

Between stigma and pink positivity: Women's perceptions of social interactions during and after breast cancer treatment.

Abstract

This study explores women's perceptions of social interaction during and after their treatment for early stage breast cancer. Analysis of interviews with 24 women between 6 months-29 years post-diagnosis, reveals that interactions can be influenced by conflicting public discourses surrounding breast cancer. For example, there is the continuing association of cancer with death and the resulting potential for a stigmatised identity (Goffman, 1963). In contrast is the ultra-positive discourse around cancer survivorship, with breast cancer in particular being associated with pink campaigning and a push towards positive thinking.

Participants described 'managing' conversations during treatment; sometimes playing down their 'private' suffering and presenting a positive ('public') image rather than risk alienating support. After treatment they were encouraged to move on and get back to 'normal'. Whilst other breast cancer patients/survivors were often good sources of support, there was also a danger of assuming that all experiences will be the same. We present data to illustrate that women often present 'public' accounts which are driven by an expectation of positivity and fear of stigmatization at all stages of breast cancer treatment and beyond.

Keywords: Breast cancer; social interactions; stigma; positivity

Introduction

Over the last 40 years, cases of breast cancer have doubled making it the most common type of cancer affecting women in the UK; 53,696 women were diagnosed with breast cancer in 2013 and 11,716 died of it in 2012 (CRUK, 2016). However, in the same period, the chances of surviving over 10 years post-diagnosis have almost doubled from 40% to 78% (CRUK, 2016). Consequently it is important to consider women's experiences both during and after treatment for breast cancer (Powers et al., 2014).

The study on which this paper is based was conducted in the UK during 2009-12. It explored 24 women's experiences of biographical disruption (Bury, 1982) during diagnosis, treatment and life beyond early breast cancer (Trusson, 2013) and was prompted by the lead author's own experiences of being treated for early breast cancer and a particular interest in the post-treatment period. Previously we have explored disruption to identities, bodies, and relationships during breast cancer treatment and beyond (Trusson et al., 2016). In this paper we focus on social interactions as reported by the participants in this study.

Previous research suggests that the period post-treatment for breast cancer can be a difficult time, often marked by fears of recurrence and physical and psychosocial problems (Trusson et al., 2016; Burris et al., 2015). At the same time, the public discourse 'tends to reflect someone

who has finished [breast cancer] treatment as 'cured', having beaten cancer' (Powers et al., 2014:9). McKenzie and Crouch (2004:152) suggest that cancer survivors generally 'are thus at odds with those around them including the very people on whom they have been most accustomed to rely for social support'.

In addition, it is important to consider the wider social context of breast cancer diagnosis and treatment; as Murray (2000) points out, illness is not experienced in a vacuum. Societal representations of cancer reveal a tension between an ongoing stigma and conversely an ultra-positive view associated with breast cancer awareness and fundraising campaigns (Kaiser, 2008). In this paper we explore the influence of these competing discourses on women's interactions with friends, family and wider society.

Background

Stigma

Goffman (1963:9) defines stigma as 'the situation of the individual who is disqualified from full social acceptance'. According to Sontag (1991), this describes the situation of a surprising number of people with cancer who find themselves shunned by friends and relatives due to cancer's history of concealment and association with death. Empirical research bears this out; for example, Peters-Golden (1982) compared the views expressed by 100 breast cancer patients with those of 100 disease-free men and women. She found that 52% of the breast cancer patients reported that sometimes friends or family members avoided them. This was reinforced

by 61% of the 'healthy' individuals who admitted avoiding people with cancer because it increased their own sense of vulnerability to illness and dying. Despite increasing survival rates, Balmer et al.'s (2014) recent review of research surrounding lay understandings of cancer suggests that these attitudes still persist, and that people fear cancer more than other life-threatening diseases. Perhaps unsurprisingly, research reveals that individuals with visible side-effects of cancer are much more likely to be stigmatised (Knapp-Oliver and Mayer, 2004). Although this latter study was based on vignettes, other research, such as Harcourt and Frith's (2008) interviews with breast cancer patients who suffered hair loss during chemotherapy, confirms that a visible cancer status can lead to unwanted attention and intrusive questions. Lally et al. (2013:483) describe this type of awkward, intrusive or inappropriate behaviour as 'bumbling'. Along with 'distancing' 'minimizing' and 'reacting with intense emotion', it is an example of an unsupportive social interaction (USI) identified in secondary analyses of interviews with women up to 15 weeks following diagnosis of breast cancer. These USIs often 'led women to avoid interactions/limit disclosure and reduce sharing their concerns' (Lally et al., 2013:483). Useful as Lally et al.'s findings are, they are limited to a brief period in women's experiences of breast cancer. In contrast, most (20) of this study's participants were between 2 and 9 years post-diagnosis, allowing an opportunity to assess whether and how such behaviours might persist.

Positivity

According to Radley and Billig (1996:227), the wider social discourse 'shapes not just how individuals think but how they feel they ought to think' about their illness. In the case of breast cancer, Powers et al. (2014:2) argue that 'societal expectations can be driven by and reflected in the media'; one example is the high profile given to breast cancer survivors (often celebrities). These stories not only highlight that cancer can be survived, but that people could even benefit from the experience (Seale, 2002). In addition, charities use what might be termed 'pink positivity' in breast cancer awareness and money-raising activities such as 'The Race for Life'. Discussing its success, chief executive of charity Breast Cancer Care, Samia al Qadhi (2008) argues that pink imagery unifies women in the common cause of raising consciousness about breast cancer and can engender a feeling of mutual support in the face of a common threat. However, former breast cancer patient Barbara Ehrenreich (2009) has criticised this impetus of positivity associated with breast cancer, arguing that it pressurises women to think in a certain way and ignores the horrors of the disease. Nevertheless this message of positivity is a prominent cultural message in the UK in the 21st century and is influential both to those affected by breast cancer and the people with whom they interact (Wilkinson and Kitzinger, 2000).

Other research with men and women post-treatment for various cancer types has found that maintaining a positive attitude 'requires a great deal of self-control and censoring of communication...in order to appear acceptable to the 'normal' majority and also to protect loved ones'

(McKenzie and Crouch, 2004:152). Although the intention may be to 'present a strong face' (Murray, 2015:97), Rosedale's (2009) study of women up to 18 years post-treatment for breast cancer, suggests that an inability to relate honestly with friends and family may result in what has been termed 'survivor loneliness' (Rosedale, 2009).

Peer support

An expectation of positivity has also been cited as a reason for women's reluctance to use an online breast cancer support group (Sandaunet, 2008); this was because of the perception that there was no opportunity to express worries and anxieties. However, other studies have shown that the special understanding shared with other breast cancer patients can be particularly helpful because they understand the "ins and outs" of their cancer experiences' (Burris et al., 2015:73). Wilson and Luker (2006:1622) identified four categories of interactions between patients being treated for various cancers: 'stoicism, sympathy/empathy, information, and humour' and found that giving and receiving support could be mutually beneficial. However, they also found some patients who rejected the cancer group identity. Similarly, Vickberg's (2001) interviews with women who were 1-5 years post-treatment for breast cancer revealed that peer support may not be universally accepted as beneficial; for some people, contact with other cancer patients/survivors may trigger or increase fears of recurrence.

This brief review reveals that, whilst there is a wealth of literature concerning cancer patients' social interactions, there are very few studies that focus specifically on breast cancer and/or consider the period beyond the first 1-2 years following diagnosis (Powers et al., 2014; Rosedale, 2009). Therefore this study of 24 women who were between 6 months and 29 years post-diagnosis (mean = 6.54 years), contributes to the health and illness literature by providing an insight into women's experiences of social interaction both during **and** after treatment for early breast cancer.

Methods

Ethical approval for this study was granted by the University ethics committee. The participants were self-selected, having responded to an invitation on the University website and local media to participate in the study. Unfortunately some women who responded could not be included as they had secondary breast cancer and consequently their experiences were beyond the scope of the study. However, all 24 women who met the criteria of having had early breast cancer were interviewed. The sample of 24 women (all White British) were aged between 42 and 80 years; the majority (18) were between 42 and 59 years old and this is reflected in the selection of data extracts which predominantly come from women in this category. Participants were between 6 months and 29 years post-diagnosis (mean = 6.54 years). Over half (15) of the participants were

employed (mainly in professional roles); 2 no longer worked and reported that this was as a result of their illness, and the remainder were retired. Most (20) of the women were married or partnered. The 4 single participants included one widow and one self-identified lesbian.

Participants were interviewed at a place of their choosing, which in most (14) cases was their home. After gaining signed consent and assuring confidentiality, the interviews began by asking participants to talk about their experiences since discovering they had breast cancer. Being able to tell their story in their own words enabled participants to include any information that they wanted to talk about, whilst a series of prompts ensured that similar topics were covered by each participant (O'Connell Davidson and Layder, 1994). The prompts were adapted from Conrad (1990:1260) who suggests the following issues as pertinent to the illness experience:

- The impact of the diagnosis/coping with a medical label
- How were relationships affected by illness (family, friends, work colleagues)?
- Adaptations needed to cope with bodily changes
- Experiences relating to check-ups
- Strategies used to 'get by'

Interviews lasted between 1-4 hours and were digitally recorded and transcribed in full. In addition, after reflecting on their interview, some participants made further comments by e-mail; these comments have, with participants' consent, been treated as extra data.

In the wider study, a narrative approach was used in order to understand the disruption of breast cancer within the context of participants' life stories (Bury, 1982). However, Murray (2000:343) notes: 'while narratives may be analysed as personal attempts to make sense of disruptions in individual biographies, they can also be analysed as social performances'. In the current paper we are interested in the different ways that women talked about their illness depending on who they were talking to. Our analysis therefore considered not only how breast cancer experiences were described, but also the context in which they were narrated, including the broader social representations of breast cancer (Murray, 2000). During the period of the study we critically examined the many and frequent ways that breast cancer was discussed and presented in charity campaigns and in the media generally.

The interview transcripts were read numerous times by the lead author to achieve familiarity with their structure and content. Key issues arising from the data were identified and connections were made with the existing literature (Murray, 2015). Broad themes identified through this iterative process were then discussed and agreed with the co-author to enhance the trustworthiness and reliability of the analysis (Mays and

Pope, 1995). In this paper, data are presented which illustrate how, throughout treatment and beyond, social interactions are informed by wider social discourses that portray breast cancer as on the one hand serious, and on the other trivialised by 'pink fluffy' imagery.

Reflexivity

In a study of social interactions, it is particularly important to consider the interviewer/interviewee relationship (Radley and Billig, 1996). For instance, interviewees may present a socially desirable (public) account rather than risk giving a 'potentially much less acceptable 'private' account' (West, 1990:1229). The approach used in the present study is what Cotterill (1992) describes as being 'a friendly stranger'; the appropriateness of which was demonstrated by Viv (2 years post-diagnosis) in the quote below:

V: That's how I cope I think, by just keeping it in. Don't talk about it.

Int: mm. Yet you're talking to me about it. Is that because I'm a stranger and-?

Viv: Yeah. Because you're not gonna be upset by me being upset. But my other friends are, so...

Int: So does it ever come up? You know if there's something on the telly or something?

Viv: Yeah, yeah

Int: Do you talk about it then?

Viv: Only to my husband a little bit. But not a lot. Try not to. My family are like forget it's ever happened. Don't talk about it.

Int: Would you like them to talk about it more?

Viv: Yeah

Some of the issues revealed in this excerpt will be considered in more detail in the analysis section of this paper, but it is included here to demonstrate the way that talking about one's health is contingent on the context and also the relationship between the narrator and listener (Radley and Billig, 1996). Some participants seemed to consider the interview as an opportunity to reveal their 'private' stories, perhaps because they did not feel a need to protect the interviewer as Viv suggests here. Alternatively, respondents may have seen the interview as a chance to express themselves that would otherwise be denied (West, 1990).

In addition, Radley and Billig (1996) point out that although the health status of the interviewer in a research project is rarely revealed, it is likely to be assumed that they are healthy (as they are working as an interviewer), which can impact on the way that people talk about their illness. In the current study the lead author (who conducted all the interviews) had experienced breast cancer. However, she did not reveal her own health status until after the participant had given her initial

account, after which the interviews often became more of a two-way conversation. Johnson (2007) similarly shared her experiences of familial breast cancer as part of her research project and also found that the interviewer's personal disclosure established a common bond with the participants which enabled 'private' accounts of their experiences to be recounted. It seemed that having a mutual understanding of the issues involved in a particular health condition meant that common experiences could be easily discussed and understood (Radley and Billig, 1996). For example, in this study discussion sometimes centred on the pros and cons of reconstructive surgery options; other times experiences of chemotherapy were compared. The benefits of talking to other women with similar experiences will be returned to later in the paper.

Findings

Analysis of the narratives revealed numerous and differing perceptions of social support at various post-diagnosis stages of breast cancer. We begin our discussion with examples of support during treatment, before turning attention to the ways in which participants reported having to 'manage other people' both during and after treatment. We then consider how the positivity associated with survivorship and pink-themed charity campaigns influenced the participants' experiences. Finally we discuss the role of peer support including problems associated with assuming a commonality of experience.

Support during treatment

Without exception, participants spoke warmly of receiving numerous phone calls, visits, cards and flowers from family, friends and colleagues during their treatment. For example, Joy (6 months post-diagnosis) said:

The house had always got somebody in it. When I came home, there was always somebody there, or somebody was coming. Even if it was only 'Hello, are you alright?' and go, there was always somebody there. Cards! I've never seen so many cards. And it was showing that, you know, people cared. But [pause] it suddenly goes don't it?

In this excerpt, Joy portrays her appreciation for these displays of affection immediately after treatment, echoing Frank's (2002:79) sentiments in relation to his experience of testicular cancer: 'these messages gave me what I think ill persons need most, a sense that many others, more than you can think of, care deeply that you live'. However, Joy's last sentence reveals a common experience reported by participants in this study, that social support was withdrawn soon after the end of treatment. According to some participants, this was when they were most in need of support because it could be a difficult time of adjustment as Malaika (6 years post-diagnosis) described:

It's like when you grieve, after 6 months everybody thinks you should be bloody over it so if after 12 months you're wobbling and the grief really does hit you, nobody's there anymore. They're there

for the first month when you're probably riding on adrenaline to try and stay afloat, so when you do start to sink, which can be sometime after, everyone's moved on to an extent. And I think that's one of the struggles I had. Not that I wanted any sympathy or any of that stuff. I needed their support and a little bit of compassion.

Malaika speaks metaphorically of being buoyed up by social support but gradually sinking when the realisation of what she had endured hit her and she was left to cope alone. This sense of isolation was echoed by Viv (2 years post-diagnosis) who described how breast cancer had affected her:

I think it's made me more self-reliant. Even though he [husband] was really good, he was really nice but [pause] you have only got yourself. You're the one going through it. If you die, you die alone don't you? So yeah, it has made me a bit harder.

In this moving account, Viv conveyed how the singularity of her experience had led to a conscious decision to be less reliant on others for support. Like Rosedale's (2009:179) participants, it seemed that Viv's experience of breast cancer 'illuminated how fragile one's connection with others really is.'

Bury (1982) argues that illness reveals starkly the true nature of relationships, and although the majority of the participants reported that their relationship with their husband or partner was stronger as a result of

their experience, Gabrielle (3 years post-diagnosis) reported that her marriage was damaged irrevocably:

My illness exposed finally for me that my husband just wasn't a copper, and he hijacked my illness. My illness became about him. He didn't do anything for me other than talk about my illness to get sympathy...and it's harsh; but that was my reality of it. Sadly my relationship did not survive my recovery. Cancer **is** life changing. I looked at it and I thought I can't do this anymore. So it was the catalyst for change but the fallout was harder than dealing with the cancer.

In this excerpt, Gabrielle, is drawing on a common trope within the public understanding of cancer where it is often portrayed as a catalyst for change. For example, Seale (2002) argues that news reports of people with cancer often feature cases of people overcoming adversity to triumph in some way. However, in Gabrielle's case it does not seem to have been a wholly positive experience because she felt let down by her husband's reaction to her breast cancer diagnosis.

Such lack of reliability was not confined to spouses however, as Catherine (2 years post-diagnosis) described:

Some people surprised me because they sort of just bolted off and wouldn't do anything. And one of them was my brother who I was very close to and he just couldn't hack it at all. Which was really weird. We've only just started to get friends again. I'm not holding

it against him but at the time it was quite painful because I would've liked him to be around. We're just getting close again now.

Instead of offering care and support as Catherine had anticipated, she reported that her brother had withdrawn from her life when she needed him most. Frank (2002:103) believes that this is the ultimate denial of an ill person's experience, arguing that 'in disappearing, they deny that anything special is happening or, alternatively, that the ill person exists at all'. This is the flipside of emotional support, which as mentioned previously, confirms that 'others care deeply that you live'. Consequently, Catherine seemed to be struggling to rebuild her relationship with her brother. However, some participants were less willing to forgive, as Malaika (6 years post-diagnosis) described:

One of my close friends at the time, and she's not a close friend at all now, I don't have anything to do with her, my daughter said "you've not been to see my mum at all and it's been nearly 3 weeks and you've not seen her since her diagnosis". And she went "I don't know how to deal with it!" And my daughter said "how the fucking hell do you think my mum's dealing with all of this?" And it was ironic how many people fell apart. And there were other people who- "I was scared you were gonna die. I couldn't come near you."

The above extracts indicate a reluctance to engage with someone who has a stigmatising condition, even if it risks damaging relationships. This supports Sontag's (1991:6) argument that because cancer seems to

strike indiscriminately it 'arouses thoroughly old fashioned kinds of dread... [and] will be felt to be morally, if not literally contagious'. Other women described how when people did visit, their behaviour was not experienced as supportive but rather the opposite, as Karen (6 months post-diagnosis) recalled:

When seeking support in the early days and now, it was often me that ended up supporting others. Two of my friends on visiting me after the mastectomy cried when they saw me and I needed to reassure them. After this I felt the need to put on a 'brave' face and minimise what was happening to me to protect them. I guess this is what I have done in all my relationships, in and outside the immediate family. (E-mail 19/5/11)

Karen describes how she prioritised other people's needs for comfort and reassurance over her own by disguising her true emotions. It seems that Karen is managing her appearance (Goffman, 1969) as socially required. However, Hochschild (2003) points out that there is a danger associated with this sort of 'emotional labour' because people can become overly concerned for the needs of others at the detriment of their own needs, as Ruth (4 years post-diagnosis) demonstrated:

The other thing I found was that people only want to hear good news. If I started to tell people how much something hurt or how dreadful I felt, then they sort of backed off. So I only ever told

them good things as that's what people want. The public don't like a moaner! (E-mail 12/2/2011)

Even though Ruth was clearly still suffering, she reported giving a false impression of having recovered so that people would not 'back off.' Ruth's reported exchange was indicative of the way that participants colluded in the misapprehension that they were 'back to normal' rather than revealing their true state of ongoing suffering. Consequently, participants sometimes missed out on receiving social support because people assumed they did not need it.

Self-censorship

Ruth's reference to only discussing 'good things' is an example of a public account, i.e. using expressions that people feel they 'ought' to use (West, 1990) rather than sharing a private account of feeling 'dreadful'. Another instance of a public account was described by Joy (6 months post-diagnosis):

You only tell them so much because you think 'oh god they don't want to hear this' and if anyone says to me "how are you?" I'd say "I'm fine" and Pam would say, "She isn't really, she'll tell you she's fine, she tells everybody she's fine". But what can you say? Well I am fine. You can't really say "Oh I don't feel very good today", that's depressing. I mean I have felt depressed, I've felt that sometimes I could scream you know, when I've thought about it.

But it's just one of them things isn't it? You've just got to gerron with your life.

It seems Joy did not want to burden other people with her problems and felt compelled to project positivity; even to the point of assuring the interviewer that she was healthy. Sacks (1975) talks about this phenomenon in his essay 'Everyone has to lie', where he considers the way the question 'how are you?' tends to be used as a greeting rather than a serious enquiry into the state of someone's health. Sacks argues that a reply such as 'I don't feel very good today' would have initiated a conversation, since the follow up would be 'why?' or 'what's the matter?' It seems that Joy has realised that there are conditions on what can be said and what cannot, what is 'speakable' and what is not, and the answer 'I'm fine' treats the question as a greeting and stops the conversation progressing.

Because of these implicit rules, if someone insisted on talking about their cancer, it seems that they felt they were expected to do so in positive terms. Joy seemed to believe this attitude to be appropriate, since she repeated phrases such as 'life goes on' and 'you've just got to gerron [get on] with it' nine times during her narrative. However, examining the context of her talk in which such comments appear reveals that they were often used as a device to enable more distressing aspects of the experience to be discussed. For example:

I still have the odd tear but you know you've just got to gerron with your life. But as I say I am fine, I am;

I mean it is a life threatening thing but you just have to get on with life don't you?

In their discourse analysis of interviews with women with breast cancer, Wilkinson and Kitzinger (2000:805) describe such comments as a conversational device used as an "upbeat" end to 'round off and close down "troubles telling," and thus relieve the listener of the burden of hearing about unpleasant experiences or having to find a solution. They suggest that such talk is a way of fulfilling a 'socially normative moral requirement' to be positive through the experience of having breast cancer. This may result from the impetus of positivity that has permeated the way that breast cancer is portrayed, particularly the 'pink, fluffy' imagery used by charities and their corporate sponsors (Kaiser, 2008). In this study Karen (6 months post-diagnosis) explicitly referred to this as a problem:

What I do hate is the pinkness of it...I have to appreciate that if that's what gets the money rolling in that's the marketing side of it, but it's the pinkness that [pause]...There are women that are 21 with breast cancer, and the pink fluffiness of it is quite annoying because I don't think it's taken quite seriously enough and just what a nasty disease it is really.

Karen veers from negative to positive statements throughout this segment, which clearly illustrates her conflicting feelings. Whilst acknowledging the good that is done by charities, Karen is wary of the way that the 'pinkness' seems to conceal the realities of actually being affected by breast cancer. Nevertheless, it contributes to the widely-held perception that maintaining a positive attitude impacts on cancer survival (Wilkinson and Kitinger, 2000). Hence any lapses into negativity, dwelling on the past or morbidity were discouraged by friends and family (McKenzie and Crouch, 2004) as Sam (2 years post-diagnosis) described:

As far as my mum's concerned, it's dealt with, it's done. Doesn't want to talk about it anymore. Er my dad was just completely in denial, wouldn't accept it. If I try to talk about it with him he just starts singing 'Always look on the bright side of life!' that's all you get from him. Like it's too difficult to talk about so.. They sound like really bad people, they're not bad people it's just they can't cope with it.

In this extract, Sam's private account of being disappointed with her family's apparent lack of understanding was coupled with her reluctance to portray them as 'bad people' to the interviewer. Nonetheless, Lally et al. (2013) argue that refusing to discuss breast cancer is an example of distancing which can be upsetting for women trying to come to terms with their illness. Malaika (6 years post-diagnosis) had a similar experience

when trying to discuss the anniversary of her cancer diagnosis with her daughter:

She says “well really Mum you should be over it now. And you know, move on.” Which I have, I have moved on but I can’t help, when this time of year comes, reflecting, so to speak.

Whilst Malaika’s daughter was probably acting with good intentions in discouraging her mum from dwelling on an unpleasant episode in her life, Malaika experienced it as denial of her need to reflect on her cancer experience.

There were further examples of conflicting public and private accounts in the participants’ narratives, where the post-treatment period was identified as a particularly difficult time for social interactions. For example, Andrea (7 years post-diagnosis) said:

Once you’ve had the treatment you begin to look normal again and then you...and that applies in work situations, family, friends, new friends, social situations, where people say ‘how are you?’ and you think, ‘what bit am I gonna not say?’ So there’s a lot of that balancing, and thinking ‘what would be good for me? What would be good for them?’ you know, so that was a constant.

It seems that once her hair grew back, Andrea was no longer instantly recognizable as someone with cancer. She was therefore able to have some control over what information she chose to reveal and to whom,

allowing her to selectively reveal both the existence of her illness and her feelings. This illustrates Goffman's (1963:57) argument that 'when differentness is not immediately apparent' decisions must be made to 'display or not to display; to tell or not to tell; [...] and in each case, to whom, how, when, and where'. Andrea likened it to what she saw as another point of difference, where she had to decide who to tell that she was a lesbian. For example, she recalled a nurse asking whether she had grandchildren and needing to consider whether it was worth going into detail about why she did not have any. Likewise, Stacey (1997:67), a lesbian who also had cancer, describes how deciding whether to 'come out,' both in terms of sexuality and cancer status, was something she had to negotiate 'almost on a daily basis'. Stacey argues that her previous experiences of homophobia lent her a different lens with which to view cancer since both her status as lesbian and as cancer patient were subject to cultural anxieties. Consequently both she and Andrea could be described as doubly victimised by virtue of their two stigmatised identities.

The examples analysed above have highlighted some of the difficulties that participants reported in their encounters with 'normals' (Goffman, 1963). We now turn to discuss their experiences of peer support.

Other women with breast cancer

When they would not, or could not talk to family or friends, then some participants turned to other women who had been through a similar experience as Connie (7 years post-diagnosis) described:

Dorothy and I were friends before but I can never, ever pay the debt that – [pause] Dorothy had had a mastectomy and there's no history of it in our family at all. I spoke to her and she was absolutely marvellous. She took it stage by stage with me; this'll happen, that'll happen, you know. I was in bits. And one thing she did, and I can never repay her for this, she said to me 'have you ever seen anybody that's had a mastectomy'? And I said 'no', and she...stripped off and not even her daughters had seen her stripped off. That meant so much, it really did. And once I had my operation I knew what that had taken for her to do.

With apparently nobody in her family to turn to, Connie's friend seemed to have helped her to restore a sense of order after the disruption of being diagnosed with breast cancer. Not only did Dorothy share information, but she also overcame her apparent embarrassment by revealing her post-mastectomy body. This act of trust in a potentially stigmatizing situation seems to have deepened their bond of friendship.

In addition to existing friendships, several participants described how they had received support from unexpected sources. In this respect, and as

might be expected, women who worked outside the home seemed to have a larger network of people to draw upon. Sophie (6 years post-diagnosis) said:

My line manager spread the word quite quickly and I got an email within the day from someone who I'd worked with for about 18 months and I had no idea that she'd had a double mastectomy. I remember it to this day; she said 'Something you've got to know is that my experience is that after the initial diagnosis everything was astonishingly untraumatic'. And those words went vroom! on my brain. And I think well if she can do it, and this is like 13 years on so things were a lot more barbaric in her day, so can I.

Sophie was previously unaware that her colleague had had both breasts removed; therefore she seems to have successfully 'passed' as normal (Goffman, 1963). Nevertheless, Sophie's colleague had apparently revealed her 'discreditable' status and risked being stigmatised in order to offer support. Similarly, Robinson et al.'s (2015) participants reported that whilst it was difficult to tell co-workers about their breast cancer, it could also prompt supportive advice.

This support was not a one-way process however. Several participants described how their experience had given them an insight into the realities of having breast cancer and some, such as Viv (2 years post-diagnosis), reported that they were more sympathetic to others as a result:

People can't understand unless they've been through it. Cus I didn't understand. Before I had [breast cancer] I had a colleague at work who had it and you just think 'oh, it's finished, just get on with it'. She used to say, 'I'll come out with you next week, if I'm still alive!' She was always saying 'if I'm still alive'. But she obviously felt like that didn't she? Bless her. I think everyone else thinks 'oh god. Get on with your life! Worse things happen!'

Viv's comments reflect a complete change of attitude resulting from her own experience of breast cancer. She no longer saw her colleague as overdramatic but as someone expressing her vulnerability; an insight that would not have been possible if she had not been through a similar thing. Another example was provided by Wendy (2 years post-diagnosis) whose friend had died of breast cancer a few years before Wendy was diagnosed:

I'm sure I could have given my late friend more had I known a little bit more. Not beating myself up about it, I can't help that, but I definitely could and I'll certainly be around for anyone else who ever needed any emotional support. And I think that's the biggest thing. All the physical stuff's out there for you but I think it's the emotional thing and it is, it's massively emotive.

Wendy is echoing a comment that came up in several interviews for this study; that the psychological aspects of breast cancer were particularly difficult to deal with. For example, June (8 years post-diagnosis) said:

'You've got to control this [pointing to her head], not this [pointing to breast]'. This echoes Burris et al.'s (2015:72) findings that 'unmet psychological need is generally at or near the top of the list of problems' following breast cancer treatment. Wendy's comments also support Frank's (2002) argument that talking to other people who have known critical illness is particularly beneficial because they treat each other with respect and affirm their experiences in contrast to 'normals' who often seem to deny them, as previously discussed. However, there are also potential drawbacks to making assumptions about common experiences, as Martha (8 years post-diagnosis) made clear:

We've got a friend who is younger than I am and has had a mastectomy. And she's out campaigning for breast awareness and I just think 'Oh shut up! Not every cancer is like yours. And not everybody wants to talk about it all the time'.

Martha's apparent irritation with her friend's very different reaction to her breast cancer illustrates Frank's (2002) argument that other people's stories are just that- they are unique to them. People have different experiences and they do not all respond in the same way. The sentiment underlying Martha's final comment that 'not everybody wants to talk about it' may have had a bearing on some participants' reactions to breast cancer support groups, as will now be discussed.

Support groups

Recognising the potential value of peer support, medical professionals often call upon an ex-patient to talk to women after diagnosis (Wilson and Luker, 2006) but this intervention seemed to provoke mixed responses from this study's participants. Some women such as Joy reported that they welcomed the reassurance of meeting a woman who had been through treatment and survived and said she 'felt better' after their chat. Others however found the presence of a stranger, no matter how well intentioned, to be too much, too soon. Malaika (6 years post-diagnosis) said:

A really lovely lady came in and gave me a leaflet for the support group and said "you're just in time for the Christmas party!" And I remember thinking "she really didn't just say that!" And when she left I said to my mum "That is one club I don't wanna be a member of. Why would I want to be a member of that club?" She was just doing her best. I do believe it was just wrong words, wrong thing to say.

It seems that the volunteer had failed to consider the shock that Malaika must have been feeling having just received her diagnosis. Furthermore, Malaika's reference to a 'club' suggests that she was resistant to the idea of being labelled as a cancer patient. Similarly, after treatment some participants seemed keen to distance themselves from the cancer identity. Maggie (7 years post-diagnosis) said:

I never felt like joining any support groups.. I wanted to get it over with and move on with my life and because I suppose I was one of the lucky ones, it hadn't spread, I sort of thought I don't particularly want to spend my time discussing it with others.

Rather than seeing it as a group with whom she had a shared experience, Maggie seemed to be focussing on perceived differences; considering herself to be 'lucky' in comparison to women suffering from ongoing cancer. Similar feelings were expressed by two other participants who described their experiences of going to (different) support group meetings when they had first started treatment and were feeling particularly vulnerable. Sam (2 years post-diagnosis) said:

I did go to a support group but I didn't like that, it was awful. I went with a friend who's older than me so everybody thought it was her, they didn't even speak to me, and she's fine, got a great pair of knockers! And the first thing [the chairperson] said was: 'We're going to start the meeting with a two minute silence to remember ...' reeled off 5 or 6 names, these friends who are no longer with us. I thought 'I've come to get a bit of support and within half an hour of being here I feel like absolute shit and I want to go home!' So I didn't go back.

Not only was Sam apparently mistaken for her friend's carer due to her relatively young age, it seems that attending the meeting had the opposite effect to the reassurance she was seeking. Similarly, Barbara

said she had tried support groups but found the expression of condolences for deceased members, whilst understandable, too much to bear. It seems that for Sam and Barbara, support groups served to reinforce the idea that breast cancer can be a terminal illness.

The reluctance to participate in either physical or online support groups may be evidence that participants in this study regarded group users as stigmatised. Similarly, Wilson and Luker (2006) found that some patients in their study avoided encounters with people with advanced cancers which reminded them of the possibility of further illness and death. Nevertheless, one participant in this study reported that she regularly attended support group meetings after being recommended to go by a counsellor during her treatment for depression. Phoebe (6 years post-diagnosis) said:

If they weren't doing the support group you wouldn't get any emotional support. Where else would you get any emotional support? I mean you can go to your doctors and to a counsellor but when you're talking to a group of people that have all had the same thing; you can say anything can't you? And you know that people understand. That's the only real support, I feel.

Unlike some of the participants described previously, it seems that Phoebe did not draw on an informal support network for emotional support. She described how she found it particularly helpful to compare experiences and be able to help somebody else in the process:

People will come up to you and say 'oh have you had a mastectomy?' 'Which one is it?' 'What have you had?' But you wouldn't say that to people in the street would you? [laughs]

For Phoebe, the support group seemed to have provided an opportunity for social niceties to be ignored to the extent where personal information could be sought and given, in the secure environment of people who were in a similar situation. This is described by Goffman (1963:137) as an 'in-group alignment'. Interestingly, in this situation straight questions regarding treatment choices seemed to be welcomed, whereas in other circumstances such questions could be considered to be intrusive. The difference was that all the women were in a similar situation and equally vulnerable. This was also the case in Gray et al.'s (2000) study of men with prostate cancer who reported that even though they generally felt that it was nobody else's business, they were willing to discuss it with other men in a similar situation.

These examples point to the potential benefits of support groups which allow honest interactions with women in similar circumstances, as previously discussed. However they also highlight an important issue with both actual groups and on-line support forums whereby women with early-stage and secondary breast cancer share the same space. Consequently, comparison to others in an apparently similar situation can cause worry as well as comfort.

Conclusion

This study has highlighted the ways in which women's social interactions following treatment for early breast cancer are influenced by wider social discourses. The findings suggest an ongoing stigma (Balmer et al., 2014); supporting previous research where social support following diagnosis of breast cancer either failed to materialise or was experienced as inappropriate (Lally et al., 2013). However, this study extended the period under consideration to the post-treatment period where an expectation that they had fully recovered from breast cancer (Powers et al., 2014) often resulted in withdrawal of social support. In addition, participants described feeling a need to present an acceptable positive response (Radley and Billig, 1996) which reflects the message of 'pink positivity' associated with breast cancer charity campaigns. However, this mismatch between the 'public' accounts and private feelings of women post-treatment for breast cancer such as ongoing fears, could lead to 'survivor loneliness' (Rosedale, 2009). The data suggest that rather than risk alienating support by divulging the less palatable 'private' aspects of their experiences (West, 1990), the participants censored their accounts about their health, prioritising other people's comfort over their own need for support.

Perhaps because of these difficulties in communication, most participants reported that they were only able to be open and honest about their feelings when sharing them with other women who had been through

breast cancer. Sometimes these were friends or family members, but there were also examples of unsolicited support from unexpected sources such as work colleagues, as Robinson et al. (2015) also found. In return, some participants reported a desire to reach out to other women going through breast cancer, having learned from their own experiences of the benefits of providing an empathetic understanding. However, the findings also highlighted the dangers of assuming that all experiences are the same and how in some cases support groups could be perceived as inappropriate.

In common with much qualitative research, this study is limited by the small number and cultural homogeneity of the participants. A further limitation is that only the participants' own perspectives on their relationships were solicited. Studies from the perspective of carers (e.g. Ussher et al., 2011) or other family members (e.g. Davey et al., 2005), reveal a different side of the story. Unfortunately, such considerations were beyond the scope of the present study but provide a basis for future research.

Despite its limitations, the study contributes to the literature by highlighting ways that accounts of health and illness differ, depending on the context and audience (Radley and Billig, 1996). The common bond established between the interviewer and participants seemed to generate trust, enabling access to 'private' accounts, whereas the data suggest that women affected by breast cancer often present 'public' accounts which

are driven by an expectation of positivity and fear of stigmatization. This disparity between expectations of behaviour and the reality of their feelings may affect social interactions throughout breast cancer treatment and beyond.

References

Balmer, C., Griffiths, F. and Dunn, J. (2014) A qualitative systematic review exploring lay understanding of cancer by adults without a cancer diagnosis, *Journal of Advanced Nursing*, 70(8), 1688-1701

Burris, J.L., Armeson, K. and Sterba, K.R. (2015) A closer look at unmet needs at the end of primary treatment for breast cancer: a longitudinal pilot study. *Behavioural Medicine* 41(2), 69-76.

Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health & Illness*, 4(2), 167-82

Cancer Research UK (CRUK) (2016)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer#heading-Three>

accessed June 2016

Conrad, P. (1990), Qualitative research on chronic illness: A commentary on method and conceptual development, *Social Science & Medicine*, 30(11), 1257-63

Cotterill, P. (1992) Interviewing Women: Issues of Friendship, Vulnerability and Power, *Women's Studies International Forum*, 15(5-6), 593-606

Davey, M., Gulish, L., Askew, J., Godette, K. and Childs, N. (2005) Adolescents coping with mom's breast cancer: Developing family intervention programs, *Journal of Marital and Family Therapy*, 31, 247–58.

Ehrenreich, B. (2009) *Smile or Die: How Positive Thinking Fooled America & The World*, London: Granta

Frank, A.W. (2002) *At the Will of the Body: Reflections on Illness*, New York: Houghton Mifflin

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. Harmondsworth: Penguin.

Goffman, E. (1969) *The Presentation of Self in Everyday Life*. Harmondsworth: Penguin

Harcourt, D. and Frith, H. (2008) Women's Experiences of an Altered Appearance during Chemotherapy, *Journal of Health Psychology*, 13(5) 597-606

Hochschild, A.R. (2003) *The Managed Heart: Commercialization of Human Feeling. Twentieth anniversary edition*. Berkeley: University of California Press

Kaiser, K. (2008) The meaning of the survivor identity for women with breast cancer, *Social Science & Medicine*, 67, 79-87

Knapp-Oliver, S. and Mayer, A. (2004) Visibility and the Stigmatization of Cancer: Context Matters, *Journal of Applied Social Psychology*, 39(12), 2798-2808

Lally, R.M., Hydeman, J.A., Schwert, K.T., and Edge, S.B. (2013) Unsupportive Social Interactions in the Weeks Immediately Following Breast Cancer Diagnosis, *Journal of Psychosocial Oncology*, 31, 468-88

McKenzie, H. and Crouch, M. (2004) Discordant feelings in the lifeworld of cancer survivors, *Health*, 8(2), 139-57

Mays, N. and Pope, C. (1995) Qualitative Research: Rigour and qualitative research, *BMJ*,

<http://www.bmj.com/content/311/6997/109> accessed 13/9/2015

Murray, M. (2000) Levels of Narrative Analysis in Health Psychology, *Journal of Health Psychology*, 5(3), 337-47

Murray, M. (2015) Narrative Psychology. In Smith, J.A. (ed.), *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage, pp.85-107

O'Connell Davidson, J. and Layder, D. (1994) *Methods, Sex and Madness*. London: Routledge

Peters-Golden, H. (1982) Breast Cancer: Varied perceptions of social support in the illness experience, *Social Science of Medicine*, 16, 483-491

Powers, N., Gullifer, J. and Shaw, R. (2014) When the treatment stops: A qualitative study of life post breast cancer treatment, *Journal of Health Psychology*

<http://hpq.sagepub.com/content/early/2014/10/16/1359105314553963.full.pdf+html> accessed December 2015

Qadhi, S. (2008) Pink positivity and breast cancer, *The Guardian*
www.guardian.co.uk/science/2008/oct/07/cancer accessed February 2010

Radley, A. and Billig, M. (1996) Accounts of health and illness: Dilemmas and representations, *Sociology of Health & Illness*, 18(2), 220-40

Robinson, L., Kocum, L., Loughlin, C., Bryson, L. and Dimoff, J.K. (2015) I Wanted You to Know: Breast Cancer Survivors' Control of Workplace Communication About cancer. *Journal of Occupational Health Psychology*, 20(4), 446-56

Rosedale, M. (2009) Survivor Loneliness of Women Following Breast Cancer, *Oncology Nursing Forum*, 36(2), 175-82

Sacks, H. (1975) 'Everyone Has to Lie.' In Sanches, M. and Blount, B.G. (eds.), *Sociocultural Dimensions of Language Use*. New York: Academic Press pp.57-80

Sandaunet, A.G. (2008) A Space for Suffering? Communicating Breast Cancer in an Online Self-Help Context, *Qualitative Health Research*, 18(12), 1631-41

Seale, C. (2002) Cancer Heroics: A Study of News Reports with Particular reference to Gender, *Sociology*, 36(1), 107-26

Sontag, S. (1991) *Illness as metaphor and AIDS and Its metaphors*. London: Penguin

Stacey, J. (1997) *Teratologies: A cultural study of cancer*. London: Routledge

Trusson, D. (2013) *Living with a new normal: women's experiences following treatment for early-stage breast cancer or DCIS* (Doctoral dissertation, University of Nottingham).

Trusson, D., Pilnick, A. and Roy, S. (2016) A new normal? : Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer. *Social Science & Medicine*, 151, pp.121-9

Ussher, J.M., Wong, W.K.T and Perz, J. (2011) A qualitative analysis of changes in relationship dynamics and roles between people with cancer and their primary informal carer, *Health*, 15(6), 650-67

Vickberg, S.M.J. (2001) Fears about Breast Cancer Recurrence: Interviews with a Diverse Sample, *Cancer Practice*, 9(5), 237-43

West, P. (1990). The status and validity of accounts obtained at interview: A contrast between two studies of families with a disabled child, *Social Science & Medicine* 30(11), 1229-39

Wilkinson, S. and Kitzinger, C. (2000) Thinking differently about thinking positive: a discursive approach to cancer patients' talk, *Social Science & Medicine* 50, 797-811

Wilson, K. and Luker, K.A. (2006) At home in hospital? Interaction and stigma in people affected by cancer, *Social Science & Medicine*, 62, 1616-27