

Title:

Cancer during pregnancy: A qualitative study of healthcare experiences of Australian women.

Running title:

Healthcare experiences of women with gestational cancer.

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The contributions of the authors include: LS conceived and designed the original study on which this manuscript is based, secured funding for the project and supervised the study. LS, KG, LC and MS completed the data acquisition, analysis and interpretation. RL, LS and MS were involved in drafting and critically revising this manuscript. All other authors contributed to the refinement of the study protocol of the original study and approved the final version of the manuscript.

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Cancer during pregnancy: A qualitative study of healthcare experiences of Australian women.

Objectives: To identify features enhancing the quality of healthcare experiences for women with gestational cancer, and explore the impact of the heterogeneous Australian healthcare system on those experiences.

Methods: Semi-structured, qualitative interviews were conducted with women diagnosed with any cancer during pregnancy in the last five years. Recruitment occurred during 2018-2019 via social media and professional, clinical and community networks. Questions related to women's experiences of their healthcare, wellbeing and psycho-social needs. Interviews were analysed thematically.

Results: Study participants($n=23$) received treatment in the private sector ($n=10$), public sector($n=8$), or both($n=5$). Five interview themes were found: *Control over healthcare; Trust in clinicians, hospitals and systems; Coordination of care; An uncommon diagnosis; Holistic, future-oriented care.* Women were most likely to have had a positive healthcare experience when (a)care was well-coordinated and adjusted to meet their unique needs/challenges, and (b)women perceived their care went beyond their immediate medical needs and encompassed future psychosocial wellbeing, including preparation for postpartum challenges.

Conclusion: Existing 'usual care' in the public and/or private sector for both the pregnancy and the cancer, is insufficient to meet these women's needs. Prioritising psychological

wellbeing including psycho-social needs, and communication and planning around fertility and postnatal challenges are essential for this population.

Key words: Cancer; delivery of healthcare; gestational; patient navigation; pregnancy; psycho-oncology.

Introduction

Women diagnosed with cancer during pregnancy are faced with a paradoxical psychological conflict between the representation of new life vis-à-vis their pregnancy and the potential threat to their own life from the cancer (Ferrari, Faccio, Peccatori, & Pravettoni, 2018). Despite this, they must make important and time-sensitive treatment decisions, which have implications for their wellbeing and physical health, and that of their unborn child (Ferrari et al., 2018). This is complicated by potential damage to ovarian reserve from cytotoxic therapies that may lead to premature ovarian failure and infertility (Jayasinghe, Wallace, & Anderson, 2018). As a result, the pregnancy coinciding with their cancer diagnosis may be their last opportunity to conceive (Maltaris et al., 2007). In the face of this, decisions about termination or continuation of pregnancy may be required. Where pregnancy is continued, women may experience anxiety about their child's risks of *in utero* exposure to cancer treatments, which may vary with the trimester of pregnancy, cancer type and stage, and treatment regimen (Ives, Musiello, & Saunders, 2012; Peccatori et al., 2013). The stress of a cancer diagnosis and treatment may have additional effects; maternal exposure to stressful events has been associated with preterm birth, low birth weight and neurodevelopmental impairments (Graignic-Philippe, Dayan, Chokron, Jacquet, & Tordjman, 2014), mediated partly by stress-related hormones (Coussons-Read, 2013; Newman et al., 2016). Women diagnosed with cancer during pregnancy or the first 12 months postpartum (gestational cancer) thus experience numerous psychological challenges as they are confronted with several, simultaneously occurring, major life events.

Gestational cancer is relatively rare, affecting approximately one in 1000-1500 pregnancies (Peccatori et al., 2013). However, the incidence is increasing (Lee et al., 2012) and the far-reaching, multi-layered consequences of the diagnosis make this an important area of clinical care and research. Despite this, there is limited research exploring the healthcare experiences of this population. Women diagnosed with cancer during pregnancy report great variability in the perceived quality of their healthcare experiences which, in turn, can affect psychological responses (Hammarberg et al., 2018). Research also suggests that the process of making time-sensitive decisions and the degree to which this process is supported by clinicians is central to the woman's coping, sense of control, and satisfaction with their care (Hammarberg et al., 2018; Ives et al., 2012; Ives, Saunders, & Semmens, 2005). In Australia, there are added complexities of decisions relating to the healthcare system in which care is received.

The Australian healthcare system

Navigating cancer care in Australia is complex for patients (Hunter et al., 2019). The heterogeneous healthcare system has dual pathways, comprising a foundational Medicare system and a private system (Department of Health, 2019). Any patient can receive free or low cost, tax-payer funded care through the public system which includes hospitals, primary care and pharmaceutical provisions (Department of Health, 2019). Individuals with private health insurance - about 44% of Australians - may also access private care in the community, private hospitals or public hospitals (where individuals are admitted as private patients) (Newton et al., 2018).

There are often out-of-pocket costs for public and private patients such as non-medical costs for transport and loss of income (Newton et al., 2018). However, these are more likely and much higher for those accessing private healthcare, and costs are not necessarily associated with the quality of care received (Paul, Fradgley, Roach, & Baird, 2017). Moreover, many patients move between the systems, having some care privately (especially diagnostic tests) and some publically. Whilst Australia has some of the best cancer outcomes in the world (Choi et al., 2019) systemic limitations have been recognised by both patients (All.Can International, 2019) and healthcare providers. In 2016, Hunter and colleagues (2019) surveyed 93.2% of Australian healthcare organisations with a dedicated

cancer service. The authors reported serious service gaps regarding the provision and affordability of bio-psycho-social and survivorship services, across service providers. They also identified the need for an integrated and holistic model of care to better support cancer patients. Cancer patients have similarly reported the need for more integrated multidisciplinary care and additional psychological support(All.Can International, 2019; Breast Cancer Network Australia, 2018).

Australian women with gestational cancer may experience these challenges, but with an added layer of complexity - they must navigate both cancer *and* obstetric care. Only one study has explored Australian healthcare experiences of this unique population. Hammarberg and colleagues(2018) interviewed 17 women with gestational breast cancer and found that the perceived quality of care was directly related to communication with and between treating health professionals, and the coordination of care. This is important given these women may receive care at different hospitals, across public and/or private settings, and from diverse medical and surgical specialities.

The current study sought to add to the empirical literature by examining the healthcare experiences of Australian women diagnosed with *all* types of cancer during pregnancy. The aim was to (a) identify the features of care that *enhanced* the quality of their healthcare experience, and (b) describe the impact of the dual pathway Australian healthcare system on this experience. Whilst gestational cancer may refer to an intra- or post-partum cancer diagnosis, this study examined cancer diagnosed during pregnancy only to investigate the challenges unique to this time.

Methods

This study analysed a subset of data from a larger project entitled INTEGRATE: Experiences of Pregnant Women with Cancer: Exploring Parenting and Mental Health Needs. INTEGRATE explored the healthcare experiences, mental health and supportive care needs of women diagnosed with cancer during pregnancy, their partners and clinicians who treat this population. The study was approved by The Royal Women's Hospital Human Research Ethics Committee(ID#18/25).

Recruitment

Women were eligible to participate if they:

- were diagnosed in the last five years with any type of cancer during pregnancy including a current pregnancy;
- received treatment within Australia;
- had sufficient English language proficiency to participate in an interview;
- were aged 18 years or over; and
- able to provide informed consent.

Women with all pregnancy outcomes (live birth/termination of pregnancy/foetal death *in utero*) could participate. However, women diagnosed in the postpartum and those with gestational trophoblastic disease were excluded, because this project was specifically interested in the experiences of women diagnosed while pregnant. Data collection occurred from November 2018 to May 2019. Recruitment was conducted nationally through advertisements distributed via social media(Facebook, LinkedIn, Twitter) and professional, clinical and community networks(e.g., community-based advocacy groups, professional associations, individual clinicians). Advertisements directed participants to a website, where they could view the study details, eligibility criteria and the study team's contact details. After providing information regarding eligibility and consent to participate via this website, participants were contacted by a researcher to confirm this information and organise an interview time.

Data collection

A semi-structured interview guide was developed by a multidisciplinary team(with expertise in oncology, psychology, psychiatry and obstetrics) and two consumers previously diagnosed with gestational cancer. Interview questions were guided by existing literature and clinical experience. Questions aimed at understanding women's experiences of their care, wellbeing and psycho-social needs. Interviews were audio-recorded, and conducted by two psychologists(MS,LC) with relevant research, clinical and interviewing experience.

Analysis

Interviews were transcribed verbatim and analysed thematically for healthcare experiences with NVivo 12, using the Braun and Clarke method(Braun & Clarke, 2006). Trustworthiness

of the analysis was determined using the quality assurance criteria outlined by Nowell and colleagues (Nowell, Norris, White, & Moules, 2017). Field notes were taken during and after the interviews by MS and LC, who regularly shared impressions and experiences of the interviews. MS repeatedly read transcripts to facilitate further immersion in, and familiarity with, the data. Prior to formal coding, tentative codes pertaining to early impressions and interview topics were identified. Two researchers (MS, KG) independently coded 20% of the interviews, before comparing findings. These tentative codes were reviewed with LC and lead researcher, LS. Once consensus was achieved, the remaining interviews were coded by MS, who regularly met with LS, LC and KG to review code accuracy. Higher-order codes were grouped into potential themes, then checked against the lower order codes and original data. Themes were vetted by MS, LC, KG and LS and refined by content and meaning, before sub-themes and illustrative quotes were identified. Saturation was defined before analysis as no new themes relating to healthcare experiences being identified, and was achieved.

Results

Sample

Twenty-eight women consented to participate. Two were lost to follow-up as they could not be contacted, and one woman withdrew from the study after data collection reporting she wanted distance from her experience. Two women who had a termination of pregnancy prior to the interview were excluded from this analysis. These women form an important cohort with unique psychological challenges. However, interview data revealed they had fundamentally different experiences to the rest of the cohort, who had experienced concurrent obstetric and cancer treatment and navigated obstetric and cancer care that required adjustment to account for potential toxicity on the foetus in an ongoing way. Subsequently, 23 interviews were included in the final analysis. Of these, 17 women had a live birth before participation and six were pregnant at interview.

Almost 80% of participants received obstetric and cancer treatment under one model of care, either in the private sector ($n=10$) or the public sector ($n=8$). The remainder ($n=5$) received treatment across both public and private settings. See Table 1 for sample descriptive information.

Themes

Five distinct but interrelated themes were identified as relevant to the perceived quality of participant's healthcare experiences:

- *Control over healthcare*
- *Trust in clinicians, hospitals and systems*
- *Coordination of care*
- *An uncommon diagnosis*
- *Holistic, future-oriented care.*

Control over healthcare

Women sought to gain control over their experience wherever possible. Many reported frustration about a perceived lack of control over their treatment. The private healthcare system provided some sense of control by offering the capacity to choose one's doctor, consistency of treating clinicians, and greater flexibility in selecting convenient appointment and treatment times. Women without private health insurance found control by choosing a specific public service where possible. Geographic proximity was an important consideration in decision-making. Women felt more in control when hospitals were close to their support network and/or home. Feelings of control were also enhanced when women felt informed about their treatment choices, particularly regarding complementary medicines, allied health services, fertility treatment, birth planning and breastfeeding. However, when limited treatment options were offered or requests for more information were dismissed, perceptions of low control were compounded. See Table 2 for quotes on '*Control over healthcare*'.

Trust in clinicians, hospitals and systems

A high level of trust in the treating doctor, team and hospital was central to a positive healthcare experience. Generally, women carefully considered their choice of hospital and doctor. If the treating doctor or clinical service did not inspire trust, women sought a second opinion or referral to another hospital/specialist. A quarter of women either regularly travelled between home and major cities for treatment, or temporarily re-located when they believed treatment was superior elsewhere, they did not trust local services or could not access services locally.

Doctors were perceived as more trustworthy when familiar to the woman (e.g., an obstetrician from a previous pregnancy, an oncologist recommended by someone they knew). Trust was high in doctors with known expertise in treating this population, or with less experience but a readiness to liaise with more experienced doctors. Large hospitals with reputable cancer services located in metropolitan centres elicited more confidence than smaller regional centres. Some women reported being advised that the public system was better equipped to provide the level of care required to manage gestational cancer, facilitating trust in that sector.

The style and quality of communication contributed significantly to perceived trustworthiness. Trust was built when doctors communicated detailed information, described the rationale behind treatment recommendations, provided empirical reports for further reading, and showed evidence of consultation with other clinicians. Treatment advice provided without explanation (particularly regarding termination of pregnancy) was poorly received and resulted in distress, distrust and seeking second opinions. Confidence and trust declined when doctors conveyed uncertainty about safety to the foetus of treatments. However, if this information was communicated in an empathic manner with perceived transparency about unknown outcomes, trust was maintained. See Table 3 for quotes on *'Trust in clinicians, hospitals and systems'*.

Coordination of care

Another defining feature of women's healthcare experiences was the quality of coordination of care within and between treating medical teams. This often occurred across hospitals in different geographical locations. Well-coordinated care within teams and between hospitals was characterised by consistency of treating doctors, prompt and accurate sharing of medical information, regular communication between cancer and obstetric teams, and concerted and coordinated efforts from all teams to plan treatment. Women reported more positive experiences of care coordination when obstetric and cancer services were geographically close. Women treated in the public system often received obstetric and cancer care in one hospital or two co-located hospitals. When care was poorly coordinated, women reported miscommunications about treatment information and wasted appointments. This culminated in women feeling it was their responsibility to ensure clinical information was being communicated; which was particularly onerous when women

weren't confident they could convey this information accurately. See Table 4 for quotes on '*Coordination of care*'.

An uncommon diagnosis

Many women reported feeling as though they were 'a special case', due to the relative rarity of gestational cancer. This was protective when associated with perceptions of 'priority care', such as enhanced access to and communication with the treating team, accommodating preferences for appointment times, and more frequent foetal imaging. However, perceptions of difference could be unhelpful. Some women described their experiences of healthcare and treatment planning using words like 'circus' and 'floundering in the dark'. This coincided with inconsistency among doctors, communication with clinicians that implied uncertainty about treatment options, and during birth when women found the presence of multiple (observing) health professionals very intrusive. Women also reported a strong sense of isolation and not fitting in with patients in treatment settings, when attending appointments and looking for information/resources. See Table 5 for quotes on '*An uncommon diagnosis*'.

Holistic, future-oriented care

Holistic, future-oriented care comprised two sub-themes: *Psycho-social needs* and *Parenting needs and planning*.

(a) Psycho-social needs

The extent to which women perceived their care went beyond their immediate medical needs and encompassed their psychosocial wellbeing, was a feature of a positive healthcare experience. This included access to allied health and complementary treatments. Participants' mental health and supportive care needs were met to varying degrees. In cases where women reported poor recognition of their mental health or wellbeing, they had not been asked or could not recall health professionals asking how they were coping. Positive care that facilitated coping (a) involved regular enquiries about psychological and social wellbeing as well as practical support, and (b) resulted in prompt, affordable and accessible services for women and their support network (partners/parents/siblings). However, accessing appropriate psychological support was difficult. Several women identified that it was not practically feasible to see a psychologist due to parenting responsibilities,

treatments and financial burdens. There were also limited low-cost options for partners or family members seeking psychological support. See Table 6 for quotes on '*Psycho-social needs*'.

(b) Parenting needs and planning

Attention to timely and comprehensive discussions and support regarding fertility preservation, breastfeeding, and preparation for postpartum challenges were features of positive healthcare experiences. Participants described frequent and sometimes lengthy separations from their newborns due to cancer treatments, side-effects, recovery from surgeries, and multiple appointments. This was perceived as hindering successful breastfeeding and delaying bonding. As general adult hospitals and chemotherapy units do not have the capacity to accommodate mothers with their infants, women relied heavily on support networks to care for their newborns. Among women who wanted to breastfeed, support from health professionals to facilitate this was highly valued, even if breastfeeding did not ultimately occur. Discussions about fertility were significant for all participants. Even when women had completed their families, being consulted (at the very least) about their choices was important. For women planning future children, there was a desire for (a) comprehensive discussions about fertility preservation options, and (b) timely referral to fertility specialists (before starting cancer treatment). See Table 7 for quotes on '*Parenting needs and planning*'.

Discussion

A diagnosis of cancer during pregnancy represents a significant deviation from what a woman may have envisioned for her pregnancy and postnatal journey. This study explored the healthcare experiences of Australian women diagnosed with gestational cancer, with a view to determining the characteristics of a positive experience for this population. Data were interpreted in the context of women requiring medical management from two distinct streams (cancer care and obstetrics), and occurring within a system comprising public and private healthcare. This study provides important information about factors contributing to a positive healthcare experience for this population, and how the overarching healthcare system plays an important but lesser role than the five themes identified as relevant to the

perception of quality care: *Control over healthcare; Trust in clinicians, hospitals and systems; Coordination of care; An uncommon diagnosis; and Holistic, future-oriented care.*

Regardless of the model of care, positive health experiences were described when women reported a sense of control in treatment scheduling, trust in their treating clinician/facility, well-coordinated care within and between clinicians including prompt and consistent clinical liaison and communication, priority care across departments, facilitating allied health access and support around postnatal challenges. The importance of communication and individualised treatment for positive cancer patient experiences has been identified elsewhere (Tam et al., 2018).

Some women suggested that the private system facilitated positive experiences in many of these areas through: choice of doctor and treatment scheduling (*Control over healthcare*), choice of clinician who they trusted (*Trust in clinicians, hospitals and systems*), who would treat them for the duration of their care (*Coordination of care*), and who they believed would prioritise and coordinate their care according to their uniqueness presentation (*An uncommon diagnosis*). However, individuals without private insurance did not report poor healthcare experiences simply due to lack of clinician choice. Rather, they found a sense of control by choosing specific public hospitals, believing the public system was better equipped to manage the complexities of coordinating their care and that care may be geographically co-located (*Trust in clinicians, hospitals and systems; Control over healthcare; Coordination of care*). Some women elected not to use private insurance even when it was available, doubting the private system's capacity to coordinate the complexities inherent in treating gestational cancer. Indeed, the existence of multidisciplinary meetings, links with tertiary institutions and the tendency for obstetric and cancer services to be geographically close in the public system suggest greater capacity for enhanced comprehensive care and coordination. This has been supported by research highlighting that private hospitals in Australia are less likely to provide comprehensive cancer services (Hunter et al., 2019) and may transfer more complex cases to the public system (Cheng, Haisken-Denew, & Yong, 2015).

Nonetheless, some aspects of the public system were perceived as suboptimal. Women were aware they were unlikely to access the same obstetrician unless the pregnancy was deemed high risk. This inconsistency was a driving factor for several women to choose private care. Experts recommend that cancer in pregnancy be classified as high risk (Peccatori et al., 2013), and if this modifiable feature of care routinely occurred in public settings, the subsequent clinician consistency may substantially improve women's experiences.

Trust was a core theme in this study, which is consistent with the vulnerable nature of this population. Trust in clinicians is associated with perceptions of competence, experience and empathic and transparent communication (Hillen, de Haes, & Smets, 2011). Participants in this study were very aware their presentation was uncommon, and were highly sensitive to communication of uncertainties about treatment options.

The management of clinical communication (both with and between clinicians and treating teams) and the inclusion of allied health and complementary treatment options were central to perceptions of quality of care. In keeping with prior work (Hammarberg et al., 2018), prompt, consistent, and honest communication between patients, treating teams and hospitals facilitated a sense of trust in treating clinicians and enhanced coordination of care, thereby contributing to a positive healthcare experience. Our findings suggest that health professionals could better meet the needs of this population through greater emphasis on shared decision-making, which is associated with increased perception of patient control and healthcare satisfaction (Shabason, Mao, Frankel, & Vapiwala, 2014). Efforts should be made to improve communication and coordination between treatment sites and clinical teams through in-person meetings or teleconferencing, regardless of treatment locations.

Another finding central to positive healthcare experiences was the need for *Holistic and future-orientated care*. This included prioritising psychological wellbeing including psychosocial needs, and communication and planning around fertility and postnatal challenges. This supports previous findings that discussions, treatment options and support around fertility and breastfeeding are important to these women (Hammarberg et al., 2018; Henry,

Huang, Sproule, & Cardonick, 2012; Ives et al., 2012; Vandenbroucke et al., 2017). This theme represented the area of greatest unmet need for these women. Our findings reflect the extent to which women struggle to balance the demands of early parenthood with the intrusion of cancer treatment and its side-effects, and their unmet needs regarding psychological support. These gaps in cancer supportive care services have been recognized (Hunter et al., 2019) and there have been calls for accessible emotional support for all women diagnosed with gestational cancer (Ferrari et al., 2018).

This study builds on previous research examining the experiences of women with gestational breast cancer in Australia (Hammarberg et al., 2018). Our findings support and expand upon these data, providing new insights into the experiences of women diagnosed with other forms of gestational cancer and the factors contributing to a positive healthcare experience. Whilst there were no discernible differences in experiences based on cancer type, the sample was not stratified and was too small to examine this in depth. Nonetheless, this is the first study looking at the unique healthcare experiences of pregnant women diagnosed with any cancer type in Australia, and the second study worldwide of healthcare experiences of women with gestational cancer.

Women with any pregnancy outcome could participate. However, interviews of two women who had a termination of pregnancy before their interview were excluded from analysis as they had very different healthcare experiences to the rest of the cohort. Previous research has highlighted great variation in women's reactions to and experiences of termination of pregnancy around a breast cancer diagnosis (Kirkman et al., 2017). This limits the extent to which the current findings apply to women with gestational cancer who have had a termination of pregnancy. Future research is needed, exploring the healthcare experiences of women with gestational cancer who are advised to and proceed with a termination of pregnancy.

Selection bias is another potential limitation. One individual withdrew from the study to distance themselves from their experiences, thus the cohort may be biased towards women wanting to share their stories because they had very positive or negative experiences. It is also possible women still receiving care through the hospital were reluctant to participate.

Whilst responses are anonymous, participants may have remained concerned about being identified and having their future care affected. This fear could also have influenced their responses.

Australian women with gestational cancer must navigate both obstetric and cancer care, within the dual pathways of the public and private systems. This study found that the overarching healthcare model, whilst important, plays a lesser role in women's experiences than factors including trust in the treating team, a sense of control, and well-coordinated care which considered the uniqueness of and challenges inherent in this presentation. Effectively meeting these needs requires going beyond 'usual care' to provide a tailored, coordinated and holistic approach that prioritises psychological wellbeing and fertility and postnatal challenges.

3. References

- All.Can International. (2019) Patient insights on cancer care: opportunities for improving efficiency Findings from the international All.Can patient survey. Retrieved from <https://www.all-can.org/what-we-do/research/patient-survey/>
- Breast Cancer Network Australia. (2018, June). Breast Cancer Network Australia's State of the Nation Report. Retrieved from <https://www.bcna.org.au/media/6656/sotn-report-lowres.pdf>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Cheng, T. C., Haisken-Denew, J. P., & Yong, J. (2015). Cream skimming and hospital transfers in a mixed public-private system. *Social Science & Medicine*, 132, 156-164.

doi:10.1016/j.socscimed.2015.03.035

- Choi, H., Lam, K. O., Pang, H., Tsang, S., Ngan, R., & Lee, A. (2019). Global comparison of cancer outcomes: standardization and correlation with healthcare expenditures. *BMC Public Health, 19*, 1065. <https://doi.org/10.1186/s12889-019-7384-y>
- Coussons-Read, M. E. (2013). Effects of prenatal stress on pregnancy and human development: mechanisms and pathways. *Obstetric Medicine, 6*(2), 52-57. doi:10.1177/1753495X12473751
- Department of Health. (2019, August). The Australian health system. Retrived from <https://www.health.gov.au/about-us/the-australian-health-system>
- Eedarapalli, P, & Jain, S. (2006) Breast cancer in pregnancy, *Journal of Obstetris & Gynaecology, 26*, 1-4.
- Ferrari, F., Faccio, F., Peccatori, F., & Pravettoni, G. (2018). Psychological issues and construction of the mother-child relationship in women with cancer during pregnancy: a perspective on current and future directions. *BMC psychology, 6*(1), 10.
doi:<https://dx.doi.org/10.1186/s40359-018-0224-5>
- Graignic-Philippe, R., Dayan, J., Chokron, S., Jacquet, A., & Tordjman, S. (2014). Effects of prenatal stress on fetal and child development: a critical literature review. *Neuroscience & biobehavioral reviews, 43*, 137-162.
- Hammarberg, K., Sullivan, E., Javid, N., Duncombe, G., Halliday, L., Boyle, F., . . . Fisher, J. (2018). Health care experiences among women diagnosed with gestational breast cancer. *European Journal of Cancer Care, 27*(2), e12682. doi:<https://dx.doi.org/10.1111/ecc.12682>
- Henry, M., Huang, L. N., Sproule, B. J., & Cardonick, E. H. (2012). The psychological impact of a cancer diagnosed during pregnancy: determinants of long-term distress. *Psycho-Oncology, 21*(4), 444-450. doi:<https://dx.doi.org/10.1002/pon.1926>
- Hillen, M. A., de Haes, H. C. J. M., & Smets, E. M. A. (2011). Cancer patients' trust in their physician—a review. *Psycho-Oncology, 20*(3), 227-241. doi:10.1002/pon.1745
- Hunter, J., Smith, C., Delaney, G. P., Templeman, K., Grant, S., & Ussher, J. M. (2019). Coverage of cancer services in Australia and providers' views on service gaps: findings from a national cross-sectional survey. *BMC Cancer, 19*(1), 570. doi:10.1186/s12885-019-5649-6
- Ives, A., Musiello, T., & Saunders, C. (2012). The experience of pregnancy and early motherhood in women diagnosed with gestational breast cancer. *Psycho-Oncology, 21*(7), 754-761.
doi:<https://dx.doi.org/10.1002/pon.1970>
- Ives, A. D., Saunders, C. M., & Semmens, J. B. (2005). The Western Australian gestational breast cancer project: a population-based study of the incidence, management and outcomes. *The Breast, 14*(4), 276-282.

- Jayasinghe, Y. L., Wallace, W. H. B., & Anderson, R. A. (2018). Ovarian function, fertility and reproductive lifespan in cancer patients. *Expert Review of Endocrinology & Metabolism*, 13(3), 125-136. doi:10.1080/17446651.2018.1455498
- Kirkman, M., Apicella, C., Graham, J., Hickey, M., Hopper, J. L., Keogh, L., . . . Fisher, J. (2017). Meanings of abortion in context: accounts of abortion in the lives of women diagnosed with breast cancer. *BMC Women's Health*, 17(1), 26. doi:<https://dx.doi.org/10.1186/s12905-017-0383-1>
- Lee, Y., Roberts, C., Dobbins, T., Stavrou, E., Black, K., Morris, J., & Young, J. (2012). Incidence and outcomes of pregnancy-associated cancer in Australia, 1994–2008: a population-based linkage study. *BJOG: An International Journal of Obstetrics & Gynaecology*, 119(13), 1572-1582. doi:doi:10.1111/j.1471-0528.2012.03475.x
- Maltaris, T., Seufert, R., Fischl, F., Schaffrath, M., Pollow, K., Koelbl, H., & Dittrich, R. (2007). The effect of cancer treatment on female fertility and strategies for preserving fertility. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 130(2), 148-155.
- Newman, L., Judd, F., Olsson, C. A., Castle, D., Bousman, C., Sheehan, P., . . . Everall, I. (2016). Early origins of mental disorder - risk factors in the perinatal and infant period.(Report). *BMC Psychiatry*, 16(1). doi:10.1186/s12888-016-0982-7
- Newton, J., Johnson, C., Hohnen, H., Bulsara, M., Ives, A., McKiernan, S., . . . Saunders, C. (2018). Out-of-pocket expenses experienced by rural Western Australians diagnosed with cancer. *Supportive Care in Cancer*, 26(10), 3543-3552. doi:10.1007/s00520-018-4205-2
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*, 16(1), 1609406917733847. doi:10.1177/1609406917733847
- Paul, C. L., Fradgley, E. A., Roach, D., & Baird, H. (2017). *Impact of financial costs of cancer on patients-the Australian experience*. Paper presented at the Cancer Forum.
- Peccatori, F. A., Azim, J. H. A., Orecchia, R., Hoekstra, H. J., Pavlidis, N., Kesic, V., . . . on behalf of the, E. G. W. G. (2013). Cancer, pregnancy and fertility: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology*, 24(suppl_6), vi160-vi170. doi:10.1093/annonc/mdt199
- Shabason, J. E., Mao, J. J., Frankel, E. S., & Vapiwala, N. (2014). Shared decision-making and patient control in radiation oncology: Implications for patient satisfaction. *Cancer*, 120(12), 1863-1870. doi:10.1002/cncr.28665
- Tam, L., Garvey, G., Meiklejohn, J., Martin, J., Adams, J., Walpole, E., Fay, M., Valery, P. (2018) Exploring Positive Survivorship Experiences of Indigenous Australian Cancer

Patients, *International Journal of Environmental Reseach and Public Health*, 15, 135.

<https://doi.org/10.3390/ijerph15010135>

Vandenbroucke, T., Han, S. N., Van Calsteren, K., Wilderjans, T. F., Van den Bergh, B. R. H., Claes, L.,

& Amant, F. (2017). Psychological distress and cognitive coping in pregnant women

diagnosed with cancer and their partners. *Psycho-Oncology*, 26(8), 1215-1221.

doi:<https://dx.doi.org/10.1002/pon.4301>

4. Tables

Table 1. Characteristics of study participants

	<i>M (SD)</i>	Range
Age at time of cancer diagnosis (years)	32.8 (3.33)	27-38
Age at time of interview (years)	34.9 (4.02)	29-46
Time since diagnosis (months)	19.17 (18.21)	0-59
Gestation at diagnosis (weeks)	17.52 (10.09)	0-35
Gestation at time of interview [†] (weeks)	22.42 (10.16)	7.5-36
	<i>N</i>	%
Relationship status		
Married/cohabitating	22	95.7
Separated/divorced	1	4.3

Highest level of education		
Secondary schooling (year 12)	1	4.3
Undergraduate degree	15	65.2
Post-graduate degree	2	8.7
Trade/TAFE/Certificate	5	21.7
State/province		
Victoria	10	43.5
New South Wales	5	21.7
South Australia	1	4.3
Queensland	2	8.7
Northern Territory	1	4.3
Western Australia	3	13.0
Australian Capital Territory	1	4.3
Urban density		
Metropolitan	13	56.5
Regional	10	43.5
Cancer type		
Haematology	5	21.7
Bowel	1	4.3
Breast	15	65.2
Cervical	1	4.3
Lung	1	4.3
Outcome/status of pregnancy		
Live birth	17	73.9
Currently pregnant	6	26.1
Healthcare setting	Obstetric	Oncology
	<i>n (%)</i>	<i>n(%)</i>
Private	12 (52.2%)	11 (47.8%)
Public	10 (43.5%)	10 (43.5%)
Combination of private and public	1 (4.3%)	2 (8.7%)

[†]=Currently pregnant women only

Table 2. Illustrative quotes for the theme ‘Control over healthcare’

Participant	Cancer diagnosis	Quote
W020	Breast cancer	<i>“I had the two kids and I’m the full time carer at home, I needed to be with a schedule... when I would be able to have those treatments and the time... I couldn’t wait to be told, I needed to be able to schedule it myself. And I was given assurances. So I was going to have that flexibility”</i>
W004	Breast cancer	<i>“ I was thinking about alternative medicine as well to coincide with western medicine. And would it be okay? Were there any journal articles to suggest something like acupuncture ...And did he know anything about that... every question I asked him he went and researched. And then forwarded a whole lot of e-mails that night of journal articles of studies that he’d found... He let me do that and so I felt empowered, but it was also my decision.”</i>

Table 3. Illustrative quotes for the theme ‘Trust in clinicians, hospitals and systems’

Participant	Cancer diagnosis	Quote
W006	Breast cancer	<i>“I have complete trust in my obstetrician... she told me straight off all of the information. And she said, if you need the chemotherapy in your second trimester, that it will be okay... She rings up people from... other hospitals... I have faith in her because she delivered [existing child]...I know that she knows the way I am. And so I've just been guided by her and trusted that the information that she's giving me”</i>
W023	Haematological	<i>“And the GP confirmed it was [Cancer]. He gave me</i>

	cancer	<i>a referral straight away to the local oncologist. I got home and realised that I don't really trust the medical system [regional area]... So, I turned around and went straight back to the doctors and asked him to give me a referral to [hospital site in metropolitan area] ...I thought, there's more chance that they'd dealt with pregnancy and cancer."</i>
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Table 4. Illustrative quotes for the theme 'Coordination of care'

Participant	Cancer diagnosis	Quote
W018	Cervical cancer	<i>"Working between the [private hospital site] and the public... you couldn't tell they hadn't been doing it for fifty years. They were just so in sync with how they got all of this information across...I never had to repeat myself, and it just made it so much easier to deal with. Yes, it was really good."</i>
W020	Breast cancer	<i>"I felt that was a really important meeting... And I turned up to the appointment, nervous, and anxious, and worried. And there was no oncology results. Because they hadn't sent them across.... It's been a little infuriating.... when information goes missing, or it isn't at hand, or scans hadn't turned up, it's not a reassuring feeling at all... I had a joke, before I went into surgery, like what if they do the wrong breast."</i>

Table 5. Illustrative quotes for the theme 'An uncommon diagnosis'

Participant	Cancer diagnosis	Quote
W017	Bowel cancer	<i>“And I think when I was pregnant... I got the highest standard of care because everyone was so worried about, you, your pregnancy everything like and it is a unique case. And I think that’s why I got such a high standard of care.”</i>
W018	Cervical cancer	<i>“There were NICU[†] people from upstairs... IVF people... obstetricians...radiologist... the oncologist... nurses... an anaesthetist... administrative staff... It was a bit insane... at one point, the anaesthetist asked everybody to leave, because it was too noisy... I felt like a little bit of a rock star, like a really special case...and then of course trying to squeeze my husband in next to me ... it was a bit if a circus. I didn’t want to be that circus act, but there I was.”</i>

[†]NICU=Neonatal Intensive Care Unit

Table 6. Illustrative quotes for the sub-theme *Psycho-social needs* under the theme ‘Holistic, future-oriented care’

Participant	Cancer diagnosis	Quote
W006	Breast cancer	<i>“They treated the cancer, the thing to get out...Your mental health is a luxury... I found that they treat the cancer not the patient... you don't really budget for cancer, how expensive everything is. And so really to then put on top of that to go and see a psychologist... it feels like a luxury... At the end of the week, there's not really much leftover for you to go and spend \$250 on a psychologist appointment”</i>
W015	Breast cancer	<i>“ ‘the door’s always open. You can come to me any time</i>

		and just let me know if you want to see someone'. I was given a mental health plan right from the first day and then, my oncologist... said... let me know if you want to see the psychologist here at the hospital. We can arrange it. We can do it now, to see her."
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Table 7. Illustrative quotes for the sub-theme 'Parenting needs and planning' under the theme 'Holistic, future-oriented care'

Participant	Cancer diagnosis	Quote
W002	Breast cancer	<i>"It's horrible. I'm not going to lie. You know exactly why you're having it [radiation therapy], but that doesn't make it any easier to be walking out of that door and leaving my baby... to leave her and go and sit in a hospital and then worry about germs as well. Before she'd had her vaccinations and things that was difficult."</i>
W010	Lung cancer	<i>"breast feeding, I can't breast feed her which I never thought I would actually care about but I have struggled with it. When she was in the NICU[†] and the... Lactation consultants would come by and give me a look. Don't come near me, I can't breastfeed"</i>

[†]NICU=Neonatal Intensive Care Unit