



When baby's chronic illness and disability interfere with breastfeeding: Women's emotional adjustment

Kath Ryan, B Pharm, PhD, MPSNZ (Associate Professor)^{a,b,*}, Lorraine Smith, B.A.(Hons), PhD (Senior Lecturer)^c, Jo Alexander, RM, MTD, PhD (Emeritus Professor of Midwifery, Maternal and Perinatal Research)^b

^a School of Nursing & Midwifery, La Trobe University, VIC 3086, Australia

^b School of Health & Social Care, Bournemouth University, Bournemouth BH1 3LT, UK

^c Faculty of Pharmacy, The University of Sydney, NSW 2006, Australia

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ABSTRACT

Objectives: to explore the emotional adjustments that women make when their baby's chronic illness or disability threatens breastfeeding.

Methods: qualitative descriptive study and exploratory secondary analysis of narratives from five breastfeeding women in the UK whose babies experienced a chronic condition.

Findings: three key themes were discerned: (1) 'Overwhelmed'—feelings of shock and helplessness. Engagement in the practical issues of breastfeeding, relying on others and receiving emotional support from them helped. (2) 'Under acknowledged'—women spoke of not being listened to or taken seriously. Focus on the medical condition de-valued the contribution of breastfeeding. (3) 'Striving for normality'—reframing the situation and readjusting goals and expectations helped adjustment to a 'normal' life.

Discussion: varying levels of emotional adjustment were experienced by the women, and a process or path reflected their efforts to cope. Adjustments are discussed in terms of practical issues of coping and biographical disruption, thereby raising awareness of challenging aspects. Breastfeeding provided a sense of control and purpose. Understanding issues around breastfeeding an ill or disabled child can help health-care providers offer more appropriate care to women who wish to breast feed in spite of chronic illness.

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Introduction

In 2006 the World Health Organization (WHO) released new charts for monitoring infant growth and development based on breastfeeding as the normative model rather than artificial feeding (WHO Multicentre Growth Reference Study Group, 2006). As a result of these charts, in official health discourse breastfeeding should now be promoted as the *normal* way to feed a baby (Berry and Gribble, 2008), so that eventually this understanding will filter into popular discourse. Previous popular and promotional discourse ('breast is best') positioned breastfeeding as *optimal*, that is, ideal or perfect but not likely to become a reality. This perception, by default, rendered artificial feeding as the *standard* method. Breastfeeding may be more difficult and pose added challenges and emotional hurdles, however, when the mother and/or baby are chronically ill or disabled. When we think of

breastfeeding and chronic illness in the same frame it is usually in terms of the capacity of breastfeeding to protect the child against the development of chronic illness in later life (Davis, 2001; Gartner et al., 2005; James et al., 2009) or in terms of promoting and protecting breastfeeding for vulnerable infants. Hence, there is a body of literature on the physical and mechanical aspects of how to maintain breastfeeding in chronically ill babies (Lang et al., 2002) and a similar body of literature on how to support chronically ill women with the 'how to' of breastfeeding (Carty, 1998; Spatz, 2004; Jackson et al., 2008) but very little on the emotional aspects of breastfeeding, especially in these situations.

Only a few researchers have considered chronic illness and motherhood (Jackson, 2000; Young et al., 2002; Davies and Allen, 2007; Wilson, 2007; Vallido et al., 2010; Lively and Smith, 2011) and even fewer have explored the links between breastfeeding, emotional adjustment and motherhood (Murphy, 1999; Schmied and Lupton, 2001; Shaw, 2004; Marshall et al., 2007; Ryan et al., 2010a, 2010b). There is very little literature (Mohrbacher and Stock, 2005) and no research on emotional adjustment when breastfeeding is threatened because of chronic illness in the baby.

* Corresponding author at: School of Nursing & Midwifery, La Trobe University, VIC 3086, Australia.

E-mail address: kath.ryan@latrobe.edu.au (K. Ryan).

Biographical disruption (Bury, 1982) (changes to previous order, identity and meaning caused by major life events – such as chronic illness – that necessitate adjustment) is a ‘powerful analytic framework’ (Wilson, 2007) useful for investigating women’s transition to parenthood and identity construction as a mother, especially when chronic or terminal illness or disability threatens normal development. Locock et al. (2008) used the concept of biographical disruption and the work of Bury (1982) and Charmaz (1983) to analyse women’s narratives of nausea and vomiting in pregnancy, highlighting the ‘disruption to the structures and behaviours of everyday life caused by (chronic) illness’ (p. 151). They suggested that biological disruption may be ‘extended to transient as well as chronic conditions’ (p. 151), especially when sense of self and identity are already in transition. The concept of biographical disruption describes the effects and consequences of chronic illness but the construct does not appear to account for the emotional adjustment process, which we define as the developmental process of identifying and modulating emotional responses and their concomitant cognitions and behaviours in response to situational demands (Cameron and Leventhal, 2003).

Previous work has also highlighted the need for further investigation of the disruption of ‘mothering as a phenomenon’ (p. 1443) and the coping strategies that women use to negotiate their ‘social/emotional distress’ (p. 1444) (Vallido et al., 2010) but, to our knowledge, no studies have looked specifically at women’s emotional response and adjustment process when chronic illness or disability threatens to interfere with their expectation that they will breast feed.

In this paper, we pose the question: In a society that is supposed to position breastfeeding as ‘normal’ what are the emotional adjustments that mothers make when their baby’s chronic illness or disability threatens their intention to breast feed?

Methods

In 2005–2006, 49 women living in the UK took part in a parent study of depth narrative interviews about their breastfeeding experiences in the previous 2 years for a module on breastfeeding for the website of personal experiences of health and illness www.healthtalkonline.org. They were recruited, with the aid of an expert advisory panel of key stakeholders in the infant feeding field and national voluntary breastfeeding support groups, to provide as wide a variation as possible in age, ethnicity, educational qualifications, marital status, region of domicile and breastfeeding experiences. Interviews, conducted in the women’s homes, lasted 35–90 mins, were video and audio recorded and transcribed in full. Transcripts were returned to the participants for validation (Macpherson and Williamson, 1992). Data were coded according to a systematic framework derived from issues identified by the interviewees and from the combined knowledge of the expert advisory panel, the researcher (KR) and another experienced qualitative researcher, a ‘buddy’. Coded data were collapsed thematically into topics that were summarised to capture the broad spectrum of experiences. Each topic summary was reviewed by the ‘buddy’ and at least two advisory panel members and, together with illustrative video, audio and written clips, posted on the website.

One of the topic summaries was entitled ‘When extra care is needed for mother and/or baby’ in which five women from within the parent study discussed their experiences of breastfeeding a baby with chronic illness or disability. For the purposes of this paper, we have chosen from that topic summary, as a theoretical sample for secondary analysis, the transcripts of all five women. Four of these transcripts appear as edited versions on the website. Their narratives stood out as different from the other 44

narratives of women with healthy babies. They were individually different but the issues they raised about needing to adjust to their situation were sufficiently similar to warrant further analysis. These five information-rich narratives were analysed thematically for the current paper. This represents an embedded design, in which we have purposively selected several information-rich cases from within the wider study to address our research question and provide as much diversity as possible to enhance the potential transferability of our findings (Table 1).

All authors became thoroughly familiar with each of the five narratives (Pope et al., 2000) in its entirety as a stand-alone entity, looking for instances of emotional adjustment. These instances were extracted with enough text to retain context and coded according to issues raised within the narratives. Then, in a process of constant iterative comparison (Pope et al., 2000) between our developing coding schema and the data, we looked across all five narratives to search for similarities and differences. Thus the data could be thought of as a series of individual narratives that each contributed to the overall analytical understanding and also contributed as a whole combined data set. The following themes were discerned within the coding to capture the essence of what it was like to breast feed in the presence of a baby’s chronic illness or disability: overwhelmed, under acknowledged and striving for normality. Quotations are identified by pseudonym.

Findings

In addition to common emotional issues related to breastfeeding (such as adjustment to motherhood, changes in body image and relationships, and often overwhelming feelings of responsibility) mentioned by many women in the parent study, there were several other concerns that were evident in these five women’s narratives. Feelings of shock, disappointment, (separation) anxiety, helplessness, vulnerability, guilt, love, selflessness, relief and empathy signified an adjustment process, in some ways similar to grieving, that the women went through as they came to terms with the chronic illness or disability and its impact on their desire to breast feed their baby.

I used to find it very, very painful being at regular mum and tots groups, seeing people breastfeeding. To use the word grieving seems terrible when people do lose babies but it felt like a grief because it was a loss of something that I had so wanted to do and was very important to me. (Rebecca)

On top of the feeling of loss (for a healthy baby and possibly breastfeeding) were the difficulties of the present and the insecurities related to the future.

We’ve talked about breastfeeding having lots to do with emotions and psychology, when you have a child with Down’s Syndrome you’re dealing with a lot more as well and I think that makes it doubly hard then because you’ve got doubts and worries and you know you’re kind of going through a bereavement and I can see why people say ‘I’m not going to worry about this, I’m just going to put them on the bottle’. (Jane)

Once they had adjusted to living with and breastfeeding a baby with chronic illness the women wanted to reach out to other women in the same situation.

Overwhelmed

The women talked about being totally overwhelmed by the situation when their baby was born with a chronic illness, especially when it was unsuspected, or when their baby had a condition that interfered with their ability to breast feed. They

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