapy based on the Contextual Model of Lazarus' Stress and Coping Theory. According to the existing literature, we concluded that when women experienced various stressful side effects, supportive care to address needs and effective coping strategies are essential to help them adapt to this difficult journey. We recognized the need to develop pre-chemotherapy care programmes, information support systems, social support groups and individual effective coping strategies to reduce chemotherapyrelated distress levels and enhance self-care at home.

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#### **Compliance with ethical standards**

**Conflict of interest** The authors declared that there is no conflict of interest to disclose.

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