The experience of pregnancy and early motherhood in women diagnosed with pregnancy associated breast cancer in WA

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What is Pregnancy Associated Breast Cancer (PABC)?

- Usually defined as breast cancer diagnosed during pregnancy
- or in the twelve months following the completion of a pregnancy

Aims

1. Describe women’s experiences when diagnosed with breast cancer during or shortly after a pregnancy.
2. Identify the psychosocial experiences of women diagnosed with PABC

Study Design

- Retrospective design
- Participants identified from a concurrent study dataset
- Qualitative method, semi structured interviews
- One breast cancer nurse conducted all interviews

Participants

- 15 participants agreed to take part (23% response rate).
- All under 45 years at time of diagnosis
- The interviews lasted approximately 60 minutes (range 30–120).

Topics explored in interviews

- Physical and emotional well-being
- Social support
- Treatment outcomes
- Fertility and contraceptive issues
- Work and financial issues
- Relationships
- Self-esteem and body image
- Health of the baby
- Breast feeding concerns
- Adaptation to mothering
- Pregnancy events (e.g. pregnancy outcome, decision regret relating to outcome choice)
- Dealing with illness and young children.
Participant Details

<table>
<thead>
<tr>
<th>Age at breast diagnosis</th>
<th>Pregnant/postpartum at breast cancer diagnosis</th>
<th>Pregnancy outcome</th>
<th>Number of previous pregnancies</th>
<th>Cancer treatment</th>
<th>Time since diagnosis (years)</th>
<th>Cancer outcome</th>
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<tbody>
<tr>
<td>38</td>
<td>Post partum - 18 weeks</td>
<td>Live birth</td>
<td>1</td>
<td>Mastectomy, chemotherapy, hormone therapy</td>
<td>9</td>
<td>Alive with no recurrence</td>
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<tr>
<td>29</td>
<td>Pregnant - 35 weeks</td>
<td>Live birth</td>
<td>2</td>
<td>Breast conserving surgery, chemotherapy, radiotherapy, hormone therapy</td>
<td>9</td>
<td>Alive with no recurrence</td>
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<td>Post partum - 39 weeks</td>
<td>Live birth</td>
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<td>Mastectomy, chemotherapy</td>
<td>13</td>
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<td>Mastectomy</td>
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<tr>
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<td>Live birth</td>
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<td>Miscarriage</td>
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<td>Ectopic</td>
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<tr>
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<td>Live birth</td>
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<td>Mastectomy, chemotherapy</td>
<td>17</td>
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<tr>
<td>39</td>
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<td>Live birth</td>
<td>1</td>
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<tr>
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<tr>
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<td>Live birth</td>
<td>2</td>
<td>Mastectomy, chemotherapy, radiotherapy</td>
<td>7</td>
<td>Alive with no recurrence</td>
</tr>
</tbody>
</table>

Analysis

- Qualitative content analysis
- Emerging themes coded
- Major and minor themes identified
- Major themes presented here

Findings

- Every woman interviewed had a unique perspective of the experience of PABC, motherhood, diagnosis and treatment.
- This was based on their beliefs, values, and life experience and largely influenced by the woman’s pregnancy status and whether they believed their family was complete.

Themes

- Four major themes emerged in participant interviews:
  - anxiety
  - decision conflict
  - isolation
  - social support

Anxiety

- Receiving a diagnosis of PABC made women highly anxious, and this anxiety pervaded their whole PABC experience.
- Women reported their anxiety was linked to the conflict between the concern for their baby’s health and the concern for their own health and wellbeing.

This anxiety manifested itself in different ways...

- Was dependent on whether women felt their family was complete and whether they already had children
- Concerned for the wellbeing of the children they already had:
  - I had two young children and I just didn’t want to die, and that was my first thought.
OR concerned for the wellbeing of their unborn child:

- Well I wanted, well obviously I wanted the baby but my health had to come first and anyway, (the) biggest thing, and I guess the other disappointment and I suppose there’s nothing I can do about it. Was the age that I was when I got it and then to be told I couldn’t have any, couldn’t have another child for two years.

Breast cancer treatment during pregnancy

- “I was sent in for tests and I had a bone scan and they had to give me the radioactive stuff in nuclear medicine and I was concerned. And they assured me that it would have no effect on the baby or a very minimal effect. I said, ‘I don’t want him to be sterile when he grows up and stuff’. They said, ‘no, no, no. He should be fine’. So that was my main concern was because of that radioactive needle I had to have.”

Breast cancer treatment during pregnancy

- “There was some sort of a check they would do. Some sort of a scan. They could strap a belt on me. I think it was his heart beat. Something they were registering. It had to reach a certain level before he could be born. And they were trying to test. And she’d come in and do the test and she’d go – oh, he must be sleeping, we’ll try again later or he just must be in a bad position. I just can’t quite get it. I’ll try again tomorrow.”

Decisional conflict & competing issues of medics

- “I remember the following week it was sort of a tug of war, because they called in a specialist obstetrician as well. And he wanted the baby to stay in utero as long as possible (37 weeks gestation) and they called in the oncologist and he wanted the baby delivered quickly because he wanted to start chemo(therapy). They were both coming in and having consultations, and my obstetrician would be going ‘tut tut, tut this baby’s not ready yet. I’m not delivering.” And I’d be taken down for ultrasounds to check the lung movement and stuff. Oh it was beautiful to see the baby on the ultrasound and he seemed unscathed, and they assured me he would be fine and all of it, it was quite a relief down the track.”

Decisional conflict between the mother & the obstetrician

- “I delivered all my other babies naturally, there’s been no hassles. I deliver very easily, very quickly. Like within a couple of hours. Please, please, please. I don’t want it.

- We’ll try for a natural delivery, but if there’s any extra stress, you’re going in for a Caesar(ean). So on that condition, we agreed. The next morning I was wheeled in, given the um epidural, and he was delivered within about two and a half hours.”

Experiences of breast and bottle feeding

- “That was hard. Not being used to that. I didn’t even think to take bottles in with me. I wasn’t told that sort of thing, you know. I just thought they’d have bottles there and oh, yeah. So, that was a nightmare. Remember to do that, and have it all ready and the right temperature, the right quantity. I’d never had to do that before. All the preparation when you go out places. To have to remember to take bottles and… So, that wasn’t easy.”
Breast feeding with a mastectomy

- "after I'd had the baby and um, I didn't feel he was getting enough milk off one breast, and I'd been told like try and change the position. So feed him on that side, then turn him around to this side and um have another go at feeding him. But then my nipple was getting so sore. So I went down to the nursery and I sat in the chair to feed and I asked one of the midwives something about the feeding, and she said oh yes dear, but um. You only feed for ten minutes on that side and then ten minutes on the other side. And I said oh, I'm sorry but I've had the mastectomy. And she said oh, oh. you're that lady. Oh sorry. And she was so apologetic. And she was apologising. And she was going I'm sorry, I'm sorry, I'm sorry. I'm like – that's OK and then I took the baby and just went back to my room. So it was like, um I didn't belong in the maternity ward..."

Making sense of the decision

- 'I think I was concerned about being able to continue breastfeeding but ultimately I thought it was probably better for me to just be alive. A formula fed baby will be fine and better to have a mother than not.'

Summary

- The view women had of motherhood played a major role in the decisions they made about their breast cancer treatment.
- Women who felt their family was complete chose the best treatment possible to improve their own chances of survival.
- Women who were pregnant or thought their family was incomplete when they were diagnosed with GBC were often prepared to delay or forego optimum breast cancer treatment and risk their own lives so that their unborn child was protected from the effects of treatment or so that they could conceive in the future.

Implications for practice and research

- Heightening of normal emotional states
- Working together as a MDT and resolve conflicts without the patient present
- Open a dialogue to engage and support a mother to make the best choices for her & her family
- Encourage her to maintain autonomy & control in the instances she can, e.g. delivery

Questions?

- Further study details: