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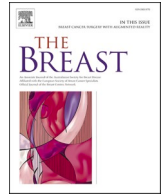
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Experiences of health professionals treating women diagnosed with cancer during pregnancy and proposals for service improvement

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ABSTRACT

Objective: To examine the experiences, needs, and perceptions of health professionals (HPs) treating women diagnosed with cancer during pregnancy (gestational cancer, GC).

Methods: Interviews were undertaken with Australian HPs who had treated women diagnosed with GC over the previous five years. HPs were recruited via social media, and professional and community networks. Questions focussed upon HPs' confidence caring for these women, whether current guidelines/training met their needs, psychological impacts of care provision, and service gaps. Interview data were analysed thematically.

Results: Twenty-seven HPs were interviewed; most were oncology HPs (22/27) with experience caring for women with gestational breast cancer and 13 had a breast-specific clinical focus (e.g. breast surgeon). Many were currently treating women with GC (48%) or had in the last 6–12 months (29.6%). Four themes were identified: *A clinically complex case*, *Managing multi-disciplinary care*, *Centralised resources for health professionals*, and *Liaison, information and shared experiences for women*. HPs found this population personally challenging to treat. They reported initial uncertainty regarding treatment due to infrequent exposure to GC, limited resources/information, and the need to collaborate with services with which they did not usually engage. Solutions offered include centralised resources, clinical liaison/care coordinators, and connecting women with GC with peer support.

Conclusions: HPs perceived women with GC as a vulnerable, complex population and experienced challenges providing comprehensive care; particularly when treatment was delivered at geographically separated hospitals. Systemic changes are needed to optimise comprehensive care for these women. Their insights can guide the development of more integrated cancer and obstetric care, and better HP support.

1. Introduction

Comprehensive cancer care is complex, and requires the coordination of services from multidisciplinary teams of health professionals

(HPs) which may be located at different sites and use different models of care [1]. The quality of care coordination depends on factors like location, size and type (public/private) of treatment facility; service availability; type/stage of cancer; and access to dedicated cancer

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nurses/coordinators [1–4]. Providing comprehensive care is more complicated when cancer is diagnosed during pregnancy (gestational cancer, GC); a reality for 137.3 in 100,000 pregnancies of which 20% are breast-cancer related [5]. Indeed, breast cancer is the most common form of malignancy in pregnant women [6].

In Australia, cancer care occurs within a mixed public-private health service model. All patients have access to a universal Medicare system (i. e., free, or low-cost pharmacy, primary and hospital care that is taxpayer funded) [7]; and individuals can also hold private health insurance that provides access to care in private or public hospitals, in the latter case, individuals are admitted as private patients. Approximately 58% of Australians have private health insurance [8]. Many patients access both private and public care simultaneously or move between the two systems for different components of their care. Approximately 300 healthcare organizations have a dedicated cancer service in either the private or public sector and these collaborate to improve coverage of cancer services across the country. The public sector, at state level, is responsible for coordinating cancer prevention, screening programs and providing comprehensive cancer care for all patients [1]. Private sector services are less likely to provide comprehensive cancer services and more likely to offer only one or two types of service (e.g., radiotherapy). Like oncology services, Australian maternity services are delivered through a mix of public and private services [9]. There are multiple models of maternity care provision that may involve combinations of private and/or public obstetricians, midwives, and general practitioners. In 2018, the majority (96%) of Australian women gave birth in hospital and of these 75% birthed in the public system [10].

Though there are overarching national strategic directions to support Australia's high-quality maternity [10] and oncological [7] care systems and enable improvements in line with contemporary practice, evidence and international developments, there are no national guidelines concerning oncological management during pregnancy. Larger metropolitan tertiary hospitals may offer both obstetric and maternity care, but few specialist cancer centres have an adjacent or co-located obstetric facility. This can be a challenge in care provision of women with GC, where coordinated care is required from a larger than usual range of HPs including obstetric and maternal-fetal medicine specialists working together under sometimes challenging, time-sensitive and rapidly changing circumstances. They may face conflicting ethical obligations and difficulties ensuring shared decision-making and informed consent are achieved, particularly regarding termination of pregnancy or pregnancy continuation with treatment [11]. The best oncology treatment for the mother may compromise the obstetric outcome or the fetus, and vice versa [12]. Consequences of treatments such as mastectomy or chemotherapy (and its associated toxicity) may limit opportunities and/or the ability to breast feed [13]. Any conflicting responsibilities require coordination across disciplines and systems that were not designed with collaboration in mind; and given the relatively small number of women with GC, opportunities for HPs to establish efficient collaboration processes are limited.

The role of comprehensive cancer care coordination in optimizing patient outcomes is recognized in Australia [7], but there is little research within the context of GC. The limited information available suggests that meeting the challenges of the complexity of care inherent in this group is central to perceived quality of care and wellbeing [4,14,15]. No previous study has investigated the *experiences of the HPs* treating this population; perspectives which are needed to better understand the barriers to comprehensive GC care. This study therefore aimed to explore HPs experiences; assess their personal and professional capacity to meet this population's needs; determine whether current guidelines and training meet HPs' professional needs; and identify areas for improvement.

2. Materials and methods

This research utilised data collected for the 'Experiences of Pregnant

Women with Cancer: Exploring Parenting and Mental Health Needs' (INTEGRATE) study, which examined the healthcare experiences and supportive care needs of women with GC, their partners and HPs treating this population. Ethics approval was received from The Royal Women's Hospital Research Ethics Committee (ID#18/25), with all participants providing informed consent. Findings on women's experiences and additional methodological details are published elsewhere [15,16]. Methodology details specific to collection of information from HPs were as follows. HPs were eligible if they had clinical experience with women with GC in the last five years within Australia. HPs could belong to any discipline in oncology, obstetrics, or mental health. Nationwide recruitment included advertisements and emails (see [Appendix A and B](#)) disseminated by the study team, professional and community networks, and social media. Advertisements provided a weblink to a participant information webpage where eligibility was self-assessed. HPs were then contacted to confirm their eligibility, obtain consent, and arrange a suitable time for a data collection interview. No compensation was offered for study participation. Representatives from all relevant disciplines and sub-specialities were invited to participate and no *a priori* sample size was set. Audio-recorded, semi-structured telephone interviews were utilised, with relevant professional and demographic information collected prior to the audio-recording (see [Table 1](#)). The interview guide (see [Appendix A and B](#)) was designed by the multidisciplinary research team to explore HPs experiences treating this population including whether current guidelines and training met

Table 1
Sample description (N = 27).

	M(SD)
Average age (years)	47.11(8.34)
Years in profession	
Medical	24.07(10.05)
Nursing	28.57(11.66)
Allied and mental health	17.67(5.05)
Estimated number of women with GC treated over career	9.15(9.75) ^b
Sex	n(%)
Male	6(22.2)
Female	21(77.8)
State	
Western Australia	2(7.4)
Queensland	3(11.1)
Victoria	18(66.7)
South Australia	2(7.4)
New South Wales	2(7.4)
Occupation	
Medical	14(51.9)
Medical oncologist	4(14.8)
Breast surgeon	3(11.1)
Haematologist	1(3.7)
Obstetrician	6(22.2)
Nursing	7(25.9)
Breast care nurse^a	4(14.8)
Cancer nurse	2(7.4)
Midwife	1(3.7)
Allied and mental health	6(22.2)
Clinical psychologist	3(11.1)
Psychiatrist	1(3.7)
Social Worker	2(7.4)
Last treated a woman with GC	
Current	13(48.1)
Last 6 months	2(7.4)
Last 12 months	6(22.2)
Last 2 years	3(11.1)
Last 5 years	3(11.1)
Type/location of practice	
Public hospital system only	15(55.6)
Private practice/hospital only	3(11.1)
Both private and public	9(33.3)
Consult in comprehensive cancer centre	6 (22.2)

^a Range = 1–40, median = 7.

^b Two breast care nurses were also midwives. GC = gestational cancer.

their needs; the psychological impact of caring for this population; and any gaps in the provision of services. Interviews were conducted by psychologists with extensive qualitative research experience who ensured that the relevant content was covered in each interview. In this study, GC was defined as cancer diagnosed during pregnancy (not postpartum), excluding molar pregnancies or trophoblastic disease. Following verbatim transcription, interview data were analysed thematically using Braun and Clarke's method [17] in NVivo 12 software. Trustworthiness was enhanced using Nowell and colleagues' principles [18]. The interviewers frequently shared field notes and, prior to formal coding, identified initial impressions and codes relating to service gaps. One fifth of the interviews were independently coded by two other study members to identify further, tentative codes. All codes were then discussed with the lead investigator until consensus on preliminary codes was reached. These codes were applied to the remaining transcripts and grouped into potential themes which were revisited against lower order codes and the original dataset. Data collection continued until saturation was achieved and no new themes emerged. Final themes and sub-themes were refined, and illustrative quotes were identified.

3. Results

Twenty-seven HPs were interviewed from five states across Australia, from the disciplines of obstetrics, oncology and allied/mental health. Nearly half were currently treating women with GC. Of the 27, 22 (81%) had experience caring for women with gestational breast cancer (GBC) and 13 had a breast-specific clinical focus (e.g., breast surgeon, breast care nurses). All except one HP practiced in a major city. On average, interviews lasted 44.3 min (range = 24.9–64.0, $SD = 10.6$). For details of the sample description, see Table 1.

4. Themes

Four themes were identified and are detailed below, with illustrative quotes edited for clarity. The two inductive themes included: 'A clinically complex case' and 'Managing multi-disciplinary care'. The two deductive themes included: 'Centralised resources for HPs' and 'Liaison, information and shared experiences for women'.

4.1. Inductive themes

4.1.1. A clinically complex case

All HPs emphasised that women with GC are a particularly vulnerable population with complex needs that are harder to meet compared with most other patients. Clinicians highlighted that each woman's management had unique challenges and described the need to be flexible and adaptive while balancing the constant risk to the mother with risk to the fetus, with compromise often necessary. Many HPs described inexperience and uncertainty balancing this risk; especially when it was their first time treating a woman with GC.

"... it's not a situation that you encounter all that often that you'd know all the facts and figures. So often you have to go and really read things and look and again if the treatment you want to give is going to cause an excessive risk ... it's about where you prioritize mother's cancer outcome versus the mother's pregnancy outcome and fetus ..." (C9, medical oncologist)

HPs urgently consulted with more experienced colleagues and tertiary hospitals and reviewed available protocols and evidence on best practice. However, few more experienced colleagues existed, and protocols/evidence were not always readily available. Some HPs stated that only doctors experienced in treating GC should lead treatment decisions.

"[They should be treated by the] tertiary hospitals ... If they're not with a clinician who has seen that before, they could be at risk of missing out on the best treatment, on the latest knowledge." (C6, breast care nurse)

"Sometimes ... accurate information doesn't exist ... you're in a situation you haven't dealt with before ... there is uncertainty. You look at the literature and see what other people have published, you talk to your colleagues ... and you're trying to advise a person what to do from a place of limited information." (C9, medical oncologist)

HPs described striving to meet the complex needs of these women, which required coordinated, holistic, priority care. This included ongoing communication with other HPs; open discussions about termination, fertility and family planning implications, evidence for safety of cancer treatments, and breast feeding; facilitating convenient scheduling arrangements; prompt allied health and mental health referrals for the woman and her partner; consideration of the family (including existing dependants, partners and support networks); and postnatal follow-up.

"I think we all go the extra mile ... I've made an arrangement to see [the patient] on a day when she's at [the hospital] for pregnancy care even though it's not one of our standard days for pregnancy care. So, I've used another clinic ... for the sake of fitting in with her program and her availability" (C13, obstetrician)

"Whoever she ended up seeing was great because when they went in to do the termination they'd already discussed egg harvesting" (C15, cancer nurse)

Many HPs observed that treating this population is more psychologically intense than treating patients who are pregnant or have cancer, but not both simultaneously. They noted the situation is often more emotionally charged, more time is spent with patients, and treatment planning is more involved. For some HPs, treating these patients was distressing and more memorable. Others found treating these women more rewarding, or similar to treating other complex presentations. Most HPs observed heightened uncertainty, anxiety, and distress in colleagues treating women with GC. Self-care, peer support and debriefing were aids to coping; however, some HPs would welcome more formal support (e.g., one-on-one supervision or psychological support).

"I do a lot of debriefs with the staff ... it's so out of their realms of normal healthy pregnancy and childbirth, I think the midwives struggle ... I think the medical staff struggle too, I think the obstetricians ... find it really difficult" (C2, breast care nurse)

"When the baby was born ... I raced into the labour ward and then to the ward to see the child and count its fingers and toes and make sure it was all right because I'd given it chemotherapy as well as the mother ... those things are very, very difficult." (C10, medical oncologist)

4.1.2. Managing multi-disciplinary care

Continuity of multidisciplinary care was difficult to maintain when care was across public and private health systems, or treatment sites were not geographically co-located (e.g., obstetric care provided in a maternity/women's hospital and cancer care in a general hospital). Consistency of clinicians and identifying the most appropriate point of contact were also issues, particularly in public obstetric services.

"When they come in and you say, 'Who is your obstetrician?' And the answer will be, 'Oh I go to Antenatal Clinic B on a Wednesday afternoon ... I saw the Registrar' ... They will often not know who is looking after them and this particular diagnosis really means that they need to have more focused care ... it's achievable but it's harder" (C18, breast surgeon)

Yet, large public tertiary hospitals were generally viewed as better

equipped to support this population, with a perceived greater sense of shared clinical responsibility across multidisciplinary teams.

“They might say to their ... oncologist ... ‘How I should have my baby? ... The oncologist would say, ‘I don’t know. You should ask the obstetrician’ ... Their questions aren’t answered, because the person they are seeing might not have the skillset. Whereas if you have that multi-disciplinary approach, then you have covered all of those important questions ... I can’t imagine how you would do that anywhere other than a tertiary centre.” (C19, obstetrician)

Other obstacles to optimal multidisciplinary care were reluctance to collaborate and delayed communication. Multidisciplinary care worked well when a team approach was led by a senior HP from each discipline; clinical responsibility was clearly allocated; regular multidisciplinary meetings occurred; and communication was frequent, responsive and consistent.

“It is about getting the right people in the room to discuss what the best management is ... surgical, medical, oncology ... allied health ... it was about getting all those people saying, ‘What are we going to do? What is the plan?’” (C3, obstetrician)

Central to the management of multidisciplinary care was how HPs defined their role and clinical responsibility. Regardless of discipline, most HPs reported their clinical responsibility went beyond providing expertise and included care coordination (e.g., proactive interdisciplinary communication and collaboration) and providing consistent information tailored to their patients’ unique needs.

“We all got in a room together, there was the obstetrician, the oncologist, myself, the anaesthetist, and the neonatologist ... [We] prioritise the team approach so that there is really a united and consistent message. And the woman knows that everyone is on the same page, providing the same information ... So, the woman becomes the centre of care, rather than the team being the centre.” (C19, obstetrician)

4.2. Deductive themes

The deductive themes were found in response to questions regarding: ‘What is missing from current care?’ and ‘What could be put in place to better support HPs and women with GC?’

4.2.1. Centralised resources for HPs

HPs consistently identified a need for centralised and coordinated resources, including up-to-date, accurate, evidence-based, clinical information and best practice guidelines. Ideally, discipline-specific information would be shared across teams to bridge knowledge gaps and minimise conflicting information being provided to patients. Information about psychosocial aspects of GC was sought across both disciplines.

“Some kind of protocol for cancer clinicians to consider the perinatal aspects ... for the obstetricians ... they’re obviously missing the cancer bits ... [a protocol] that could pull both sides together.” (C1, clinical psychologist)

“It would be better if there was an integrated state-wide national service that was coordinated ... a database telling you how many of this and what has been done and all that ..., that’ll be very useful.” (C10, medical oncologist)

HPs were also interested in opportunities to consult with more experienced HPs, a registry of patient outcomes, and a list of interdisciplinary resources and supports.

“It would be really great to have someone that’s dedicated to these issues ... someone that we could just pick up the phone and they can give us advice” (C15, cancer nurse)

“Having adequate access to the various supportive [professionals] ... breast care nursing, psychology, social work, financial support, where needed. Having those available and well known is important. Having ... links with obstetricians who are also comfortable in this ... confidence comes from access to modern knowledge.” (C7, breast surgeon)

Some noted that HPs would benefit from additional training on managing complex cases, multidisciplinary care, leading team meetings, and communication training (e.g., addressing difficult conversations and active listening).

“That stuff about having difficult conversations with patients. I think we could all benefit. And, for some people, it doesn’t come naturally. So, very specific training could be helpful.” (C3, obstetrician)

4.2.2. Liaison, information and shared experiences for women

HPs identified the need for a designated clinical liaison or case coordinator to connect obstetric and oncology care. This liaison would ideally be a clinician who is involved in team meetings, facilitates team communication, coordinates appointments and referrals, and is accessible to patients. Where available, a cancer nurse performed this role.

“Someone who’s thought about the ... implications of being pregnant with a cancer diagnosis ... issues around the question of termination ... what’s going to happen to my child if I die ... how do I manage drugs and breastfeeding and feeling sick from cancer and feeling sick from pregnancy ... Having a resource person who has experience and thoughtfulness around those issues” (C12, obstetrician)

“Knowing that there’s one identified person who’s the coordinator of all of their care ... tends to decrease anxiety” (C6, breast care nurse)

HPs reported that women with GC also had unmet information needs. A centralised information hub (e.g., a single organisation/resource) accessible to women with GC was suggested.

“I think information is key about the risks of these treatments on the pregnancy ... [women need] reassurance that they’re doing okay by the baby or that the baby wouldn’t be unduly affected. And ... getting all this information in a timely way” (C21, clinical psychologist)

HPs noted that women wanted to connect with others with GC. HPs commented that where they had previously treated women with GC, they may facilitate this via their own networks. However, a centralised facilitator was recommended.

“It would be nice for women to be able to speak to other women who have been very specifically in that scenario ...” (C18, breast surgeon)

“Speaking to someone who’s actually ... been through this situation ... being pregnant, having cancer is really invaluable ... I’ve got a couple of women that I’ve used a few times ... patient peer support type people” (C24, haematologist)

5. Discussion

In Australia, the provision of well-coordinated cancer care with open communication has been consistently identified as challenging but integral to positive patient experiences [19]. This may be more pronounced in women with GC who have multifaceted needs and receive care across several disciplines. This is the first study exploring the experiences of HPs treating these women and the challenges they face to providing comprehensive care. In this study, HPs considered women with GC to be vulnerable, complex patients. Barriers to comprehensive care included treatment delivery at multiple, often geographically separated hospitals and interdisciplinary communication hampered by lack of staffing continuity. Solutions offered included dedicated team leaders, centralised resources, clinical liaison or cancer care

coordinators (this could potentially be upskilling of a breast care nurse), interdisciplinary educational resources, prioritising interdisciplinary meetings, and developing ways to connect women with GC with peer support.

HPs highlighted that usual care is insufficient to meet these women's needs, and holistic care including psycho-social and antenatal needs must be prioritised. This is encouraging as recent patient accounts similarly emphasised that prioritised, tailored and holistic care that goes beyond medical treatment is supportive [4,15]. These findings are consistent with large-scale Australian research identifying serious service gaps in cancer supportive- and survivorship care across service providers and the need for more integrated, holistic, multidisciplinary care [1]. However, this study highlighted the dissonance between what patients want and HPs are trying or able to provide, and availability of enabling services and structures. As a result, HPs in this study perceived the need to bridge this service gap by going the 'extra mile' for these patients.

Tertiary centres and public hospitals, where teams are co-located and interdisciplinary meetings occur routinely, were perceived as better equipped to care for women with GC. However, care across multiple hospitals remains the norm and is challenging, especially without shared Electronic Health Records (EHR). In these settings, HPs should prioritise communication and regular interdisciplinary meetings, allocate dedicated and consistently available team leaders; or when possible, refer patients to centres with co-located care.

Some HPs reported a greater emotional impact from caring for these women compared with other patient groups and spent more time on their care. Additional support for HPs treating women with GC is required (e.g. communication training has been associated with reduced HP occupational stress [20,21], and was mentioned by HPs). Supports suggested by HPs included cancer care coordinators, increased access to more experienced clinicians/mentors and centralised resources. Care coordinators may reduce the continuity of care challenges, a common problem in complex conditions which can adversely affect patient outcomes [22].

The value of dedicated cancer care coordinators has been recognized by professional bodies [23] and by women with GBC [4]. Where available, cancer nurses currently serve in this role; however, their availability is inconsistent, and their obstetric expertise varies. They may also help to centralise resources, something noted as lacking by HPs in this study. Currently, no centralised service is available and the closest are international charities [16,24]. Formalised ways to connect women with GC that do not necessarily rely solely on individual HPs are also needed and have been suggested by women with GC [16]. Technological advances may facilitate these connections and improve collaboration via shared EHR, telehealth integration and virtual multidisciplinary meetings for patients treated across teams and locations. Notably, HPs in this study reported face-to-face meetings were important; literature emerging on the impact of virtual medicine during COVID-19 may provide insights into the successes and pitfalls of this practice and how it could be applied to HP teams treating GC.

In sum, recommendations arising from this study include that:

- Systemic changes such as co-location of services and integration of supportive care are needed if comprehensive cancer and obstetric care is to be provided for women with GC.
- HPs would benefit from more interdisciplinary education and opportunities for mentorship.
- Clinical liaisons or cancer care coordinators would greatly enhance care for these women.
- The collation of evidence, available resources, training opportunities and shared information would support HPs treating this population.
- Formalised ways to connect women with GC with peer support are needed.

Study limitations include that most participants came from

metropolitan areas, which was unsurprising given women with GC are commonly referred to tertiary centres. Consequently, the study results cannot be generalised to HPs in regional/rural areas, where the challenges highlighted may be further compounded. This study was not designed to focus on discipline- or subspecialty-specific challenges and it is acknowledged that such a focus may have given rise to different results. All HPs were Australian, and an international sample may have yielded different perspectives. Though representatives of all relevant disciplines were invited and eligible to participate, not all HPs involved in GC care (e.g., neonatology, radiotherapy) were represented in the sample, and almost all oncology HPs worked predominantly in breast cancer. This reflects the high rates of breast cancer in the GC population. A more diverse sample may provide other data.

Despite these shortcomings, this study has many strengths. It is the first study exploring the experiences of HPs treating women with GC and the challenges these clinicians face when providing comprehensive care. As such, these data are novel. The study has methodological rigor: the interview schedule was developed by a multidisciplinary team of clinicians, and data were collected and analysed by experienced researchers following a formalised methodology. Data saturation was comfortably achieved and despite the multiple disciplines represented in the sample, the data were consistent in identifying universal themes. Taken together, the findings provide an excellent starting point from which to consider supporting HPs to provide optimal care for women with GC.

6. Conclusion

This is the first study exploring the experiences of HPs treating women with GC and the challenges and barriers to providing comprehensive care which they encounter. Most HPs had experience with GBC and many had a breast-specific clinical focus. The findings and solutions offered add unique insights, which can be utilised to develop more integrated cancer and obstetric care for women with GC, and better supports for HPs providing this care.

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request, and subject to approval from the hospital's research ethics committee.

Ethics approval

Ethics approval was received from The Royal Women's Hospital Research Ethics Committee (ID#18/25).

Declaration of interest

None.

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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 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.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.breast.2022.03.003>.

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