## Introduction

Gestational cancer is defined as any type of cancer diagnosed within 3 months before abortion, within nine months before delivery, or within 12 months of delivery. A report by the National Cancer Registration and Analysis Service (NCRAS) (2018) estimates that 1 in 1,000 pregnancies have the added complication of a cancer diagnosis. Data from the NCRAS, collected between 2012 and 2014 reveals a gestational cancer diagnosis for 3,272 women aged between 15 and 44. There were 784 cases of gestational breast cancer, 504 cases of melanoma of the skin, 498 cases of cervical cancer, 286 cases of haematological cancer, 240 cases of ovarian cancer and 188 cases of colorectal and anus cancer recorded. Eastwood-Wilshere et al. (2019) predict that this rate is increasing because women are choosing to delay pregnancy until later life. Although a gestational cancer diagnosis only affects a small percentage of pregnancies, it has a significant impact on the psychological wellbeing of women and their partners, as they are in receipt of bad news at what should be a happy time.

This literature review aims to answer the question ‘what are women’s experiences of a gestational cancer diagnosis’, to broaden nurses’ and midwives’ understanding and so enable enhanced delivery of support and care.

## Method & Search Strategy

To develop a literature search question, the framework of PEO was used (Polit and Beck, 2014), where the ‘population’ is pregnant women, the ‘exposure’ is gestational cancer diagnosis and the ‘outcome’ is their experience. A systematic search was carried out in November 2020, using Medline, CINAHL Complete, PsycINFO and Complementary Index databases, using key words and synonyms closely aligned to the research question (see table 1). Boolean operators were used to focus the search on the research question.

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| Cancer during pregnancy ‘AND’ psychological |
| Gestational cancer ‘NOT’ diabetes |
| Maternal cancer ‘AND’ during pregnancy |

**Table 1 – search terms**

There were 250 results returned after removing duplicate research papers.  These were filtered using inclusion and exclusion criteria (see table 2).

| Inclusion | Exclusion |
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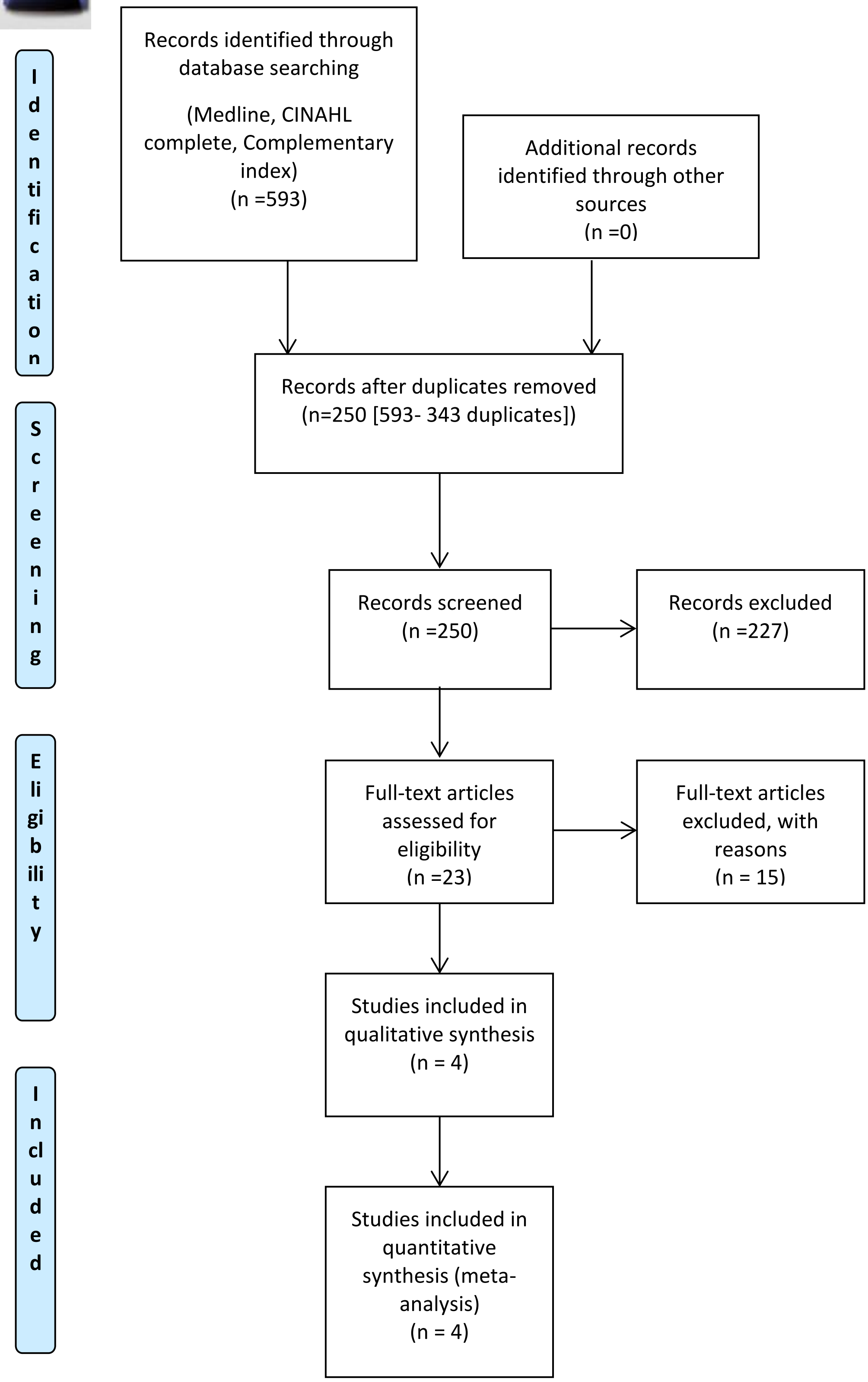
| Full text | Research published before 2010 |
| Double-blind peer reviewed | Not gestational cancer |
| English language | |
| Clear focus on gestational cancer | |

**Table 2 – inclusion and exclusion criteria**

A Preferred Reporting Items for Systematic Reviews and Meta- Analyses (PRISMA) flow chart (see figure 1) was used to depict the process of filtering the papers (Moher et al., 2009).  After reviewing the titles and abstracts 227 papers were discarded because they did not meet the inclusion criteria. The remaining 23 research papers were read in full and 15 of these papers were discarded, due to insufficient focus on the research question.  The eight remaining papers were analysed using the relevant Critical Appraisal Skills Programme checklist (Critical Skills Appraisal Programme, 2018).  All the studies were deemed to be of high quality based on the CASP review, thus relevant for inclusion in the review.

**Figure 1: PRISMA flowchart** (see over)


Identification
Screening
Eligibility
Included
Records identified through database searching
(Medline, CINAHL complete, Complementary index)
(n =593)
Additional records identified through other sources
(n =0)
Records after duplicates removed
(n=250 [593- 343 duplicates])
Records screened
(n =250)
Records excluded
(n =227)
Full-text articles assessed for eligibility
(n =23)
Full-text articles excluded, with reasons
(n = 15)
Studies included in qualitative synthesis
(n = 4)
Studies included in quantitative synthesis (meta-analysis)
(n = 4)

Data from the final eight papers were plotted in a table (see table 3), enabling the researcher to identify themes from them. These were further developed in group supervision and presentation to an academic supervisor and third year nursing student peers.

### Table 3: Summary of data from the papers reviewed.

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| Betchen et al. (2020)<br>Being a mother after a cancer diagnosis during pregnancy: Maternal psychosocial functioning and child cognitive development and behaviour<br>USA | 69 mothers diagnosed with gestational cancer and their 71 children (2 sets of twins) aged 6 months-12 years. | Quantitative<br>Correlation design | Maternal self- report<br>Medical chart review<br>Basic symptom inventory (BSI)<br>Impact of Events Scale (IES) | 68% of women received chemotherapy<br>Women reported more trauma and psychological distress if baby was delivered preterm<br>Preterm infants/ low birth weight was associated with maternal avoidance<br>Where mothers had depression and pain, children demonstrated less discipline<br>Children with highest language performance had mothers with lowest physical symptoms |
| Faccio et al. (2020)<br>Motherhood during or after breast cancer diagnosis<br>Italy | 38 women, 18 with gestational breast cancer diagnosis and 19 without. | Qualitative<br>Phenomenology | Individual semi-structured interviews | Women expressed fear for their child and own survival<br>Women with a previous diagnosis considered breastfeeding to be fundamental<br>Some women felt that GBC meant breastfeeding was not a viable option<br>GBC patients felt the foetus provided them with strength and support<br>Women with GBC were worried medical appointments meant they would be unable to dedicate enough time to construct relationship with baby<br>Women believed treatment side effects (fatigue) meant they would not be good mothers<br>Women's relationships with partners were central – there was heightened support requirements from partners for GBC and previous BC patients compared to healthy women<br>• |
| Kozu et al. (2020)<br>Experiences of Japanese pregnant women with cancer in decision- making regarding cancer treatment and obstetric care.<br>Japan | Purposive sample 8 women with gestational leukaemia, cervical, breast and digestive cancers diagnosed between 2005-2011. | Qualitative<br>Phenomenology | Semi-structured interviews | • If foetus was respected the woman felt she gained strength, if not she felt isolated<br>• Quick turnaround in medical meetings caused confusion for women<br>• Concern highlighted about potential disabilities in the baby due to treatment.<br>• Mothers expressed concern that they may not be able to look after themselves and a disabled child<br>• Concern that delaying treatment for the pregnancy could result in progression of disease or disrupt care of other children |

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| | | | | • Anxiety about termination versus continued pregnancy (as possibly the last chance to experience childbirth)<br>• Anxiety about fertility and the effects for their husbands<br>• Time pressures around decision making were highlighted |
| Hammarberg et al. (2018)<br>Health care experiences among women diagnosed with gestational breast cancer<br>Australia | 17 women diagnosed with GBC between the years 2008-2013. | Qualitative<br>Phenomenology | Individual semi-structured interview | • Participants reported distress on receipt of conflicted advice<br>• Participants wanted their concerns to be believed and taken seriously<br>• When GBC was confirmed, women were shocked but most felt as though their choices were respected and that they were allocated enough time to ask questions etc<br>• Some women reported feeling disempowered when they had no say in treatment<br>• The breast cancer nurse was a helpful constant and a valued advocate<br>• Women diagnosed with GBC relied on family and partners to manage their distress<br>• Most women offered counselling or peer support, and found it helpful and reassuring<br>• All participants were more concerned about treatment side-effects on the baby than themselves<br>• Women received mixed messages about breast feeding<br>• Women felt dissatisfied with information about the impact of treatment on future fertility |
| Lu et al. (2017)<br>Maternal Cancer During Pregnancy and Risks of Stillbirth and Infant Mortality<br>Sweden | 984 women diagnosed with gestational cancer in pregnancy and 2,723 within 12 months of delivery. | Quantitative | Review and statistical analysis of records from 1973-2012 Swedish Medical Birth Register (MBR) | • Gestational cancer positively associated with stillbirths (8.2 per 1,000 births)<br>• Gestational cancer positively associated with preterm birth (mostly between 28-31 weeks). Most associated with iatrogenic factors rather than spontaneous<br>• Preterm birth - 89% (estimated) resulted in neonatal mortality |
| Vandenbroucke et al. (2017)<br>Psychological distress and cognitive coping in pregnant women diagnosed with cancer and their partners<br>Belgium | 61 couples (122 participants) participated, following a gestational cancer diagnosis | Quantitative<br>Correlation design | Cancer and Pregnancy Questionnaire (CPQ)<br>Cognitive Emotion Regulation Questionnaire (CERQ) | • There was no significant difference between distress levels in the woman or their partner<br>• Women were more inclined to maintain pregnancy<br>• Those women who internalised concerns scored higher on the questionnaires and had a higher risk of psychosocial impact<br>• Nulliparous parents were more concerned regarding pregnancy and |

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| | | | | delivery compared to multiparous parents<br>• The higher stage of cancer at diagnosis, the greater the concern from women about disease progression and treatment<br>• Partners were more inclined to maintain the pregnancy when the cancer stage at diagnosis was higher |
| Henry et al. (2012)<br>The psychological impact of a cancer diagnosed during pregnancy: determinants of long-term distress<br>USA | 74 women diagnosed with gestational cancer, recruited from the cancer and pregnancy registry. | Quantitative | Chart review<br>Self-administered questionnaires | • 20.9% experienced significant distress<br>• Distress mostly expressed through intrusive thoughts<br>• Women had a risk of higher long-term distress- due to lack of fertility assistance, being advised to terminate, having a preterm baby or undergoing surgery<br>• Risk of distress increased with caesarean delivery, no baby weighing, insufficient milk production or a cancer recurrence |
| Ives et al. (2012)<br>The experience of pregnancy and early motherhood in women diagnosed with gestational breast cancer.<br>Australia | Retrospective sample of 8 women with gestational breast cancer. | Qualitative<br>Phenomenology | Semi structured interviews | • High levels of stress and anxiety reported around women's health and that of the babies<br>• Heightened anxiety about delivery and transition from breast to bottle<br>• Anxiety if women were having chemotherapy and could not breastfeed.<br>• Second time mothers' priority was to protect their child(ren) – they wanted best cancer outcome to watch children grow up<br>• First time mothers- prioritised their unborn child but understood their own health was also important<br>• One woman terminated pregnancy and still felt a deep sense of regret<br>• Women reported anxiety about receiving treatment<br>• Conflict reported between obstetrician and oncologist. Obstetrician wanted baby to mature in womb for as long as possible whereas oncologist wanted the baby delivered to treat the mother<br>• Guilt for baby being in neonatal unit after preterm birth<br>• Preterm birth resulted in greater amount of stress and anxiety<br>• One woman reported that she felt isolated on the maternity unit due to single mastectomy and wanting to breast feed |

## Findings

Two themes were discovered.  These were feeling distressed about the diagnosis and treatment of gestational cancer and fears for the baby.

### Feeling distressed about the diagnosis and treatment of gestational cancer

Feeling distressed about the diagnosis and treatment of gestational cancer was the strongest theme, reinforced in data from six of the papers reviewed.  Henry et al. (2012) used self-administered questionnaires to explore the psychological impact of a gestational cancer diagnosis in seventy-four women in the USA.  Participants completed the Brief Symptom Inventory-18 and Impact of Event Scale, on average 3.8 years following their cancer diagnosis.  Data analysis revealed that 20.9% (n=28) women in this study experienced significant levels of distress linked to their diagnosis, particularly when they chose not to heed clinicians' advice to terminate their pregnancy, when they were advised to deliver pre-term or to undergo surgery post-delivery, as they felt unsupported.

Similar findings were revealed in a qualitative study about the experiences of women diagnosed with gestational breast cancer (Ives et al., 2012).  Data collected from semi-structured interviews with 15 women who had received a gestational breast cancer diagnosis highlighted their experiences of feeling stress and anxiety in relation to the thought of receiving treatment and to receiving conflicting advice from their obstetrician and oncologist. Women also reported experiencing distress due a sense of isolation when receiving care on the maternity unit.

Hammarberg et al. (2018) used a phenomenological approach to explore the lived experiences of health care of 17 Australian women who had been diagnosed with breast cancer, up to five years previously.  Participants reported experiencing feelings of distress when they experienced communication difficulties and inconsistencies between members of the interdisciplinary team as a result of the way that information was communicated to them, especially when it related to information about the best treatment option and impact on survival.  They described how 'poorly coordinated and unsatisfactory care' made them feel like 'misfits' and disempowered as it impacted the action of shared decision-making. Having access to a dedicated breast care nurse had a positive impact on women's experiences of their care.  Some women felt supported through access to counselling and peer support groups where they could express concerns, although gestational cancer is rare, so they reported feeling out of place at times.  Where external support was unavailable, women relied on partners and families to manage their distress (Hammarberg et al., 2018).

Notably, research undertaken by Vandenbroucke et al. (2017), which aimed to identify women and their partners who are at high risk of distress based on their coping profile, revealed that women and their partners experience a similar level of distress.  The sample of 61 pregnant women and their partners completed the Cognitive Emotion Regulation Questionnaire (CERQ) and the newly constructed Cancer and Pregnancy Questionnaire (CPQ).  Findings confirmed that distress was linked to the coping mechanisms employed by women and their partners, specifically if they internalised their concerns (n=20; 32.8%), whether about the cancer, the pregnancy, or the child's health.  Where they coped by positive means (no specific examples given) or blaming others, the potential for distress was lower.

Betchen et al's. (2020) quantitative data from 69 women and 71 children (2 sets of twins) aged between 6 months and 12 years sought to explore the impact of women's maternal psychosocial wellbeing following a gestational cancer diagnosis on their child's development.  They discovered an inverse relationship between the distress displayed by mothers (through depression, anxiety, somatic symptoms such as pain) and the development of language skills in their children.  In addition, the children of mothers who displayed psychosocial symptoms displayed higher levels of behavioural challenges.  These findings illustrate the wider impact of maternal distress.

Time was a key factor influencing distress about treatment.  Kozu et al. (2020) interviewed eight post-partum women who had made decisions about treatment whilst pregnant.  Participants reported distress caused by the need to make crucial decisions regarding both their diagnosis and the progression of pregnancy, within the limited time frame of the pregnancy.  The haste of medical meetings resulted in women feeling anxious and uncertain about the future.  In addition, distress was caused by having to communicate with young male doctors, who women felt were unable to relate to their current situation.

The data presents a strong theme of distress about the diagnosis and treatment of gestational cancer, for women and their partners.  Distress is predominantly attributed to inconsistencies in information about treatment between members of the interprofessional team and to the way that information is delivered to the women and their partners.  It is influenced by the time constraints for treatment decision-making within the constraints of the length of pregnancy.  The use of tools to assess coping mechanisms can indicate mothers and their partners at the highest risk of distress in order that psychosocial interventions can be implemented.  This may help to reduce the potential for maternal distress to impact on child development.

### Fears for the future, for mother and baby

Fears for the baby was a strong theme in the data.  This is a realistic concern, confirmed by Lu et al. (2017), in their statistical analysis of 3,947,215 birth records.  Calculated incidence ratios confirmed that gestational cancer diagnosis was positively associated with stillbirths, at a rate of 8.2 stillbirths per 1,000 births. There was also a positive correlation between gestational cancer and pre-term delivery and/or the delivery of small-for-gestational-age babies.  The positive association with preterm birth was due to iatrogenic instead of spontaneous preterm birth. This data supports the need to monitor foetal growth when making treatment decisions.

Both Hammarberg et al. (2018) and Kozu et al. (2020) reported participants' persistent fears around the side-effects of cancer treatment on the foetus, whether the development of a disability or the cause of a pre-term delivery.  These fears were balanced against the survival of the mother but considered the impact of treatment toxicities for both mother and baby (Hammarberg et al., 2018).  Vandenbroucke et al. (2017), whose study was concerned with maternal distress and coping found that multiparous parents prioritised their own health so that they could protect the children they already had, whereas nulliparous parents had more concern for the baby.  Betchen et al. (2020) reported that 68% of mothers interviewed proceeded to have treatment for their gestational cancer, but experienced major anxiety as a result.

Faccio et al. (2020) collected qualitative data from 38 women, 19 of whom had gestational breast cancer and 19 who did not. Thematic analysis of interview data revealed that women with gestational breast cancer (GBC) were afraid for their own survival, as well as that of their child, due to the risk of still-birth or premature delivery. Participants with GBC expressed particular concern around the potential inability to breast feed, viewing breastfeeding as fundamental to bonding with their baby. They were also worried that they would be inadequate mothers due to treatment side effects such as tiredness and the pressure of attending hospital appointments. The relationship with their partner was discovered to be fundamental in helping them to manage their fears.

Women in the studies by Ives et al. (2012) and Hammarberg et al. (2018) experienced anxiety when advised to terminate their pregnancy or deliver their baby pre-term and when they were in receipt of conflicting advice about the possibility and safety of breastfeeding following a single mastectomy or whilst undergoing chemotherapy. This result in a feeling of disempowerment in respect of treatment decision-making, as well as being fearful about the future health of their child. One woman interviewed by Ives et al. (2012) reported feeling persistent and great sense of regret regarding the decision she made.

The theme of ‘fears for the future, for mother and baby’ reflects the emotional impact of a cancer diagnosis during pregnancy and the associated uncertainties about the side effects of cancer treatment for both mother and baby, both in terms of survival, or disability arising from the toxicity of cancer treatment. It also reflects fears around breastfeeding for women diagnosed with GBC and generalised concerns about the effects of treatment or time pressures of hospital visits impacting on the process of bonding with their baby.

## **Discussion**

The two themes of ‘feeling distressed about the diagnosis and treatment of gestational cancer’ and ‘fears for the future, for mother and baby’ that developed from the data, have a common element of communication, particularly consistency of communication, running through them. Where communication is poor or inconsistent, women experience distress and anxiety and feel disempowered in the decision-making process. The feelings of distress can continue several years beyond remission from the cancer. This is not a new phenomenon, with similar concerns for the health of the mother and baby and concerns about the functional ability to be a parent whilst needing support themselves being reported in the work of Schmitt et al. (2010). A recent systematic review by Leung et al. (2020) supports the findings of this literature review, highlighting distress caused by women's concerns about their baby and pressures of decision-making.

The Mental Health Foundation (2018) propose that one in three people with a diagnosis of cancer (not gestational cancer specific) will experience a mental health condition such as anxiety or depression at some point throughout their diagnosis and recovery, linking this to communication between service providers and lack of support after treatment has finished. The data in this literature review confirms that women with gestational cancer are very likely to experience distress and anxiety that persists beyond diagnosis and treatment. It often begins with anxiety linked to communication and inconsistency of the message being communicated, reflecting inadequate communication between the oncology and obstetric teams (Ives et al., 2012, Hammarberg et al., 2018, Kozu et al., 2020). Whilst work has been done to improve support available for women with a gestational cancer diagnosis (Macmillan Cancer Support, 2021, Mummy's Star, 2020, Brauten-Smith, 2020), including the provision of advocacy services the Mental Health Foundation argue that person-centred care and greater collaboration and communication between service providers, in this case the oncology and obstetric teams. Notably, Vandenbroucke et al. (2017) found that the use of the CERQ and the CPQ tools enables professionals involved in a women's care to predict whether they would benefit from additional psychosocial support to help them manage their distress.

Having a clear understanding of all their options for treatment is fundamental to person-centred care and to women and their partners being involved in all decisions regarding treatment and progression of the pregnancy, as advocated by the Royal College of Obstetricians & Gynaecologists (2011). The data in this literature review reveals that women and their partners continue to experience distress and feel disempowered because they receive poor or inconsistent communication between and from health professionals that results in conflicting advice (Ives et al., 2012, Hammarberg et al., 2018, Vandenbroucke et al., 2017, Kozu et al., 2020). This finding suggests that there is a potential to improve services and thus improve the experience of women diagnosed with gestational cancer, namely by enhancing collaboration and communication between service providers.

## **Implications for practice**

The implications for practice identified from this review are to improve the communication and consistency of information between the oncology and obstetric teams and to promote the use of assessment tools, such as the CERQ and CPQ, to identify women likely to need additional psychosocial support, so that it can be signposted or set up for themselves and their partners (Ives et al., 2012, Hammarberg et al., 2018, Vandenbroucke et al., 2017).

Eastwood-Wilshere et al. (2019) propose that women with gestational cancer need to be managed in a multidisciplinary high-risk obstetric unit, with involvement from obstetrics, obstetric medicine, oncology, radiation oncology, radiology, palliative care, midwifery, nursing and social work. Continuity of care from a named midwife has been shown to have a significant positive impact on the experience of pregnancy and childbirth (Sandall et al., 2015). In their review of services, Sandall et al present the model used at Guy's and St. Thomas' hospital where the booking midwife coordinates all antenatal and postnatal care and attends all multidisciplinary consultations for those women, where they have high medical risk. This ensures that the women have access to specialist services and shared care plans. It is highlighted as an effective model for practice that would benefit all women diagnosed with gestational cancer, since it supports consistency of messages about treatment and obstetric concerns through a named midwife, during the pregnancy.

Effective communication is a fundamental nursing and midwifery role (Nursing and Midwifery Council, 2018). The named midwife is well placed to administer CERQ and CPG assessment tools, and to initiate or signpost women and their partners to appropriate support services during the pregnancy. Macmillan, Breast Cancer Now and Mummy's star offer support and advocacy, both through the pregnancy and after it. Clinical Nurse Specialist roles are well established in oncology. A close working relationship between the named midwife and the clinical nurse specialist within the multidisciplinary team context, will support handover of care from the obstetric team to the oncology team following delivery of the baby, in order that a woman's needs continue to be supported in a seamless way during oncology treatment and follow up care.

## Limitations

There are limited papers exploring women's experiences available for review. Available papers predominantly rely on participants who are postpartum, so there is a potential for recall bias to influence the findings. Many women who participated were disease-free so data from potential participants continuing to live with gestational cancer is missing. In addition, there is a bias towards research with women diagnosed with gestational breast cancer, where there are specific concerns raised around breast-feeding, an act that is heavily linked to the process of bonding with a baby. These factors may have influenced the findings of this literature review.

## Conclusion

In conclusion, women with a diagnosis of gestational cancer have been found to experience feelings of distress about the diagnosis and treatment of gestational cancer and fears for the baby and for themselves. The distress is clearly linked to inconsistencies of information about treatment between members of the multidisciplinary team and to the way that information is communicated. Communication and support are enhanced when women have a named midwife. Effective communication is supported when the named midwife attends all multidisciplinary meetings concerning that woman with medical risk due the diagnosis of gestational cancer. The use of cognitive assessment tools can help to highlight women at higher risk of psychosocial distress in order that appropriate support services are initiated or signposted. Following the birth of the baby, the named midwife should ensure a clear handover to the oncology clinical nurse specialist, in order to ensure continuity of care and support for the woman and their partner as required.

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