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

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

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 reflected 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 care professionals 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...
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 psycho-social 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 (NCR, 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 (Titter 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
recruited from a large specialist oncology centre in England in 2005 and last follow up interviews were carried out in August 2007. Nineteen women were approached and 10 agreed to participate. Reasons for non participation included not wanting to be ‘reminded’ of the cancer and the need for a relatively long term commitment to the project. Interview data were available across the four interview points for nine of the women, and across three interview points for one woman providing a total of 39 interview transcripts.

Interviews

Interviews were undertaken at specific time intervals over the first year following the initial diagnosis. The first interview was conducted as early as possible after diagnosis and close to the time of start of treatments, the second interview around three months afterwards, the third, six months later, and the final interview at twelve months following diagnosis. All the interviews took place in the women’s homes and were tape recorded and transcribed; each interview took around one to one-and-a-half hours.

Data analysis

Kohler Reissman’s (Kohler-Reissman, 2008) guidance on thematic narrative analysis was adopted. The content of each woman’s narrative was analysed with reference to the social and local context through which the concept of the cancer journey was made real. Four key steps enabled our approach: defining our concept of narrative; constructing text with attention to language and form; establishing our comparative ‘unit of analysis’; bound by local and social context. Mapping the longitudinal stages of symptom experience through co-analysis of lengthy transcripts helped demonstrate Frank’s (Frank, 1995) concept of the ‘journey’ across time. Our concept of narrative was defined as context bound and relational, reflecting the biography of the body as a whole. Thus, the cancer journey served as a comparative unit of analysis, enabling us to present the narrator’s understanding of the genesis of her illness through researcher generation of both individual and group case typologies (Frank, 1995).

Interpretive analysis of the longitudinal data aimed to elicit how the experience of breast cancer stimulated the narrative construction or elaboration of illness representation (Chan and Molassiotis, 2001). Content analysis was conducted independently and across the data sets by three researchers. The three researchers first analysed one complete set of transcripts (=4 interviews over time) then agreed the core themes and coding framework, with third party checks of the interpretive coding process for subsequent transcripts.

This enabled comparison of patterns and themes across and within cases. We committed to the case-centred approach identified by Kohler-Riessman (Kohler-Reissman, 2008) in order to preserve the rich sequential nature of the interviews, while discussing themes across cases.

Researchers’ perspectives

The three researchers who analysed the data were all registered nurses who had worked with cancer patients. Doctoral and post-doctoral experiences of the researchers influenced data interpretation as did their understanding of the cancer patient’s journey. Throughout all stages of the analysis the researchers communicated regularly to enable the analysis to be undertaken iteratively, including scheduled meetings at two monthly intervals over the course of one year.

Ethics

Ethical committee approval was obtained from the local NHS ethics committee.1

Discussion of findings

Participant Characteristics

Ten out of nineteen women agreed to take part in the study. The only difference between respondents and non-respondents was age: the non-respondents tended to be slightly older, mean = 57.5 compared with a mean age of 51 for the participants. The youngest participant was 34. All of the women described themselves as ethnically ‘white’ from Christian backgrounds. Four of the women were married professional full time workers at the time of diagnosis, three women were cohabiting and two worked part time, two were retired and one woman lived alone. All ten women were actively engaged in radical treatment which involved mainly a combination of chemotherapy and radiotherapy (n = 4), or hormone therapy plus radiotherapy (n = 3); with eight having previously undergone surgery. The stage of cancer at the time of the first interview varied across the sample, although the majority of the women were at an early stage, being diagnosed with Grade 2 (n = 5) or Grade 1 (n = 3) breast cancer.

Narrative themes

The three core themes identified from the analysis of the transcripts of the interviews were symptom experience, coping and meaning, and relationships. The core themes are evident across all cases. In this paper we present examples of how coping with the overwhelming impacts of breast cancer treatment, in particular hair loss, fatigue and disfigurement impacts upon inter-personal relationships. As follows, changes in relationships are illustrated in Tables 1–3 in the context of family and friends, return to work, and cancer care professionals; and elaborated upon in three vignettes.

The experience of breast cancer diagnosis and treatment is shared by many women. However, the deeper personal impact of such a diagnosis reflects the particular treatment experiences through which each woman experiences and copes with changes in her inter-personal relationships over time. To illustrate, we present ‘Carole’s’ story of hair loss. Similar issues were raised by another four of the interview participants. This narrative has been selected as it illustrates how this common side effect of treatment permeates into aspects of this woman’s relationships, sense of self and social life.

Carole:

“When you lose your hair you think oh God will I ever look the same when my hair grows back? Will I look the same person as I was before? No because it is very important how you look because it does affect the way you feel on the inside…. how you look on the outside” (Interview 2)

Over the next few months Carole’s hair started to grow and she felt better about her changed appearance;

“My hair’s coming back and that makes you feel better. I think because you are starting to look more like your normal self and feel it, then you feel better and I think it’s all a bit surreal really… and your hair falling out and I just think that that is so soul destroying and nobody can explain to you what it does to you

1 All of the women in the study have pseudonyms to protect their identity.
mentally when you look at yourself in the mirror and you see yourself and it doesn't look like that person". (Interview 3)

Some months later Carole describes discussions with her sister and her partner about her appearance. She starts to take charge, caring less about other people's opinions.

“It's funny because it was my sister's birthday last week and we went up and they were showing a video...it was in the summer when I had no hair, it was really funny to see myself, you know, like that because you just forget don't you, you know, you just think “did I really walk around like that?”... I just want it to grow longer length really more than anything; I can't do anything with it now [laughed]. It was easier before, when I didn't have any! Or when it was just like a nice length. Somebody said to me "oh it looks like Kylie Minogue's" so I said that's because we've both been ill with the same thing [laughed] she said “oh my God, I'm sorry". I said don't worry about it.... I just went into work one day and said I can't wear that wig any more I can't wear them scarves, you know, they smell of cancer and.... [Laughter] and just said I'd have to go bald. Now they probably can't remember what I looked like with no hair so it soon goes out of people's minds". (Interview 4)

The relationship context of recovery is an important feature of adaptation for all of these women. Carole's story reflects the evaluation and re-evaluation of who she is in the context of her changing appearance, her identity and self-hood; illustrating the 'restitution' narrative identified by Frank (Banning, 2007) as a heroic means of transforming physical identity loss during the cancer experience.

As follows, 'Susan' describes the more subtle disabling effects of fatigue on her ability to engage in social activity and relationships.

Fatigue was a common symptom for all of the women, each of whom describes different means of coping. Susan highlights the many ways in which fatigue suggests long term impacts upon personhood, sense of self and social relationships. During the first few months of treatment Susan considers the reasons for her debilitating tiredness;

“I am tireder, but that's to say that's one of the symptoms as well of the tablets, because they can cause extreme fatigue”. (Interview 1)

Over time, the situation worsens for Susan;

“I'm not sleeping. I'm having nightmares. I can't raise any enthusiasm for anything. I just don't want to be bothered”. (Interview 2)

Molassiotis (Molassiotis, 2005) and Lawrence et al (Lawrence et al., 2004) have described the complex features of post-treatment fatigue, noting associated 'symptom clusters' of depression and insomnia. Indeed, over the next six months Susan starts to find ways to excuse herself from the social activities she enjoyed before her diagnosis:

“'I've been busy this week. And I just feel like I'm telling a series of lies the whole time and it's trying to remember now whoever you said what to. And some days I can quite happily say to myself it's the stress and the tablets that are making me tired and I accept it for what it is and not do a lot. But if I decided I'm going to do this, this and this and then I can't do it because I've got up so tired because I've been dreaming all night. And because you're tired your enthusiasm isn't there"” (Interview 3)

Susan is annoyed about the impact the tiredness has on her life; she explains how she has always been a busy person and that she cannot do as much as she used to:

Table 2
Return to work: coping with disfigurement and limited resources.

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<thead>
<tr>
<th>1st Interview</th>
<th>2nd Interview</th>
<th>3rd Interview</th>
<th>4th Interview</th>
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<tr>
<td>Coping at work:</td>
<td>Major financial worries:</td>
<td>Does not want to return to work:</td>
<td>Resigns following a worsening of post-treatment (infected) lymphoedema.</td>
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<td>“I've got cancer, they've got a headache” (pharmacy assistant)</td>
<td>Caretaker for her own mother who is in hospital. Husband also pays nursing home bills for his mother.</td>
<td>appreciates life outside of work now.</td>
<td>Diagnosed with clinical depression one year on.</td>
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<td>Social isolation:</td>
<td>“feel closeted”</td>
<td>‘Phased return’ to work part time, very difficult, weepy; prefers “less responsible” part time work.</td>
<td>Asserts work-life balance - Works less, lives more.</td>
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<td>“paid full pay until op finished”</td>
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<td>“I am very clear with them [work] about boundaries and that I am having a break at lunchtime. I do have to be on call but equally I insist that the reason for ringing is necessary. I don't think about work when I get home”</td>
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<tr>
<td>I can't think too much about work because I can't deal with that as well, so I need to just cut that off completely</td>
<td>Need “to strike a balance between work and home...long hours on call being at work...so I need to look at that because it was stressful”.</td>
<td>Something that as a nurse I can learn from is being a patient...I have learnt so much about change, I need to make some changes to improve patients' lives and journeys”.</td>
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Table 1
Family and friends: changes in relationships.

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<tr>
<td>Diagnosis:</td>
<td>Marital Stress:</td>
<td>Support from daughter:</td>
<td>Marital breakdown: “All came crashing down”.</td>
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<td>“I told immediate family only”</td>
<td>“I haven't returned to 'routine’ with my husband”.</td>
<td>“I enjoyed time with daughter (holiday).</td>
<td>Barely coping: “Still doing all housework/cleaning”.</td>
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<td>“nobody knew”</td>
<td>“there is a lack of order and purpose in our relationship now”.</td>
<td>It helps me cope, feel good, relax”</td>
<td>No physical relationship, reports: “he is terrified”</td>
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<td></td>
<td>“No sex at all”</td>
<td>Career stress: “depressed relative”</td>
<td>Plans for separation: Friends helping find new home (and furniture)</td>
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<td></td>
<td>Talk with other women who have had similar experience:</td>
<td>“she relies upon me”</td>
<td>Attitude to cancer diagnosis: “in some ways it's been positive – feel more understanding of other people”</td>
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<td>“not everyone is the same (reacts to things in the same way)”,</td>
<td>Women friends:</td>
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<td>Loss of friends: “some friends just can't cope with my diagnosis”.</td>
<td>“we have a laugh”.</td>
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<td>Changes to lifestyle: “wish husband would stop smoking.</td>
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<td>“take on more housework”.</td>
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<td>Doesn't want people to know about diagnosis:</td>
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<td>“no one treats me any different”.</td>
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Table 3
Professional care: communication gaps and multi-agency support.

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<th>1st Interview</th>
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<th>4th Interview</th>
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<tr>
<td>Personalised care: values being asked about personal life, family, first names, “Intimacy matters”</td>
<td>Communication problems [consultant]: “I thought it was appalling ... he told me ‘I should have had a mastectomy instead’”</td>
<td>Information needs: “They all do a marvellous job, brilliant, caring (doctors, nurses) but I want information”</td>
<td>Medical examination for social welfare - incapacity withdrawal. Tribunals activity: “This has been so stressful but Macmillan have been brilliant – I got a legal advisor and a new welfare officer”</td>
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“I've always been a busy person. I used to work three early mornings. I only do one now. Well, as the day goes on I'm definitely more tired. And like I say it's... because somebody said to me, "You're turning into an old woman, you." And I thought, little do you know". (Interview 3)

Susan refers to her recent cancellation of a family holiday:

“I thought, if I can't get the best out of this for what it's costing, I don't want to go. You want to get out of it exactly what you want. Not to feel ill along the way and not get the best out of what you're paying for. I've never felt so lethargic, so down, so less interested, and so tired". (Interview 3)

The extent of the tiredness is overwhelming. Susan describes feeling unprepared.

“I think everybody's prepared for the physical side, nobody takes into account the emotional or the stress that it does on you and the tiredness that it can, and well I am putting the tiredness down to some of the stress. No, I didn't expect half this. I knew the radiotherapy would make me tired but I didn't think it would last so long. You see, everybody focuses on, you have the chemotherapy and you'll lose your hair, nobody focuses on, yeah they might say to you well you know you might be sore, you might be tired; but nobody can explain that tiredness to you. It is something you actually have to experience because you just think I am not working". (Interview 3)

Susan's description of social pressures and isolation as she struggles to make sense of her extreme fatigue suggests the impact of the personal stress described by Remmers et al., (2010). She vacillates between feeling responsible for “doing too much” and relating tiredness to her recovery.

“Know it is the amount of things I have tried to do, it's not because I've been ill or I am recovering. I have done too much. I know we all get tired as the day goes along, but it is not like that kind of tired, it's you are more tired and you think to yourself, I haven't done enough to be this tired, why am I this tired?” (Interview 4)

Chan & Molassiotis (Chan and Molassiotis, 2001) Montezari (Montezari 2008) and Fallowfield (Fallowfield and Hall, 1991) have reiterated the need to identify and manage the specific after-treatment effect of cancer-related fatigue, suggesting the detrimental psychosocial impact upon wellbeing and survival. As follows, the effects of fatigue remain overwhelming for all of the women, but for some, return to work is a compounding challenge.

The impact of breast cancer experience on work can be seen in 'Anne's story (aged 43) which has added poignancy as she was a health care professional and had to adapt to the role of being a patient. At the first interview, the overwhelming sense of coping with the symptoms and treatment dominated Anne’s life and that at time work “…is somewhere distant… I can’t think too much about work because I can’t deal with that as well, so I need to just cut that off completely.”.

Three months later finds Anne feeling more positive about the cancer experience having finished chemotherapy and realising the need to change her work priorities “…to strike a balance, a balance between work and home...long hours on call being at work so I need to look at that because it was stressful”.

Anne also recognised how she needed to change as a health care professional “...something that as a nurse I can learn from is being a patient...I have learnt so much about change, I need to make some changes to improve patients' lives and journeys”. At the fourth and final interview, Anne reports that she has returned to work but her work life has changed significantly from previously when she worked “…70/80 h a week, working in the evening, was on call, and would have meetings at eight in the morning” to “…it is nine to five and I am very clear with them about boundaries and very clear that I am having a break at lunchtime. I do have to be on call but equally I insist that the reason for ringing is necessary...and I don't think about work when I get home...Now I am home and always have tea together...Life is so precious now, I try to enjoy life more...”.

This aspect of Anne's post-treatment journey illustrates how such a life threatening and overwhelming experience can have a positive effect as she re-evaluates her role and asserts a work-life balance. Many of the women describe making similar changes to their work and family life. However, not all of the women in this study succeeded in making such positive change. Below, Deirdre narrates how her experience of disfigurement impacts upon her intimate relationships, mental health, and ability to sustain her work and livelihood.

Deirdre’s story

’Deirdre’ (age 51) focuses upon the breakdown of her long term relationship with her partner, Billy, and the impact of her distressing experience of lymphoedema, burns and bodily disfigurement on her return to work. She relates how these overwhelming physical impacts affected her psychological and social recovery.

“I've got a lot of discomfort and stuff, and mentally, but there's other people worse than me, so you know, I'm not really bothered about that. I'm a fighter and I don't give up. I'd love to get married and be happy with him [Billy] cause when he's good he's wonderful. And that's all I would ask, but I think he's a depressive person and when I'm ill or depressed he gets even worse. I don't feel as if I'm getting the support”.

The impact of bodily disfigurement on breast cancer survivors' experiences of changing personal and sexual relationships is significant yet specific, practical advice remains lacking (Manganiello et al, 2011). Deirdre relates how this affects her quality of life and ability to cope.

“There's not been a proper physical relationship this year...so that really upset me. And I just think it's because I'm disfigured and look horrible, he can't bear to touch me. He said it's not that. He thinks it's going to hurt me, he's frightened I'm going to die of cancer again, all the rest of it, and we've just gone round in circles... And then he says something, you know, when we shout, he say means things about... well, 'if you were out to work proper like everyone else, and...’ He's sorry afterwards, but it's...
(Macmillan Cancer Support, 2009) too late when he's said it. And I was struggling like mad you know. I keep house for him. I do all the cooking and cleaning and shopping, he has to do nothing". (Interview 1)

Deirdre returned to work in a local retail outlet after six months, but due to her painful arm, restricted movement and experience of anxiety she sought medical advice and decided to resign. One year on she was diagnosed as clinically depressed.

"I tried to wean myself back into work, 4 h and it turned into ten all of a sudden. I knew that would happen because it's that kind of shop. So the pressure was on and I started with an infection and then it was lymphoedema, my arm was swollen, my bust was swollen. And so I ended up going to hospital and they said 'straight back on the sick, you can't work like that, it's impossible, you shouldn't have done it'. (Interview 3)

Deirdre's experience supports the findings of a Macmillan Cancer Support survey (2009) which reveals that up to '57% of patients have had to give up work, or change their job role or hours as a result of their diagnosis'. Although Deirdre did return to work following diagnosis she was unable to cope with the demands of her role due to her worsening experience of pain, loss of movement and related effects. This created significant physical, and mental distress for Deirdre at a time when she most needed to recuperate.

"Yeah, I had a bad breakdown at Christmas. It just got to that stage. I didn't want to carry on with this trouble. I was sick to death of it… I have days where I feel so grateful and thankful and then other days where, you know, I feel in despair sometimes..." (Interview 3)

Despite her despair Deirdre paints a pragmatic picture of the misery of post-treatment burns, infection and lymphoedema. She asserts her right to information and her frustration with the limits of clinical care and communication.

"Oh, I was in a mess. All the skin broke down completely. Just came off from underneath. It was like an open, weeping… You know that in so many cases it's going to happen. I was warned that it might get sore but not to that extent. … I couldn't wear clothes. I couldn't get dressed properly". (Interview 3)

Deirdre reflects on how abandoned she felt:

"I spent the whole weekend in bed just crying my eyes out… It was awful. Because of where it was; it was all up around the breast and the chest wall. I was in the shower, and I'm not mad, I'm in the shower crying to God to please stop it for me. And, you know, I didn't think after all I'd been through that it would end like that. So it was a big shock to me... I felt dumped and it was horrible". (Interview 3)

Although her case is individual, Deirdre's story reflects the relational means through which many women with breast cancer respond and cope with the psychosocial and sexual impacts of disfigurement (Banning, 2007). Deirdre's distress echoes the 'chaos' narrative described by Frank (Frank, 1995) as one of the common features of cancer experience; hope is crushed, and shock and confusion reigns. Grief, according to Frank, is always present; this is not, however, a static emotional state but one that changes in the context of lived inter-personal relationships over the longer course of time.

Conclusion

The cancer journey offered an innovative methodological opportunity. Advancing narrative analysis in the field, the heuristic framework aligned our analysis with the initial and follow up stages of the interview process, which took place from the earliest point of breast cancer diagnosis through to living with and beyond cancer treatment in the UK National Health Service (NHS). The narratives produced by these women indicated that their cancer journey was not fixed or static; instead, their stories illuminated an unstable process of renewal and despair in the context of their lived inter-personal relationships. Their story-telling demonstrated the inter-subjective meaning making identified by Richardson (Richardson, 2000) at the clinical interface; in this case revealing the deeply inter-personal existential crises that the first year of breast cancer diagnosis and treatment represents.

In this study all of the women identify how their individual symptom experience reflects and affects their coping and inter-personal relationships, which change over time. The study is limited to the first year following breast cancer diagnosis and represents the overwhelming impacts personal to each sufferer. We have demonstrated that each of these impacts highlight commonly reported treatment effects. Thus, despite the significant body of knowledge informing health professionals about the psychosocial needs of women with breast cancer, the women in this study still describe feeling unprepared for the impact upon their everyday ability to cope. Professional information-giving is limited and the financial burden is significant; almost all the women in this study returned to work following treatment and report some degree of related stress. This study reinforces the view that real efforts need to be made to highlight factors that employers can address in order to support cancer survivors in their return to the work environment (Macmillan Cancer Support, 2006; NCRI 2010; Hansen et al., 2008; Feuerstein et al., 2010; Macmillan Cancer Support, 2009): This is pertinent to longer term survival, reflecting the need to better support women and their partners in the transition from diagnosis to treatment, during treatment, and in the follow up stage of return to 'normal' life. In spite of the policy commitment to UK cancer care reform, long term after-care remains lacking; there is unmet need for fatigue management, adaptation to hair loss and disfigurement, and sexual health and relationship counselling for women and their partner/supporters.

These narrative accounts demonstrate the value of the methodological story-telling device; providing a platform for women to voice and share their particular and common experiences. Breast cancer is a life threatening and long term chronic illness, which requires co-ordinated multi-agency support in the first year of survivorship. The potential for service user led innovation is suggestive; the identification of a range of common and individual needs reveals the value of promoting a reflective narrative approach to patient involvement in service development. The cancer journey framework proved a useful heuristic device; demonstrating how changes across time denote particular stages of crisis, recovery and transition in the context of lived relationships in the domestic, social and work environment. To conclude, we suggest that narratives of cancer experience are a useful illustrative means of demonstrating the multi-dimensional aspects of inter-personal relationship issues and supports. Women's experience of coping with changes in their relationships bears relevance to symptom experience and survivorship. Narrative representation of breast cancer is a useful pedagogical resource for the effective planning and delivery of supportive cancer care services in and outside of the UK NHS and in allied education.

Conflict of interest statement

None declared.

Acknowledgements

Thanks to research assistant, Lisa Brunton, RN, MSc who conducted the interviews. This research was conducted with the help
of funding from the Christie Hospital Charitable Trust research programme grant.

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