European Journal of Oncology Nursing 15 (2011) 226–232

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Coping, meaning and symptom experience: A narrative approach to the overwhelming impacts of breast cancer in the first year following diagnosis

M. Tighe [a,*], A. Molassiotis [b], J. Morris [c,1], J. Richardson [d,2]

[a] Faculty of Health, University of Plymouth, 7 Portland Villas, Drake Circus, Plymouth PL4 8AA, United Kingdom
[b] School of Nursing, Midwifery and Social Work, University of Manchester, Jean McFarlane Building, Oxford Road, Manchester, M13 9PL, United Kingdom
[c] Faculty of Health, University of Plymouth, Knowledge Spa, Treliske, Truro TR1 3HD, Cornwall, United Kingdom
[d] Faculty of Health, University of Plymouth, 8 Portland Villas, Drake Circus, Plymouth PL4 8AA, United Kingdom

Keywords:
Breast cancer
Survivorship
Relationships
Narrative-representation
Cancer journey
Clinical education

A B S T R A C T

Purpose: Women's experience of breast cancer treatment is a complex feature of survival which reflects and impacts upon the quality of their inter-personal relationships. We aimed to explore and present the issues and means through which these women relate their symptoms, treatments and effects. We utilised the 'cancer journey' as a heuristic device to chart women's experiences in the first year following diagnosis.

Method: Thirty-nine interviews were conducted over one year with a convenience sample of 10 women newly diagnosed with breast cancer recruited from a specialist oncology centre in England in 2005. Transcriptions of the interviews were analysed using a thematic narrative approach.

Results: The findings suggested how women related coping and meaning to their experience of relationships, return to work, and self-management of breast cancer symptoms. The overwhelming impact of breast cancer was personal to each sufferer and yet reflects commonly reported treatment effects. These included unmet need for fatigue management, the impact of adaptation to hair loss and disfigurement, and the evident need for sexual health and relationship counselling.

Conclusion: The multi-dimensional aspects of womens' relationships with family, friends, co-workers and care professionals impacts significantly on their coping strategies and how they make sense of their breast cancer experiences, which consequently bears upon symptom experience, and experience of survival. We suggest that narrative representation bears witness to the common and differing experiences of how women newly diagnosed with breast cancer cope with symptom experience and survival over time. Narrative representation of breast cancer is a useful pedagogical resource for supportive cancer care and highlights the needs of women that need to be addressed by health care professionals.

Introduction

Breast cancer is the most common form of cancer in the UK, with a lifetime risk affecting 1 in 8 women (Cancer Research UK 2010). It is a devastating diagnosis, not just for the person involved but for the family and friends who become carers and supporters during this traumatic life event (Fallowfield and Clarke, 1991). Although breast cancer does occur in men it is most commonly diagnosed among women over the age of 50 (Cancer Research UK, 2010). Death rates from breast cancer have fallen by a third since the 1980s: improved access to screening, and provision of a wider range of treatments, including supportive care, is evident. Cancer survivors can experience symptoms for more than 10 years after treatment (Harrington et al., 2010). It is reported that there are an estimated 2 million cancer survivors in the UK (Maddams et al., 2009), and this is expected to rise. There is a clear need to understand the historical trajectory of cancer survivorship in the context of post-treatment strategies for on-going after care and support (NCRI 2010) DH (1995).

Previous literature demonstrates how a choice of treatment options enables women's decision making processes, meets their information needs and reduces the incidence of psychological morbidity associated with the disease (Fallowfield, 1999; Fallowfield and Clarke, 1991; Fallowfield and Hall, 1991; Fallowfield et al., 1994; Kinnersley, et al., 2008). Conventional medical options generally

* Corresponding author. Tel.: +44 1752 586549.
E-mail addresses: maria.tighe@plymouth.ac.uk (M. Tighe), alex.molassiotis@manchester.ac.uk (A. Molassiotis), jenny.morris@plymouth.ac.uk (J. Morris), janet.richardson@plymouth.ac.uk (J. Richardson).
[1] Tel.: +44 1872 256461.
[2] Tel.: +44 1752 586535.

1462-3889/$ – see front matter © 2011 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejon.2011.03.004

involve one or more of the following interventions: radiotherapy, chemotherapy, surgical mastectomy, lumpectomy, and adjuvant pre and post surgical combination of some or all of the above. However, despite the greatest number of evidence based trials, surveys and outcomes, the specific therapeutic effects of multi-level forms of intervention remain difficult to identify, while women's age, stage of diagnosis, and lifestyle means and choices are significant psychosocial indicators of morbidity or survival (Banning, 2007; Cancer Research UK, 2010; Fallowfield, 1999; Fund, 2009).

Women's experience of diagnosis and treatment is a complex feature of breast cancer survival. The impact of emotional stress and physical disfigurement on sexual identity and couple relationships is well documented ((Illingworth et al., 2010; Manganiello et al., 2011; Remmers et al., 2010)). Such aspects are often neglected in traditional bio-scientific claims to advances in life expectancy. Kerr and others have suggested that effective professional communication helps improve recovery from surgical intervention (Kerr et al., 2002), Fallowfield (Fallowfield et al., 2002). Professional communication needs to include improved attention to individual needs assessment and quality of life indicators, which suggest how the social and psychological impact of breast cancer diagnosis and treatment impacts upon women's longer term survival (Department of Health, 2007; Ferrell et al., 1998; Fund, 2009; Ganz et al., 2004; Mandelblatt et al., 2005). Cancer 'survivorship' is a concept which has gained popular ground in the past decade, engaging public, private and third sector services (Department of Health, 2007). Survivorship reflects the chronic longer term nature of the illness and the move to improve cancer care through effective partnership working: this includes specialised pathways to information, shared decision making and choice of treatment for all affected. Supportive care is a core element of cancer survivorship, involving a more integrated approach to self-help innovations. However, more recent scholarship advises the need to clarify the application of the survivorship concept, noting the benefits that professionals may gain through accessing a deeper understanding of the relationship between cancer experience and cancer care (Doyle, 2008). Illingworth et al. (2010) further this view and suggest how inter-personal relationships feature in each aspect of the cancer experience.

The impact of cancer experience on survivors capacity to 'return to work' is important: Macmillan Cancer Support (2006) critiques the UK government's 'pathways to work' strategy, suggesting that health and social after-care for cancer survivors is lacking. The report highlights that '91% of cancer patients' households suffer loss of income (and/or increased costs) as a direct result of cancer'.

In this paper we recognise the inter-relationship between survivorship experience and post-treatment care. We suggest that the 'cancer journey' is a useful heuristic device because it furthers a shared language between patients, professionals and carer-supporters. In the UK the cancer journey is understood to reflect the longer term emotional and psychological needs of people affected by the disease, grounded in the everyday realities of living and dying with cancer (DH (1995) (Calman & Hine Report)). The adoption of the psychosocial model of the cancer journey is a contemporary UK health care policy(NCRI, 2010, Department of Health, 2007). The role of service users in motivating awareness of the need for radical improvements in UK cancer care is significant (Tritter and Barley, 2001). For example, Brohn (1987) elucidates the psychological, emotional and spiritual dimensions of living with the disease, and calls for a shift in professional perspective that responds to the existential crisis that a cancer diagnosis portends. Over time, such compelling narratives have helped inform the UK Cancer Care Reform Strategy (Cancer Research UK, 2010; Department of Health, 2007, NCRI, 2010). The use of narrative inquiry in health research and clinical education is increasingly commonplace (Bleakley, 2005). Greenhalgh & Hurwitz (Greenhalgh and Hurwitz, 1999) and Skultans and Cox (Skultans and Cox, 2000) illustrate how constructing social meaning helps order the chaotic suffering experience. Life threatening chronic illness presents and reflects a deeply personal existential crisis (Frank, 1995, 2000). Illness narratives offer an insight into suffering as it is lived during the course of everyday relationships. Frank (Frank, 1995, 2000) and Sontag (Sontag, 1978) have drawn on personal experience to narrate the role and range of cancer beliefs and attitudes following life threatening diagnosis. Building upon the strategic use of narrative as a methodological device, Kohler-Reissman (Kohler-Reissman, 2008) discusses how the 'storifying experience' enables the teller to structure his or her lived experience. The narrative researcher's task is distinct; to identify thematic 'connections' that span the longer timeline of dramatic and cognitive events.

> "Telling narratives is a major way that individuals make sense of disruptive events in their lives….how we create our realities and ourselves through the strategic choices we make in social interaction" (Seale 2004; 375 (Ed) reproducing Kohler Reissman 1990).

The 'illness narratives' first identified by Kleinman (Kleinman, 1988) have evolved as a qualitative methodological means; however, the adoption of illness narratives as a methodological device is one which Kleinman himself resists. He requests that researchers return to their primary aim; to improve the care of those who suffer through informing the clinician about the embodied socio-political and emotional context in which people live their lives (Kleinman, 1996). The use of metaphor is especially illuminative in this regard. Richardson and Grose (2009) demonstrate how metaphor conjures up powerful images that reflect the embodiment of cancer.

However, there are significant gaps in qualitative longitudinal data within psychosocial oncology that suggests the need to explore the experience of women over the longer course of time (Mandelblatt et al., 2005). In this study, we set out to deepen the understanding of women's symptomatic experiences of breast cancer treatment in the first year of diagnosis. Adopting a thematic narrative approach to inquiry we explored how the personal story of breast cancer revealed the differing contexts through which each of these women related their similar and various symptoms, treatments and the effects of treatment. We utilised the 'cancer journey' as a heuristic framework to chart the course of each illness narrative over time. In order to preserve the narrative focus we have presented the sequential stages of the thematic process in a concurrent paper (Richardson et al., in press). We present the narrative material that best illustrates the common trajectories of hair loss, fatigue and disfigurement, in particular, exploring how women cope and make sense of these overwhelming impacts in the context of wider inter-personal relationships and return to work.

Methods

Design

We used a thematic narrative approach to undertake in-depth analysis of longitudinal interview data obtained over the course of one year; using the 'cancer journey' as the device to aid 'story-telling'.

Sample

Interviews were undertaken with a convenience sample of women newly diagnosed with breast cancer. The women were