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Women's experience of lactational mastitis

'I have never felt worse'

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BACKGROUND

Mastitis is a common problem for breastfeeding women in the postpartum period.

METHODS

Ninety-four breastfeeding women participating in a case control study of mastitis provided a free text comment about their experience of mastitis. Women were recruited from the emergency department, wards or breastfeeding clinics of the Mercy Hospital for Women and the Royal Women's Hospital, Melbourne, in 2002–2004.

RESULTS

The main themes which emerged from the free text comments were: acute physical illness; negative emotions; life disrupted; to continue breastfeeding or not? A minor theme was 'support for mastitis research'.

DISCUSSION

Women with mastitis often experience a rapid onset physical illness accompanied by strong negative feelings, which leads some women to consider stopping breastfeeding while others are determined to persevere. General practitioners need to provide emotional support for women with mastitis and acknowledge that breastfeeding may be difficult for new mothers.

Mastitis is a common problem for breastfeeding women in the postpartum period with approximately 20% of Australian women experiencing mastitis in the first six months.¹⁻³ However, few studies have investigated this illness from the perspective of the women themselves. Classically, mastitis is described as 'an infectious process in the breast producing localised tenderness, redness, and heat, together with systemic reactions of fever, malaise, and sometimes nausea and vomiting'.⁴

The aim of this article is to explore the themes identified in the free text comments collected in a case control study of mastitis and to give examples of women's comments.

Methods

Breastfeeding women participating in a case control study of mastitis⁵ completed a questionnaire primarily aimed at investigating factors associated with mastitis. Women in this study had mastitis defined as: 'at least two breast signs or symptoms (pain, redness or lump)

and one systemic symptom (fever or flu-like illness) present for at least 12 hours'. They also needed to be able to read and write English. The final item on the questionnaire invited women with mastitis to provide a free text comment: 'We are interested in your experience of mastitis. Please describe how you have been feeling and how mastitis has affected you'.

The aim of the question was to give women the opportunity to explain how mastitis had affected them personally. Free text comments can be helpful in identifying new issues not covered in the survey, can help in the development of new survey questions, and can give participants the chance to comment directly about the research question and the research process.⁶

The comments were analysed by assigning codes (units of meaning) to the participant's words, phrases or sentences.⁷ The researcher then grouped these codes into themes identified from the data.⁷ To illustrate each theme, comments have been presented in poetic form. Social scientists are using forms of writing such as poetic representation to 'recreate lived experience and evoke emotional responses'

as 'evocative writing touches us where we live, in our bodies'.⁸

Approval was received from the Royal Women's Hospital, Mercy Hospital for Women, and La Trobe University Research Ethics Committees before commencement of the study.

Results

One hundred women with mastitis completed the questionnaire, either in the breastfeeding clinics (n=38), wards (n=32) or emergency department (n=25) of the Mercy Hospital for Women and the Royal Women's Hospital, Melbourne, in 2002–2004 (site of recruitment missing for 5 women). Sixty-nine percent (69/100) of the women were primiparous, their mean age was 34 years and 51% (51/100) had private health insurance. The median age of the infants was 16 days (mean 34 days, range 6–728 days). Six women did not provide any free text comments (free text comments: n=94). Women's comments ranged from one short sentence to paragraphs of about 50 words.

Data analysis of the women's comments identified 46 codes; the number of codes for each woman ranged from one to seven. Four main themes and one minor theme emerged from these codes. The main themes which emerged from the free text comments were:

- 'acute physical illness'
- 'negative emotions'
- 'life disrupted'
- 'to continue breastfeeding or not?'

The minor theme was 'support for mastitis research'.

Acute physical illness

Breast pain is the primary symptom in mastitis; almost half the women (n=46) mentioned breast pain. Many women described severe or intense pain in one breast or occasionally in both breasts.

'Severe pain in the breast exacerbated by touch (including clothes) and attachment for feeds...'

Three women also commented on lumps within the breast, for example: '...I had a very hard, sore right breast with lumps running between my nipple and armpit. My

breast was also very red and hot.'

Although the focus of mastitis is breast pain, women's symptoms were not confined to the breast. Mastitis is an inflammatory process and many women reported symptoms of a generalised flu-like illness (n=80). These symptoms included high fever, lethargy, myalgia, sweating and rigors. Twenty-two women mentioned headache.

'Feeling very sore, very bad headache, joints very sore, hot and cold and generally miserable.'

In addition to the traditional flu-like symptoms, women reported a wide range of other symptoms: dizziness or faintness (n=7), nausea or vomiting (n=5), backache (n=3), sleeping difficulty (n=3), anorexia (n=2), diarrhoea (n=1), breathing difficulty (n=1), and thirst (n=1) (Table 1).

In contrast to the majority of women who described an unpleasant experience, two women made comments that indicated they were 'not too bad'.

'I am in the very early stages so have not experienced any symptoms other than breast tenderness and redness.'

Negative emotions

The early weeks after the birth of a new baby are a time of great transition, especially for first time mothers. Women are recovering physically from the pregnancy and birth, while being 'on call' day and night for the new baby. The episode of mastitis led some women to struggle to cope with the demands of new motherhood. Emotionally many women felt depressed (n=16), distressed (n=13), anxious (n=5) or tearful (n=5). Four women were coded as experiencing helplessness. One woman described feeling 'detached' from her baby. Other emotional responses were those of frustration or impatience with the illness: '...It's frustrating because you've also got to take into account the baby – it stresses you out. When you have a fever, you just can't do anything.'

Fear was expressed by some women: two women were fearful of recurrence of mastitis and two women expressed a fear of death (Table 2).

Table 1. Acute physical illness

Lethargy/fatigue tender breasts+++ nausea hot sweats/cold shivers.

Table 2. Negative emotions

I have never felt worse. Makes you feel very ill, no energy and painful in the breast region. It has made me feel very sad and I wish I could have prevented it in the first place. I said to my partner, I'm on my way out. I felt as if I might die.
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Life disrupted

Some women found that the onset of mastitis was rapid and unexpected: 'Felt unexpected, sick and tired.' Women found that having mastitis disrupted their normal functioning: they were often unable to look after their baby and the entire family may have been disrupted: 'Found it very difficult looking after myself, let alone a newborn, a husband and two other children under the age of four.'

Continue to breastfeed or not?

Four women were contemplating giving up breastfeeding, while seven were experiencing negative feelings about breastfeeding. In contrast, two women stated that they would persevere with breastfeeding. Many of the women with mastitis had concerns about their milk supply:

'Feeling very uncomfortable. I feel bad because I cannot satisfy my son's demand for milk.'

Support for mastitis research

Three women gave a response aimed to encourage the researcher in her work or a plea to help women with mastitis: 'I hope you are able to find a cure for mastitis.'

Discussion

There are some limitations of open text comments. Participants who make comments are more likely to have strong feelings on the topic.⁶ Some of these comments were made by women who attended emergency departments after hours or were admitted to hospital with mastitis. Therefore, they may represent the more severe end of the spectrum. On the other hand, there were some women who were so unwell they were not invited to participate in the study, or who participated but did not make a comment.

While some of the issues were raised by only a small number of participants, it cannot be assumed that these issues were not relevant to other participants as well.⁶ For example, only small numbers of women mentioned loss of appetite and difficulty sleeping, but these problems may have occurred for other women.

Furthermore, because of the self selected nature of free text comments, the findings cannot be used to estimate prevalence of particular problems identified by participants.⁶ For example, some participants were concerned about milk supply, but further quantitative studies on representative samples of women would be needed to explore the proportion of women for whom this is important.

A small number of qualitative studies have explored women's experience of breastfeeding in general. Hoddinott and Pill⁹ reported that first time mothers perceived a secrecy about the realities of the first few weeks after birth, particularly about feeding difficulties. Bailey and Pain¹⁰ also identified that women spoke about having an image of breastfeeding as 'natural', which did not help them with the actual experience. Women were often faced with the reality of having difficulties with breastfeeding which included nipple and breast pain. Shakespeare et al¹¹ reported that women often experienced unexpected breastfeeding difficulties; the difficulties were not just physical, the women were emotionally distressed as well. Over half the women in Schmied and Barclay's¹² sample found breastfeeding to be disruptive, unpleasant and distressing. Most texts

(professional and popular) do not acknowledge the personal distress that may be associated with breastfeeding.

A recent Swedish study of 14 women with inflammatory symptoms of the breast had similar findings to this study: themes included 'overcoming physical pain and difficulties', 'living through emotional turmoil' and the availability of support (professional and practical).¹³

Authors have suggested that 'the messages that health professionals give women about breastfeeding should be realistic and honest, so that women know that establishing breastfeeding may be tough',¹¹ and that 'breastfeeding difficulties may in some measure be reduced if mothers were given insight into the demands of breastfeeding'.¹³ General practitioners 'can help mothers by providing information, encouragement and interpersonal support'.¹⁴ General practitioners should recognise that mastitis in itself may have emotional consequences for some women, and they should continue to support breastfeeding women through their illness with the aim of an ongoing, successful breastfeeding experience.

Implications for general practice

- Mastitis is a common illness with emotional as well as physical implications for lactating women.
- General practitioners should refer women with breastfeeding problems promptly to lactation consultants or breastfeeding counsellors.
- General practitioners can help women by acknowledging the difficulties involved in breastfeeding and providing support and encouragement.

Conflict of interest: none.

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