



A new normal?: Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer



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ABSTRACT

Increasing numbers of women are surviving breast cancer, but little is known about the long-term implications of having survived a life-threatening illness and living with embodied reminders of its potential to return. Twenty-four women aged between 42 and 80 (median = 51) who had been treated for early stage breast cancer in the UK between 6 months and 29 years previously, were recruited through local media and interviewed. Analysis of their narratives revealed challenges in the post-treatment period that were conceptualised as biographical disruption and liminality. Although no longer ill, an ongoing fear of recurrence combined with embodied changes prevented a return to 'normal' i.e. a pre-cancer state in terms of health status, identity and relationships. We argue that following the biographical disruption of breast cancer, a 'new normal' entails a continual renegotiation of identities, daily lives and futures as time passes and lives evolve.

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1. Introduction

Breast cancer is the most common type of cancer affecting women in the UK during their lifetime (Cancer Research UK, 2015a). It is diagnosed by clinicians as either primary (or early stage) meaning that it has not spread beyond the breast or lymph nodes, or secondary cancer (metastasis) where it has spread to another area of the body (e.g. lungs or bones), which is usually deemed incurable (Cancer Research UK, 2015b). Breast cancer differs from many illnesses in that, although there are many theories about its aetiology, the exact cause remains unknown. In addition, following treatment for primary breast cancer there is the possibility of recurrence and subsequent development of secondary breast cancer (Cancer Research UK, 2015c).

Encouragingly for those who are diagnosed with the condition, life expectancy has increased. Recent predictions suggest that 78% of women diagnosed with breast cancer in 2010/11 will survive more than ten years after treatment, compared with 40% forty years

earlier (Cancer Research UK, 2015a). Consequently there is a need for greater understanding about the post-treatment period (Powers et al., 2014; Blows et al., 2012). Oncologist and academic Siddhartha Mukherjee argues that for a woman who has experienced breast cancer:

Cancer will become a chronic condition. she will live in its immediate shadow for decades, never quite certain about her outcome ... Having entered the world of cancer, her life will be permanently altered. For her, cancer will become the new "normal" (Mukherjee, 2011:27).

From a sociological perspective, the question then emerges of what constitutes this 'new normal'. In this study of women who were several years post-treatment for breast cancer, we consider the long-term implications of surviving a life-threatening illness and living with embodied reminders of treatments which include surgery to remove affected cells (lumpectomy), or the entire breast (mastectomy). The analysis presented here explores how women 'engage with and manage the myriad challenges' (Murray, 2015:91) in the post-treatment period, including living with fear of recurrence and the impact of bodily changes on perceptions of femininity and sexuality. This analysis furthers our understanding of what it is like to live in the afterlife (as opposed to the aftermath (see Roy, 2012)) of early breast cancer and its treatment.

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1.1. Background

Bury's (1982) concept of illness as a biographical disruption, developed from a study of those with rheumatoid arthritis, has been highly influential in the study of experiences of illness. Bury argues that chronic illness disrupts normality and initiates a process of re-examining expectations for self, daily life, and future hopes and plans. Similarly, a cancer diagnosis can also often be experienced as biographical disruption (Balmer et al., 2015; Liamputtong and Suwankhong, 2015; McKenzie and Crouch, 2004). There are typically no obvious indications of breast cancer other than a lump in the breast tissue found either through self-examination or breast screening. Although Liamputtong and Suwankhong (2015) suggest that biographical disruption can be instigated on first discovering symptoms, Holmberg (2014:179) observed during her fieldwork in a breast cancer clinic that 'it was the naming process that tore the women from their everyday lives.' Such a diagnosis is typically accompanied by a rapid transition to the 'sick role' (Parsons, 1951), where compliance with medical guidance is expected, and normal roles and responsibilities are suspended until health is restored.

A range of studies have also revealed particular challenges associated with the period following treatment for breast cancer, including: ongoing fears of recurrence (Costanzo et al., 2007); distress at the simultaneous loss of medical and social support (Allen et al., 2009); and emotional vulnerability (Powers et al., 2014), with potentially permanent effects on daily living. Furthermore, the physical consequences of breast cancer treatment can have long-term implications for identity, self-esteem, confidence, social relationships, body image and sexual relationships (e.g. McCann et al., 2010; Thomas-MacLean, 2005; Wilmoth, 2001).

Studies have suggested there is a need for ongoing care and support (such as counselling) to help women cope with changes to their bodies and relationships during the transition from treatment to 'normal' life. In this context, normality is equated with resumption of pre-cancer roles and self-management of breast cancer symptoms (Tighe et al., 2011; Thomas-MacLean, 2005). However, this seems to suggest that a return to the previously lived 'normal' is possible whereas Balmer et al. (2015:468) argue that 'living after cancer is a persistently disruptive experience'. As such, it can be argued that patients can experience biographical disruption not only at point of diagnosis, but also when they leave the sick role and enter an interim state situated between being ill and being fully restored to a pre-diagnosis state of health. This interim state may be conceptualised as liminality (Powers et al., 2014; Blows et al., 2012; Crouch and McKenzie, 2000).

The term liminality, adopted from anthropology, describes situations in which people find themselves 'betwixt and between' classifiable states (including states of health and illness) and is characterised by loss of status, ambiguity and marginality (Turner, 1969:95). Just as Thompson (2007:343) found that liminality was particularly useful for understanding experiences of ovarian cancer which can recur, leaving affected women 'in a perpetual state of uncertainty', we argue that it is also useful for understanding experiences of breast cancer due to the possibility of recurrence.

Despite the apparent suitability of the concept of liminality in understanding the post-cancer experience, a review of the literature which applies it in this context (Blows et al., 2012) found that most studies do not consider experiences beyond 5 years post-treatment. Furthermore, just one study was identified which focussed specifically on breast cancer (Crouch and McKenzie, 2000) but only included 7 participants. Therefore, this study of 24 women who had completed treatment up to 29 years earlier enables a longer term and more in depth consideration of ongoing disruptions to identities, bodies and relationships, from diagnosis of

breast cancer to the end of treatment, and well beyond. We argue that biographical disruption and liminality are useful concepts to apply in understanding the range of experiences associated with falling between states of illness and health, and having permanently altered bodies.

2. Method

The data presented in this paper are taken from a study conducted in the UK between 2009 and 2012 (Trusson, 2013a). The qualitative approach taken was consistent with the research aims of understanding and interpreting women's experiences of early breast cancer which often contain contradictions and inconsistencies that can be difficult to capture by quantitative means (Benton and Craib, 2001). Furthermore, a narrative approach was deemed appropriate due to its suitability for studying the impact of change and disruptive episodes on people's lives (Murray, 2015). According to Murray (2015), narrative research in which people are encouraged to talk about their lives in their own words, can provide a way of restoring a sense of order when everyday lives are disrupted by events such as illness.

After gaining University ethics approval, women who had been treated for early stage breast cancer were invited to participate in the study via a University website and local media. This method of recruitment had the benefit of enabling access to women who had completed hospital-based treatment and who otherwise would have been difficult to reach. Details of the sample are in Table 1 below:

Participants were interviewed in depth at a place of their

Table 1
Sample characteristics.

Characteristic	Number of participants
Age:	
42–49	9
50–59	9
60–69	3
70–79	2
80	1
Education:	
University	14
Below university level	10
Occupation:	
Retired	7
Professional role	13
Non-professional/voluntary work	4
Ethnicity:	
White-British	24
Relationship status:	
Married	16
Long-term heterosexual partnership	4
Widowed	1
Single	3
Time since diagnosis:	
Up to 12 months	2
1–4 years	8
5–9 years	12
10–20 years	0
20+ years	2
Surgery:	
Lumpectomy (+reconstruction)	5 (1)
Mastectomy (+reconstruction)	11 (7)
Other treatment(s):	
Radiotherapy and/or chemotherapy	14
No radiotherapy/chemotherapy	10
Location of interview:	
University social club	5
Public café	4
Participant's office	2
Participant's home	13

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