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RUNNING HEAD: PSYCHOLOGICAL ASPECTS OF GESTATIONAL CANCER

Psychological aspects of gestational cancer: A systematic review

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ABSTRACT

Objective: Gestational cancer is defined as any type of cancer diagnosed during pregnancy or within 12 months of delivery. To date, existing studies on the psychological aspects of this type of cancer have not been evaluated for methodological quality. The aim of this systematic review was to identify the psychological aspects of gestational cancer.

Methods: Five journal databases were searched to identify peer-reviewed articles reporting upon the psychological aspects of women with gestational cancer. Studies published from journal inception to December 2019 were included, and Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines were followed. The Mixed-Method Appraisal Bias Tool was used, to assess the methodological quality of the studies. A narrative description was developed for the psychological outcomes reported in quantitative studies. Qualitative data was synthesized using thematic analysis.

Results: Five papers were eligible for inclusion (two qualitative and three quantitative studies). Factors that contributed to women's psychological distress during gestational cancer included disease characteristics, sociodemographic factors, the baby's health, pregnancy-related factors and cognitive emotion regulation. Four main themes emerged from the qualitative studies; concerns about the baby's health, lost opportunities, 'not fitting in', and healthcare decision-making.

Conclusions: These findings suggest that (a) women with gestational cancer experience psychological distress that is associated with concerns about their babies' health, and (b) their healthcare experiences are affected by communication within multidisciplinary care teams.

KEYWORDS

Cancer, gestational, oncology, pregnancy, psychological distress, psycho-oncology, systematic review.

1. BACKGROUND

Cancer is diagnosed in approximately 1 in every 1000 pregnancies.¹ Termed ‘gestational’ cancer, this includes any type of cancer diagnosed during pregnancy or within 12 months of delivery.² Although rare, the incidence of gestational cancer is rising.³ An Australian study reported crude incidence rates of gestational cancer increased from 112.3 to 191.5 per 100,000 women between 1994-2007.⁴ Whilst a relatively small number of women are diagnosed with gestational cancer, complex physical and psychological issues are raised by a cancer diagnosis in the perinatal period.

Literature describing the epidemiological details and medical management of gestational cancer exists.⁵ The psychosocial aspects of cancer and pregnancy are also been well documented- as *separate* health conditions,⁶⁻¹⁰ much less is known about the psychosocial experiences of women with *concurrent* cancer and pregnancy. Some healthcare professionals posit that the simultaneous occurrence of two life-changing events would amplify the psychosocial stressors associated with these individual events.¹¹ Furthermore, according to the diathesis-stress model of disease,¹² a cancer diagnosis may exacerbate any existing pregnancy-associated physical, psychological and emotional vulnerabilities in patients.

Both cancer and pregnancy are often associated with emotional vulnerability, which can give rise to challenges for women diagnosed with cancer during pregnancy. Firstly, patients must make healthcare decisions that may impact upon the life of their unborn or new baby, as well as existing family members, while learning about the

implications of both cancer and pregnancy. This must occur while they are becoming familiar with two new sets of medical terminology. Secondly, women with gestational cancer have psychological issues that are unique to their dual-diagnosis. After completing cancer treatment, they may have continued anxiety about the health of children exposed to chemotherapy *in utero*, their future fertility, and the safety of another pregnancy.¹³ Clinical experience shows that peri- and post- natal bonding as well as attachment processes may also be disrupted, due to ongoing anxiety about the health and developmental milestones of their child.¹⁴ This occurs amidst the loss of opportunities for mother-infant engagement in cases where the mother must continue her cancer treatments during the post-partum.

Despite these unique and complex psychological challenges, there is a paucity of empirical research on the psychological aspects of women with gestational cancer. Most studies focus on medical treatment and do not address the *psychological* needs of these women. To date, reviews of existing psychological studies^{11, 14-16} are not systematic, and the methodological quality of the studies has not been evaluated. Consequently, there is no empirically informed understanding of the unique issues faced by these women that could inform the development of evidence-based psychological interventions

To address this gap, this study aimed to systematically review the literature on pregnant women diagnosed with cancer, to (a) identify the psychological aspects of gestational cancer, (b) describe the methodological quality of research in this area, and (c) make recommendations for future research.

2. METHODS

This systematic review followed the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA),¹⁷ and adhered to a predefined protocol (PROSPERO registration #CRD42018091781, http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018091781).

2.1. Eligibility

Studies were included if they were primary research studies published in any language in peer-reviewed journals from inception onwards. Studies had to present psychological aspects or outcomes related to gestational cancer, defined as a cancer diagnosis during pregnancy or within 12 months of delivery.² Studies were excluded if they did not contain a specific psychological outcome component and/or were grey literature. Studies of gestational trophoblastic disease (including molar pregnancy) were excluded, as these pregnancies are not viable.

2.3. Search strategy

Database searches were conducted from journal inception to 31st December 2019, in MEDLINE, EMBASE, CINAHL, PsycINFO and the Cochrane Library. Hand-searching (manual scanning) of the retrieved article reference lists were also conducted. A research librarian and the lead researcher (VL) developed the search strategy, using a combination of Medical Subject Headings and keywords relating to

cancer, pregnancy and psychological wellbeing for the index and free-text terms.

Search terms were agreed *a priori*, and were intentionally broad to reduce the risk of relevant literature being removed at initial e-journal searching.¹⁸ The search strategy used the following terms: (“neoplasms” OR “cancer” OR “carcinoma” OR “tumour”) AND (“pregnancy” OR “pregnancy complications” OR “abortion” OR “termination”) AND (“psychology” OR “wellbeing” OR “hope” OR “meaning” OR “emotion” OR “distress” OR “anxiety” OR “depression” OR “grief” OR “guilt” OR “shame”).

Potentially relevant articles were identified by examining the titles and abstracts, then were retrieved for evaluation against the inclusion criteria. Records of the electronic searches were imported into Endnote X9 referencing management software.¹⁹

2.4. Study selection

The search returned 3,889 unique articles. A single reviewer (VL) screened all titles and abstracts, with 3,697 studies excluded because they did not address gestational cancer. To ensure inter-rater reliability, an additional investigator (LS) assessed the full text of the remaining studies to determine eligibility for inclusion, and 100% consensus was reached. Data extracted from all eligible articles included author and country, study aims, study design, demographic characteristics, gestational characteristics, disease characteristics and summary of results.

2.5. Methodological quality appraisal

Two reviewers (VL, LS) independently assessed the quality of the studies included. Disagreements about study quality were resolved by consulting a third reviewer (CB). The quality of the included studies was appraised using the Mixed Methods Appraisal Tool (MMAT), which was originally designed to appraise quantitative, qualitative and mixed-studies included in health-related, systematic, mixed-study reviews.²⁰ MMAT was selected as it has been recognised as the most reliable tool for appraising mixed-methods research²¹ and had recently been used with success in mixed-methods psycho-oncology reviews.^{22,23}

The retained studies were rated on four methodological aspects, which varied depending on study design (e.g. quantitative or qualitative). These studies were then assessed as either meeting MMAT criteria or not. Each area represented 25% of the total quality score (ranging from 0-100%).

2.6. Data analysis

Due to the small number of quantitative studies and the heterogeneity of the quantitative outcomes reported, a narrative description of the findings was conducted. For qualitative studies, data was synthesised using thematic analysis. EndNote library references were first imported into the NVivo 12 software program. The investigator (VL) then used inductive line-by-line coding for the text within the Results and Discussions sections of included qualitative studies. These codes were subsequently analysed across the qualitative studies and discussed between all investigators, who

then agreed on a conceptual framework to identify *a priori* themes. The resultant framework synthesis is recognised as a pragmatic approach to data synthesis²⁴ and systematic in qualitative analysis.²⁵

3. RESULTS

3.1 Studies' characteristics

Five studies were eligible for inclusion, two qualitative and three quantitative papers (see Figure 1). No intervention studies for women with gestational cancer were found.

Of the five studies included in the review,²⁶⁻³⁰ four limited their analyses to the perspectives of pregnant women diagnosed with cancer only,^{26,27,28,30} while one also included partners' perspectives.²⁸ Four studies comprised predominantly multiparous women.²⁷⁻³⁰

Three studies included women with breast cancer only,^{26,27,29} and two included women with other cancers.^{27,28} Regarding stage of cancer, one study included women with stage I-III cancer and recurrent cancer,²⁸ whilst another study also included women with advanced stage cancer (stage IV).²⁷ In three studies, no information on cancer staging was provided.^{26,29,30} Across all five studies, the participants' age at cancer diagnosis ranged from 22 to 43 years. Most women were pregnant at the time of their cancer diagnosis while other women had miscarriages, terminations or were within 12 months post-partum. Two studies included women who had live births only;

^{26,27} whilst two studies included women who had live births and women who had experienced miscarriage or termination of pregnancy.^{29,30} One study did not provide information on pregnancy outcomes.²⁸

All five studies were observational and cross-sectional in nature. Three studies used quantitative designs²⁶⁻²⁸, and two utilised qualitative designs.^{29,30} Studies were conducted in Australia^{29,30} (n = 2), the USA^{26,27} (n = 2), and Belgium and the Netherlands²⁸ (n = 1). The average sample size for the quantitative studies was 47 participants (range 6-74), and for the qualitative studies was 16 individuals (range 15-17). For data analyses, the quantitative studies typically relied on regression analyses, while the qualitative studies used thematic or content analyses.

The demographic, gestational and disease characteristics of the participants are described in Table 1 (the quantitative studies) and Table 2 (the qualitative studies). Tables 3 and 4 describe the study characteristics of the quantitative and qualitative studies, respectively.

3.2. Quality assessment findings

The methodological quality of the available studies on women with gestational cancer was relatively poor. Table 5 provides an overview of the methodological quality of the studies using the MMAT criteria. Overall, the studies met between 25 – 75% of the MMAT quality criteria. The qualitative studies had higher MMAT scores than the quantitative studies. Both qualitative studies scored 75%, whilst the average MMAT score of the three quantitative studies was 33% (range = 25 – 50). The most

common methodological weaknesses of the quantitative studies related to sample size, response rates and the use of unvalidated measurement tools, while the qualitative studies did not appropriately consider researchers' influence on the findings. Inter-rater reliability (percentage agreement) of methodological quality was 95% and Cohen's Kappa coefficient was 0.90. This indicates "almost perfect" agreement between assessors (range = 0.81 – 0.99) according to guidelines outlined by Landis and Koch.³¹

3.3. Quantitative findings

The papers assessed a range of concepts relating to psychological aspects of gestational cancer, of which psychological distress featured most prominently. Only one quantitative study measured psychological distress using validated psychometric instruments; the Brief Symptom Inventory-18, (BSI-18)²⁷ and Impact of Event Scale (IES).²⁷ The other two studies conceptualised 'distress' as specific 'concerns' about aspects of cancer and pregnancy, and used the terms 'distress' and 'concerns' interchangeably. These concerns were specific to having both cancer and pregnancy, and measured with Likert-type responses on newly constructed and thus, not formally validated instruments; the Bandyk Concerns Questionnaire (BCQ)²⁶ and Cancer and Pregnancy Questionnaire (CPQ).²⁸

Only one study examined the prevalence of psychological distress in women with gestational cancer. Henry and colleagues,²⁷ found that women reported high levels of distress on the IES and BSI-18, with clinically significant levels of distress experienced by 51.5% (IES) and 20.9% (BSI-18) of women. Although

Vandenbroucke and colleagues²⁸ did not discuss prevalence, they reported statistically similar overall levels of distress and concerns for women and their partners on the CPQ.

3.3.1. Factors associated with psychological distress and maternal concerns in gestational cancer

More advanced disease stage was associated with increased concerns about the disease and general aspects of cancer treatment for women with gestational cancer, but was not associated with an inclination to maintain their pregnancies as measured by the CPQ.²⁸ Thus, disease staging was not correlated with women's wishes to carry their pregnancies to term. However, the converse was true for these women's partners, who were concerned about cancer treatment regardless of disease stage, but at more advanced stages were more inclined for the women's pregnancies to be maintained compared to the partners of other women who had an earlier stage of disease staging.

Nulliparous parents reported more concerns about the pregnancy and delivery and reported less satisfaction with the healthcare treatment received, compared to multiparous parents.²⁸ No other associations were found between participants' sociodemographic factors and distress.

Complications with their babies' health were related to increased parental distress. Women whose babies were born preterm reported significantly higher distress than those whose babies were born at term.²⁹ There were also non-significant associations between having a caesarean delivery or delivering a baby of low birth

weight (<10%), and women's reported distress scores. When women ranked their cancer and pregnancy concerns on the BCQ,²⁶ concerns about the impact of chemotherapy on their babies' development was among their top three concerns.

Various pregnancy-related factors predicted increased distress scores. Women who had surgery post-pregnancy reported statistically higher IES scores than those who did not.²⁷ However, in the same study, BSI-18 scores were not significantly associated with any cancer and pregnancy-related variables.

Lack of discussions about fertility, breastfeeding and termination was a source of distress to women with gestational cancer. Women who did not receive fertility assistance reported significantly higher IES scores compared to those who received assistance.²⁷ Regarding breastfeeding, there was a non-significant association between having insufficient milk production to breastfeed and higher scores on the IES and BSI-18.²⁷ Being able to breastfeed was the sixth-ranked concern on the BCQ.²⁶ Women who were advised to terminate their pregnancies reported non-significant associations of increased distress on the IES,²⁷ while the "possibility of getting an abortion" was the sixth-ranked concern on the BCQ (co-equal with breastfeeding).²⁶

One study²⁸ assessed significant associations between distress and cognitive emotion regulation strategies among women and their partners using the CERQ (a validated tool).³² Women and their partners who mainly used internalised coping strategies had significantly higher levels of concerns about cancer and pregnancy than those who used 'positive coping' strategies (e.g. acceptance, positive reappraisal) or blamed themselves and others for their cancer diagnosis.

3.4. Qualitative findings

Findings from the qualitative studies^{29,30} were inductively coded, generating four narrative themes; concerns about their babies' health, lost opportunities, 'not fitting in', and healthcare decision-making.

Theme 1: Concerns about their babies' health

Women worried about the potential ill-effects of their oncology treatment on their unborn baby's life, future health and development.

"I said, 'I don't want him to be sterile when he grows up and stuff'. They said, 'no, no, no. He should be fine'. So that was my main concern was because of that radioactive needle I had to have..."³⁰

Some women chose to prioritise their baby's wellbeing over their own, even delaying their oncology treatment until after delivery, to minimise any risk to their baby.

"It was 'maybe this' and 'maybe that' and I just couldn't- I wouldn't put my own body through that, so to do that to an unborn child, I couldn't fathom."²⁹

Women reported valuing reassurances from their treating professionals about the health of their unborn child.

"And I'd be taken down for ultrasounds to check the lung movement and stuff. Oh it was beautiful to see the baby on the ultrasound and he seemed

unscathed, and they assured me he would be fine and all of it... it was quite a relief down the track.”³⁰

Theme 2: Lost opportunities

Women reported experiencing significant distress and regret about unmet expectations of aspects of their pregnancy and motherhood. These included having to make healthcare decisions that affected delivery plans, fertility, and the viability of the pregnancy. Forgoing breastfeeding was particularly distressing. Women who had undergone a mastectomy valued opportunities to breastfeed before commencing chemotherapy.

“And even though it’s five and a half years ago, I still remember vividly the doctors giving me some tablets to dry up my milk. And that was the hardest- I think that was the hardest part of everything.”²⁹

While women reported understanding the need for the most effective cancer treatment, however invasive, they also reported concerns about their future fertility.

“Well obviously I wanted the baby but my health had to come first... I guess the other disappointment... was the age that I was when I got it and then to be told I couldn’t have any, couldn’t have another child for two years.”³⁰

When treating clinicians’ advice on delivering the child conflicted with the women’s birth plans, they reported attempting negotiations.

“I delivered all my other babies naturally...Please, please, please. I don’t want it... We’ll try for a natural delivery, but if there’s any um extra stress, you’re going in for a Caesar(ean). So on that condition, we agreed...”³⁰

Theme 3: ‘Not fitting in’

Women reported often feeling isolated in their experiences and not belonging to peer support groups.

“I just felt like there was no one else in my situation, like no-one I could talk to about that. And I went to a couple of support groups and things like that, and I just felt really out of place, and didn’t really feel like they understood exactly.”²⁹

Due to the low prevalence of gestational cancer, patients sometimes felt that their healthcare team were sympathetic to, but not sufficiently experienced in meeting their specific needs. This impacted on their satisfaction with their care.

“They [Maternity department] really struggled to deal with me because I didn’t really fit into any boxes. You know, here I was, this pregnant woman, but I had cancer... I just felt they didn’t quite know how to deal with me.”²⁹

Theme 4: Decision-making

Women often needed to make difficult decisions about their healthcare that impacted on the life of their unborn or new baby and existing family members. Many women

understood that their own health was important, wanting the best cancer treatment possible to maximise their chances of a positive outcome, particularly when they had borne children before the cancer diagnosis.

“I had two young children and I just didn’t want to die, and that was my first thought.”³⁰

Healthcare decisions were heavily influenced by opinions of the treating team. Thus, when different specialists in their team struggled to provide consistent information on the most appropriate treatment course, women found this distressing.

“it was sort of a tug of war, because they called in a specialist obstetrician as well. And he wanted the baby to stay in utero as long as possible... and they called in the oncologist and he wanted the baby delivered quickly because he wanted to start chemo(therapy)...”³⁰

Nonetheless, women ultimately made decisions about their treatment and pregnancy based on tightly held values, and wanted their choices respected.

“So the doctor that we spoke to, her only- only- suggestion was for me to terminate, and then follow the treatment from there... There was no way I could have gone through a termination – not a hope in Henry!”²⁹

4. DISCUSSION

This systematic review appraised quantitative and qualitative studies of pregnant women diagnosed with cancer to identify the psychological aspects of women's experiences. Two significant findings emerged. Firstly, women experienced psychological distress that was associated with concerns about their babies' health. Secondly, women's healthcare experiences were often affected by communication within multidisciplinary care teams.

Distress and maternal concerns about their babies' health were prominently reported by the women in the studies reviewed, and identified as a major theme. This is consistent with research reporting elevated levels of pregnancy-specific distress in women with comorbid medical conditions complicating pregnancy (e.g. hypertension, diabetes).³³ In the studies reviewed, women with gestational cancer reported being concerned about the toxicity of chemotherapeutic agents during pregnancy.^{26, 29, 30} Whilst some evidence suggests that women may be overestimating the risk of chemotherapy on short and long-term neonatal outcomes,³⁴ variations in risks associated with chemotherapy exist depending on the trimester of pregnancy.^{5, 35, 36} The use of chemotherapy during pregnancy is a relatively new and highly complicated area of healthcare, which is difficult to study. As data emerges, particularly from large longitudinal studies, this may inform our understanding of the risk of chemotherapy during pregnancy.

In addition to concerns about their babies' health, women in the studies reviewed also reported experiencing a conflict between competing concerns, which may have contributed to their psychological distress. Women reported making difficult healthcare decisions by weighing considerations about their own health, fertility and breastfeeding preferences, against the impacts of their decisions on the lives of their new or unborn babies and existing family members.³⁰ Furthermore, women's preferences may not have aligned with those of their partners'.²⁸ Overall, women reported wanting to maintain the pregnancies more than their partners.²⁸ However, when women had more advanced disease, their partners were more likely to report wanting to maintain the pregnancies. This was possibly because partners who were afraid of maternal mortality to cancer preferred having the baby as a way to seek meaning and connection to their partner.²⁸ Some women chose to terminate their pregnancies because not doing so was assessed as having adverse effects on their own and their significant others' lives.³⁷ Women reported varied accounts of what this had meant in the context of breast cancer, whilst reporting grief over their loss.³⁸ Addressing the psychological aspects of pregnancy termination during gestational cancer are warranted, but are beyond the scope of this review.

One of the factors that may have compounded the psychological distress of women with gestational cancer is difficulties with traditional supports. Whilst peer-support programs for people with cancer have significant psychological benefits for patients,³⁹ this review suggests there are limitations to the type of peer support groups that exist for women with gestational cancer. As a result, women with gestational

cancer who access general cancer support groups may feel like outsiders (as the only pregnant patient, only patient with a new baby) and feel isolated in their experiences.²⁹ This sense of social isolation can also occur as women may feel they do not belong in either oncology or maternity wards.⁴⁰

Women with gestational cancer also report that generic information and support for cancer patients does not often match their age and life stage. This is similar to the experiences found in a focus-group study of 65 young women diagnosed with cancer. The study reported an overarching theme of 'Nothing Fit Me', and described women repeatedly reporting that they lacked information tailored to their needs, as resources often targeted older women instead of younger women in their child-bearing years.⁴¹ For example, participants wanted information on the effects of hormone therapy (e.g. Tamoxifen) on fertility and induced menopause for women under fifty.⁴¹

The second major theme to emerge was women's concerns about communication with their healthcare team. Women reported that their healthcare decisions were heavily influenced by the opinions of their treating team, and that they were distressed when they received inconsistent information about the most appropriate treatment course. This is consistent with a recent review of the mother-child relationship in women with gestational cancer, which highlighted the potential differences in the treatment priorities and objectives of oncologists and obstetricians.¹⁴

Women also sometimes reported dissatisfaction with their healthcare when they perceived poor interdisciplinary communication between cancer and obstetric teams, who may be in different geographic locations and would not ordinarily collaborate. The importance women placed on communication with their treating teams suggests that more can be done to support patient-provider communication. Multidisciplinary teams are considered the gold standard of cancer care and are associated with improved clinical outcomes.⁴² However, poor communication can lead to negative outcomes including compromised patient safety, inefficient use of valuable resources such as unnecessary investigations.⁴³

Team communication is also essential to ensure psychological distress does not go undetected or unmanaged.⁴³ Women reported that while the members of their healthcare team were often sympathetic to their distress, the various specialists were sometimes perceived as insufficiently experienced in meeting the specific needs of women with gestational cancer. In practice, healthcare communication between multiple specialists may be better facilitated within an integrated and more specialised approach to psycho-oncologic care for women and their families. Within these complex decision-making processes, greater attention to the psychosocial aspects of women's individual experiences is in line with the recent paradigm shift in psycho-oncology care from disease-focused management to a patient-centred approach.⁴⁴

4.1. Clinical Implications

Whilst the medical management is well described for women with gestational cancer, recommendations for psychological management are limited.^{15, 16, 45}

Healthcare providers could play a significant role in addressing women's distress about their babies' health, by communicating research findings about risk estimates (e.g., for chemotherapy) in discussions with women. Women's concerns about their babies' health are specific to the context of managing their dual health conditions, and healthcare support needs to be appropriately tailored to this reality. The oncology-related psychosocial distress women with gestational cancer experience should also be understood within the context of the mother-infant dyad,¹⁴ in order to develop a more sophisticated understanding of post-partum psychological adjustment.⁴⁶ The absence of intervention studies for women with gestational cancer that was discovered during this review suggests a missed opportunity to provide psycho-oncology support for affected women in the perinatal period.

While women with gestational cancer may find their experiences of the healthcare system to be particularly confusing, this may be mitigated by a stable physician-patient relationship that is reinforced by an integrated support team.⁴⁷ A recent overview of strategies for implementing multidisciplinary cancer teams suggested practical guidelines including effective communication; conflict management; and incorporating patients' choices, comorbidities and psychosocial factors into decision-making.⁴⁸ For women with gestational cancer, a comprehensive psychosocial assessment of their often-unmet needs (e.g. fertility, breastfeeding)

could also inform the development of an individualised care plan (accounting for the stage of pregnancy and the cancer stage and subtype).⁴⁹ Health information technology (e.g. electronic patient records) has the potential to facilitate these processes. This can occur via documentation of a well-communicated and coherent treatment plan that contains clear schedules and timelines for women's appointments and their objectives.

Regular quality communication between obstetric and oncology teams is an essential component of healthcare provision for this population. Women with gestational cancer may also feel more supported if their treating team were caring for the mother and baby as a unit, rather than communicating different opinions based on differing priorities.¹⁶ However, a single model of care may not be practical, due to different types of gestational cancer with diverse treatment needs and varying health settings (e.g. public vs private).⁵⁰ Different models of reciprocal care recommend options for how treatment is delivered. One example of an alternative model of assistance includes patient-centred home care, coordinated by a specialised multidisciplinary team with a reference hospital to employ shared care.⁵¹ Alternatively, multidisciplinary treatment services for women with gestational cancer may be delivered in a single specialist clinic. Further economic evaluation of health policies for treating women with gestational cancer would be beneficial, to determining the most cost-effective and evidence-based models of healthcare delivery.

4.2. Study Limitations

This review is limited to data available in English-language studies, thus women from culturally and linguistically diverse (CALD) backgrounds were not represented. Past research has demonstrated that women of Anglo-Saxon heritage are more likely to have higher health literacy and better access to healthcare.⁵² As such, the findings of this review cannot be generalised to the experiences of indigenous and CALD populations, who often report worse outcomes from cancer due to later diagnoses and poorer care continuity and treatment compliance.⁵³ In medical research, when compared to studies with a large N, studies with small sample sizes can be of lower methodological quality⁵⁴ in that the internal and external validity of these studies are often undermined. Low rates of gestational cancer could have limited the opportunities to conduct large scale or methodologically sophisticated studies, thus contributing to the poor quality of the limited existing research.

Under the system of classifying evidence according to the Australian National Health and Medical Research Council,⁵⁵ numerous studies in this area consist of single case reports, cross-sectional case control studies or purely descriptive quantitative or qualitative studies (i.e. Level IV evidence).⁵⁶ Cross-sectional studies were over-represented and do not capture the coping trajectories of women with gestational cancer. There was inconsistency across studies regarding methods of data analysis and reporting instruments, with two of the five studies using newly constructed and unvalidated psychometric tools. Variability in both the time of recruitment as well as

the time of cancer diagnoses among the participants could have introduced a degree of statistical heterogeneity in the review. Clinical diversity in patient characteristics could have impacted on the ways the psychological aspects of gestational cancer were reported, which could have resulted in different implications for their healthcare. Despite these limitations, this is the first systematic review of empirical evidence on the psychological aspects of pregnant women diagnosed with cancer.

5. CONCLUSION

This systematic review aimed to identify the psychological aspects of the experience of women with gestational cancer. This review highlights the paucity of literature on the psychological care of women with gestational cancer, suggesting the need for methodologically sound studies using representative sampling strategies and psychometrically validated instruments. Longitudinal designs would be valuable in future research, to research the temporal patterns of factors associated with study outcomes. This review also illustrates the need for an evidence-based model of psycho-oncology care for women with gestational cancer,¹⁴ as well as empirical research exploring the efficacy of specific treatment interventions.

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CONFLICT OF INTEREST

The authors have declared no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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TABLE 1 Participants' demographic, pregnancy and cancer characteristics for quantitative studies

Authors (year)	Demographic characteristics N [†] , (SD) [‡] [Range]	Gestational characteristics (SD) [Range]	Disease characteristics (SD)
Bandyk & Gilmore (1995) ²⁶	N = 6 Mean age = 35.5 [31–39] All women were married.	Mean gestational age at diagnosis (weeks) = 12.7 (7.4) [2–22] Mean gestational age at delivery (weeks) = 36.4 (3.1) No foetal or infant deaths.	Breast cancer Stages unknown All women underwent mastectomy.
Henry et al. (2012) ²⁷	N = 74 Mean age at diagnosis = 34.2 (4.5) 65.8% had other children before the index [§] pregnancy.	Mean gestational age at diagnosis (weeks) = 14.7 (8.4) Mean gestational age at delivery (weeks) = 36.4 (3.1) No foetal or infant deaths.	Various cancers including 65% Breast, 11% Hodgkin's lymphoma, 5% Ovarian, 5% Melanoma, 14% Other Stages: I=52%, II=25%, III=14%, IV= 8% Mean time since diagnosis (years) = 3.8 (2.5)

Vandenbroucke et al. (2017) ²⁸	N = 61 Median age at diagnosis = 32 [22–42] 55.7% of women had other children before index [§] pregnancy. 70.5% of women retrospectively recruited after delivery. 61 partners	Median gestational age at diagnosis (weeks) =16 [22–42]	Various cancers including 62% Breast, 21% Haematological, 6% Cervical, 5% Ovarian, 3% Other Stages: I=37%, II=45%, III=10%, IV=8%
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[†]N=Number of participants, [‡]SD=Standard Deviation, [§]= the pregnancy during which cancer was diagnosed.

TABLE 2 Participants' demographic, pregnancy and cancer characteristics for qualitative studies

Authors (year)	Demographic characteristics N [†] (SD) [‡] [Range]	Gestational characteristics	Disease characteristics (SD)
Hammarberg et al. (2018) ²⁹	<p>N = 17</p> <p>Age at diagnosis, [31–43]</p> <p>Age at interview, [32–47]</p> <p>All women were married at diagnosis.</p> <p>65% had other children before the index[§] pregnancy.</p> <p>70% accessed private healthcare.</p>	<p>Gestational age at diagnosis:</p> <p>First trimester = 29%</p> <p>Second trimester = 24%</p> <p>Third trimester = 35%</p> <p>Postpartum = 12%</p> <p>Outcome of pregnancy:</p> <p>Miscarriage = 6%</p> <p>Premature birth (<37 weeks) = 53%</p> <p>Term delivery = 41%</p>	<p>Breast cancer</p> <p>Maximum time since diagnosis (years) = 5</p>
Ives et al. (2012) ³⁰	<p>N = 15</p> <p>Mean age at diagnosis = 35.3 (5.0) [29–43]</p> <p>80% had other children before the index[§] pregnancy.</p> <p>All were retrospectively recruited after delivery.</p>	<p>Gestational age at diagnosis:</p> <p>First trimester = 7%</p> <p>Second trimester = 7%</p> <p>Third trimester = 13%</p> <p>Postpartum = 73%</p>	<p>Breast cancer</p> <p>Mean time since diagnosis (years) = 9 (3.2)</p>

[†] N=Number of participants, [‡]SD=Standard Deviation, [§]=the pregnancy during which cancer was diagnosed.

TABLE 3 Study characteristics of included quantitative studies

Authors(year), country	Study aim(s)	Methodology: study design, measures, and data analyses	Demographic and clinical factors	Main findings	Additional notes
Bandyk & Gilmore (1995), USA ²⁶	To identify the concerns of women who had received chemotherapy for breast cancer while pregnant	Cross-sectional study <i>Pregnancy Concerns:</i> Bandyk Concerns Questionnaire (BCQ) ²⁴ <u>Data analyses:</u> Ordinal rankings based on means of Likert-type responses on BCQ items	<i>Demographic:</i> Gestational age at diagnosis Child-specific information Pregnancy information <i>Clinical:</i> Chemotherapy course	Highest ranked BCQ concerns were “living to see my child grow up”, “receiving proper treatment for the breast cancer” and “future effect that chemotherapy have on baby”.	Participants: - Patients speaking only Spanish were excluded. Methodology: - Newly constructed BCQ scale not yet validated.
Henry et al. (2012), USA ²⁷	To identify the variables associated with long- term psychological distress in women with gestational cancer	Cross-sectional study <i>Psychological distress:</i> Impact of Event Scale (IES) Brief Symptom Inventory-18 (BSI-18) <u>Data analyses:</u> Multiple linear regression analyses	<i>Demographic:</i> Participant’s age Other children <i>Clinical:</i> Cancer staging Pregnancy, birth and cancer treatment information	Increased psychological distress was significantly correlated with not receiving fertility assistance; baby being born preterm; undergoing surgery post-pregnancy.	Participants: - Sample was the largest of the selected studies. Methodology: - General trends (not significant) also presented.

		between demographic variables and distress.			
Vandenbroucke et al. (2017), Belgium & Netherlands ²⁸	To identify women and partners at risk of high levels of distress, based on their coping profile	Cross-sectional study <i>Cancer and Pregnancy Concerns/ Distress: Cancer and Pregnancy Questionnaire (CPQ)</i> ²⁶ <i>Cognitive Emotion Regulation Strategies: Cognitive Emotion Regulation Questionnaire (CERQ)</i> ³⁰ <u>Data Analyses</u> K-means cluster analyses on the CERQ scales MANOVA analyses on CPQ scores between women and their partners and between coping clusters	<i>Demographic:</i> Nulliparous or multiparous Participant's age Gestational age <i>Clinical:</i> Cancer type and stage	Women were more inclined to maintain their pregnancy than their partners. Women and partners using internalising coping strategies reported higher distress than those using other coping strategies. More advanced disease stage was correlated with women's concerns about treatment and partners' inclination to maintain the pregnancy.	Participants: - Women were recruited from the European cancer in pregnancy registry. Methodology: - Newly constructed CPQ scale not yet validated - Only breast cancer patients (62.3%) included in the analyses.

MANOVA= *multivariate analysis of variance.*

TABLE 4 Study characteristics of included qualitative studies

Authors(year), country	Study aim(s)	Methodology: theoretical framework and questions used	Main findings and themes:	Additional notes
Hammarberg et al. (2018), Australia ²⁹	To explore the health care experiences of women with GBC [†] to inform and improve their clinical care.	Thematic Analysis Semi-structured interview explored healthcare experiences, including: <ul style="list-style-type: none"> - Views about care at the time of and after diagnosis - Whether patients' needs were met - Suggestions for improvement (regarding interactions between healthcare professionals, information received, quality of care received, follow-up care). 	Communication: <ul style="list-style-type: none"> - Interdisciplinary: Women worried when they received conflicting advice from healthcare professionals about their cancer treatment. - Patient: Women valued communication when information was consistent, women's choices were respected via shared decision-making and when specialists were working well together. Comprehensive care: <ul style="list-style-type: none"> - The spirit: Peer support was perceived as helpful when it came from women who had survived GBC, but not in general breast cancer support groups. - The mind: Women had information needs relating to the impact of cancer treatment on their baby's health, breastfeeding and future fertility. - The body: Women reported wanting allied health professionals included in their care, to manage treatment side-effects. 	Participants: <ul style="list-style-type: none"> - No apparent differences between accounts of women who received care in the public versus the private system (70% private patients). Methodology: <ul style="list-style-type: none"> - Interview guide was developed based on advice from an expert reference group (clinicians and a consumer). - No reports on how study findings were influenced by researchers.
Ives et al. (2012), Australia ³⁰	To explore the psychosocial experiences of pregnancy, in women diagnosed with	Content analysis Question topics in semi-structured interviews included treatment outcomes, social support, the baby's health, pregnancy-related	Anxiety: <ul style="list-style-type: none"> - Women reported anxiety associated with the conflict between concern for their baby's health and their own health. Decision conflict:	Participants: <ul style="list-style-type: none"> - Women with GBC were retrospectively identified from a concurrent study dataset.

breast cancer during or shortly after pregnancy.	issues and adaptation to motherhood.	- Women were torn between protecting their unborn child and receiving the best cancer treatment to survive to see their live children grow up. - Women reported competing interests from the obstetricians and the oncologists.	Methodology: - Only two themes of four extracted were reported.
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[†] GBC= gestational breast cancer.

TABLE 5 Study quality assessment based on MMAT criteria

Methodological quality criteria	Quantitative studies		
	Bandyk & Gilmore (1995) ²⁶	Henry et al. (2012) ²⁷	Vandenbroucke et al. (2017) ²⁸
Relevant sampling strategy		*	*
Representative sample			
Valid measurements		*	
Acceptable response rate	*		
Total %	25(*)	50(**)	25(*)
Qualitative Studies			
	Hammarberg et al. (2018) ²⁹		Ives et al. (2012) ³⁰
Relevant data sources	*		*

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Relevant data analyses	*	*	
Considered how findings relate to context	*	*	
Considered how findings relate to researchers’ influence			
Total %	75(***)	75(***)	
<hr/> *=Yes. Higher scores indicate higher quality.			

Figure 1

PRISMA Flow Chart of Literature Search.

PON_5502_PRISMA Flow Chart.png

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