

An exploration of the effects of information giving and information needs of women with newly diagnosed early-stage breast cancer: A mixed-method systematic review

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Abstract

Aim: To review the information needs of women with newly diagnosed early-stage breast cancer and the effects of information giving by measuring patient-reported outcomes.

Design: A mixed-method systematic review using PRISMA guidelines.

Methods: The major electronic nursing databases were searched from inception until 31 December 2019 using key terms. Included studies were assessed using the Crowes Critical Appraisal Tool.

Results: Four quantitative studies and two qualitative studies, comprising of 537 participants (age range from 25 to 98 years), were included for the ultimate qualitative synthesis of this review. There was high-level evidence that demonstrated the prevalence of these groups of women's information needs and their improvement in fighting spirit and decrease in helplessness/hopelessness for information giving interventions; low-level evidence of long-term adjustment and well-being improvement; and limited evidence indicating that inadequate information, including restricted information, too much information and conflicting information could cause some ramifications.

KEYWORDS

early-stage breast cancer, females, information giving, Information needs, patient-reported outcomes, systematic review

1 | INTRODUCTION

Breast cancer (BC) is the most common cancer among women worldwide with a relatively favourable prognosis (Bray et al., 2018). The status quo of BC in China differs from developed countries in various aspects. Firstly, BC is the leading cause of cancer-related death among women in Western countries (Bray et al., 2018); whereas, in China, it is the fifth cause of death among types of cancer (Wu et al., 2019). Secondly, although the prognosis of BC in China has

been improved significantly, the survival rate is still lower than that in developed countries. The five-year survival rate of BC in the United States, according to the data from those diagnosed with BC from 2008 through 2014, is 90.9% (Siegel et al., 2019). In the UK, figures of 2010–11 have shown that about 87% of women survive their disease for 5 years or more (Cancer Research UK, 2018). However, in China, the average of BC five-year survival rate is 83.2% during 2010–14 nationwide; even in Beijing, the capital of China and one of the most developed cities, this figure is 86.8%; and in some

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rural areas, it is even lower than 60% (Allemani et al., 2018). One further difference of BC between in China and in Western countries is the age of diagnosis. In China, young patients (under 40 years old) account for approximately 20% of the total cases (Li et al., 2011), whereas this ratio is lower than 7% in Western countries (Dieng et al., 2014). In addition, the most commonly diagnosed age group of BC incidence in China is 40–50 years old and the mean age is 48–49 years, which is about 8 to 10 years younger than that reported in developed countries (Li et al., 2011, 2016).

Early-stage BC, defined as cancer that has not spread beyond the breast or nearby lymph nodes, includes “ductal carcinoma in situ and stage I, stage IIA, stage IIB and stage IIIA breast cancers” (National Cancer Institute (NCI), 2019). Women diagnosed at the early stage of BC are generally treated as a specific group of people with a chronic disease. This is because early-stage BC is now perceived as probably curable with surgery, although it is still with potential risk of recurrence, and patients need to undergo adjuvant therapies after surgery to reduce the risk of cancer returning (Harbeck & Gnant, 2017). As a chronic disease, uncertainty in BC patients and information needs are ongoing issues, which may continually affect women's adjustment competence and quality of life (QoL) (Hagen et al., 2015). Indeed, research has demonstrated that patients newly receiving a cancer diagnosis would require informational support most urgently (Dieng et al., 2014).

Health information related to BC diagnosis and its treatment is crucial for women. Evidence shows the importance of information giving for people confronting a cancer diagnosis, which may comprise obtaining control, reducing anxiety, coping with stress, improving patients' compliance and participation, creating realistic expectations and engendering a sense of safety and security (Mills & Sullivan, 1999). Moreover, according to Matsuda et al. (2014), psychoeducational interventions involving psychological and educational support could help women with early-stage BC in improving knowledge about the disease and treatment; assist them to improve their physical well-being and functional adaptation; raise their emotional adjustment and coping abilities; encourage them to decrease the incidence of symptoms and to prolong the length of survival; and eventually be beneficial to enhancing their overall QoL. However, although awareness of the significance of information provision has increased, the unsatisfied patients' information needs can still be commonly seen in clinical settings, which may cause poor healthcare outcomes (Halbach et al., 2016).

Traditionally, healthcare workers have taken responsibility for providing BC patients with relevant health information directly, in the form of face-to-face talking or offering the information pamphlets. Such pamphlets, however, even though filled with reliable health information, are often not so useful at the initial phase of facing a cancer diagnosis, because women are generally in a confused state of mind at that time (Williams & Jeanetta, 2016). Furthermore, communication between patients and healthcare professionals is not always successful for many reasons, such as uncomfortable settings, the use of expert language or lack of time (Hemsley et al., 2012). Thus, patients often appear ill-informed or not fully understanding of such

information, particularly when they are asked to participate in making treatment-related decisions together with healthcare workers and to assume corresponding responsibilities (Obeidat et al., 2011).

In order to better understand the disease of BC itself and the information provided by healthcare professionals, patients may research online by themselves, which is more often for younger females who may be more skilled at online technology (Balka et al., 2010). The quality of the current online health information related to BC is usually reliable, especially from the websites built by the government or those non-profit providers; hence, both patients and healthcare workers regard the Internet as a major source of health information in recent years (Arif & Ghezzi, 2018; Nghiem et al., 2016). In fact, almost 35% of the US population and more than 50% in the EU search for online health information frequently (Fox & Duggan, 2013). Despite this, studies show that the Internet sourced information from the contemporaneous but unregulated websites have poor accuracy; and unfortunately, it is challenging for patients to find websites with applicable and appropriate information by wide Internet searches (Arif & Ghezzi, 2018). Consequently, although BC-related health information is available in various ways, patients' needs for accurate and timely information are still not satisfied.

Therefore, although information provision has been improved significantly during the past few decades, there is still a gap for meeting patients' information needs in cancer care that healthcare professionals should be aware of. Since prior reviews on cancer patients' information needs often focused on the general population with cancer, a review specifically for women with BC may be needed. This is because patients' information needs can be affected by various factors, such as gender, age, educational levels, occupations and cultural diversity; types and stage of cancer, or rather, chances of cure and recovery; and patients' coping styles (Khoshnood et al., 2019).

2 | AIMS

The aims of the present review were to investigate the information needs of women who have been newly diagnosed with early-stage BC and to explore the effects of information giving by assessing the patient-reported outcomes. Males were excluded in this study, because the incidence of BC in males is so low (less than 1%) that most of the present evidence of these patients is based on small and single-centre studies (Gucalp et al., 2019). Throughout the present review, information giving is defined as all related information for women with newly diagnosed early-stage BC, which is provided by healthcare providers, especially by nurses, in oral, written or other forms.

3 | METHODS

As patient-reported outcomes naturally incorporate a great deal of qualitative description and quantitative assessment, a mixed-method systematic review that comprised quantitative and qualitative studies was conducted. The present review was reported according to

the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009) (File S1).

3.1 | Literature search

To identify relevant studies, electronic searches were conducted in several databases, including EBSCOhost CINAHL Complete, MEDLINE, PsycARTICLES and PsycINFO, Web of Science and PubMed. The search was limited to the period from January 2009 through December 2019. Synonyms of keywords were considered to find the appropriate articles; search terms were used with Boolean operators “OR” and “AND” to locate articles from the databases (Tables 1 and 2).

Other resources were used to search relevant but unpublished evidence, involving Open Grey, searching with “Patient education for women with breast cancer” (2009–2019); ClinicalTrials.gov, searching with PIO framework; and BRITISH LIBRARY ETHOS e-theses online service. Finally, manual reviews of reference lists were conducted throughout the review process to identify relevant articles for inclusion.

3.2 | Inclusion and exclusion criteria

Studies were included if they met the following inclusion criteria: 1) published in English for which full text was available; 2) specifically focused on women with newly diagnosed early-stage BC, with no more than one cancer, no recurrence or metastases, no evidence of additional diseases and no age limitation; 3) focused on information needs and reported the data incorporating the effects of any means of information giving; 4) used subjective and/or objective measures to report the data, including women's perception or experiences of information needs, or statistical outcomes such as anxiety, depression, quality of life or adjustment and coping.

TABLE 1 Terms of literature search strategy with PICO framework

Population	Intervention(s)	Outcome(s)
OR Female*	AND	Information giving
OR Women	AND	Information provision
OR Breast cancer	AND	Patient education
OR Breast neoplasms	AND	Preoperative nursing
OR Breast tumour	AND	Preoperative visit nursing
OR Breast carcinoma	AND	Nursing intervention*
OR Breast malignancy	AND	Educational intervention*
OR Early breast cancer	AND	Psychoeducational intervention*
OR Early-stage breast cancer		
OR Operable breast cancer		

Note: The limiters of searching strategies are “Published from 01 January 2009 onwards” at first and then are “English Language” and “full text.” Expanders are to “Apply related words.” Search modes are Boolean/Phrase.

*These terms (the key words) have been used both in their singular and plural forms in the process of literature search.

3.3 | Literature selection

The eligible full-text studies were selected after the results of the literature search had been identified.

3.4 | Quality assessment of the included studies

The Crowe Critical Appraisal Tool (CCAT), developed by Crowe and Sheppard (2011), was used to assess the risk of bias within the included studies. Comprising eight categories (Preamble, Introduction, Design, Sampling, Data collection, Ethical Matters, Results and Discussion) and with description of items for each category, this instrument has indicated the validity and reliability for the assessment of qualitative and quantitative studies within a mixed-method review (Crowe et al., 2012).

3.5 | Data extraction

Elements of data extraction, such as authors (year), study design, country, setting, sample, age, educational level, diagnosis, religious beliefs, description of intervention characteristics, outcome measures and key findings of the study, were included.

3.6 | Data analysis and synthesis

The Joanna Briggs Institute mixed-method synthesis of the findings was used to analyse and synthesize the data. This approach, based on the Bayesian meta-analysis, translates the findings of the initial quantitative synthesis into qualitative themes firstly, then pools these themes with the findings of initial qualitative synthesis (Pearson et al., 2015).

TABLE 2 Terms of literature search strategy with PEO framework

Population	Exposure	AND	Outcome(s)
OR Female*	Breast cancer	AND	Information needs
OR Women	Breast neoplasms		Information seeking
OR	Breast tumour		Information-seeking behaviours
OR	Breast carcinoma		Health information needs
OR	Breast malignancy		Health information seeking
OR	Early breast cancer		
OR	Early-stage breast cancer		
OR	Operable breast cancer		
OR	Diagnosis		
OR	Surgery		

Note: The limiters of searching strategies are “Published from 01 January 2009 onwards” at first and then are “English Language” and “full text.” Expanders are to “Apply related words.” Search modes are Boolean/Phrase.

TABLE 3 Records of database search

Databases (With the Limiter of Published from 01 January 2009 onwards)	PICO	PEO
CINAHL complete	182	209
MEDLINE	125	369
PsycARTICLES and PsycINFO	12	25
PubMed	256	829
Web of science	175	278
Total	750	1,710
Additional records identified through other sources	4	
Duplicates removed (using the EndNote, version X9)	1,820	

4 | RESULTS

4.1 | Study selection

The electronic database search yielded a total of 2,464 titles and abstracts for screening. Manual searches of reference lists did not find any extra studies. Following removal of duplicates with the assistance of EndNote X9, 1,820 papers were left altogether (Table 3). After screening the titles and abstracts using the inclusion criteria, 25 papers were included for full-text screening, wherein 19 were extracted (Figure 1). Therefore, six studies were included for the final analysis.

4.2 | Description of characteristics of the included studies

In these six included studies, four were quantitative studies and two were qualitative studies. It could be worthy to highlight

that the following three papers, Drageset et al. (2010), Drageset et al. (2011) and Drageset et al. (2012), were scrutinized thoroughly because of the duplicate authors. After analysing and comparing the study designs, characteristics of the participants and methods of data collection, it could be seen that these studies were all conducted in Norway, with 21 Norwegian women as participants; and the data were “collected from February 2006 to February 2007,” “in the hospital on the day before surgery, and before preoperative information.” Therefore, it was reasonable to state that these three papers were published based on the same study. Consequently, to avoid participant duplicates in the present review, two of these papers were excluded (Figure 1). However, results reported in these two excluded articles that related to the topic of the present review were used as additional evidence in the discussion section.

There were 537 women in total across the 6 studies, with 27 dropouts for various reasons (such as unwillingness to participate or side effects). All participants had early-stage BC with no metastases or recurrence at the time of the studies. The four quantitative studies had sample sizes ranging from 47 to 249. Sample sizes of the two qualitative studies were 21 (Drageset et al., 2010) and 28 (Obeidat & Lally, 2014), respectively. Age of the participants except for the dropouts ranged from 25 to 98 years old. One of the studies (Sherman et al., 2012) particularly mentioned participants' religious preference. Other individual characteristics of the participants, especially their levels of education, which may directly affect the information needs, were presented (Table 4).

Tables 5 and 6, respectively, show the summary of intervention characteristics in the included studies; the outcome measures used by quantitative studies, including subjective measures and objective descriptors with the evaluation of patient-reported outcomes; and women's experience of being diagnosed with early-stage BC in the two qualitative studies, including these women's information needs of the disease and its treatment, their responses to the diagnosis and surgery, and their coping attitudes.

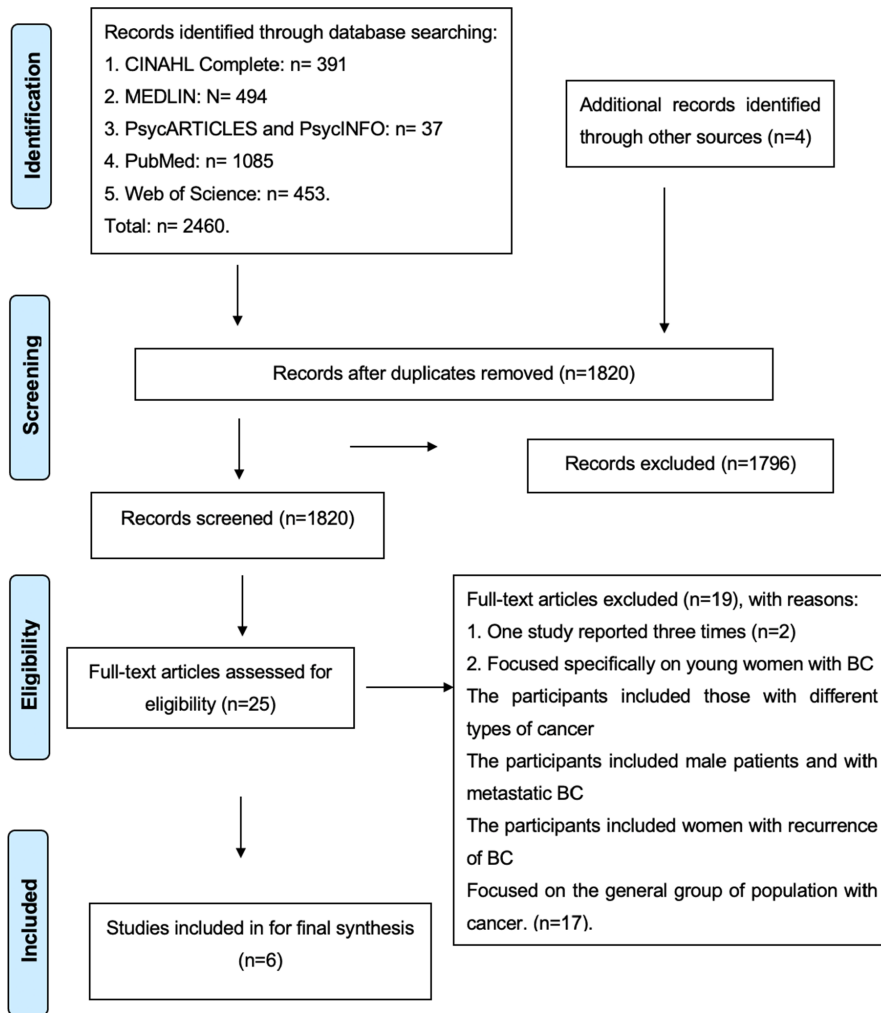


FIGURE 1 Study selection process using the PRISMA Flow Diagram (Moher et al., 2009)

4.3 | Quality assessment of the included studies

Quality was assessed on a scale from 0 to 5, with 5 denoting high quality (Table 7). Reasons for downgrading the quantitative study scores in the category of Design were mainly due to their limited information on intervention delivery and how such intervention was tailored to individual participants (Andreis et al., 2018; Foley et al., 2016). For the pilot trial of Foley et al. (2016), since the sample size was too small, the unequal allocation between the experimental group ($n = 13$) and the control group ($n = 26$) was perceived as a critical factor of the study outcome, thus affecting the score in Design category. Moreover, a lack of description of participant characteristics, especially their educational levels, which may be one of the key factors in information needs, was noted for the two studies of Dastan and Buzlu (2012) and Foley et al. (2016). The time for data collection and its impact on the result were taken into account for the two studies by Foley et al. (2016) and Drageset et al. (2010). The Sampling category scores of the included studies were affected by poor reporting of sampling methods and lack of elaboration on the strategies of recruitment.

4.4 | Main findings from data synthesis

Table 8 shows the main findings after data synthesis of the included studies. Altogether, the six studies demonstrated women's responses to the diagnosis of early-stage BC, their coping strategies to the disease and relevant treatments, their information needs at different phases (from receiving the diagnosis to the ongoing recovery) and the effects of various types of information giving. These studies have revealed that receiving a diagnosis was one of the most critical moments for women and individuals had different responses to it. According to data synthesis, women's reaction to being diagnosed with the early-stage BC could be classified into either positive or negative aspects. The positive reaction may include fighting the disease (Dastan & Buzlu, 2012; Foley et al., 2016), seeking information, focusing on the positive aspects, enjoying life and doing those positive or meaningful things (Drageset et al., 2010). The negative reaction may involve avoidance, denial, helplessness, hopelessness, anxious preoccupation (anxiety/depression), fatalism and/or pushing rumination about the disease away (Dastan & Buzlu, 2012; Foley et al., 2016). In addition, the information sources were diverse.

TABLE 4 Characteristics of the participants and designs of the included studies

Authors (Year)	Study design	Country	Setting	Sample	Age (Y)	Educational level	Diagnosis
Andreis et al. (2018)	Observational study (Quantitative study)	Italy	Medical Oncology Unit	N0 = 104 N1 = 7 N2 = 97	Range: 25–68 M = 45.8	L1 = 29 L2 = 52 L3 = 16	BC with no recurrence or metastases
Dastan and Buzlu (2012)	RCT	Turkey	Outpatient clinic	N0 = 88 N1 = 12 N2 = 76	I: M = 50.42 (N2 = 38) C: M = 46.13 (N2 = 38)	-	BC in stage I-II
Foley et al. (2016)	RCT; Pilot study	Ireland	Hospital-based settings; home	N0 = 47 N1 = 8 N2 = 39	I: Range: 49.5–61.5, M = 54 (N2 = 13) C: Range: 44–64, M = 52 (N2 = 26)	-	Operable BC
Sherman et al. (2012)	RCT	USA	Hospital-based settings; home	N2 = 249	Range: 33–98 M = 53.8	L2 = 48 L3 = 149 L4 = 7 Unclear=45	Early-stage BC
Drageset et al. (2010)	Qualitative study	Norway	Hospital	N2 = 21	Range: 41–73 M = 54	L1 = 5 L2 = 9 L3 = 7	Operable BC
Obeidat and Lally (2014)	Qualitative study	Jordan	Clinical settings; home	N2 = 28	Range: 29–70 M = 48.5	L1 = 6 L2 = 11 L3 = 11	Early-stage BC (Clinical stage 0–II)

Note: Sample: N0 = participants, N1 = withdrawals, N2 = final population within data collection; BC = breast cancer; age: M = median age or mean age, Y = years; I = intervention group, C = control group; educational level: L0 = elementary school, L1 = secondary school, L2 = high school (with or without diploma), L3 = college/university (with or without degree), L4 = postgraduate degree; (-): data not available; RCT = randomized control trial.

TABLE 5 Characteristics of the interventions or exposure of the included studies

Authors (Year)	Description of intervention characteristics	
	Experimental Group(s)	Control Group
Andreis et al. (2018)	From October 2010 to September 2016, a psychological and information support programme with 13 support groups was organized into 8 meetings, which provided women with adequate information that helped them to distinguish false beliefs in BC, to strengthen their knowledge and to cope with changes caused by cancer and medical treatments. Each meeting conducted every 15 days and lasted 2 hr.	No control group
Dastan and Buzlu (2012)	A psychoeducation programme that consisted of education and support was conducted. The psychoeducation was presented through 265 slides with the use of images in Microsoft PowerPoint, including sessions of basic information, nutrition, psychosocial factors, coping with cancer, interpersonal relationships and problem-solving. Patients were encouraged to share their thoughts, experiences and feelings about the disease and to help each other mutually. In addition, 5 people with a history of BC were invited to share their stories and experiences.	No programme
Sherman et al. (2012)	There were three intervention groups. Group 2: received usual care plus four phase-specific psychoeducational videos. Group 3: received usual care plus a telephone counselling intervention. Group 4: received usual care plus four phase-specific psychoeducational videotapes and telephone counselling. The psychoeducational videos included four themes, with three topics for each theme. Four themes: Coping with Your Diagnosis, Recovering from Surgery, Understanding Adjuvant Therapy and Your Ongoing Recovery. Three topics for each theme: Health Relevant Information, Information for Skill Development and Psychosocial Support. Purposes of the telephone counselling included: 1) reduce anxiety, 2) shape reality-based appraisals, 3) facilitate attainment of support, 4) process information, 5) encourage adaptive behavioural change, 6) promote functional communication and 7) promote reintegration of a holistic concept of self.	Group 1: With usual care neither psychoeducational videotapes nor telephone counselling; but educational information was available.
Foley et al. (2016)	An Apple iPad with a specifically developed application was provided to each patient a week before her BC surgery. Tailored information about individual patient's specific type of operation was released only through the application. The iPads were requested to return one week postoperatively at patients' routine outpatient's appointment.	Standard information group
Authors (Year)	Description of exposure	
Drageset et al. (2010)	To describe coping strategies used by women between diagnosis of BC and surgery, the interviews were conducted in the hospital on the day before surgery and before preoperative information. The interviews lasted 97 min on average.	
Obeidat and Lally (2014)	To understand the impact of early-stage BC diagnosis and surgical treatment experiences for Jordanian women, a native Arabic speaker and a female nurse conducted interviews from October 2010 to January 2011, either in the clinical settings or in the women's home. The interviews lasted from 15 min to 90 min.	

The majority of women most frequently received information from communication with healthcare professionals, including surgeons, physicians and nurses (Sherman et al., 2012). Among these studies, however, television was women's most commonly used source of BC knowledge (Obeidat and Lally, 2014); moreover, 13 women gained personalized information from the internet by using an iPad tablet device containing a specialized application that was provided to the study's participants (Foley et al., 2016). Due to this diversity, individuals' information needs and their attitudes towards the information they received were different.

Within these studies, most of the participants were satisfied with the information they received or expressed their satisfaction

of attending the educational programmes; meanwhile, few women considered that the information they received was too much (patients in the iPad group of the study of Foley et al., 2016), poor (two patients in the control group in the study of Foley et al., 2016), or limited or inadequate (Obeidat and Lally, 2014).

5 | DISCUSSION

The present review examined information needs of women with early-stage BC and the effects of information giving for them in the period from awaiting surgery to subsequent treatment. After

TABLE 6 Outcome measures of the included studies and key findings

Authors (Year)	Outcome measures	Data collection	Key findings
Andreis et al. (2018)	BIS; HADS	T0: at the beginning of the meetings T1: at the end of the meetings	<ol style="list-style-type: none"> Satisfaction/Dissatisfaction with the body: T0, 54%/46%; T1, 55%/45%; the most dissatisfied aspect "embarrassment for body image" ("quite a little" and "very much"): T0, 61%; T1, 92%; the least problematic aspect "social interaction" ("not at all" and "a little"): T0, 79%; T1, 83%. The HADS: 1) Levels of anxiety: scores ≥ 11: T0, 20%; T1, 19%; scores 8–10: T0, 32%; T1, 29%; scores ≤ 7: T0, 48%; T1, 52%; no statistically significant difference. 2) Levels of depression: scores ≥ 11: T0, 10%; T1, 6%; scores 8–10: T0, 20%; T1, 18%; scores ≤ 7: T0, 70%; T1, 76%, an improvement from T0 to T1 ($p = .040$).
Dastan and Buzlu (2012)	MAC Scale	T0 (1st time): baseline, before the intervention T1 (2nd time): Assessment at 6 weeks T2 (3rd time): Assessment at 6 months	<ol style="list-style-type: none"> Sub-dimension analysis (in mean scores) within the I (intervention group) <ol style="list-style-type: none"> "fighting spirit" and "avoidance/denial": a significant increase "Fighting spirit": T0, 50.6 ± 5.23; T1, 53.5 ± 4.77; T2, 54.13 ± 3.93; $p = .006$. "Avoidance/denial": T0, 2.26 ± 0.94; T1, 2.57 ± 1.08; T2, 2.60 ± 0.97; $p = .001$. "anxious preoccupation" and "fatalism": a significant decrease "Anxious preoccupation": T0, 25.50 ± 3.71; T1, 21.39 ± 3.27; T2, 19.42 ± 3.71; $p = .015$. "Fatalism": T0, 19.18 ± 3.36; T1, 17.81 ± 2.89; T2, 16.73 ± 2.50; $p = .058$. "helplessness/hopelessness": no significant difference. Sub-dimension analysis (in mean scores) between the two groups <ol style="list-style-type: none"> "Fighting spirit": a significant increase T0. I: 50.6 ± 5.23, C: 51.36 ± 4.93, $p = .683$; T1. I: 53.5 ± 4.77, C: 43.31 ± 4.14, $p = .000$; T2. I: 54.13 ± 3.93, C: 38.05 ± 4.73, $p = .000$. "helplessness/hopelessness," "anxious preoccupation" and "fatalism": a significant decrease "Helplessness/hopelessness" T0. I: 12.47 ± 2.53, C: 10.55 ± 2.69, $p = .324$; T1. I: 10.47 ± 2.25, C: 14.28 ± 2.60, $p = .000$; T2. I: 10.00 ± 2.16, C: 12.42 ± 2.21, $p = .000$. "Anxious preoccupation" T0. I: 25.05 ± 3.71, C: 23.47 ± 4.03, $p = .189$; T1. I: 21.39 ± 3.27, C: 26.89 ± 3.23, $p = .000$; T2. I: 19.42 ± 3.71, C: 26.86 ± 3.37, $p = .000$. "Fatalism" T0. I: 19.18 ± 3.36, C: 18.92 ± 4.58, $p = .123$; T1. I: 17.81 ± 2.89, C: 19.97 ± 2.99, $p = .002$; T2. I: 16.73 ± 2.50, C: 22.28 ± 2.75, $p = .000$. "avoidance/denial": no significant difference.

(Continues)

TABLE 6 (Continued)

Authors (Year)	Outcome measures	Data collection	Key findings
Foley et al. (2016)	ITFQ; HADS; ISQ; Mini-MAC Scale	T0 (at enrolment): the ISQ, ITFQ, Mini-MAC Scale T1 (at 7 days postsurgery): ISQ and Mini-MAC Scale HADS: T0, 1-day prior to surgery; T1, 1-day postsurgery; T2, 7 days postsurgery.	<ol style="list-style-type: none"> IT Familiarity: about 50% (of all the participants) used the iPad or smartphone to search information on BC. Information satisfaction (ISQ): No statistically significant differences between the I and C, T0 and T1. Sub-dimension analysis of the Mini-MAC Scale <ol style="list-style-type: none"> "Fighting spirit," "helplessness/hopelessness," "anxious pre-occupation" and "avoidance": no significant differences between the I and C, T0 and T1. "Fatalism," no significant difference at T1; a significant difference at pre-surgery (T0), with median score I: 3 (2.8–3.2), C: 2.4 (2.2– 2.85), $p = .004$. The HADS: 1) T0, T1 very similar in both groups. 2) Levels of anxiety and depression significantly lower in control patients at T2 Median of anxiety, I: 4(2.5–8), C: 2(0.8–4.3), $p = .029$. Median of depression, I: 2(1–4), C: 0.5(0–1.3), $p = .022$.
Sherman et al. (2012)	PAL-C; SRHS; PAIS; BCTRI	T0: at enrolment T1: within 1 week after the diagnosis but prior to surgery T2: within 72 hr postsurgery T3: during discussions of adjuvant therapy T4: Within 14 days of the patient's completion of adjuvant therapy.	<ol style="list-style-type: none"> Physical adjustment: only a significant main effect for time; no significant group differences, or Group \timesTime interactions, or Group \timesTime differences. <ol style="list-style-type: none"> Incidence of the side effects: fewer side effects over time from T2 (with a mean of 6–7) to ongoing recovery (a mean of 4–5). Severity of the side effects: only a significant main effect for time, $F(2, 146) = 5.86, p = .004$. Overall health status: for all group, a similar improvement over time, means (higher scores indicating better perceived health): T0 (8.5–8.9)T4 (9.4–10.4). Emotional adjustment: a significant change over time. <ol style="list-style-type: none"> Psychological well-being: For all groups, $F(2, 313) = 3.44, p = .033$, from T2 to T4; for group 3, the change over time was different from other groups, an improvement from T0 to T3, a decrease from T3 to T4, $p = .002$. Side effect distress: no significant main effect for group or time, but a trend for Group \timesTime interaction ($p = .077$). Social adjustment: an improvement over time. <ol style="list-style-type: none"> Vocational environment: a significant main effect for time, $F(2, 265) = 3.80, p = .024$; mean scores T2: 4.4–6.0, T4: 4.3–5.0, no significant group or Group \timesTime interactions Domestic environment: no statistically significant main effect for time, group, or Group \times Time interactions Social environment: T2: 5.2– 6.0 (lower scores denote better social environment scores), T4: 3.5– 4.2; a statistically significant main effect for time, $F(2, 309) = 13.0, p < .0001$; no significant group or Group \timesTime differences.
Drageset et al. (2010)	Themes in summary	Interviews, on the day before surgery, before preoperative information	<ol style="list-style-type: none"> Step-by-step; 2) Pushing away; 3) Business as usual; 4) Enjoying life; 5) Dealing with emotions; 6) Preparing for the worst; 7) Positive focus.
Obeidat and Lally (2014)	Themes in summary	Retrospective interviews	<ol style="list-style-type: none"> Knowledge about breast cancer and its treatment; 2) Communication of cancer diagnosis and treatment; 3) Educating on treatment side effects.

Note: Abbreviations: BCTRI, Breast Cancer Treatment Response Inventory; BIS, Body Image Scale; C, Control group; HADS, Hospital Anxiety and Depression Scale; I, Intervention group(s); ISQ, Information Satisfaction Questionnaire; ITFQ, Information Technology Familiarity Questionnaire; MAC Scale, Mental Adjustment to Cancer Scale; Mini-MAC Scale, Mini-Mental Adjustment to Cancer Scale; PAIS, Psychosocial Adjustment to Illness Scale; PAL-C, Profile of Adaptation to Life Clinical Scale; SRHS, Self-Report Health Scale.

reviewing the included studies systematically and critically, the reviewers have found high-level evidence which demonstrated the global prevalence of information needs of these women and

highlighted their fighting spirit enhancement and helplessness/hopelessness decrease. The results also showed preliminary evidence of women's long-term adjustment and well-being improvement for

TABLE 7 Quality assessment of the included studies using the CCAT

Author (Year)	Preamble	Introduction	Design	Sampling	Data collection	Ethical matters	Results	Discussion	Total score/40
Andreis et al. (2018)	5	4	3	5	4	5	5	5	36
Dastan and Buzlu (2012)	5	5	4	4	4	5	5	4	36
Drageset et al. (2010)	5	5	5	4	3	5	5	5	37
Foley et al. (2016)	5	3	3	4	4	5	4	5	33
Obeida and Lally (2014)	5	5	5	5	4	5	5	5	39
Sherman et al. (2012)	5	5	4	4	5	5	5	5	38

Note: A scale from 0 to 5 was used to rate each category, with 5 denoting high quality.

TABLE 8 Main findings from data synthesis

Category	Evidence
Prevalence of information needs	<p>The IT Familiarity Questionnaire indicated that information needs are high when receiving the diagnosis of early-stage BC (about 50% of the participants used the iPad or smartphone to search information on BC) (Foley et al., 2016, p. 56).</p> <p>Quotes: "Information is important for me, but I don't want to receive it all at once"</p> <p>"Initially, I spent a lot of time on the Internet reading, but I decided I had to stop. There's little to be found there that's positive. I like to have control, and then I suddenly found out that everything is beyond my control"</p> <p>"I'm not so afraid when I know what's going to happen. It's very important for me to know" (Drageset et al., 2010, p. 152)</p>
Effects of information giving	<p>1. Appropriate and timely information</p> <p>According to the synthesis from the quantitative data, benefits of information giving included leading to an improvement in levels of adjustment to cancer, such as increasing the "fighting spirit," decreasing "helplessness/hopelessness," "anxious preoccupation" and "fatalism" (Dastan & Buzlu, 2012; Foley et al., 2016); and improving the overall levels of depression (Andreis et al., 2018)</p> <p>Two themes from the qualitative data: being prepared, managing uncertainty (Drageset et al., 2010; Obeidat & Lally, 2014)</p> <p>2. Conflicting/inadequate information</p> <p>Quotes: "I asked her [the gynecologist] about the signs of breast cancer and she told me that with breast cancer there should be an enlargement in the breast and a change in the breast tissues and color, the nipple becomes black and there should be discharges from the nipple. I decided to check my breast for these signs, I did and I had none of the signs the gynecologist told me about. The mass was growing larger with time but I was assured that my breast was similar to the other one. I had no enlargement in it, it was not yellow and no fluid was coming out from the nipple." This information misled patients about treatment (Obeidat & Lally, 2014, p. 552)</p> <p>3. Too much information</p> <p>Quotes: "Information is important for me, but I don't want to receive it all at once"</p> <p>"Initially, I spent a lot of time on the Internet reading, but I decided I had to stop. There's little to be found there that's positive. I like to have control, and then I suddenly found out that everything is beyond my control" (Drageset et al., 2010, p. 152)</p> <p>Increase the anxiety levels (a significantly higher level of anxiety in the iPad group 7 days postsurgery) (Foley et al., 2016)</p> <p>4. Not enough/unavailable information</p> <p>Quotes: "... the surgeon did not explain to me what stage do I have, is it early or advanced. From searching on the internet, I found that in the early stages of the disease, only the mass can be removed not the entire breast, the surgeon did not explain any of this to me and I did find it only after the surgery [mastectomy]..."</p> <p>"I was being asked so many questions from those around me and I wished if I have asked the physicians these questions and knew its answers. Every time I had a question I was keeping it for the next time because there was no chance to ask the physician." This led to unawareness of their surgical treatment (Obeidat & Lally, 2014, p. 552)</p>

psychoeducational support. Furthermore, it was notable that inadequate information provision, including limited information, too much information and conflicting information, may lead to some adverse outcomes. These issues will be discussed in turn below.

5.1 | Prevalence of information needs

Seeking information on relevant topics had become one of the major activities of women when facing a cancer diagnosis. For them,

information needs were the most fundamental in their initial and continual occurrence. The patients needed information to overcome the disease and make decisions on treatment choices; moreover, they were eager to understand exactly what was happening to their body, about the necessary treatment and the possible prognosis (Obeidat and Lally, 2014). In the specific period of waiting for surgery, it was stressed that besides the general needs of information, information on the anaesthetic and surgical procedures was also desired by patients (Drageset et al., 2011).

The present reviewers highlight that, besides the participants in the retrospective study (Obeidat & Lally, 2014), in which the data were collected retrospectively and may potentially have affected the judgement on initial information needs when they received the cancer diagnosis, the majority of women in the present review showed their strong desire for health information after being diagnosed with BC. It was recognized that information-seeking behaviours could consist of asking questions of healthcare workers, listening to the stories shared by other people with BC, searching any available resources related to this disease or even voluntarily participating in the research projects. This may be an explanation of why information needs were universal issues.

Despite the common occurrence, it is not surprising that the context and situation of the individuals should be considered in relation to understanding these women's information needs. Interestingly, some women would choose only positive information on their illness (Foley et al., 2016); some may prefer that they could receive the information progressively, while others needed as much information as possible immediately (Drageset et al., 2010); moreover, a few women may be fatalistic to the diagnosis and following treatment, and did not want to seek any related information (Foley et al., 2016). Therefore, it is notable that information needs differed from one patient to another.

5.2 | Effects of information giving

5.2.1 | Appropriate and timely information

Effect in adjustment

Providing information accurately and promptly could improve the overall levels of adjustment. Adjusting to the difficulties associated with BC diagnosis and surgery was perceived as an essential ability to cope and live with cancer for the rest of these women's lives, since the surgical treatment would potentially lead to the impairment of body image, decrease in self-esteem and sexuality, sense of loss in womanhood and femininity (Dastan & Buzlu, 2012; Drageset et al., 2011). According to Lubkin and Larsen (2013), adjustment should comprise of patients' managing strategies of medical and physical challenges, in addition to the functioning domains in cognition, emotions, behaviours and psychology. In the present review, adjustment to illness had been categorized into physical, emotional and social dimensions (Sherman et al., 2012); and mental adjustment with 5 sub-dimensions, including "fighting spirit," "helplessness/

hopelessness," "anxious pre-occupation," "avoidance" and "fatalism" (Dastan & Buzlu, 2012; Foley et al., 2016), in which the levels of adjustment were assessed by several relevant measures. Additionally, it has been proposed that psychological adjustment could be evaluated via positive indicators using measures of quality of life; and negative indicators, assessing the levels of anxiety and depression (Brandão et al., 2017).

The present reviewers did not find significant benefits of information giving in improving physical adjustment and social adjustment. The study of Sherman et al. (2012) indicated an improvement in the incidence and severity of side effects, the overall health status of physical adjustment, the psychological well-being and side effects distress, and social adjustment. However, this improvement was most likely affected by time and there were no significant differences among the control group and the intervention groups; moreover, since the usual care in the control group had also included educational support, it would be difficult to distinguish the exact impact of psychoeducation and telephone counselling. Accordingly, there may be positive effects of the additional information giving in improving physical and social adjustment, but the evidence was not strong, because the adjustment levels in the control group patients were also improved during the same period (Sherman et al., 2012).

About the sub-dimensions of the mental adjustment, however, evidence showed a dramatic improvement, especially in enhancing the "fighting spirit" and diminishing the "helplessness/hopelessness" (Dastan & Buzlu, 2012; Foley et al., 2016). This improvement was essential for women to self-care and cope with stress and loss, as hope and fighting attitudes were powerful. It was perceived that the presence of hope in people receiving a cancer diagnosis may enable them to improve physical and psychological well-being, while the absence of it may lead to despair and being inactive in treatment (Felder, 2004). Being hopeful and continuing to fight against cancer may also help women adjust to their new situations after treatment. After communicating with healthcare workers and knowing the favourable prognosis of early-stage BC, although related difficulties and problems still existed and could be long-lasting, some women expressed that their extra strengths had been activated: "I think I have strength when I'm in difficult situation. The reaction comes later when everything is over" (Drageset et al., 2010).

It has been testified that educational support can improve psychological well-being and the overall levels of depression in the long run (Andreis et al., 2018; Sherman et al., 2012). However, according to Foley et al. (2016), the levels of anxiety and depression were much higher in the iPad group than in the control group. This may be because the iPad and the specifically developed application in it had over-reminded the women in this group about their disease conditions. Besides, the smaller sample size of the experimental group than that in the control group was also considered as an important factor in this unexpected outcome.

Effect in being prepared

Information giving helps women to be prepared. Being prepared means accepting the diagnosis of cancer and starting to participate

in the following treatment actively and cooperatively, which is perceived as an essential expression of self-care and self-management (Knobf, 2013). Women were supposed to be involved in making decisions of surgical treatment since it may improve their mental health, physical and social functioning (Obeidat et al., 2011). However, it was challenging for women to make a quick decision, on account of being surrounded by stress, fear, uncertainty and ambiguity after being diagnosed with early-stage BC (Drageset et al., 2011). Women's worries and concerns when awaiting surgery were not only in relation to the surgery itself but also to their conditions of postsurgery (Drageset et al., 2011). Information provision enables women to be prepared for making a more informed decision that fits best with their individual values and preferences (Obeidat et al., 2011). Furthermore, the scheduled date of the surgery and involvement in confirming the date helped some of the participants to build feelings of control and calm and to be ready for what was coming next (Drageset et al., 2011).

Knobf (2013) argues that being prepared also means stabilizing a new balance after the shock of being diagnosed with BC and accepting the challenges, especially in the worst cases. According to the "Carrying On" theory of Knobf (2002), which focuses on information and support needs of people with cancer, the responses and behaviours of women diagnosed with early-stage BC will follow the cancer trajectory, including stages of "being focused," "dealing with uncertainty," "developing awareness" and "balancing" (Knobf, 2002, 2013). This theory highlights that after communicating with healthcare providers and receiving information, women's awareness of BC will be developed and a new normal will be balanced (Knobf, 2013). Having received the concrete, understandable and appropriate information, women were found to be more optimistic by its generally favourable prognosis and become more positive after the initial shock, loss of control and fear of death (Drageset et al., 2010).

Effect in managing uncertainty

The direct and most beneficial effect of information giving could be managing uncertainty. Miller (2014) argued that uncertainty is completely common and can occur because the events that may happen in the future could be somehow predictable but should never ever be considered as realities that there was a natural relationship between uncertainty and people's information needs. Moreover, according to Hagen et al. (2015), uncertainty could be categorized into three main aspects, including uncertainty resulting from limited information, uncertainty related to the course of treatment and uncertainty of living with cancer in everyday life. According to Drageset et al. (2011), uncertainty during the specific period from diagnosis to surgery also had three main themes, including uncertainty about the surgical treatment, being unable to know whether the breasts have to be removed and uncertainty of the future.

Information seeking and communication with healthcare workers for information needs were perceived as essential and corresponding behaviours of coping with uncertainty were (Knobf, 2013). As ignoring uncertainty may provoke or worsen some emotional

feelings, such as fear and loss of control (Drageset et al., 2011), the importance of managing uncertainty was noticed. In the present review, additional evidence of information giving in reducing uncertainty was found in the study of Drageset et al. (2012). This has demonstrated that nurses were key information sources; that the adequate information from nurses and other healthcare professionals facilitates reduction of uncertainty (Drageset et al., 2012).

5.2.2 | Too much information

Methods of patient education and types of information giving have been enhanced significantly in recent years. Patients used to gain information from health professionals, such as physicians, surgeons, oncologists and/or nurses; printed resources, including leaflets or brochures provided by healthcare workers, magazines or newspapers; traditional media, such as TV and radio; and/or other people's experiences who had the same disease (Rutten et al., 2005). At present, however, thanks to technology advances of the Internet and mobile communication, health information has become easier to obtain (Foley et al., 2016). It has been recognized that there is a trend to use the applications in smartphone or other mobile equipment to deliver healthcare information (Pandey et al., 2013). It was anticipated that the use of new technologies in healthcare settings and the consequently widened methods of information giving would be beneficial to patient education outcomes. Unfortunately, according to Miller (2014), too much information may bring about a sense of losing control and hinders the participants from managing uncertainty.

Too much information for women diagnosed with BC could lead to negative effects. In the study of Foley et al. (2016), the overall levels of hospital anxiety and depression prior to surgery and one day after surgery were similar in the two groups, while at the seven days postsurgery, significantly higher levels of anxiety and depression in the intervention group were seen. This, to some extent, may be due to the smaller sample size in the iPad group and its reluctant impact on the statistics. More importantly, however, the method itself of information giving in the iPad group should also be taken into account. This iPad provided a specifically designed application through which all information relevant to BC tailored for each individual was available. As could be expected, this type of information giving provided too much information in a limited time. Therefore, the use of new methods of information giving based on the Internet should be thoroughly assessed before generalization.

Because of the potential ramifications of too much information at one time, some women preferred receiving smaller quantities of information regularly: "Information is important for me, but I don't want to receive it all at once"; furthermore, gaining an overload of information in a short time may result in a temporarily chaotic feeling: "Initially, I spent a lot of time on the Internet reading, but I decided I had to stop. There's little to be found there that's positive. I like to have control, and then I suddenly found out that everything is beyond my control" (Drageset et al., 2010).

5.2.3 | Conflicting/inadequate information

With the broadening sources of information, the consistencies of information from different sources are crucial for patients as such information will be used to make treatment decisions (DeRouen et al., 2015). Babrow et al. (1998) argued that it would be more challenging for those who were provided with inconsistent information in dealing with the complexity of decision-making. Making a surgical treatment decision for women after having been recently diagnosed with early-stage BC was a significant task (Obeidat et al., 2011). For most women with early-stage BC, it was difficult to make a decision about mastectomy or breast conserving surgery if they had not been informed well about the potential risks (Lee et al., 2012). This could be harder for younger women who perceived the breast as an indispensable part of their whole body (Drageset et al., 2011; Recio-Saucedo et al., 2016).

As elaborated in the category of "Too much information," women newly diagnosed with BC may receive information from non-professional people with the same disease and similar experiences (Rutten et al., 2005). When such was consistent in the form of information provided by healthcare professionals, it was good for social relationships and may be beneficial for illness treatment and recovery. However, if such information was conflicting, or even consisted of misconceptions, unfortunately, the information recipients could be misled, especially when the providers were someone the recipients deeply trusted (Obeidat & Lally, 2014). For example, it was shown that one woman had refused to undergo surgery for 3 years after her diagnosis, because she had "heard from lay people that cutting into a cancer would cause it to spread in her body" (Obeidat & Lally, 2014).

5.2.4 | Not enough/unavailable information

Some women felt that they did not receive enough personalized information as desired from their communication with the doctors; fortunately, most of them had the opportunity to call the hospital nurses and could gain adequate and professional information (Drageset et al., 2012). Those women who were unable to gain information they needed from external sources may not make an informed decision of surgical options, especially while the surgeon has not explained in detail (Obeidat & Lally, 2014).

Not enough information is an issue that cannot be easy to identify, because the individuals' information needs are different (Drageset et al., 2010). Although the importance of providing the right amount and type of information has been emphasized by a prior study (Luker et al., 1995), how much information is the right amount can be hard to tell. According to Epstein and Street (2007), patient-centred care requires healthcare professionals to listen to patients' self-reported concerns of symptoms, side effects and/or support needs to maximize therapy efficacy and safety and improve healthcare outcomes. In this sense, patient-initiated communication

between women with early-stage BC and healthcare providers can lead to higher quality of communication and help providers better understand women's information needs.

6 | CONCLUSIONS

6.1 | Strengths and limitations

This is a comprehensive mixed-method systematic review that aimed to synthesize the present literature for evidence of the information needs of women after being diagnosed with early-stage BC and the effects of information giving for these women. This mixed-method review design meant that both quantitative and qualitative studies were included; thus, the data extracted maximized the breadth of evidence for this field. Importantly, this review has strengthened the evidence of these specific groups of women's information needs and the benefits of information giving in increasing fighting spirit and diminishing helplessness/hopelessness.

However, as a mixed-method systematic review, it should be recognized that the total number of the included studies is quite small, which means further research on this topic with an expanded population is warranted. Therefore, the results of the present review should be interpreted with caution because of the above inevitable limitations.

6.2 | Conclusion

In the present study, considerations were given to the prevalence of information needs for women with newly diagnosed early-stage BC; the benefits of proper information giving; and the negative effects of too much information, conflicting information and restricted information. Across the set of studies reviewed, it was found that these women's information needs occurred worldwide; that accurate and timely information could assist them in increasing hope and fighting spirit and potentially improve long-term adjustment levels, while inadequate information may bring about adverse effects, such as leading to uncertainty, a sense of losing control, difficulty in treatment decision-making and/or treatment delay. Nurses, along with other healthcare professionals, should provide health information appropriately, accurately and promptly.

7 | RELEVANCE TO CLINICAL PRACTICE

The results from the present review are important to deliver evidence-based practice and improve patient education outcomes in clinical settings. Although women can access credible information about the disease of BC itself and its possible treatment directly on various sources, such as trusted websites and printed pamphlets, healthcare professionals are still perceived as the most reliable and

trustworthy information sources, particularly when the patients have to make a decision on treatment options. Therefore, health-care workers, especially nurses, who can spend more time than physicians with patients, play an essential role in information giving and providing professional advice. Healthcare professionals can lead psychoeducational programmes for early-stage BC patients to help them in improving their knowledge about the disease, surgery, follow-up treatment and its complications.

However, for the individual patient, BC is not only a medical problem but also an event which has serious psychological, emotional and social impact. The professional and holistic approach is required for effective nursing activities. Accordingly, nurses, and other health information providers, should encourage women to be involved in the communication positively and from the outset, so that their unique information needs would be understood and addressed. Moreover, besides providing information accurately, appropriately and promptly, it would be of equal importance to pay attention to providing too much information at one time and its potential ramifications for some women. Furthermore, it should be noticed that healthcare activities of information giving should take women's psycho-emotional needs into account, which may include communication, talking and explanation, rather than just providing the cold information itself, such as via an application in the electronic equipment with tailored BC information.

In China, according to a well-known Chinese saying, "Prolonged illness makes the patient be a doctor," which reveals that the more the patients understand their own condition of the disease, the better they can take care of themselves. This may indirectly indicate the importance of information giving in the initial phase of a disease. For this reason, it also can be assumed that providing accurate health information promptly would be essential to Chinese women.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

ETHICAL APPROVAL

None.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available in Nursing Open at <http://doi.org/doi>, reference number [reference number].

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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