EMPIRICAL RESEARCH - QUALITATIVE

Women's experiences of gestational breast cancer and their interactions with the healthcare system: A scoping review

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Abstract

Aim: To report the evidence of women's experiences following a diagnosis of gestational breast cancer (GBC) and their interactions with the healthcare system.

Design: A systematic scoping review.

Data Sources: This scoping review systematically searched Medline, CINAHL, PsychINFO, EMBASE and SCOPUS, in addition to six grey literature databases in October 2021. A 2020 PRISMA flow diagram depicting the flow of information.

Review Methods: Guided by six steps in Arksey and O'Malley's Framework (2005). One researcher completed the literature review, and four independently screened the titles and abstracts related to the eligibility criteria.

Results: Totalling 25 articles, these studies comprise 2 quantitative, 20 qualitative, 1 mixed-method and 2 other documents, a book and debate. Thematic analysis was guided by Braun and Clarke (2006) to identify an overarching theme of adjustment that underpinned women's narratives and was reinforced by four major and several minor themes. The four major themes were: psychological impact, motherhood, treatment and communication. The relationship between the themes contextualizes the enormous complexity concerning women's experiences with GBC.

Conclusion: Cancer management for GBC is complex and multifaceted. At a time of conflicting emotions for women, Multidisciplinary teams are well placed to provide support, normalize the woman's experience of motherhood, demonstrate an understanding of treatment effects, and communicate in a considerate and empathetic manner with information that is timely and relevant. GBC management involves doctors, nurses, midwives and many other healthcare professionals, which can add to the impost of diagnosis.

Impact: This scoping review contributes to a better understanding of women's experience of GBC. The results may inform improvements in the support and communication for these women with GBC and their families.

KEYWORDS
birth, breast cancer, gestation, healthcare professionals, healthcare system, nursing, patient care, patient experiences, patient navigation, pregnancy
1 | INTRODUCTION

Breast cancer diagnosis during pregnancy is uncommon, yet it is the most frequently diagnosed cancer (Peccatori et al., 2018). Gestational breast cancer (GBC) is defined as breast cancer diagnosed during pregnancy or in the first 12 months after the completion of a pregnancy (Kakoulidis et al., 2015; Lee et al., 2012). GBC prevalence ranges from 0.76% to 3.8% of women diagnosed with breast cancer (Ives & Saunders, 2010; Peccatori et al., 2018). It is likely to be underestimated as GBC is restricted to premenopausal women who can conceive; a more accurate prevalence is expected to be more than 7% (Peccatori et al., 2018).

The trend for delayed childbearing associated with an age-related increase in GBC is reported in high-income countries (Islam & Bakheit, 2015; Loibl et al., 2015). In Australia, women under 45 years account for approximately 20% of new cases of breast cancer diagnosed annually (Ives & Saunders, 2010). One in four (25% or 74,657) of the women who gave birth in 2019 were aged 35 years or over (Australian Institute of Health Welfare [AIHW], 2021). Of these, 21% are 35–39 years, and 4.5% are aged 40 years or above (AIHW, 2021). Since 1999 the rate of women giving birth in the older age groups has almost doubled for women aged 40–44 years and quadrupled for those aged 45–49 years (AIHW, 2021). In the United States, the birth rates of women aged 35–39 years and having their first pregnancy have increased for women of all ethnicities (Matthews & Hamilton, 2014). The international relevance of this finding suggests that economic pressures women face in high-income countries increases their risk of GBC.

1.1 | Background

In recent years, treatment options for GBC have led to more intensive breast cancer therapies during pregnancy (Durrani et al., 2018; Loibl et al., 2015). However, a standardized approach to treating GBC may not be suitable (Kakoulidis et al., 2015). Additionally, cancer management options for women with GBC are complex and multifaceted.

Women feel confronted dealing with multiple teams of healthcare professionals during early diagnosis, management and surveillance (Ives et al., 2012) at a time when they want to be celebrating a pregnancy or newborn. Multiple teams can lead to conflicting advice, delays and disagreements. One case study outlined how a woman was shocked with contradictory information from several specialists. Three gynaecologists, one surgeon and two oncologists delivered conflicting advice to her. She was confused, angry, suspicious and horrified, resulting in mistrust of the medical profession (Zanetti-Dällenbach et al., 2006).

Understanding women’s experiences with GBC requires a woman-centred approach to recognize the needs of the individual during this most challenging time. The purpose of this scoping review was to collate, summarize and report the evidence of women’s experiences following their diagnosis of GBC and their interactions with the healthcare system.

2 | THE REVIEW

2.1 | Aim

This scoping review aims to report the evidence of women’s experiences following a diagnosis of GBC and their interactions with the healthcare system.

2.2 | Design

A scoping review is a recommended method when not much is known about a topic (Arksey & O’Malley, 2005) such as the case with GBC. Scoping review was used to gain a deeper understanding of an issue and allow for a broad exploration of related literature rather than focusing on answering specific questions (Moher et al., 2015). Scoping reviews inform more about priorities for research, clarifying concepts and identifying knowledge gaps (Arksey & O’Malley, 2005; Pollock et al., 2021). The theoretical framework for scoping reviews developed by Arksey and O’Malley (2005) guided the review with the incorporation of refinements by Levac, Colquhoun and O’Brien (Levac et al., 2010). The systematic review used elements from Joanna Briggs Institute (Peters et al., 2015) to enhance the clarity and rigour of the protocol development and review process. The six steps of Arksey and O’Malley’s (2005) framework are to: identify the research question; search for relevant studies; balance the feasibility of the search with comprehensiveness; use an iterative approach to select studies and extract data; chart the data using quantitative summaries and qualitative thematic analysis; report summarized results; and consult with key stakeholders to discuss the findings (Arksey & O’Malley, 2005).

The research question was developed using a modification of PICO: population, intervention, comparator and outcome. The format was then used to create a search strategy to optimize the number of relevant papers identified. The question developed through this process was: “What are women’s experiences of gestational breast cancer and their interactions with the healthcare system?”

2.3 | Search methods

The databases searched were Medline (hosted by OVID); CINAHL (Complete); Psych INFO, EMBASE; and SCOPUS. Search strategies used keywords and controlled vocabulary for databases where this was required. Terms were combined using Boolean operators “AND” and “OR.” The searches were conducted on October 4, 2021. A sample of the search strategy used for the Medline database is presented in Table 1.

Unpublished reports such as dissertations, government documents and healthcare websites were accessed for relevant or emerging research. Alternate grey literature websites, additional papers from reference lists, and databases searched using keywords, including Google Scholar, OATD, Trove, Worldcat and Base.
TABLE 1  Search strategy for Medline using MeSH terms and key words

| Step 1: #1 "Breast cancer"+ OR "breast neoplasm"+ OR "breast carcinoma"+ AND Step 2: #2 Pregnancy* OR birth* OR gestation* AND Step 3: #3 patient experiences* OR patient preference OR health behaviour OR "patient navigation" OR patient care" OR "client Satisfaction" OR "patient participation" OR "consumer participation" OR "client participation" OR "patient satisfaction" OR "client satisfaction" OR "psychosocial" OR "social psychosocial" OR "psychosocial factors" OR "patient-centred care" OR "accountable care organisations" OR "client characteristics" OR "attitude of health personnel" OR "attitude to health" OR "health personnel attitude" OR "decision making" OR attitude AND Step 4: #4 "Delivery of health care" OR "health care system" OR "health care utilization" OR "health care professionals" OR "health care personnel" OR "health personnel" AND Step 5: Combine #1 AND #2 AND #3 AND #4

No restrictions were placed on language, year of publication or study type to identify all relevant articles. Editorials, reviews and letters to the editor were excluded, as were articles where the full text was not discoverable. Full-text screening requires that four terms be met for inclusion to hold. Once collated, duplicates were removed. A summary analysis for the quantitative papers and a thematic analysis was used for the qualitative reports, guided by Braun and Clarke (2006). This review adhered to the PRISMA 2020 statement (Page et al., 2021). The PRISMA flow diagram (Figure 1) depicts the stream of information during the initial screening process.

2.4  |  Search outcome

In the final analysis (Figure 1), 25 studies were used. The included studies consist of 2 quantitative, 20 qualitative, 1 mixed-method study and 2 other documents, a book and a debate. The total number of participants in these studies was 213.

The published studies included articles from Australia (n = 6), United Kingdom (UK) (n = 3), Italy (n = 3), Switzerland (n = 1), Africa (n = 1), Singapore (n = 1), Japan (n = 1), Brazil (n = 1) and Canada (n = 1). Narrative reports on websites explored the unique journeys of women with GBC who received treatment. These accounts were from the United States of America (USA) (n = 1), Australia (n = 3), Canada (n = 1) and the UK (n = 2) (Table 3). Narratives reported the complexities for the women physically, spiritually, emotionally and practically, as well as the impact on their families.

Two quantitative studies observed events that affected women with GBC and non-GBC. One study used a psychological self-administered questionnaire (Henry et al., 2012) to measure subjective distress in women with cancer during pregnancy. The second study used retrospective data to analyse the demographic and diagnostic variables between the characteristics of women with GBC and non-GBC groups (Dusengimana et al., 2018).

Twenty qualitative studies and narrative reports using various qualitative methods, including grounded theory, were used (Gomes et al., 2021; Rees, 2015), phenomenology (Connell et al., 2006; Facchin et al., 2021; Kirkman et al., 2017; Rodsten, 2017), case studies (Zanetti-Dällenbach et al., 2006), qualitative content analysis (Kozu et al., 2020), narrative reports and a longitudinal qualitative study (Connell et al., 2006). These studies used qualitative techniques and narratives to understand women's perceptions of events concerning GBC. The studies centred on a rich understanding of the woman's experiences with GBC.

Other characteristics of the studies included a mixed-methods study by Ives (2009), which identified specific psychological issues for women diagnosed with GBC and four themes: motherhood, isolation, support and decision-making (Ives, 2009). In a separate book chapter, the same author raised psychosocial issues experienced by women with GBC (Ives et al., 2016).

2.5  |  Quality appraisal

Scoping reviews aim to provide a descriptive overview of the reviewed material without critically appraising individual studies. It remains unclear as to whether the lack of quality assessment of the studies limits the uptake and relevance of scoping study findings (Levac et al., 2010). Arksey and O'Malley (2005) state that quality assessment does not form part of the scoping review, thus it was not performed as part of this review.

2.6  |  Data abstraction

Full-text articles were reviewed for eligibility by SH and independent authors (KY, CN, and MM), and reasons for exclusion were documented. The screening tool used identified eligible studies (Table 2). Screening of titles and abstracts assessed by three authors independently (SH, KY, MM) excluded 449 studies. Articles about women's experiences with GBC and their interactions with healthcare were extracted. A matrix charting table involved data extraction, and descriptions of the characteristics and narratives were collated in tabular form (Table 3).

A stakeholders' consultation is the last stage of Arksey and O'Malley's framework (Arksey & O'Malley, 2005). Consultation is an opportunity for exchanging knowledge and providing methodological rigour, perspective, meaning and applicability to the scoping review (Levac et al., 2010). The consultation provided an effective independent review of the findings through the lens of clinicians practicing in a contemporary clinical context. Multiple healthcare professionals were approached but declined to review.

Two clinical stakeholders in the field of cancer (a Medical Oncologist and an Oncology Clinical Trials Nurse) were consulted regarding the findings of this scoping review, reflecting their
clinical experiences and understandings as per step six of Arksey and O’Malley’s (2005) framework. The Medical Oncologist was identified through a specialist referral cancer centre and had experience managing women with GBC. The Medical Oncologist’s experiences resonated with the complexities of issues for women diagnosed with GBC and the difficulty in providing coordinated, simultaneous care between specialties noted in this review. This specialist stated that shared decision-making and management of women among multidisciplinary teams could be complex as there is no specific team in charge, and each treatment decision must be in consultation with the other teams and the woman.

The clinical trials nurse was identified through professional networks and had previous experience in cancer chemotherapy services caring for women diagnosed with GBC. The Oncology Clinical Trials Nurse stated that the issues identified in her experiences caring for women diagnosed with GBC are genuine. They all experience anxiety, financial stressors and relationship issues; women want to go back to just being a mum. Cancer treatments can affect fertility, preservation options, such as embryo cryopreservation and oocyte (egg) cryopreservation, are expensive and difficult to obtain. The Nurse also identified inconsistency in information and...
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<tr>
<th>No</th>
<th>Author (year)</th>
<th>Country</th>
<th>Aim</th>
<th>Design</th>
<th>Sample size (n)</th>
<th>Key findings</th>
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<tbody>
<tr>
<td>1</td>
<td>Stafford et al. (2021)</td>
<td>Australia</td>
<td>To identify features and explore the impact of healthcare experiences for women with GBC</td>
<td>Qualitative</td>
<td>23</td>
<td>Identified five themes as relevant to the perceived quality of participant healthcare experiences: control over healthcare, trust in clinicians, hospitals and systems, coordination of care, an uncommon diagnosis, and holistic, future and oriented care</td>
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<td>2</td>
<td>Gomes et al. (2021)</td>
<td>Brazil</td>
<td>To investigate how the diagnosis of cancer during pregnancy occurred and assess its repercussions on the family experience of maternity</td>
<td>Qualitative Grounded Theory</td>
<td>10</td>
<td>10 of the 12 participants were women diagnosed with GBC. Surprised by a GBC diagnosis contains three subcategories, for example, diagnosing cancer during pregnancy, facing illness, and seeking alternatives to deal with the situation</td>
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<td>3</td>
<td>Facchin et al. (2021)</td>
<td>Italy</td>
<td>To describe and understand women’s subjective experience of being diagnosed with breast cancer during pregnancy</td>
<td>Qualitative Interpretative Phenomenological Analysis</td>
<td>5</td>
<td>Interviewed five women at treatment initiation. Three main themes identified: overwhelming emotions, two, the sense of difference and three: sources of strength</td>
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<td>4</td>
<td>Facio et al. (2020)</td>
<td>Italy</td>
<td>Explore themes of the developmental process of becoming a mother among three samples: women with breast cancer, women with GBC and women with no history of cancer</td>
<td>Qualitative</td>
<td>4</td>
<td>Four main themes identified fear and worry, the meaning of motherhood, mother foetus relationship and partner support. The psychological aspects of women with GBC to be considered part of care in clinical practice</td>
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<td>5</td>
<td>Kozu et al. (2020)</td>
<td>Japan</td>
<td>To clarify the experience of pregnant women with cancer in decision-making and the role of the nurse</td>
<td>Qualitative</td>
<td>2</td>
<td>Two of the eight women in the study were diagnosed with GBC. The study categorized the decision-making experiences into three phases: interaction between the woman, her foetus, family and medical staff; dilemma and uncertainty; redefinition of the women’s own decisions</td>
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<tr>
<td>6</td>
<td>Liow et al. (2022)</td>
<td>Singapore</td>
<td>To describe the experiences of ethnically diverse Asian women with GBC</td>
<td>Qualitative</td>
<td>7</td>
<td>Three main themes emerged: being a sick woman, juggling between a mother and a patient and seeking normalcy</td>
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<td>7</td>
<td>Chinn (2019)</td>
<td>Canada</td>
<td>To describe the experiences of young women with GBC</td>
<td>Narrative report</td>
<td>1</td>
<td>The accounts of young women and 8 months of pregnancy when diagnosed with GBC, discussed early delivery, genetic testing, treatment, breastfeeding and being positive</td>
</tr>
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<td>8</td>
<td>Watkins (2019)</td>
<td>Australia</td>
<td>To describe a young woman with a hormone receptor-positive (HER2) breast cancer, pregnancy, chemotherapy and recovery</td>
<td>Narrative report</td>
<td>1</td>
<td>A woman aged 40 was diagnosed with GBC with her second baby. She was undertaking extensive treatment, supportive systems and positive outcomes</td>
</tr>
<tr>
<td>9</td>
<td>Beeston (2019)</td>
<td>Australia</td>
<td>To describe a young woman with GBC who has a hormone receptor-positive (HER2) breast cancer</td>
<td>Narrative report</td>
<td>1</td>
<td>A 36-year-old woman discovers she is 7 weeks pregnant with her second baby, examines her breasts and finds a lump. She describes being diagnosed with HER2</td>
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<td>10</td>
<td>Richards (2019)</td>
<td>United Kingdom</td>
<td>To describe four individual accounts and experiences of women diagnosed with GBC</td>
<td>Narrative reports</td>
<td>4</td>
<td>The accounts of these four women with GBC, describe their experiences, psychological impact, emotional distress, difficult decision-making process and treatment effects</td>
</tr>
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<td>11</td>
<td>Ferrari et al. (2018)</td>
<td>Italy</td>
<td>To analyse the psychological issues and construction of the mother–child relationship with cancer during pregnancy</td>
<td>Debate</td>
<td>0</td>
<td>Women raised several issues with GBC concerning psychological management, information, communication and decision-making. Early assessment and evaluation to prevent adverse psychological outcomes</td>
</tr>
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<td>12</td>
<td>Hammarberg et al. (2018)</td>
<td>Australia</td>
<td>To explore the healthcare experiences of women diagnosed with GBC to inform and improve clinical care of women in this predicament</td>
<td>Qualitative</td>
<td>17</td>
<td>Two overarching themes explored were communication and comprehensive care. The communication theme had two subthemes interdisciplinary and patient communication. Comprehensive care involves the psychosocial consequences of being diagnosed with and treated for GBC. The study also found several subthemes are the spirit, the mind and the body</td>
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<td>13</td>
<td>Dusengimana et al. (2018)</td>
<td>Africa</td>
<td>To evaluate the characteristics, diagnostic delays, and treatment of women with pregnancy-associated breast cancer seeking care at a rural cancer referral facility in Rwanda</td>
<td>Retrospective Cohort Study</td>
<td>12</td>
<td>GBC is an important clinical challenge among patients diagnosed with breast cancer in Rwanda. GBC women did not experience more significant diagnostic delays; most had treatment modifications</td>
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<td>14</td>
<td>Gray (2018)</td>
<td>Australian</td>
<td>To describe how one woman 12 weeks pregnant battled breast cancer and chemotherapy</td>
<td>Narrative report</td>
<td>1</td>
<td>Woman’s experiences of the psychological impacts of surgery, radiotherapy, chemotherapy, treatment, physical side effects and new baby concerns. The participant reported being petrified and suffered chronic side effects of severe nausea and inability to breastfeed</td>
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<td>15</td>
<td>Kirkman et al. (2017)</td>
<td>Australia</td>
<td>To understand how women themselves might experience the convergence of abortion and breast cancer</td>
<td>Interpretative Phenomenological</td>
<td>2</td>
<td>Two of the five women’s accounts illustrate the different meanings of abortion in women’s lives, with the concomitant need for diverse support, advice and information</td>
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<td>16</td>
<td>Rodsten (2017)</td>
<td>United Kingdom</td>
<td>To explore the experiences of women diagnosed with breast cancer while pregnant, including factors that may make these experiences unique to the condition</td>
<td>Qualitative: Interpretative Phenomenological Analysis</td>
<td>11</td>
<td>Chapter 1.3: Pregnancy-associated breast cancer findings include the need to investigate further the emotions and behaviours of the GBC and a real need to ascertain which therapeutic approaches, psychological interventions and types of support will work for whom and in what context. Gestational Breast Cancer is complex and challenging</td>
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<td>No</td>
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<td>17</td>
<td>Ives et al. (2016)</td>
<td>Australia</td>
<td>To describe some psychological and social issues for younger women diagnosed with breast cancer. Issues raised by women experiencing GBC.</td>
<td>Book</td>
<td>n/a</td>
<td>Chapter 7: Managing cancer during pregnancy highlights the issues raised by women with GBC. Specific issues raised by women who have experienced a cancer diagnosis during pregnancy include, effective communication, motherhood, motivation, fertility, breastfeeding, isolation, support and information, decisions and choices.</td>
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<td>18</td>
<td>Rees and Young (2016)</td>
<td>United Kingdom</td>
<td>To explore the experiences and perceptions of women diagnosed with breast cancer during pregnancy.</td>
<td>Case Study</td>
<td>3</td>
<td>Breast cancer during pregnancy impacts on young women's lives, assumptions about their pregnancies and new motherhood. They need practical and psychological support in caring for young children.</td>
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<td>19</td>
<td>Rees (2015)</td>
<td>United Kingdom</td>
<td>To describe experiences and perceptions of young women with a history of breast cancer in the UK. Chapter 6: Embodies experiences of being diagnosed during pregnancy. Chapter 7: Diagnoses during pregnancy were biographically disruptive. Chapter 9: Diagnosis during pregnancy spanning three key dimensions and perceptions were analysed.</td>
<td>Thesis: Qualitative study using grounded theory</td>
<td>3</td>
<td>Chapter 6: Provided evidence that women were at odds with their bodies in several important ways, such as danger, risk, child risk, recurrence, a gap in the treatment expectations between their own and others. Chapter 7: Significant accounts of women who during pregnancy described as being biologically disruptive. Chapter 9: When combining the three analytical frameworks, several key areas for women identified a diagnosis precluded the opportunity to have in-vitro fertilization (IVF) treatment or embryo preservation, the identity of breastfeeding taken away, given birth prematurely, fear about the impact of this child and others.</td>
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<td>20</td>
<td>VanTromp (2015)</td>
<td>United Kingdom</td>
<td>Describes a mother's experience of GBC.</td>
<td>Narrative report</td>
<td>1</td>
<td>A woman experiences being 5 weeks pregnant and a diagnosis of GBC. Findings include termination advice, feelings of terror and fear for the unborn child. After the mastectomy, fear of physical reminder. Treatment modalities and 10 years of hormone therapy. Story of hope and encouragement for other women.</td>
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<td>21</td>
<td>Pietrangelo (2018)</td>
<td>United States of America</td>
<td>To describe how one woman experienced her family and her health after being diagnosed with GBC.</td>
<td>Narrative report</td>
<td>1</td>
<td>After 5 years of infertility and a newly diagnosed gestational breast cancer, a series of life-altering events. These experiences are conflicting emotions, life and death decisions, being terrified, second expert opinion, chemotherapy, lumpectomy, side effects, birth and further chemotherapy, a double mastectomy and evaluating the risks, an individual choice.</td>
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<td>Aim</td>
<td>Design</td>
<td>Sample size (n)</td>
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<td>22.</td>
<td>Henry et al. (2012)</td>
<td>Canada</td>
<td>To examine the consequences of maternal cancer diagnosis and treatment during pregnancy on maternal, foetal and neonatal outcomes by measuring the psychological distress</td>
<td>Quantitative</td>
<td>74</td>
<td>Seventy-four women completed the IES and BSI-18 following their cancer diagnosis. On average women experienced clinically significant levels of distress up to 51% than 33% of breast cancer patients and higher than 15% found 1 year post-diagnosis. The study suggests the long-standing impact of cancer diagnosis during pregnancy.</td>
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<tr>
<td>23.</td>
<td>Ives (2009)</td>
<td>Australia</td>
<td>To identify the specific psychosocial issues for women diagnosed with GBC among three groups of women</td>
<td>Aged, matched case–control study (part of the thesis)</td>
<td>16</td>
<td>The three groups were 1; women with a confirmed diagnosis of GBC, 2; women with an actual diagnosis of breast cancer who subsequently conceived, and 3; women with a confirmed diagnosis of breast cancer who did not have GBC and did not subsequently conceive. The findings include no significant difference between the three breast cancer groups in all but two areas, for example, constantly feeling under strain and vaginal dryness. The study identified four main themes motherhood, isolation, support and decision-making.</td>
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<td>24.</td>
<td>Connell et al. (2006)</td>
<td>Australia</td>
<td>Explores issues about fertility, contraception, pregnancy and breastfeeding after breast cancer</td>
<td>Longitudinal qualitative study Phenomenology</td>
<td>13</td>
<td>Pregnancies occurred during the study. The women experienced mixed responses towards the pregnancy, for example, elated, trepidation, influenced by fears of recurrence, acceleration, metastasis and the debate of termination. Breastfeeding decisions for women who had viable pregnancies during the study changed over time.</td>
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<td>25.</td>
<td>Zanetti-Dällenbach et al. (2006)</td>
<td>Switzerland</td>
<td>To evaluate the psychological management in pregnant breast cancer patients</td>
<td>Case Study</td>
<td>1</td>
<td>Healthcare professionals raised concerns about understanding the ethical framework, breaking bad news, risk communication, shared decision-making and biopsychosocial care. The case report illustrated the different phases of psychological care and the delicate balance in the decision-making process.</td>
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Note: IES is a self-administered, 22-item questionnaire measuring subjective distress following a stressful event in three subscales: intrusion, avoidance and hyperarousal. BSI-18 is a self-administered, brief screening inventory measuring levels of distress in three subscales: anxiety, depression and somatization.
advice from multiple healthcare professionals. The women found it hard to trust the information provided because of the differences in each report.

2.7 | Synthesis

During the familiarization and description process, searching for themes, reviewing themes, defining and naming themes, the overall compelling extracts produced an overarching theme, four major themes and seven subthemes outlined in Figure 2. Two authors (KY and MM) and a research assistant (PC) independently reviewed the themes. The qualitative studies were analysed in this review using Braun and Clarke’s (2006) thematic analysis guide (Braun & Clarke, 2006).

3 | RESULTS

3.1 | Themes

The overarching theme of adjustment underpinned the narratives of participants. Four significant themes depicted women’s experiences of GBC: psychological impact, motherhood, communication and treatment. Seven subthemes identified in the literature (Table 4) describe the in-depth understanding of women. Practical and social aspects, being positive, identity, maternal, breastfeeding, healthcare professionals and physical impact subthemes, will be described following the major themes (Figure 2).

3.2 | Overarching theme: Adjustment

Adjustment describes how women use their thoughts and behaviours to regulate their distress and coping mechanisms, a process that changes over time. They emerged with positive well-being as an outcome (Folkman & Greer, 2000). The direct impact on the overall adjustment of women’s psychological well-being is related to the identity associated with motherhood, the treatment choices offered and their relationship with the multidisciplinary team.

3.3 | Major theme: Psychological impact

The first major theme, psychological impact, relates to the emotional rollercoaster after the GBC diagnosis. Fear, anxiety and distress were often reported. Fear of imminent death causes great distress for women (Gomes et al., 2021). Words used to describe their fears included shock (Faccio et al., 2020), scared and vulnerable (Facchin et al., 2021), hopelessness (Henry et al., 2012), horrified (Zanetti-Dällenbach et al., 2006), mad panic (Rees & Young, 2016) and a worrying time (Richards, 2019). Many stressors may be resolved in the short term, however, some of the women with GBC experience long-term distress (Henry et al., 2012), altered body image (Facchin et al., 2021) and guilt (Rees & Young, 2016).

The experience of anxiety and distress for women with GBC warrants specific attention by healthcare professionals to generate appropriate support services promptly (Connell et al., 2006; Facchin et al., 2021; Hammarberg et al., 2018). The treatments can also have a psychological impact on relationships with their unborn child, other children, future children and partners (Faccio et al., 2020; Gomes et al., 2021; Hammarberg et al., 2018; Pietrangelo, 2018; VanTromp, 2015). One woman reflected in the study by Liow et al. (2022), “I don’t want (another pregnancy) anymore because it happened to me after I gave birth. So, I don’t want to have another breast cancer again... it’s very traumatizing” (p. 4).

Younger women with breast cancer experienced significantly more anxiety and distress than their older counterparts (Ferrari et al., 2018; Ives et al., 2016). The stressors for all women with breast cancer directly responds to uncertainty (Ives, 2009). In addition to having limited social support (Ives et al., 2016), feelings of uncertainty (Ferrari et al., 2018), low self-esteem (Ives et al., 2016), concerns for future relationships (Ferrari et al., 2018), risk of treatment-related menopause (Rees, 2015) and practical issues (Ives, 2009).
3.3.1 Subtheme: Practical and social aspects

Practical and social aspects for a woman can have psychological implications for herself, family, friends and others. The practical issues for young women include carers’ responsibilities (Richards, 2019), physicality changes resulting from treatment (Rees, 2015), career and financial burdens (Ives, 2009), and isolating circumstances like ‘feeling different’ (Ives et al., 2016, p. 82). Added distress and concerns can be triggered by practical aspects such as the expense of baby formula (Dusengimana et al., 2018), additional support deficits at home (Ives, 2009), living long distances from family and friends (Ives et al., 2016), limited access to support services and community support groups (Hammarberg et al., 2018).

Assessing the anxiety levels experienced by the woman and her family is essential. Healthcare professionals can provide early psychosocial assessment and services to the women to elicit and support groups (Hammarberg et al., 2018).
lead to an inability to cope and bond effectively with the baby (Ives et al., 2016; Rodsten, 2017). Healthcare professionals are pivotal in identifying and recommending resources to ensure that women and their families are well supported. Suggesting a multidisciplinary approach to emotional and social care can link women with GBC with the most appropriate services (Hammarberg et al., 2018; Ives et al., 2016; Rodsten, 2017).

Families play significant roles in the overall well-being and adjustment of women diagnosed with GBC (Gomes et al., 2021; Rodsten, 2017). Psychosocial adjustments are facilitated by a supportive social environment and impede where support is lacking (Rees & Young, 2016). More than half of the studies described how women worried about how their partner would cope with the news of a diagnosis, additional responsibilities and the impact on their family (Facchin et al., 2021; Gomes et al., 2021; Ives et al., 2016; Kirkman et al., 2017; Kozu et al., 2020).

Isolation, distance and disconnection from family or friends contribute to psychological stressors for women (Ferrari et al., 2017; Stafford et al., 2021). Women experienced feelings of uncertainty with limited family support or connection (Ferrari et al., 2018; Gray, 2018; Hammarberg et al., 2018; Ives, 2009; Ives et al., 2016; Rees, 2015; Richards, 2019). The significant compounding factors include fear of being unable to manage motherhood duties, cancer treatment and other practical roles (Ives et al., 2016; Liow et al., 2022; Rodsten, 2017). The importance of family and social support is associated with improved recovery and psychosocial adjustments (Gray, 2018; Hammarberg et al., 2018; Liow et al., 2022).

3.3.2 | Subtheme: Being positive

Some women explained the importance of being positive when diagnosed with GBC, a sense of pride and wanting to help other women (Ives et al., 2016). One woman’s sense of pride was illustrated in her statement that she stated, “I just almost want to stand as a bit of a symbol maybe like to be strong and that you can do it and the fact that I did it with a tiny baby which for most people they struggle anyway with that, being a mum for the first time, I went through all of that on top you just think I did it so you can do it” (Ives et al., 2016, p. 256).

A maternal instinct, such as a ‘fighting spirit’ to protect her child and her well-being, indicates a positive adjustment (Faccio et al., 2020; Ferrari et al., 2018; Gray, 2018; Zanetti-Dällenbach et al., 2006). The findings of positive adjustment included: experiences of prioritizing care and decisions (Ives et al., 2016); determination to defeat cancer (Beeston, 2019; VanTromp, 2015); maternal instincts to protect the child (Rodsten, 2017); belief in the prospect of their children (Gomes et al., 2021).

3.4 | Major theme: Motherhood

Motherhood, the state of being a mother, is viewed differently by women. The maternity experience of women with GBC alters and is challenging. The challenges are; concerns about the values and beliefs of breastfeeding (Faccio et al., 2020), the fear of transferring the disease or genetic disposition to their newborn (Ives, 2009) and the effect of treatment on the baby (Hammarberg et al., 2018). Could pregnancy cause or accelerate cancer (Connell et al., 2006).

The stage of pregnancy when diagnosed with GBC greatly influenced women’s decisions about their cancer management. Each woman’s response to these life events and mothering decisions was unique and based on her life’s experience, beliefs and values (Connell et al., 2006; Ives et al., 2016; Rees & Young, 2016; Rodsten, 2017).

3.4.1 | Subtheme: Identity

Identity is vital for women as it defines them. Women may instinctively question whether their primary identity in this situation is that of a patient, a mother or a new mother (Rodsten, 2017). Motherhood provides identity changes and transformations through having children (Ives, 2009; Rees & Young, 2016; Richards, 2019; Rodsten, 2017).

Women with GBC can be conflicted with the motherhood role and femininity (Rees & Young, 2016). Women also acknowledged that surgical treatment decisions and reconstruction often challenged the balance of femininity, preservation and removal (Facchin et al., 2021; Liow et al., 2022). One woman reported that the option of a lumpectomy versus a total mastectomy was a big decision (Chinn, 2019).

3.4.2 | Subtheme: Maternal practices

Women with other children often struggle to maintain their parental role due to the side effects of treatment (Ferrari et al., 2018; Gomes et al., 2021; Ives, 2009). Physical engagement with the baby and the family is a desired maternal practice (Gray, 2018; Rees, 2015; Rodsten, 2017; VanTromp, 2015). Life uncertainty can cause women to be overprotective and limit their children’s independence just in case they are left without a mother (Henry et al., 2012; Ives et al., 2016; Rodsten, 2017).

These women are confronted with difficult maternal decisions about the life and death of an unborn child (Kirkman et al., 2017). Therapeutic termination of pregnancy might be advised (Gomes et al., 2021; Kirkman et al., 2017). However, one woman stated, “she thinks her husband ‘saw the here and now’ I was so emotionally overwhelmed at the time.” She described repressing her feelings regarding termination until she had finished her cancer treatment (Kirkman et al., 2017, p. 5). The decision for women, either way, comes with internal conflict (Gomes et al., 2021), distress, or “feeling a deep sense of regret” (Kirkman et al., 2017, p. 261).

3.4.3 | Subtheme: Breastfeeding

Breastfeeding symbolizes many maternal practices such as protection, growth and development benefits for the baby. For society,
it is economical and environmentally beneficial for the mother. Breastfeeding assists the uterus in returning to the pre-pregnant state. Breastfeeding assists in bonding with their child and is associated with women’s concept of what it is to be a ‘good mum’ (Connell et al., 2006; vanTromp, 2015; Watkins, 2019).

When decisions during diagnosis and treatment change regarding advice to breastfeed or not, women experience significant distress (Connell et al., 2006; Faccio et al., 2020; Hammarberg et al., 2018; Henry et al., 2012; Richards, 2019). Women expressed mourning for the loss of breastfeeding about having the choice taken away (Ferrari et al., 2018; Gray, 2018; Hammarberg et al., 2018; Rees, 2015; Richards, 2019). Conversely, the study by Liow et al. (2022) revealed seven Singaporean women diagnosed with GBC were “largely undisturbed by their inability to breastfeed” (p. 5). The decisions regarding breastfeeding are determined by the different values and priorities of disease or survival (Liow et al., 2022). For Western women, “breastfeeding represents the ultimate contract between mother and baby” (Rodsten, 2017, p. 68).

3.5 | Major theme: Communication

The flow of information and communication shared with a woman with GBC is essential, and there must be a continuous dialogue (Zanetti-Dällenbach et al., 2006). Several studies identified that clinical information and the use of nationally or internationally endorsed guidelines such as Breast cancer in pregnancy: recommendations of the international consensus meeting (Amant et al., 2010), and Cancer, pregnancy, and fertility: European Society of Medical Oncology: clinical practice guidelines for diagnosis, treatment and follow-up (Pecellant et al., 2013) are essential for better outcomes. These guidelines provide treating clinicians with evidence-based information, treatment options and outcomes that assist with the clinical decision-making process for women (Connell et al., 2006; Ferrari et al., 2018; Hammarberg et al., 2018; Ives, 2009; Ives et al., 2016; Pietrangelo, 2018; Rees, 2015; Rodsten, 2017; Zanetti-Dällenbach et al., 2006).

3.5.1 | Subtheme: Healthcare professionals

How healthcare professionals communicate affects how women with GBC manage their diagnosis and treatment (Hammarberg et al., 2018). Healthcare professionals require skills, competence, a level of expertise in GBC management, and compassion while speaking to a woman who has been recently diagnosed (Ferrari et al., 2018; Hammarberg et al., 2018; Pietrangelo, 2018; Rodsten, 2017; Zanetti-Dällenbach et al., 2006). Consultation with mothers and family often involves multiple clinicians from different departments and sites (Ives, 2009; Pietrangelo, 2018; Rodsten, 2017; Zanetti-Dällenbach et al., 2006).

Misinformation can cause confusion (Faccio et al., 2020; Pietrangelo, 2018; Rodsten, 2017; Zanetti-Dällenbach et al., 2006), resulting in women with GBC seeking other professional opinions or abandoning treatment altogether (Pietrangelo, 2018; Rodsten, 2017; Stafford et al., 2021; Zanetti-Dällenbach et al., 2006). Women with GBC must receive timely and relevant information from skilled healthcare professionals (Facchin et al., 2021; Ives et al., 2016; Rodsten, 2017; Stafford et al., 2021; Zanetti-Dällenbach et al., 2006).

Accurate information is imperative in assisting women’s decision-making (Gomes et al., 2021; Hammarberg et al., 2018; Henry et al., 2012; Ives et al., 2016; Zanetti-Dällenbach et al., 2006).

Delivering clinical information and providing adequate time is essential for women with GBC, as these define the direction of treatment, continuation of pregnancy and decision-making (Connell et al., 2006; Hammarberg et al., 2018; Ives, 2009; Kozu et al., 2020; Rodsten, 2017; Stafford et al., 2021; Zanetti-Dällenbach et al., 2006). Conflicting information among clinicians delivered to these women was evident regarding breastfeeding (Faccio et al., 2020), further children (Connell et al., 2006), cancer treatment (Hammarberg et al., 2018), pregnancy termination (Gomes et al., 2021), fertility (Ives, 2009), early delivery (Kozu et al., 2020), and breast cancer recurrence (Richards, 2019). Some women voiced concerns about several clinicians’ limited knowledge of women’s reproductive health and GBC (Kirkman et al., 2017). The importance of communicating and explaining complex medical information in layman’s terms could prevent misinterpretation. As stated by one woman in Richards (2019), “Nobody explained it was incurable; I wish they had because if I had realised what was at stake, I might have made a different decision” (p. 1).

3.6 | Major theme: Treatment

Treatment for GBC involves multidisciplinary teams and sub-specialties, which include surgery: lumpectomy or mastectomy; chemotherapy; hormone therapy; endocrine and radiotherapy; diagnostic tests; imaging modalities; termination of pregnancy and induced childbirth (Connell et al., 2006; Gray, 2018; Ives et al., 2016; Kirkman et al., 2017).

The treatment options and decisions were complicated for women as they attributed to changes such as treatment-induced infertility (Stafford et al., 2021). In addition to a mastectomy (vanTromp, 2015), self-esteem issues from altered appearances (Liow et al., 2022), invasive procedures (Watkins, 2019), recovery after caesarean surgery (Henry et al., 2012), fear of not being able to take care of their child due to the course of treatment (Ives et al., 2016) and unexpected side effects (Richards, 2019). Treatment decisions where pregnancy is to continue may cause women to experience anxiety about their child’s risk of in-utero exposure or passing chemicals onto the baby via milk (Rees & Young, 2016; Stafford et al., 2021).

The subsequent studies found the treatment to be challenging and traumatic while undergoing surgery, months of chemotherapy, welcoming a baby, recovering from a caesarean section, and undergoing radiation (Beeston, 2019; Connell et al., 2006;
Gray, 2018; Hammarberg et al., 2018; Henry et al., 2012; Ives, 2009; Ives et al., 2016; Liow et al., 2022; Pietrangelo, 2018; Rees, 2015; Richards, 2019; Rodsten, 2017; VanTromp, 2015; Zanetti-Dallenbach et al., 2006).

The women often operated between being mothers and patients (Liow et al., 2022). Treatment modalities can create isolating effects for the women, such as preterm birth (Richards, 2019), physical effects of a mastectomy and lymph node clearance (VanTromp, 2015), breastfeeding difficulties (Rees & Young, 2016), chemotherapy (Gray, 2018) delays in diagnosis (Rodsten, 2017), radiotherapy appointments, interruptions for women wanting to attempt pregnancy through hormone therapy (Ives, 2009) and coping physically overall (Pietrangelo, 2018; VanTromp, 2015).

3.6.1 | Subtheme: Physical impact

Women with GBC can experience significant physical effects from their disease and pregnancy (Ives et al., 2016). Some short-term physical changes can include alopecia, skin changes, nausea, tiredness, allergic reactions, weight changes, difficulty lifting or carrying her baby, and procedure recovery (Facchin et al., 2021; Ives et al., 2016). Women often need to adjust to permanent changes in infertility, the impossibility of breastfeeding and partial or total mastectomy (Connell et al., 2006; Gomes et al., 2021; Ives et al., 2016).

For women, the breast signifies their femininity. A breast cancer diagnosis during pregnancy can result in the loss of identity and a sense of inadequacy (Facchin et al., 2021). The physical impact of losing a breast can be very challenging and long-lasting (Facchin et al., 2021). During the treatment phase, surgical options such as breast reconstruction are offered during or after chemotherapy. Breast reconstruction is often selected by young women to quickly regain their feminine appearance and identity (Liow et al., 2022).

4 | DISCUSSION

This scoping review provided an in-depth insight into women’s experiences of a GBC diagnosis, treatment and their interactions with healthcare system. Synthesis of the selected literature identified an overall theme of adjustment, four major themes and seven subthemes. Adjustments determined from women’s narratives described their resilience in adapting to cancer-related changes for their own and child’s well-being.

The course of adjustment to a health crisis is a multifaceted process (Alder & Bitzer, 2008). Adjustment to cancer and pregnancy has been identified by Alder and Bitzer (2008) in the literature on the development of theories, models and frameworks. Kübler-Ross (2009) formed a framework for understanding adjustment to their proposed five stages of grief. Gloger-Tippelt (1983) created a model of developmental stages during pregnancy, while Lazarus and Folkman (1984) established a theory of appraisal, stress and coping (Gloger-Tippelt, 1983; Kübler-Ross, 2009; Lazarus & Folkman, 1987). These all share a similarity in that adjustment is not a normative process, where one stage sequentially follows the next stage.

Kübler-Ross (2009) state the stages of adjustment of denial, anger, bargaining, depression and acceptance are individual responses to loss. These stages support and identify the range of feelings outlined by Lazarus and Folkman (1987). Consideration should be given to these frameworks when situating the overarching theme of adjustment for women responding to a diagnosis of GBC. Should the situation require imminent action, greater emphasis is on problem-focused coping, whereas, if the situation requires accepting or getting used to a case, the emphasis is on emotional-focused coping (Lazarus & Folkman, 1987).

As part of the adjustment process, problem-focused coping strategies are used continuously. Women may feel they have some control over the treatment plans and find problem-focused solutions with their treating team. The subthemes identified as adjustment problem-focused strategies are physical impact, practical and healthcare professionals. Conversely, women can express anger and frustration using emotional-focused coping modes; these are more prominent in the subthemes of identity, maternal practices, breastfeeding and being positive (Carroll, 2020). Coping strategies are not mutually exclusive (Alder & Bitzer, 2008; Carroll, 2020).

Women’s experiences of GBC are often overwhelming and more pronounced due to the unexpectedness when combined during pregnancy. Leung et al. (2020) systematically reviewed the psychological aspects of gestational cancer in the literature. The study identified the paucity of literature on the psychological care of women with gestational cancer (Leung et al., 2020). Similar studies by Ives et al. (2016) and Vandenbroucke et al. (2017) support the findings that women with cancer and pregnancy experience high anxiety levels. Kyriakides (2008) described the psychological impact for young women with cancer and pregnancy as a “feeling of being thrown into a world of uncertainty” (p. 250). Zagouri et al. (2016) study of cervical cancer and pregnancy noted that radical surgery and pelvic radiation are the foundations for cervical cancer treatment. Facing possible fetal death and termination of pregnancy requires considerable psychosocial adjustment.

Faccio et al. (2020) found a lack of studies in the literature representing pregnancy and cancer experiences and the transition to motherhood. This scoping review found women diagnosed with GBC to have unique perspectives of motherhood and pregnancy (Ives & Saunders, 2010; Vandenbroucke et al., 2017). Leung et al. (2020) also identified the challenges and complex decisions for women with GBC amounted to experiencing regretful aspects of their pregnancy and motherhood, including birth plans, breastfeeding, genetic counselling and fertility options (Durrani et al., 2018; Leung et al., 2020).

Women often experience conflicting information, inadequate information and difficulties circumventing complex decisions (Leung et al., 2020). The level of explanation provided to women with cancer and pregnancy regarding the risks and available treatments should be accurate, timely, relevant and culturally appropriate (Ives et al., 2012). Women and clinicians’ mistaken assumptions of cancer...
complex decision-making required of the woman was particularly challenging, primarily when many clinical specialties deliver information.

The scoping review cited four studies from the same author, however, only two were included in the final scoping review. Two of the author’s articles used qualitative and quantitative data on women experiencing GBC (a thesis and a book chapter). We did not select the other two author’s articles because one duplicated the thesis, and the other was an expert review of GBC management and outcomes.

4.1 Clinical implications

The implications of this review suggest raising awareness of women’s experiences with healthcare professionals through education and training opportunities, leading to changes in providing early identification for psychological support and improved information and communication.

The clinical implications of treating women with GBC require healthcare professionals to provide women-centred care that identifies women as both mothers and patients. This scoping review highlights the limited research investigating the complex issues for women with GBC and their long-term impacts.

4.2 Limitations and strengths

It is considered a limitation when the quality appraisal of the studies included in scoping reviews is not performed. Scoping reviews aim to provide a descriptive overview of the revised material without critically appraising individual studies. It remains unclear whether the lack of quality analysis limits the uptake and relevance of scoping study findings (Levac et al., 2010).

The literature search conducted during this scoping review also has limitations. Despite trying to capture literature more broadly about women’s experiences with GBC, studies from different cultures and other countries were limited. Therefore, our findings may not apply to all populations of women with GBC.

A strength of our review is that we searched five health-related and grey databases for relevant or newly emerging research areas gaining valuable insights into women’s experiences with GBC. The second strength involved the clinician review of women’s experiences resonating with the complexities outlined in the literature. A third strength, all six stages of Arksey and O’Malley’s (2005) framework have been incorporated into the scoping review.

5 CONCLUSION

This review provided a broad overview of women’s experiences with GBC and their interactions with the healthcare system. The review found that women with GBC have difficulty adjusting as they assume the new role of a patient and mother, requiring decisions about treatment and the future, which will affect their relationships with others. Limited studies focused on this interaction between the roles of being a mother and a patient with GBC in the healthcare system. The clinical implications for practice and policy include having knowledgeable and competent healthcare professionals as part of the treating team to ensure accuracy, consistent and timely access to information and support. The review suggests recommendations to include early identification of the psychological impact of women diagnosed with GBC and individualized care.

AUTHOR CONTRIBUTIONS

SH, CN, KY, MM: Made substantial contributions to conception and design, or acquisition of data or analysis and interpretation of data; SH, CN, KY, MM: Involved in drafting the manuscript or revising it critically for important intellectual content; SH, CN, KY, MM: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; SH, CN, KY, MM: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.
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DATA AVAILABILITY STATEMENT
Data openly available in a public repository that issues datasets with DOIs. The data that support the findings of this study are openly available in [repository name e.g “figshare”] at [doi], reference number [reference number].

PATIENT OR PUBLIC CONTRIBUTION
This is a systematic scoping review of the literature using Arksey and O’Malley’s (2005) framework, including stakeholder consultation of two healthcare professionals.

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