

## The Role of Hair Loss in Cancer Identity: Perceptions of Chemotherapy-Induced Alopecia Among Women Treated for Early-Stage Breast Cancer or Ductal Carcinoma in Situ

**Background:** The trauma of chemotherapy-induced alopecia is well documented.

However, less is known about how the stereotypical cancer identity affects social interactions.

**Objective:** The aim of this study is to explore women's experiences of hair loss resulting from breast cancer treatment, from a sociological perspective.

**Methods:** Twenty-four women who had been treated for early-stage breast cancer or ductal carcinoma in situ were interviewed. References to hair (loss) were isolated from their narratives.

**Results:** Findings confirm previous research that hair loss can be traumatic. The stigma attached to both having a cancer patient identity and nonconformity with norms of appearance means that women must decide how much to reveal and to whom. An unexpected finding was that distressing experiences were reported by some women who had not lost their hair.

**Conclusions:** Hair is important to identity; therefore, there are implications for social interactions whether women decide to disguise their hair loss or not. There may also be implications for women who do not lose their hair because they fail to conform to the stereotypical appearance of the bald cancer patient. Future research should consider the role of stereotypes in patient experiences.

**Implications for Practice:** Nurses should provide sufficient information and support to prepare patients for the impact on self-perception and social interactions when facing hair loss. Also, patients should be forewarned about the possible implications of not conforming to the cancer stereotype. In addition, greater education among the wider population about the possible side

effects of cancer treatments may prevent women feeling stigmatized while already undergoing a stressful experience.

**KEYWORDS:** Alopecia; Breast cancer; DCIS; Hair loss; Identity; Stigma; Stereotypes

### **Introduction**

Hair is an important indicator of identity. Hair forms our impression of a person, and can be fashioned to demonstrate religious beliefs or music preferences<sup>1</sup>. Hair is an important part of physical appearance, particularly for women, as it symbolizes health, femininity and attractiveness and influences body image and identity<sup>2</sup>. Consequently, hair loss as a result of chemotherapy treatment for breast cancer can have profound implications for women's mental health and social interactions<sup>3</sup>.

Illness-related appearance changes can also change the way that the ill are perceived by other people<sup>4</sup>. In the case of cancer, this is perhaps most obvious when people suffer chemotherapy-induced alopecia. Not all chemotherapy drugs have the same side-effects but those used to treat breast cancer tend to result in total alopecia<sup>5</sup>. Despite the numerous unpleasant side-effects of chemotherapy including vomiting, nausea and tiredness, a previous study found that hair loss was reported to be the most traumatic aspect of the treatment by 46% of respondents<sup>6</sup>. The trauma of chemotherapy-induced alopecia has been well-documented in the psychological literature<sup>7</sup>. It is also a common topic in the medical literature as solutions are sought to alleviate the distress caused by this common side-effect of cancer treatment<sup>5</sup>. However the experience has not been widely considered from a sociological perspective despite the 'importance of the body to social interaction' because 'other people respond to the [ill] person in terms of their

physicality<sup>4(p.252)</sup>. This study explored the impact of hair loss sociologically to add to the minimal literature that exists from this perspective.

The findings are taken from a larger qualitative research project conducted in the UK which explored women's experiences of diagnosis and treatment for either early stage breast cancer (ESBC) or ductal carcinoma in situ (DCIS)<sup>8</sup>. DCIS (sometimes referred to as 'pre cancer') is a condition where some of the ducts of the breast have begun to turn into cancer cells. As these cells are contained within the ducts it is unlikely that they will have spread to the lymph nodes or anywhere else in the body<sup>9</sup>. Therefore, although women who are diagnosed with DCIS generally have surgery to remove either the affected part of the breast (lumpectomy) or the whole breast (mastectomy), they rarely require chemotherapy. Similarly, women with ESBC which has not spread beyond the breast would not typically require chemotherapy, unlike those who are diagnosed with invasive cancer<sup>10</sup>.

Two sociological theories guided this study. Firstly, Parsons' theory of illness as a social role, the 'sick role' which comes with certain expectations (for instance looking ill, being confined to bed or otherwise restricted in daily activities) and certain benefits (such as absolution from certain responsibilities)<sup>11</sup>. Secondly, Goffman's theory of stigma which he defined as 'the situation of the individual who is disqualified from full social acceptance'<sup>12(p.9)</sup> because of not conforming to the relevant stereotype.

Goffman's theory was used in a previous sociological study of hair loss in cancer patients which was exploring fatigue in 35 people (26 women and 9 men) undergoing chemotherapy for either lung (16) or breast (19) cancer<sup>13</sup>. The topic of hair loss arose spontaneously and as a matter of uppermost concern which stimulated further investigation of the issue. Rosman argues that the

implications of visible hair loss for people's social relationships are often underestimated by medical professionals<sup>13</sup>. She found that chemotherapy-induced alopecia was more distressing for women than for men<sup>13</sup>; however, this is contested by other research involving 11 men and 8 women who had experienced chemotherapy-induced alopecia<sup>14</sup>. Hilton et al. argue that men and women are equally negatively affected by hair loss but highlight other differences between the sexes such as how the impact of losing body hair (other than the visible hair on their head or face) was only discussed by men, and only women discussed being encouraged to disguise their baldness.

Batchelor argues that 'present-day views of the body in western society seem to reflect a growing relaxation with the symbolism of hair'<sup>5(p.150)</sup>. This is reflected in the willingness of some well-known women to be seen without hair (such as TV presenter and former model Gail Porter) which may have made baldness slightly more acceptable<sup>15</sup>. Nevertheless, exposing baldness can also mean revealing a key indicator of cancer<sup>13</sup> which, despite increasing numbers of cancer survivors, is still associated with death<sup>16</sup>. Harcourt and Frith found that women undergoing chemotherapy as part of their breast cancer treatment felt 'stigmatized on two accounts – first, that they had cancer and, second, that they were visibly different'<sup>17(p.604)</sup>.

Health professionals are aware of the importance of hair to public presentation and social interactions, therefore nurses are trained to minimize distress by offering advice and practical help for anyone who wants to disguise their hair loss<sup>18</sup>. The current practice in the UK is that women who are scheduled to have chemotherapy that is likely to induce alopecia are given a voucher from the National Health Service to redeem at a wig supplier so that they can choose their own wig. Most women tend to opt for a wig that looks like their existing hair, in order to

‘pass’ as normal and lessen the shock for other people<sup>12</sup>, consequently wigs are perceived to be a form of camouflage<sup>19</sup>.

Hair loss can be traumatic because of the importance of hair to women’s body image and femininity<sup>2</sup>. However, Freedman argues that instead of treating this as a psychiatric illness, it should be seen as society’s intolerance of people who look different<sup>2</sup>. This intolerance can extend to women who have not lost their hair during their treatment for breast cancer and consequently fail to comply with the stereotypical view of a cancer patient. As such there can be a double bind for women who may be stigmatized when they lose their hair but equally if they do not. We will draw on extracts from the participants’ accounts in order to demonstrate how this occurs.

## **Methods**

Women who had been treated for early breast cancer (including DCIS) were invited to participate in the study via an item on a university website, an article in a local newspaper and a local radio interview with the lead author. Women with secondary breast cancer were excluded as their experiences were beyond the scope of the study. In the sample of 24 women, 18 had been treated for early stage breast cancer (ESBC) and 6 for DCIS and most were between 2 and 9 years post-treatment. All participants had undergone surgery (6 had lumpectomy and 18 had mastectomy); 9 women had chemotherapy and one participant was still undergoing treatment at the time of interview. The participants were all White, native English speakers aged between 42 and 80 (average 54), and all except 4 of them were married or in a long-term relationship. Fourteen of the participants were educated to the University level, and 13 of these were employed in professional occupations. The remaining woman was a retired teacher and engaged

in voluntary work. Of the 10 women who had not been educated at the University level, 7 were retired, one worked part-time in retail, and 2 were involved in voluntary work.

After gaining University ethical clearance, semi-structured interviews were conducted at a place of the participant's choice. Over half (14) of the participants opted to be interviewed in their own home, therefore steps were taken to ensure the interviewer's safety in line with British Sociological Association guidelines<sup>20</sup>. After giving signed consent, interviewees were encouraged to describe in their own words their experiences since they first discovered they had ESBC/DCIS<sup>21</sup>. Follow-up questions were then used in order to maintain some similarities between the themes covered in the accounts of the participants which would allow for comparison of their experiences.

In the wider study<sup>8</sup>, narrative analysis was used which entailed reading the transcripts numerous times to make connections between the emerging data and the existing literature.<sup>22</sup> Following discussion and agreement with the co-author to ensure reliability, themes were developed based on commonly reported experiences. These included experiences of diagnosis and treatment and the implications of breast cancer treatments for bodies and relationships. One of the major themes that emerged was labelled 'bodily changes' and encompassed not only permanent changes resulting from breast surgery, but also hair loss which, although temporary, has important implications for identity<sup>1</sup>. For the purposes of this article, the interview transcripts were searched for references to hair, wigs and baldness. This revealed that 13 participants discussed this issue even though only 9 had actually lost their hair, which indicated the centrality of hair (loss) to the breast cancer experience.

## Results

When describing their experiences of breast cancer treatment, the majority of the women who lost their hair reported that they found it distressing. This was in line with previous research where women discussed hair loss ‘as an event more traumatic than the actual loss of a breast’<sup>2(p.336)</sup> This was illustrated in this study by Karen (43) who, following diagnosis of ESBC, had undergone a mastectomy 6 months previously. At the time of interview, Karen was about to have the 5<sup>th</sup> of 6 rounds of chemotherapy and was completely bald. She described how she felt about losing her hair in comparison to the loss of her breast:

I was more affected by that to tell you the truth, I thought I would be fine about it but when it came to the actual, my friend came to shave it off before there was big clumps, I got really, really upset.

As a former nurse, Karen was aware that she would lose her hair, but was seemingly unprepared for the emotional impact it would have. She had chosen to shave her hair rather than wait for it to fall out completely, which may have been a way of taking control over the timing of the hair loss<sup>19</sup>.

Hair loss was the most visible sign of illness and what seems to have been particularly upsetting was the speed at which this happened, as Sam (42) recalled:

We sat in a beer garden, it was the summer and honest to god it was quite, it was a bit windy and my hair was coming out in clumps like tumbleweed.

Sam’s experience shows that participants had to come to terms with their hair loss quite quickly, adding an additional layer to the distress felt as a result of their recent cancer diagnosis.

Although the majority of participants reported that hair loss was distressing, an exception was Kate (47) who said:

My hair started to drop out. And it was fantastic; because I was convinced it [the chemotherapy] hadn't worked. Because I didn't feel ill, it hadn't worked. ..then suddenly it just came out one day. And [laughs] and..I was delighted cus that was the only way I knew it was working.

Although hair loss 'as part of a life-giving process is rarely acknowledged by women' <sup>2(p.339)</sup>, Kate may have been attempting to give a potentially horrific moment a positive twist, by seeing her hair loss as a sign of cure rather than a profound disruption . It is also possible that hair loss assuaged feelings of guilt Kate may have felt about not suffering side-effects as a result of chemotherapy, as most people do.

### **Identity**

Women reported that when they were seen without hair, it affected the way that they were perceived by other people. Some participants discussed how they struggled to maintain a feminine appearance after losing their hair as well as their breast(s), as Catherine (47) described:

I remember going out running once, um because I just didn't bother wearing my wig half the time and this little child just couldn't keep their eyes off me you know. It was like my bald head..and this child said "Mummy, is that a man or a woman?"

Outward appearances that are changed through illness can alter the way that other people construct the identity of the sufferer<sup>4</sup>, and Catherine's reported experience underlines the importance of hair in terms of femininity. Hair (or lack of it) provides clues to a gendered



identity, and it is unusual for a woman to be seen with a bald head, hence the child's apparent confusion.

The impact of hair loss on identity extends to self-perception. Participants described how 'their old identity and sense of self had already been challenged...with diagnosis and surgery. By the time they lost their hair, they were struggling to keep a sense of themselves'<sup>23(p.505)</sup>. This idea was demonstrated by Andrea (64) who said:

I lost all my hair on my body; I mean they don't tell you that. But being dark, to lose your body hair, you know eyebrows and things like that. I've got some photos, not many, but I don't look like me, they look like another person.

The way Andrea expresses this loss resonates with a woman in a previous study<sup>24</sup> who described hair loss as her former self being erased. As such, Freedman suggests that hair loss is not just a biological event, but can be experienced as a 'symbolic precursor to the loss of the self'<sup>2(p.336)</sup>, thus underlining the centrality of hair to many women's sense of identity<sup>3</sup>. What is also noteworthy about Andrea's account is that she was the only participant to mention losing her body hair. Andrea was also the only self-identified lesbian in the study and elsewhere in her narrative had discussed how she was not particularly distressed by her double mastectomy as she dressed in male attire and her breasts were not an essential part of her gendered identity.

Although it is difficult to make assumptions based on the experiences of the one participant who identified herself as gay, it may be that Andrea placed more importance on body hair than the women who were concerned with managing a feminine appearance. This fits with Hilton et al.'s findings where none of their female participants mentioned loss of body hair. They argue that 'this would disclose that their usual body state was not 'naturally' hairless'<sup>14(p.582)</sup>. Further

research would be useful in order to explore this interesting finding and how it may be related to sexuality as well as gender.

### **Cancer identity and stigma**

Not only is baldness strongly associated with the cancer identity but women who are seen without hair can be construed as not conforming to social norms<sup>3</sup>. Consequently women who chose not to cover their heads found that they were subjected to attention which sometimes made them feel uncomfortable. For example Karen, who as mentioned previously was bald at the time of the interview, described the reactions she got when she went out with her head uncovered:

People look, but then that's human nature isn't it really? And..I stare back at them and they look away quite quickly so it's just the odd glance you know. But last week it suddenly occurred to me, I don't think about what other people think.

Even though she claimed not to place too much importance on other people's reactions, Karen recognised that her decision to not disguise her baldness meant she had relinquished control over who knew about her illness. While she reported that in most cases she was happy to be bald in public, even posting photographs of herself with and without a wig on Facebook, she also reported not being comfortable to be seen by her neighbours who she did not really know:

It was more difficult for me going out in the cul-de-sac without anything on [my head] because these are people I've lived with for quite a while. Although I say I'm not bothered by it, I don't want local people who have seen me before and will see me after who I don't talk to, don't know, so um I dunno really it's a funny old thing. And yet I can quite happily go anywhere else, into town, and it wouldn't bother me.

This is consistent with Goffman's argument that stigma is dependent on previous knowledge about a person<sup>12</sup>. Karen perceived that her baldness was a clear statement to her neighbors that she had cancer because they had this prior knowledge of her. She was therefore more comfortable with strangers for whom her appearance would be more acceptable, whereas she may have been concerned that her neighbors would gossip about her.

Even when hair began to grow back, women reported that they still felt under scrutiny. For example, Ruth described what happened when she did not wear a wig on holiday:

It was beginning to grow by that time, probably had about a quarter of an inch, I did look peculiar. I looked like a mad woman I decided; like they used to shave people in asylums, I'm sure people thought I was a mad woman.

Ruth's comments reveal the association between shaved heads and madness because shaved heads were in the past associated with incarceration in institutions such as prisons and asylums<sup>25</sup>.

Another participant, Barbara (61), reported that although she had originally opted not to wear a wig, eventually she came to resent the sympathetic looks that her cancer identity engendered:

I think the worst thing that bothered me was people used to look at me and be sort of 'aah'. And then they sort of say 'for the grace of God it's not me'.. I got to the stage with my hair; I'd had enough sort of that I did get a wig which was great. .I wanted to move on from people knowing that I was ill to looking different, looking okay again.

Barbara's decision to wear a wig was associated with a feeling of leaving the sick role behind, along with the public scrutiny and sympathy that she sensed was provoked by her bald head.

## Wigs

Women undergoing treatment for breast cancer are encouraged to disguise their baldness which protects the women from public scrutiny by ‘maintaining the illusion of health’ and serves to protect others ‘to shield them from their own vulnerabilities’<sup>2(p.338)</sup>. In the current study, participants described concealing their cancer identity out of consideration for other people’s feelings, mirroring previous research where the decision to cover baldness was ‘primarily aimed at reassuring others, rather than their own benefit’<sup>17(p.602)</sup>. For example, Ruth (59) who is a teacher said:

I see a lot of my pupils up in town so I thought I don’t want them seeing me in a scarf. I used to have a little hat I would wear which was quite sweet and that was warm. Cus it was cold actually. But I did wear a wig up into town because it does say, doesn’t it instantly when you haven’t got hair? So I had this dreadful wig, I used to love taking it off you know, get home, peel it off.

Ruth was aware that her lack of hair, even if covered with a scarf, would immediately reveal that she had cancer and apparently felt a need to withhold this information from her pupils. Although Ruth disliked the wig, she wore it when out in public to disguise her baldness.

Another participant, Gabrielle who was 42 when she underwent chemotherapy, reported that she was not adversely affected by the loss of her hair because she had always had thin hair anyway.

However, she described the effect of her hair loss on her young daughters:

I’m not sure but the impact on my children was pretty devastating. I think there was a major -I think, you know, watching someone that you love lose their hair.

This finding is echoed in other research which reveals that children can become distressed and/or embarrassed by seeing their mother lose their hair; therefore women cover their baldness to protect their children from the trauma associated with hair loss<sup>17;23</sup>. Gabrielle used her wig as a way of minimizing her daughters' distress, opting for a wig that looked like her existing hair in order to maintain her pre-illness appearance. This was the case with most of the other women in the study who wore a wig as camouflage<sup>19</sup> but again, Kate who was 41 when she underwent chemotherapy for early stage breast cancer was an exception. Kate described what happened when she learned that she would lose her hair:

Before it all happened I went out, I bought my wig, the sexiest wig I could possibly find. I wasn't going to look like me; I was going to look like somebody else. I'd got this rock chick hair and everything...brown, dark brown.

It appears that Kate's reaction to illness was to try to create a new persona. Frith et al. reported similar findings amongst some of their participants who were anticipating chemotherapy-induced alopecia. Not only did they accept hair loss as 'an inevitable consequence of treatment' but they saw it as an 'opportunity to re-invent their image through wigs'<sup>19(p.388)</sup>. When asked to elaborate on why she had decided on that strategy Kate said:

Oh I decided I was going to have about seven! I was going to have red ones and green ones! I don't know; just do the things that you'd never normally do! It's not forever, it doesn't matter.

Kate seemed to perceive the experience to be a temporary jolt in her life trajectory. She reacted to the loss of her hair by embracing the opportunity to alter her appearance in ways that she felt unable to do in ordinary life. Interestingly, Kate reported that she chose to look like a 'rock

chick' – a stereotypically strong female identity and therefore presumably somebody she felt was stronger than she was and perhaps better able to deal with the trauma of breast cancer treatment.

Some women discussed the problems they had when attempting to cover baldness. Karen said:

I find the wig very uncomfortable and hot. I've worn it once for a girly night out just after my hair went. And then all the thing about the scarves, I've got loads of hats and scarves and all sorts but it's just the hassle of it, it gets loose, you have to keep redoing it and to me that's- So on the odd occasion I wear a bit of make up just so I don't have that pallor as such but even then I don't do that all the time really I'm too lazy.

It seems that trying to maintain 'normality' constitutes a considerable amount of effort that falls to the person with stigma rather than other people to accommodate it<sup>17</sup>.

Although wigs may enable people to control information about their illness, there are consequences to concealing baldness<sup>2</sup>. For instance, Catherine (47) described how she liked to connect with other women who had experienced breast cancer:

If I see somebody with extraordinarily short hair...I say, 'ooh your hair's interesting, is it out of choice or not'? And if it is out of choice I say 'it looks really good'! And if they say it's not I say 'do you mind me asking why'? I don't presume its breast cancer, but it usually is.

This illustrates how the inability to identify others may hamper efforts to provide support or share experiences.

### **Benefits of cancer identity**

In some cases, being identified as a cancer patient was reported to have had some benefits. For example most of the participants reported receiving a good deal of social support and Karen, who was working during the time she was having her chemotherapy, said:

I can get away with murder at work at the moment! You know, 'Karen can do no wrong'. And I'm milking that I must admit... but it's, people say to me 'oh this kindness is only time-limited to when you finish chemo!'

It seems that Karen's visible cancer identity had enabled her to enjoy the benefits of the sick role<sup>11</sup> such as sympathy and exemption from some duties. Consequently, her experience was made easier because it was clear that she had cancer<sup>17</sup>. However she was aware that this was a time-limited concession and that she would be expected to resume her pre-illness workload once she began to look 'normal' again:

I suppose it is a concern because as soon as your hair grows back that's it...you're all done and dusted, you've had your treatment 6 months ago and... I just know that isn't it.

Karen is describing the strong association between hair loss and cancer treatment. It seems that there is an assumption that once hair returns, then people are 'cured' and they are able to resume their pre-cancer roles and responsibilities and are no longer entitled to the benefits afforded by the sick role. This is to underestimate the traumatic nature of having breast cancer. Women reported that the immediacy of being thrust into a harrowing course of treatment meant that they tended to prioritise the physical aspects of the experience and side-line the emotional elements<sup>26</sup>. Although it had not happened to Karen at the time she was interviewed, she seemed to be aware of the expectations that would arise once she began to 'look normal'.

## No hair loss

Karen's suspicions seem to have been confirmed by the experiences of another participant for whom 'looking normal' turned out to be a disadvantage. Phoebe, who was diagnosed with ESBC at the age of 40, had a mastectomy but did not need to have chemotherapy. Phoebe reported that when she returned to her work as a librarian she had an unexpected response:

P. They sent an e-mail out, with my consent, to say 'Phoebe won't be shelving, she's waiting for an appointment' you know vague sort of thing, 'won't be doing any shelving, hope you'll all support her in this.' And then I started getting bullied about it.

I. Who was bullying you?

P. A couple of colleagues. They would send me nasty texts and then things on Facebook ... Cus I wasn't shelving. The fact that I would be doing everything else and covering for other people when they were shelving, and they knew everything that I'd had done. I went off for a couple of weeks cus I was finding it quite difficult. It was 'oh get back to work there's nothing wrong with you'. And then someone else said 'it's all over, what's she-?' You know. And more or less saying I wasn't working, that they were doing all the work. And these were supposed to be sort of friends. They'd known everything I'd had done.

Not only did Phoebe report being unsupported by her colleagues but said that they accused her of malingering. Phoebe seemed incredulous at their lack of sympathy despite the fact that she had been very open about her treatment, repeating the phrase 'they knew everything that I'd had done'. Phoebe attributed it to having had no visible signs of illness:



I think they thought cus I looked well and I never had chemo. You know if you lost your hair and you look completely different, I think they might have more sympathy. But because I looked well. In the end I said ... ‘what I’m going to do, I’m going to rip my top off and say... that’s why I’m not doing shelving!’ ... It got to the point where I thought ‘right I’m just going to have to show them! If they don’t believe me, you know, what I’ve had’. If... you lose your hair they seem like sympathetic but because it’s something they can’t see, they think it’s nothing.

Because it is normal for breasts to be hidden, Freedman argues that breast cancer is an ‘invisible, silent disease’ which only becomes visible when people lose their hair <sup>2(p.338)</sup>. It seems that Phoebe’s colleagues were intolerant because she was not fulfilling her part of the sick role by looking ill and Phoebe was unable to prove her incapacity without actually stripping off and revealing her missing breast. Consequently, Phoebe reported that her return to work was the most upsetting aspect of her experience:

In some ways that was worse than all the treatment I’ve had because you feel like you’re going absolutely crazy. The treatment it’s sort of practical isn’t it? But someone sending you messages and badgering you and...gossiping about you and you can see them doing it in little corners and you feel like [sighs] and then you daren’t tell anybody...It was awful.

This suggests that having a ‘normal’ appearance due to the lack of visible evidence of breast cancer treatment can also have negative implications.

Phoebe was one of several participants who cited hair loss as a major issue even when they had not gone through it themselves. For example, Malaika, who at 39 was diagnosed with DCIS and

underwent a mastectomy, reported feeling that she was perceived as inauthentic because she did not lose her hair:

I remember a few people said to me when I spoke to them on the phone ‘have you still got all your hair?’ I was like yes, what a bizarre question! But that’s what they associate with it. And actually, seeing some people give you that, and I became possibly paranoid I don’t know but, that thing behind people’s eyes where you know ‘I had a mastectomy due to breast cancer’ and the first thing ‘she’s got a big head of hair’. You can almost hear the cogs turning with that ‘mm? Bit strange!’ and that’s not necessarily what they were thinking but it’s just that flicker.

Malaika seemed to believe that people viewed her as somehow fraudulent because she failed to conform to the stereotypical cancer patient. However Malaika acknowledged that she was ‘possibly paranoid’, a finding which is echoed in other research which suggests that sometimes breast cancer patients make incorrect assumptions about other people’s opinions<sup>2</sup>. Malaika reported that she took solace in the fact that although she had lost a breast, she had kept her hair:

I berated myself, I thought ‘you’re being ungrateful...there are women out there that aren’t surviving this, there are women out there that are losing their **hair** and you’re sitting here feeling sorry for yourself.’ And so I went through all this mixed emotion, like ‘how dare you feel sorry for yourself when you’ve got off lightly’ [participant’s emphasis]

Interestingly, Malaika reported that she considered that she had ‘got off lightly’ perhaps because the breast is hidden whereas the hair is so visible. Malaika’s mass of long, dark hair was very

much a part of her personal identity<sup>27</sup> and this is perhaps reflected in the importance she placed on retaining it. It could also be that Malaika felt guilty which she alluded to in this reported conversation with a woman who had chemotherapy but had not lost her whole breast:

[I said] ‘you’ve had aggressive cancer and you’ve had chemotherapy and you lost your **hair**’ and.. she said ‘yeah I know but at least I’ve got my breast’ [participant’s emphasis]

This extract is interesting in terms of how body parts are weighed against one another in terms of value and significance, in this case hair versus breast. However, it resonates with the responses of participants who actually had lost their hair (discussed earlier), for whom losing their hair was more distressing than the loss of their breast(s).

Another reason for being grateful that treatment did not entail hair loss was expressed by Connie (51) who had a mastectomy but did not have chemotherapy because of other health problems:

There was only a very small group of people that knew. But...had I had to have chemo then obviously it would have been a different ball game...If I’d had to have chemotherapy that would have been as difficult for me as the surgery. You know the hair loss and everything else.

Keeping her hair meant that Connie could hide her illness. However, this seemed to be more to do with her husband than Connie who explained:

C Jim wouldn’t tell a single person. He didn’t tell a single person that he worked with, he didn’t tell anyone at all, no no.

I Why do you think that was?

C He's just like that with everything. Personal things are, you know I think women tend to chat to each other a lot to do with breast cancer and whatever, and men don't. He doesn't at all.

Hair loss would have immediately marked Connie out as having cancer<sup>17</sup> but as she had no obvious signs of the disease; her husband's secrecy could be maintained. Connie seemed to accept this reluctance to share private information with other people as being a male attribute rather than a personal slight.

### **Limitations**

The findings of the study are limited by the relatively small number of participants and also the reliance on unsolicited references to hair loss in some of the women's narratives. It is therefore suggested that these findings do not offer a high degree of generalizability but are useful in identifying areas for further investigation. There are currently very few studies looking specifically at breast cancer patients' experiences<sup>7</sup>, therefore it would be useful to interview women of various ages, ethnicities and sexualities specifically about their attitudes to hair loss and the impact on social relationships before, during and after breast cancer treatment.

Furthermore, there appear to be no studies of women's views where they have not lost their hair when undergoing treatment for breast cancer. Therefore this is an area which merits further research, particularly from a sociological perspective.

### **Implications for Practice**

The practical recommendation from this research is for nurses to provide sufficient information about chemotherapy-induced alopecia to enable women to cope with the impact on their self-

perception and social interactions. It is important that nurses support women in their decisions about whether or not to disguise their hair loss, and offer advice on the possible implications of these decisions<sup>17</sup>. In addition, this research has revealed a need for greater education amongst the wider population about hair loss as a possible, but not inevitable, side effect of cancer treatment. This may help people to treat current and future patients more sensitively and thereby offset any additional trauma associated with the experience of having cancer.

## **Conclusion**

The findings confirm previous research that chemotherapy-induced alopecia can be traumatic for many women<sup>2,7</sup>. Ways and means of disguising hair loss were discussed in terms of protecting loved ones from seeing hair loss<sup>17,23</sup> as well as protecting themselves from unwanted attention, whether this was actual or merely perceived. In line with previous studies, it highlights the importance of (loss of) hair to social interactions within families and friendship groups as well as in wider society<sup>2,17,23</sup>.

However, an unexpected finding was that women who had not lost their hair reported traumatic experiences because they failed to conform to the stereotypical bald cancer patient and therefore were ‘incongruous with our stereotype of what a given type of individual should be’<sup>12(p.13)</sup>.

Where the only evidence of treatment is a missing breast, which is concealed<sup>2</sup>, there may be a risk of being accused of malingering<sup>11</sup> as there is no visible proof of illness or treatment.

Consequently they were not afforded the levels of support and sympathy which were reported by women who had revealed their baldness<sup>17</sup>. Therefore it seems that visibility of the stigmatizing illness is key to the way that people relate to others, whether this is in a positive or negative way.

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