

The Experiences and Perceptions of Women Diagnosed with Breast Cancer during Pregnancy

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Received: June 06, 2016, Accepted: July 12, 2016

ABSTRACT

Objective: Although much has been documented about the experience of breast cancer, the accounts of young women have been relatively neglected, despite that around 20% of the breast cancer diagnoses occur in women under the age of 50. In particular, the voices of young women diagnosed during pregnancy are missing from research. Breast cancer is the most common cancer associated with pregnancy, and it is diagnosed in about 1 in 3000 pregnancies. **Methods:** This study presents data from three women drawn from a larger study of women who had been diagnosed under the age of 45 and had completed their treatment for breast cancer. Semi-structured qualitative interviews were undertaken, with a methodology informed by social constructionist grounded

theory and feminism. **Results:** The findings here report the ways that having breast cancer during pregnancy disrupted taken-for-granted assumptions about their pregnancies, new motherhood, and their future life course, and how this occurred within the context of gendered ideas about femininity and motherhood. **Conclusions:** Breast cancer during pregnancy has a far-reaching impact on young women's lives, and women affected may need practical support in caring for young children, and counselling may be appropriate. Further research is needed in this important area.

Key words: Breast cancer, pregnancy, young women

Introduction

Breast cancer is the most common cancer associated with pregnancy,^[1-3] and, according to the Cancer Research UK,^[2] breast cancer is diagnosed in one in 3000 pregnancies.

Some women are able to continue their pregnancy, delaying treatment, whereas others may need to consider a termination.^[4] Despite a focus in the literature on breast

Access this article online

Quick Response Code:



Website: www.apjon.org

DOI:
10.4103/2347-5625.189814

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Cite this article as: Rees S, Young A. The experiences and perceptions of women diagnosed with breast cancer during pregnancy. *Asia Pac J Oncol Nurs* 2016;3:252-8.

cancer experience, there exists almost no research on the subjective meaning of the experience of being diagnosed with breast cancer during pregnancy (BCDP).

Breast cancer during pregnancy

Many women diagnosed with breast cancer are able to continue their pregnancy, but some may have to delay treatment until they are later in the pregnancy or have given birth. Breast surgery can be received when pregnant, although there may be a slightly higher risk of miscarriage in the first trimester,^[5] radiotherapy is not advised until after the birth.^[4] Chemotherapy can be given if the second or third trimester has been reached, and recent studies suggest that cancer during pregnancy and chemotherapy treatment do not result in impaired cognitive, cardiac, or behavioral outcomes in children.^[6,7] Some women may need to have a termination if they are early in their pregnancies or if the cancer is found to be very advanced.^[5] Pregnancy rates in women living after breast cancer are 70% lower than the general population, and thus young women may be left infertile after having to terminate a pregnancy to receive breast cancer treatment.^[5] BCDP, therefore, raises complex issues and may mean that women must make highly emotional decisions, causing disruption to expectations about pregnancy and early motherhood.

Previous research has shown that receiving a cancer diagnosis and treatment at a young age can cause profound emotional distress and result in long-term problems,^[8-13] and BCDP is likely to result in particular emotional, physical, and practical issues. The literature specifically investigating young women's subjective experiences of breast cancer is sparse, and young women diagnosed during pregnancy have been occasionally involved in such studies. For example, one woman in Burles'^[14] study of young people with serious illnesses was diagnosed with BCDP, and one woman in Kirkman *et al.*'s^[15] study of young women with breast cancer was diagnosed early in her pregnancy. Further in-depth insight into the accounts of young women diagnosed during pregnancy is, therefore, badly needed.

Such experiences occur within the context of gendered norms about femininity and motherhood. After breast cancer treatment, women may have difficulties with breastfeeding, such as an inability to lactate in the affected breast.^[16] Breastfeeding is intertwined with social expectations of mothers, and it is "treated as not only compatible with, but also indicative of maternal mortality."^[17] Therefore, a threat to a woman's ability to breastfeed may be experienced as a threat to her femininity and identity as a mother.

An exploratory qualitative study was undertaken to explore young women's experiences of breast cancer, and three women recruited were pregnant at diagnosis. This study reports on the experiences and perspectives of these three women to contribute to the small amount of knowledge about this phenomenon.

Methods

This research was situated within the interpretivist paradigm, assuming that to understand a social phenomenon, researchers must explore it from the perspectives of those who have or are experiencing it.^[18,19] Grounded theory methods^[19,20] were utilized with the goal of producing an understanding of BCDP grounded in the accounts of participants.^[21-23] Data collection and analysis were conducted concurrently, and Charmaz's guidelines for analysis were used.^[19] In addition, integral to the methodology were key feminist methodological and ethical principles regarding the status of situated knowledge and the position of the researcher, a nonoppressive approach, and a critical lens.^[24-26] Feminist research aims to develop knowledge which is reflective of women's own voices, and positions women's subjective meanings as central to understanding their experiences.^[24,27] It also compels researchers to reflect on their own position within the research, as well as to seek to understand the influence of social structure, such as gender relations.^[28,29] Thus, feminism together with grounded theory positioned the young women as central to the research, enabled close and in-depth analysis of the data, and resulted in an exploration of the women's perspectives as well as the influence of the social context, in which they were embedded. To increase rigor in the research, the methods of collection and analysis were made explicit,^[30] and reflexivity^[24,27] permeated the research process. Further, a stakeholder panel was assembled made up of three women who fit the study criteria.^[31] SR met with the panel three times over the course of the research to gain their input on the topic guide, patient-facing materials, and interpretation of the data. The interviews were transcribed verbatim by SR, and direct quotes have been used as evidence for any claims in the analysis.

Ethical approval was granted by the University's Internal Ethics Committee. Participants were approached through gatekeeper organizations and using snowball sampling, given the sensitive nature of the phenomenon under the study. Semi-structured, in-depth interviews were carried out by SR with the women who agreed to participate, and these lasted between 1 and 2 h. Data analysis was carried

out with NVivo computer software (QSR International, Australia). SR conducted the analysis of the overall study data, and AY assisted in further analysis of the data discussed here.

Below are the case histories of the three interviewees who were pregnant when they were diagnosed, all with their first and, at the time of the interview, only child.

Catherine

Aged 38 at the time, Catherine found a lump when she was 31 weeks pregnant with her first child, and was eventually diagnosed at 34 weeks. The interview took place approximately 15 months after her diagnosis. Catherine had an induced early delivery at 36 weeks and a wide local excision under general anesthetic (lumpectomy) shortly afterward, followed by chemotherapy, radiotherapy, and long-term preventative treatment (herceptin and tamoxifen).

Lyndsey

At 27 weeks pregnant and aged 31, Lyndsey found a lump in her breast. She had a lumpectomy under general anesthetic while pregnant, and then chemotherapy and radiotherapy after giving birth. Lyndsey was interviewed around 14 months after her diagnosis. Lyndsey had received zoladex during chemotherapy to protect her ovaries, and was receiving herceptin as a preventative treatment.

Dawn

At 25 weeks pregnant, Dawn found a lump, and she was diagnosed with breast cancer 2 weeks later at the age of 27. She underwent two lumpectomies under general anesthetic when pregnant, and her labor was induced at 32 weeks. Following the birth of her child, she had chemotherapy and radiotherapy. Dawn's child was in intensive care for several weeks after the birth. The interview took place about 3 years after her diagnosis. Dawn's cancer was "triple-negative" which means that it would not respond to the current long-term treatments, and so she was not on any preventative medication after her initial treatment.

Results

Disrupted expectations

For all the young women in the study, being diagnosed at a younger age contradicted their taken-for-granted ideas about themselves as young, healthy women. The three women with BCDP also found the diagnosis disturbed their expectations of and plans about pregnancy.

"It was like someone had just said: 'Did you know you're having a baby tomorrow?'"

—Catherine

Catherine described this process as "a mad panic" and "comedy" because she had to suddenly prepare to have a baby when she had thought she had many weeks to get ready. However, this was elsewhere described as a difficult and emotional time.

"It was what should have been one of the happiest times of my life but it is tainted with one of the worst things you could ever be told."

—Lyndsey

The perceptions held by the three women were that it was unfair to have been diagnosed during pregnancy and to have that part of their lives disrupted. However, all were aware that they had been diagnosed earlier in their pregnancy, the outcome may have been very different.

"We found the lump early enough that we didn't have to make any horrible decisions about this much-wanted baby."

—Catherine

Missing from this and other research are the voices of women who have had to terminate a pregnancy to commence the life-saving breast cancer treatment, some of whom will then be unable to have more children as a result of the treatment's impact on their fertility.

Implications for motherhood

After their children were born, Catherine, Dawn, and Lyndsey all received chemotherapy and radiotherapy. The women found their expectations of new motherhood profoundly challenged as a result of their treatment. For example, the women were all unable to breastfeed once chemotherapy began because of the risk of passing chemicals onto the baby via milk.

"Everybody else, y'know, at the NCT [National Childbirth Trust] Group continues to breastfeed for six months or even longer."

—Catherine

Catherine described this as one of the most difficult aspects of the experience.

"That was one of probably the biggest kind of emotional things... I do feel a bit bitter about the fact that this thing is making me stop breastfeeding because it's like um, you know it's the best thing to do, but also it's the closeness."

—Catherine

Breastfeeding is intertwined with social expectations of mothers,^[17] and having the option to breastfeed taken away from them had implications for the young women's position as mothers, as Catherine's quote illustrates.

All the three women had to give birth to their children prematurely to begin treatment, which not only disturbed their expectations for the circumstances under which their child would be born, but also raised significant fears about the impact of this on their children. They had all been initially concerned about their child's welfare, but each emphasized to me that their children were doing well:

"There's no sign that he was premature, he's bigger than most boys."
—Lyndsey

"There's nothing wrong with [child], you wouldn't know she was Prem or had been through all that strife."
—Dawn

"She was fine, she was seven pounds five... That's a normal weight."
—Catherine

Dawn went on to say that she could not let the treatment affect her too much:

"I could never sort of allow myself to be that poorly really because, um, because I had to be fine, I had to be okay to look after her really. Um, and y'know she's still here, which is proof that I did an okay job I guess!"
—Dawn

These accounts further illustrate the significance of gender, suggesting that the women perceived a threat to their position as good mothers as a result of having to give birth early, or receive breast cancer treatment when their children were very small.

Future fertility

Cancer treatment can have major implications for a young woman's life course. For example, some young women are able, and choose to, have eggs harvested, sometimes fertilized, and frozen, to provide a better chance of having children after chemotherapy treatment (which can damage fertility). Women diagnosed during pregnancy are not offered this because it is not possible to undergo egg harvesting when pregnant, and any further delay to treatment could allow the cancer to grow or spread.

Dawn was aware that treatment could impact on fertility, and this shaped how she approached motherhood while enduring grueling chemotherapy:

"It was really hard [but] it was likely that I wouldn't be able to have more children afterwards so I kind of still wanted to do that, do most of the things for yourself really."
—Dawn

Instead of resting and allowing her family to take charge of the childcare, she felt that she wanted to do it herself because she may not have another chance to experience taking care of a newborn baby.

When I asked Catherine about her future pregnancies, she said:

"Whilst on Tamoxifen they don't recommend that you get pregnant and I'm on Tamoxifen until the age of 44 so I think that's probably a bit old for me."
—Catherine

Catherine had conceived her child through *in vitro* fertilization (IVF) treatment, and she wondered if her estrogen receptor-positive cancer was caused by the IVF.

"Maybe having children and being pregnant was never meant to happen to my body."
—Catherine

On the other hand, Lyndsey was positive about her future fertility because her cancer was HER2-positive (stimulated to grow by a protein receptor) and estrogen receptor-negative and so, she did not think it was caused by her pregnancy.

"We'll try probably in about another year... When you're told that there's a possibility you're not going to be able to have that it makes you want it even more."
—Lyndsey

Lyndsey had also received zoladex during her chemotherapy, a promising recent development in protecting ovaries from the effects of chemotherapy.^[32] This made her feel more confident about future pregnancies.

The loss of fertility was experienced in the context of gender norms about fertility and womanhood.

"The thing about not being able to have kids as well y'know, that's difficult, because that just takes away your, I guess your femininity, just a little bit more."
—Dawn

Although Lyndsey was hopeful about having children in the future, she also expressed fears about dying young from breast cancer and leaving her family behind.

"If there's a risk on my future, of me not living a full life... Do I want to bring children into that and like leave them? 'Cause mums play such a huge part and you realise that even more when you've got them that you don't want them to be just with their Dads."

—Lyndsey

Lyndsey's account illustrates that she would feel guilty leaving her husband to raise their son without a mother, and this guilt extended to future children, causing her to feel ambiguous about the morality of future pregnancies.

Sense of pride

Lyndsey felt proud of having come through the experience, and wanted to encourage and help other women who are diagnosed.

"I just almost want to stand as a bit of a symbol maybe like to be really strong and that you can do it, and the fact that I did it with a tiny baby which for most people they struggle anyway with that, being a mum for the first time, I went through all of that on top you just think 'I did it so you can do it'."

—Lyndsey

Wanting to help others going through cancer or other difficulties was a common theme in many of the interviews. For Lyndsey, she had not only been through breast cancer, but had done so while also becoming a new mum, and she recognized how difficult and daunting this had been, but wanted to show to other women going through a similar experience that it is possible.

Discussion

There has been very little research conducted about the experience of being a young women diagnosed with BCDP, and although this study did not specifically set out to do so, three women who had been diagnosed when pregnant volunteered to be interviewed. As a result, this paper aims to contribute to the small amount of sociological knowledge about this phenomenon. Being diagnosed with breast cancer when pregnant raised significant emotions, and the young women's accounts revealed the impact of such an experience.

The women found that it spoiled what should have been a happy stage in their lives, disturbing how they had foreseen their pregnancies progressing. The treatment interfered with their lives as new mothers, making them feel different to their peers, and they regretted the loss of certain experiences such as breastfeeding. It also caused them to think differently about future pregnancies. While Catherine

and Dawn doubted they would have more children because of the impact of treatment, Lyndsey reflected on the meaning of bringing children into the world while living with the risk of recurrence and of a shortened life span. Previous research has looked at women's perceptions of pregnancy and motherhood after having treatment for breast cancer.^[33,34] They found that having children was seen as a way of restoring one's identity or getting one's life course back on track. Being diagnosed during pregnancy precludes the possibility of harvesting and freezing eggs or embryos, which can leave women, like Dawn, who had anticipated having a number of children but found herself with low ovarian function, feeling that there is little possibility for future pregnancies, and of living the life course which was previously anticipated.

These experiences occurred within the context of gendered societal ideas about motherhood, fertility, and femininity. A number of studies have looked at the experience of breast cancer in terms of its impact on femininity and gender identity, and it has been noted that breast cancer treatment represents a threat to a woman's gender identity as a result of, for example, breast loss.^[35-39] Both the roles of "mother" and "patient" entail social obligations, but these obligations may conflict.^[40] The accounts of the women in this study diagnosed with BCDP support this idea, highlighting how their need to give birth prematurely, and to undergo treatment which prevented them from breastfeeding, meant that they felt a sense of guilt in relation to their position as good mothers. In addition to experiencing guilt and being unable to breastfeed, Dawn described how she could not "allow herself" to be ill because she needed to take care of her child. The women looked to the health of their children to feel reassured that their need to step into the patient role during and shortly after pregnancy had not caused harm to their children. A previous study^[41] highlighted the lack of professional support to mothers of young children with cancer to cope with their feelings of guilt about the way their children had suffered as a result of their cancer. The young women diagnosed with BCDP in this study may also have benefitted from professional support which addressed the women's feelings of guilt in the context of the conflict between the social roles of motherhood and patienthood.

Limitations

The data here are limited because of the small numbers of women interviewed who were pregnant during diagnosis, and therefore the results are indicative and cannot be generalized to the wider population of women diagnosed with BCDP. However, important themes for wider exploration were able to be identified, and the impact of

such an event on young women's lives is illustrated. The women were between 14 months and 3 years on from their diagnosis. Retrospective interviews rely on what the women remembered and what they were willing and able to talk about. However, this could be seen as a strength of the design, as the aim was to explore their perceptions. The use of one-off interviews means that the accounts are a snapshot of a particular time in the women's lives and illness trajectories. On the other hand, I was able to ask women to think back since their diagnosis, and to think about how they felt at different points. The small size of the sample enabled an in-depth exploration of the participants' experiences, but it inevitably restricts the generalizability of the findings, and further research should explore their experiences in greater numbers. The three women who were pregnant when diagnosed were all white, able-bodied, and married to men, and further research may benefit from including black and minority ethnic, and sexual minority women diagnosed with BCDP. An important omission from this study is the inclusion of accounts of women who were unable to continue with their pregnancies.

Conclusion

In the previous literature, women diagnosed during pregnancy have been mostly absent from research, despite the large amount of research about the experience of breast cancer, and the fact that breast cancer is diagnosed in 1 in 3000 pregnancies in the UK. This investigation of three women diagnosed with BCDP has revealed the far-reaching and long-term impact on young women's lives, and has sought to situate it within the social context, exploring the influence of gender. Young women with BCDP may require practical support to help them to care for children, especially if they do not have a strong support network, and they may benefit from counseling which addresses the feelings of guilt and concern about their children's suffering.

Acknowledgments

Many thanks to Dr. Christine Harrison and Dr. Eileen McLeod for their supervision and guidance throughout this research. Acknowledgments also go to the organizations which assisted with recruitment, namely, Breast Cancer Care, CoppaFeel!, Breast Cancer UK, and BUST Bristol.

Financial support and sponsorship

The Economic and Social Research Council (ESRC) funded for this study.

Conflicts of interest

There are no conflicts of interest.

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