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Women's Experiences of an Altered Appearance during Chemotherapy

An Indication of Cancer Status

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Abstract

This study explores breast cancer patients' experiences of chemotherapy treatment, with a focus on the impact of an altered appearance during this time. We present two key themes from the thematic analysis of interviews with 19 women: anxiety that chemotherapy will render them identifiable as a 'person-with-cancer'; and problematic interactions with others. We discuss how changes in appearance can reveal disease status to others, demonstrate the personal impact of temporary changes to appearance, relate these findings to literature on psychosocial aspects of disfigurement and consider the provision of psychosocial care for women experiencing an altered appearance during chemotherapy.

Keywords

- *appearance*
- *cancer*
- *chemotherapy*

Introduction

AMONG the many challenges faced by people with cancer is the impact of changes to their body and appearance that can act as vivid, constant reminders of the disease and its treatment. These can be especially difficult to manage if the individual has invested much of their self-worth in the affected part of the body (White, 2000) and where the prevailing western body ideal is being youthful, fit, slim and attractive with healthy hair, no scarring and being able to function without the need for aids or support.

Yet surprisingly, the personal impact of changes to appearance due to cancer is often underestimated. Most research in this area has focused on the impact of differing types of surgery upon self-reported body image that has been assessed using quantitative measures (see, for example, Moyer, 1997 for a review of the impact of surgical procedures among breast cancer patients). In contrast to this focus on surgery, relatively little attention has been given to the personal experience of changes to appearance resulting from chemotherapy. These changes can be widespread and include hair loss, changes in weight, mouth ulcers, dark circles around the eyes, ridges in finger and toe nails and hardening and increased visibility of veins where chemotherapy drugs are administered. These visible changes typically occur alongside bodily sensations including feelings of sickness and nausea and an altered sense of taste. Furthermore, for women, chemotherapy is associated with premature menopause and its resultant impact upon appearance and body image.

To date, the limited literature into individuals' experiences of chemotherapy has focused primarily on hair loss (alopecia). The available research suggests this is often very traumatic and, for some patients, can be the most feared side-effect of treatment (Batchelor, 2001; Münstedt, Manthey, Sachsse, & Vahrson, 1997). Patients have ranked hair loss as a particularly severe and worrying side-effect of chemotherapy, second only to the effect of treatment upon their family or partner (Carelle et al., 2002). When compared with earlier research (Griffin et al., 1996), Carelle et al.'s study suggests that patients increasingly rate psychosocial side-effects and hair loss as more severe than physical side-effects of the treatment. With specific reference to patients undergoing treatment for breast cancer, Freedman (1994) found that alopecia can be

harder to handle than the loss of a breast and that patients are often unprepared and embarrassed by hair loss. Women with breast cancer who lost their hair have reported poorer body image than those who did not (Baxley, Erdman, Henry, & Roof, 1984).

Rosman (2004) described female breast and lung cancer patients' experiences of chemotherapy-induced alopecia in terms of the use of camouflage and hiding and its impact on identity, in particular feelings of being stigmatized. Rosman also found that the process of losing hair enhanced women's awareness that they had a life-threatening disease.

Chemotherapy-induced hair loss is usually temporary and it has been suggested that its negative impact may be softened as hair starts to re-grow (Pendley, Dahlquist, & Dreyer, 1997). However, this often entails patients having to make further adjustment to an altered appearance as their hair may grow back with a texture and colour that is different to how it was before (for example, hair that was previously straight will often grow back curly after chemotherapy).

Health care professionals clearly have a sense that appearance changes can be very difficult for their patients to handle, but they are often unsure of how best to support patients or how to meet their psychosocial needs in relation to an altered appearance (Clarke & Cooper, 2001). Randall and Ream (2005) found that nurses considered themselves to be key in the management of alopecia but were typically unclear as to whether their efforts to help patients manage it were effective. Our own discussions with oncology staff caring for people undergoing chemotherapy have revealed similar uncertainties.

To date, most existing research has not focused specifically on participants' experiences of appearance changes, but rather on experiences of chemotherapy more generally. The current study therefore set out to explore experiences of an altered appearance during chemotherapy treatment following diagnosis of breast cancer, with the aim of providing feedback and guidance to health care professionals responsible for the provision of care.

Method

The current article is part of a larger qualitative study using both semi-structured interviews and visual methods (photography) to gain an insight into women's experiences of chemotherapy (see

Frith & Harcourt, 2005). A qualitative approach was deemed appropriate in order to gain a more in-depth understanding of women's experiences than would be obtained from a quantitative study. The design of the study also reflected the relative dearth of existing research in this specific area, the desire not to be driven by any pre-conceptions held by the researchers as to what the key aspects of participants' experiences would be and the growing acceptance of the important role that qualitative research has to play in shaping provision of care. Participants in this study were 19 women who had been diagnosed with breast cancer and were due to undergo chemotherapy as part of their treatment. For all but one of the women, this was their first experience of chemotherapy. Ages ranged from 35 to 68, with a mean of 44 years. All of the participants were in a long-term relationship, and 14 had had children. One woman described herself as a lesbian. One participant was Black and the rest were White. Thirteen were employed, two retired, two were full-time parents and two were unemployed. Twelve participants had undergone a mastectomy and the remaining seven had had a wide local excision prior to the chemotherapy treatment.

An initial interview in which women were asked about their expectations and concerns about chemotherapy, with a particular focus on appearance, was conducted close to the start of their treatment. Women were then given a single-use, disposable camera and asked to take photographs that depicted their experiences during their treatment, particularly those relating to their appearance and body. These photographs were used as the basis for a second interview that was conducted after they had completed their chemotherapy, and which focused on their experiences of the treatment including any changes to their body and appearance. Reflections on the use of photography in this way are available elsewhere (see Frith & Harcourt, 2007). The interviews were conducted by the authors and took place in participants' own homes, except in two instances where the participants chose to be interviewed in a hospital setting. The interview data were subjected to an inductive thematic analysis (see Braun & Clarke, 2006) which involved reading and familiarizing ourselves with the transcripts, identifying potential themes by coding the interview transcripts, drawing comparisons across the interviews and identifying and developing the main themes that emerged from the data, rather than trying to fit the codes into a

pre-existing framework. We adopted thematic analysis as an essentialist or realist method, which reports experiences, meanings and the reality of participants, rather than as a constructionist method which examines the ways in which events, realities, meanings and experiences are the effects of a range of discourses operating within society (Braun & Clarke, 2006). Themes were then discussed, named and defined by the authors. Themes and conclusions have been presented to groups of health care professionals working in this area and who verified that the analysis resonated with their encounters with this patient group. We chose not to take the analysis back to participants for verification because this would have placed an additional burden on those who were still undergoing additional cancer treatment and would put participants' views, rather than our interpretation, at the heart of the research (Meyrick, 2006). A summary of the research was sent to each participant after the analysis had been completed. They were encouraged to contact us with any feedback, but the only responses we received were acknowledgements and thanks. Extracts from the data are provided below in order to illustrate this analysis. Pseudonyms are used throughout this article.

Findings

The analysis found that women were dealing with a range of complex issues as a result of their diagnosis and chemotherapy treatment. This article focuses on their accounts of how an altered appearance identifies them as being a person with cancer and the impact this has upon themselves and others. Participants' specific experiences of anticipating and coping with hair loss (another major theme in these interviews) are reported elsewhere (see Frith, Harcourt, & Fussell, 2007).

Being visible as a person with cancer

This theme relates to women's expectations and actual experiences of how their appearance would alter during chemotherapy. Changes such as hair loss, looking tired and pale, feeling sick and losing weight were anticipated and, in due course, were experienced and reported by the participants. These changes are characteristic of the stereotypical view of people with cancer and, even before treatment

had started, women were confident that these changes would render them immediately identifiable as a 'person-with-cancer' and that their diagnosis would no longer be a private matter:

It's going to be so obvious that it is going to be cancer, people are gonna say 'she's had her medication, she's not just decided to shave her head' ... everyone's immediately gonna know ... this is gonna be sort of like two neon fingers pointing right at me. (Louise, 41, mastectomy)

Participants referred to the visibility of hair loss in contrast to the relative privacy of other changes (e.g. scarring after breast surgery), which were not immediately evident to others.

I knew that I could have reconstructive surgery for my breast and that I've got prosthetics for now. Nobody else can tell, but when they look at you and you've got no hair they know instantly something's wrong ... at the moment nobody sort of knows, but as soon as this happens, they're all gonna know, it's gonna show to everyone ... the World's going to see that I'm not well. (Tracy, 37, mastectomy)

It was not only the lack of hair that women thought would identify them as having been diagnosed with cancer. While they described using wigs and scarves in order to camouflage their hair loss, these means of disguise were also described as being stereotypical indicators of cancer treatment. Somewhat ironically, these efforts to conceal their altered appearance in effect served to make their diagnosis more visible. Participants felt confident in their assertion that people would make these assumptions because they themselves had made such inferences in the past:

If you've got a scarf on your head, all over your head and you can't see your hair, you might as well have a placard saying 'I've got cancer' because I've been there, I've seen people and I've thought 'oh she's got cancer'. (Jean, 40, mastectomy)

Data from the interviews conducted after their chemotherapy was completed illustrated women's actual experiences of an altered appearance. Some were surprised that the changes had acted as a reminder to themselves about their disease status and had been shocked at their appearance:

Walking past mirrors—it's that shock value when you're not expecting something and you don't want anything reminding you when you're not expecting it. That's how I felt ... all the bruises I had from all the cannulars and blood samples and things and it

just sort of, made me look more ill. (Lucy, 41, mastectomy)

In some instances, women's actual experiences were akin to their expectations. For example, changes to appearance were deemed to have attracted uncalled-for attention when in public and had led women to feel uncomfortable and self-conscious. However, other women found that their expectations, for example of how they would react to the visibility of their cancer status, did not always correspond with their actual experience. Some women anticipated they would proudly display their altered appearance as a symbol of what they were going through but they had not necessarily predicted how conscious they would feel when faced with the reality of the situation:

Initially, before I started the treatment I thought, you know wear a scarf. And it's like a combat badge you know, look at me I'm going through this and aren't I doing brilliantly ... but the reality is very different, I mean I just didn't want to feel that people were looking, the first time I went out in my scarf I felt so self-conscious. (Lucy, 41, mastectomy)

While being visible as a person with cancer was mostly viewed as a negative experience, some women were able to cite benefits of other people being able to guess their cancer status merely by looking at them. For example, it was felt that this would offer an explanation for their behaviour or mood. In the following quotation, a participant describes feeling guilty when her elderly parents helped her with her shopping and believes that, in this instance, being clearly visible as having cancer made the situation easier:

Mum and dad have been helping me with my shopping, 'cos I've not been supposed to lift and such like, and I feel guilty stood at the checkout while they're packing all the bags and stuff, like and you assume that people are looking at you and thinking 'well, she's younger than they are, why isn't she doing it for them?' (Lucy, 41, mastectomy)

In summary, this theme encapsulates women's expectations and experiences that chemotherapy treatment would alter their appearance in a way that would make their cancer diagnosis clearly obvious to others.

Dealing with others

This theme refers to participants' encounters with other people, both known and unknown to them.

Women were aware that other people tended to focus on their appearance as an indicator of their health and the changes that publicly identified a woman as having cancer had led to a loss of privacy (see earlier). Before starting treatment they were concerned that they would be labelled and treated differently once their cancer status became known, whereas they wanted to be treated as normally as possible. Whereas the previous theme is concerned with the way in which an altered appearance imparts information to others and makes women identifiable as a 'person-with-cancer', this theme is concerned with the implications of being identified in this way and the fear of being treated differently by others.

They make judgements. They look at you and you judge a book by its cover, and I just, my cover's going to be different. (Tracy, 37, mastectomy)

I can't think of anything else why a woman would have no hair apart from alopecia or something like that, um, it's kind of a visible sign. My worry is that people are gonna start treating me very differently. (Miranda, 35, wide local excision)

I don't mind people knowing that I've got cancer, it's how they're going to deal with me. (Louise, 41, mastectomy)

They were particularly concerned that they would be treated with sympathy or pity or that people would try to instil their own opinions about the cause and appropriate treatment for cancer:

But I think a) it's a shock to other people and b) they feel sorry for you. I don't want anyone to feel sorry for me you know, I like to feel proud of myself do you know what I mean? I don't want people to look on me as though um, well they're sorry for me. (Linda, 58, mastectomy)

It looks pretty drastic you know, and people's opinions about cancer will vary you know, some people run away, some people start offering me Jesus, God-clapping stuff probably, you know. (Louise, 41, mastectomy)

During the post-treatment interviews, women talked about how people had reacted to them and had indeed often treated them differently. One woman described how she had not been recognized by people who knew her:

A lot of people just didn't recognize me because I looked different ... in [supermarket], only a few days ago, I had a woolly cap on and I spoke to quite an elderly lady in the village, and she said 'Do I

know you?' So I pulled off my cap, but of course it wasn't any better really because she said 'Oh my goodness'. (Barbara, 68, mastectomy)

In contrast, most participants described situations in which they wished for anonymity. In order not to draw attention to themselves they had sometimes changed their plans, avoided social situations or reduced their engagement with others because they did not want to be seen as looking different—for example, not going to a choir that a woman had been a member of, avoiding shops and not going into the garden or answering the door without wearing a headscarf or wig. In the following quotation, Lucy explained how a normal, everyday event was now stressful because of the potential social interaction:

I just wanted to fade into the background. I didn't want to draw any more attention to myself than I thought I already was, even though I probably wasn't, and I couldn't meet people's eyes. Like at the checkout usually you have a chat with the checkout girl, but no, head down just wanting to get through, get out. (Lucy, 41, mastectomy)

Women described situations in which other people, notably complete strangers, wanted to discuss or question them about their disease and treatment. This reaffirms to participants their belief that their diagnosis was now visible to others:

She [a person at the same holiday resort] said 'you've obviously had cancer, you've obviously got cancer'. I said 'no I've had cancer', I said 'I'm having treatment' and I told her a little bit about it, and she said 'well we guessed it was 'cos you had a bandanna on all day and all evening, so we guessed, you know, you'd lost your hair'. (Anne, 52, wide local excision)

Dealing with other people's desire to talk about the cancer became particularly tedious when women merely wanted to carry on with everyday activities and social engagements. While women appreciated others' concern for them, they also wanted to be able to discuss other topics and interact with others in a way that was unrelated to cancer. As Fiona pointed out, if she felt well enough to go out and therefore could be seen in public then she would prefer that her health was not the topic of conversation. However, women felt obliged to engage in conversation about their health, rather than to appear rude:

If I look a bit tired or something, everybody jumps on it you know, 'cos they're worried about me, um,

which, you know, I'm the same person, they shouldn't be any more worried. I mean yes that I, you know I'm feeling a bit poorly, but you know that's fine, but when I'm out and about, I'm obviously fine, so treat me, and talk about something else. (Fiona, 37, mastectomy)

This theme also includes women's awareness that, in addition to their own emotional distress, other people were often finding the situation upsetting and stressful and may be unsure as to how to react. Participants' dealings with other people include an acknowledgement of others' distress and attempts to protect their feelings during this time. For example, participants often reported wearing hats and scarves, using make-up and making positive gestures such as smiling. Women explained that these actions were primarily aimed at reassuring others, rather than for their own benefit:

I felt it was important for everybody really, probably, to see me looking more normal if I could ... even though I was made up, after I'd had the chemotherapy I looked different, my eyes went funny, looked smaller, and I was pale underneath the make up you know, but I felt it was important to still try to um, to get some control over it really, to try and be the same if I could ... I had to put my wig on which is a bit silly really because she (a friend) didn't mind it at all but I didn't want to upset her, because she was very upset when she heard I was diagnosed. She was upset, personally upset you know I didn't want to upset her that's why I did it, I didn't worry about it, but I didn't want to have her upset, did I? (Linda, 58, mastectomy)

And I could see the look on other people's faces and I know now that people look at me and they do look and they do stare, and then they smile and I smile back at them, because I don't want to make them feel uncomfortable. (Jane, 46, wide local excision)

Dealing with significant others, notably partners and children was particularly important. Some women reported feeling less attractive as a result of the changes to their appearance and, despite repeated reassurances to the contrary, this had had a negative impact upon their confidence and relationship with their partner:

I don't think I, I didn't anticipate how, um, how ugly it would make me feel. I felt very, I felt very, I didn't feel like me, I felt very, I didn't feel sexy, I didn't feel, didn't let R [husband] near me for weeks and weeks and weeks 'cos I felt so ugly, and he used to tell me all the time 'but you're beautiful. I love you, you've got no hair, so what?' (Anne, 52, wide local excision)

Managing their interactions with children was a very pertinent issue for many women and warrants specific mention within this theme. Some women discussed concerns about how they would prepare their children for their altered appearance and, in the second interview, talked of their children's reaction to it. Many described this as being particularly difficult because they did not want their altered looks to upset or scare them. There was considerable variation in the extent to which they revealed or disguised their altered appearance when near their own children or grandchildren and the extent to which they discussed the situation, largely dependent upon the child's age. Women also had to deal with the reactions of children when they were in public, notably staring, whispering and questioning. While this could be upsetting for some women, it was typically considered less of an issue than if adults had acted in the same way and was seen as children's inquisitiveness and a natural reaction to a novel situation:

Children notice, they notice me more, even more so than ever, I think. Yeah, you can see them tugging at their mummy going [makes whispering noises] you know, they just do, that's just the way they are. They don't mean to be 'cos they just, you know, they just have a different view. You know we'd say 'oh no, no', you know, 'mustn't say anything, mustn't', you know, 'don't embarrass the lady', but that's a normal, natural reaction for them. If somebody looks a little bit different, you know. (Fiona, 37, mastectomy)

It is important to stress that women's interactions with others were not always negative. Some described how their fears about being noticed and stared at had been unfounded and how public situations became more bearable once they had had a positive experience.

I felt, I felt so different, well, I mean the first time I went out with a wig on I felt very, very self-conscious, we just popped down to [supermarket] which is just down the road and I thought everybody was going to be looking at me but I, but I looked around and they weren't. Nobody noticed. So that you know, I got my confidence back then and then didn't worry after that. (Linda, 58, mastectomy)

In summary, this theme refers to ways in which women's encounters and interactions with others were affected by their perceptions of their altered appearance, their belief that others were now aware

of their diagnosis and their desire to protect and support other people during this time.

Discussion

While comparatively little research has focused specifically on the personal impact of an altered appearance during chemotherapy treatment, the current study offers an original insight into this aspect of women's experiences of cancer diagnosis and treatment. Previous research into the psychological impact of chemotherapy has reported patients ranking hair loss as the second most severe side-effect of treatment (Carelle et al., 2002). Our findings support those of Rosman (2004) in demonstrating that it is the outward changes that publicly identified participants as having cancer and as a consequence, presented them with an additional array of potential stressors. In essence their appearance acts as a visible indicator of their disease status to both themselves and others, including those who may have previously been unaware of it. Hair loss is seen as a confirmation of identity as a cancer patient (Rosman, 2004).

Previous research (Freedman, 1994; Richer & Ezer, 2002; Rosman, 2004) has reported that people undergoing chemotherapy meet the stereotypical appearance of a 'cancer patient' and can be recognized as such by other people. The current study highlights women's fears and experiences of being treated differently as a result of their diagnosis becoming public knowledge. While the issue of looking different during chemotherapy treatment has received surprisingly little attention, research among Chinese women (Lam & Fielding, 2003) has highlighted women's concerns about looking different after surgery and fears about social exclusion when society is intolerant of diversity of appearances.

Participants in our study described, sometimes at length, trying to safeguard other people's feelings and also deal with their (sometimes overly protective) reactions. This concurs with the theme of 'living with it' in Richer and Ezer's (2002) grounded theory study of 10 women's experiences of chemotherapy which included the need to support and spare the family while also dealing with unwanted attention such as probing questions and sympathy. This finding also parallels reports in the literature about the frequent experiences of people with visible differences (disfigurements), in particular loss of privacy and anonymity, dealing with the reactions

and questions of others and attempts at camouflage. While it is frequently noted that visible differences can be classified according to whether they are permanent, temporary or amenable to change (e.g. by reconstructive surgery) (see Rumsey & Harcourt, 2005), researchers in the field of appearance and visible difference have tended to focus on the impact of those that are permanent (notably cleft lip/palate, dermatological conditions and burns) while less attention has been given to those that are temporary. The findings presented in this article demonstrate how, for these women, the impact of supposedly temporary changes to appearance is akin to the reports given by people with a permanent visible difference. The current findings suggest that the psychosocial impact is no less just because the changes are temporary.

Much of the existing disfigurement (visible difference) literature has documented the problems experienced in social interactions when an individual has an appearance that is in some way different to 'the norm' (see Rumsey & Harcourt, 2005). Indeed, having a visible difference has been described as a 'social disability' (MacGregor, 1979). The women in our study similarly reported difficulty around social encounters. Some women had a sense of obligation to try and make things as easy as possible for other people. For example, the effort directed towards camouflaging the changes to appearance through the use of wigs, scarves and hats was partly in order to protect other people's feelings. This is in line with findings by Rosman (2004). The limitations and potential problems associated with relying on camouflage techniques in order to cope with a permanent visible difference have been highlighted previously and include the possibility of over-reliance so that an individual will not be seen without it (Coughlan & Clarke, 2002). Our research suggests that the possible problem of over-reliance on camouflage is also an issue for women whose appearance is temporarily different. The visible difference literature states that individuals fear that others will have to see 'the real me' if they are seen without camouflage make-up (Coughlan & Clarke, 2002) and in our study, women feared that others would see 'the real diagnosis' if their hair loss, for example, was evident. However, these attempts at disguise (e.g. wearing a bandana) were not always successful since they themselves were synonymous with cancer treatment, a finding also discussed by Williams, Wood and Cunningham-Warburton (1999).

The participants in our study had lost the privacy they may have previously been granted around who did or did not know about their cancer diagnosis and treatment. They felt that changes to their appearance had rendered their diagnosis to be public knowledge, and even their attempts to camouflage their appearance had further identified them as a person with cancer (see earlier). People with cancer often feel they have no control over their situation (Brennan, 2001) and our findings illustrate how this extends to not being in command of who is, or is not, aware of the diagnosis. People diagnosed as being HIV positive have similarly expressed their desire to retain control over others' knowledge of their HIV status, yet they have also reported how the physical changes to their appearance (e.g. loss of body fat, particularly on the face) have deprived them of this privacy (Persson, 2004; Power, Tate, McGill, & Taylor, 2003; Tate & George, 2001).

The experiences of women in our study parallel those of people with a visible difference who sometimes feel 'marked out' as different and as a result engender uncertainty, uncomfortable interactions and avoidance by others who are unsure as to how to react (see Rumsey & Harcourt, 2004). Goffman's (1963) work on stigma is often cited within the early visible difference literature when trying to explain these experiences. Despite increased knowledge and openness to discuss cancer over recent years, the disease is still associated by many as being stigmatized (Brennan, 2004; Lebel, Bezjak, Irish, & Devins, 2006). This helps to explain the experiences of some of the women in our study who were in effect feeling stigmatized on two accounts—first, that they had cancer and, second, that they were visibly different. Looking different had made it clear that they had cancer and the privacy they had previously had about their disease had been taken away. Rosman (2004) has also described patients' experiences of chemotherapy-induced alopecia as stigmatizing, and Lebel et al. (2006) have recently reported disfigurement to be correlated with stigma among 85 head and neck cancer patients.

Similarly, research with people diagnosed as having HIV/AIDS has also described participants' experiences in terms of appearance and stigmatization. Participants have reported being self-conscious of their appearance when meeting new people and those already known to them, including family. This often leads to avoiding social situations, and resulting isolation (Tate & George, 2001). Participants describe weight loss and lipodystrophy

(fat wasting of the face, limbs and upper trunk) as being an indicator of their HIV status (Persson, 2004; Power et al., 2003; Tate & George, 2001), yet are reluctant to disclose their status because of the stigma and discrimination associated with the condition (Duffy, 2005). Duffy (2005) cites the work of Kleinman (1988, p. 160) who stated people 'feel shame, not because of the cultural meaning of illness, but rather in response to the reactions of family and especially health professionals'. Furthermore, participants in the current study and in research with those with HIV/AIDS (Tate & George, 2001) have discussed how the changes to appearance are an outward expression of illnesses that are stereotypically associated with death.

Dealing with the reactions of children to their altered appearance and diagnosis was a particular concern for the women in our study. The issue of how best to tell a child about their parent's cancer diagnosis has long been a concern for patients, researchers and clinicians (see Brennan, 2004). Similarly, the visible difference literature is peppered with accounts of the reactions of children to a person with an appearance that is somewhat unusual (see Lansdown, Rumsey, Bradbury, Carr, & Partridge, 1997).

One aspect that is clear from this study is that women were worrying about the possible changes to their appearance before they had occurred. This demonstrates how fears about an altered appearance can be as consuming as the reality. Most of the disfigurement literature centres around experiences relating to appearance only after such changes have taken place. Those providing care and support for people who are about to embark on (or who are currently undergoing) treatment that will alter their appearance (if only for a relatively short period of time) should also be aware of the impact this can have on the individuals concerned. Attempts should be made to facilitate the discussion of appearance-related issues with women who are undergoing chemotherapy treatment in order that concerns about an altered appearance can be aired and appropriate support made available, if necessary before such changes take place. They may also benefit from advice on how to deal with people's reactions to their altered appearance, such as strategies promoted by organizations such as the charity Changing Faces (www.changingfaces.org.uk) who support those dealing with disfigurement.

There are some limitations in this study, specifically we recognize the limits of a volunteer sample

and recognize that the accounts of these 19 women undergoing treatment at a single centre might not represent those of all women undergoing chemotherapy following a diagnosis of breast cancer. Also, we do not claim that these findings are relevant to the experiences of women from other demographic backgrounds nor do they represent men's experiences. Much of the available research pertaining to appearance in general has tended to focus on women's experiences and reported higher levels of appearance-related concerns among women than men (see Feingold & Mazzella, 1998). However, it would be erroneous to believe that appearance, including hair loss, is not an issue for men. Research evidence suggests that rates of appearance dissatisfaction are increasing among men (Rumsey & Harcourt, 2005) and Cash (1992) found that 60 per cent of men with hair loss described negative social or emotional consequences of balding.

The impact on men of an altered appearance during cancer treatment is often under-estimated, possibly reflecting a pre-conception that issues such as hair loss are a greater concern for women than for men. Such beliefs are unfounded (Brennan, 2004) and further research is needed to explore the themes identified in the current study among a male population.

Further research could usefully explore the incidence of appearance-related concerns among people undergoing chemotherapy treatment and explore possible relationships between this and psychosocial distress in terms of concepts such as appearance-related anxiety and quality of life. Research could also investigate these issues among different cancer groups and examine whether these findings regarding changes in appearance as an indicator of disease status are pertinent among other patient groups. A detailed comparison of the specific experiences and support needs of men and women undergoing chemotherapy-induced alopecia is also warranted.

In conclusion, this study has highlighted the negative psychosocial impact of an altered appearance during chemotherapy treatment, since this acts as a visible indicator of the cancer diagnosis and thereby impacts upon patients' interactions with other people. There is potential value in facilitating the discussion of appearance-related issues with women who are undergoing chemotherapy in order that concerns about an altered appearance can be aired and appropriate support provided.

References

- Batchelor, D. (2001). Hair and cancer chemotherapy: Consequences and nursing care—a literature study. *European Journal of Cancer Care*, *10*, 147–163.
- Baxley, K. O., Erdman, L. K., Henry, E. B., & Roof, B. J. (1984). Alopecia: Effect on cancer patients' body image. *Cancer Nursing*, *7*, 499–503.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.
- Brennan, J. (2001). Adjustment to cancer—coping or psychosocial transition? *Psycho-Oncology*, *10*, 1–18.
- Brennan, J. (2004). *Cancer in context: A practical guide to supportive care*. Oxford: Oxford University Press.
- Carelle, N., Piotto, E., Bellanger, A., Germanaud, J., Thuillier, A., & Khayat, D. (2002). Changing patient perceptions of the side effects of cancer chemotherapy. *Cancer*, *95*, 155–163.
- Cash, T. F. (1992). The psychological effects of androgenetic alopecia in men. *Journal of the American Academy of Dermatology*, *26*, 926–931.
- Clarke, A., & Cooper, C. (2001). Psychological rehabilitation after disfiguring injury or disease: Investigating the training needs of specialist nurses. *Journal of Advanced Nursing*, *34*, 18–26.
- Coughlan, G., & Clarke, A. (2002). Shame and burns. In P. Gilbert & J. Miles (Eds.), *Body shame* (pp. 155–170). Hove: Brunner-Routledge.
- Duffy, L. (2005). Suffering, shame and silence: The stigma of HIV/AIDS. *Journal of the Association of Nurses in Aids Care*, *16*(1), 13–20.
- Feingold, A., & Mazzella, R. (1998). Gender differences in body images are increasing. *Psychological Science*, *9*, 190–195.
- Freedman, T. (1994). Social and cultural dimensions of hair loss in women treated for breast cancer. *Cancer Nursing*, *17*, 334–341.
- Frith, H., & Harcourt, D. (2005). Picture this: Using photography to explore women's experiences of chemotherapy. *Health Psychology Update*, *14*(3), 2–9.
- Frith, H., & Harcourt, D. (2007). Using photography to capture women's experiences of chemotherapy: Reflecting on the method. *Qualitative Health Research*, *17*, 1340–1350.
- Frith, H., Harcourt, D., & Fussell, A. (2007). Anticipating an altered appearance: Women undergoing chemotherapy treatment for breast cancer. *European Journal of Oncology Nursing*, *11*, 385–391.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice-Hall.
- Griffin, A. M., Butow, P. N., Coates, A. S., Childs, A. M., Ellis, P. M., Dunn, S. M., & Tattersall, M. H. N. (1996). On the receiving end V: Patient perceptions of the side-effects of chemotherapy. *Annals of Oncology*, *7*, 189–195.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.

- Lam, W. W., & Fielding, R. (2003). The evolving experience of illness for Chinese women with breast cancer: A qualitative study. *Psycho-Oncology, 12*, 127–140.
- Lansdown, R., Rumsey, N., Bradbury, E., Carr, A., & Partridge, J. (Eds.). (1997). *Visibly different: Coping with disfigurement*. Oxford: Butterworth-Heinemann.
- Lebel, S., Bezjak, A., Irish, J., & Devins, G. M. (2006). Stigma and the psychosocial impact of head and neck cancer. Abstracts of the 8th World Congress of Psycho-Oncology. *Psycho-Oncology, 15*(2, Suppl), 304.
- MacGregor, F. C. (1979). *After plastic surgery: Adaptation and adjustment*. New York: Praeger.
- Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of Health Psychology, 11*(5), 799–808.
- Moyer, A. (1997). Psychological outcomes of breast-conserving surgery versus mastectomy: A meta-analytic review. *Health Psychology, 16*, 284–298.
- Münstedt, K., Manthey, N., Sachsse, S., & Vahrson, H. (1997). Changes in self-concept and body image during alopecia induced cancer chemotherapy. *Supportive Care Cancer, 5*, 139–143.
- Pendley, J. S., Dahlquist, L. M., & Dreyer, Z. (1997). Body image and psychosocial adjustment in adolescent cancer survivors. *Journal of Pediatric Psychology, 22*, 29–43.
- Persson, A. (2004). Incorporating pharmakon: HIV, medicine and body shape change. *Body & Society, 10*(4), 45–67.
- Power, R., Tate, H. L., McGill, S. M., & Taylor, C. (2003). A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals. *Sexually Transmitted Infections, 79*, 137–141.
- Randall, J., & Ream, E. (2005). Hair loss with chemotherapy: At a loss over its treatment? *European Journal of Cancer Care, 14*(3), 223–231.
- Richer, M. C., & Ezer, H. (2002). Living in it, living with it, and moving on: Dimensions of meaning during chemotherapy. *Oncology Nursing Forum, 29*(1), 113–119.
- Rosman, S. (2004). Cancer and stigma: Experience of patients with chemotherapy-induced alopecia. *Patient Education and Counselling, 52*, 333–339.
- Rumsey, N., & Harcourt, D. (2004). Body image and disfigurement: Issues and interventions. *Body Image, 1*, 83–97.
- Rumsey, N., & Harcourt, D. (2005). *The psychology of appearance*. Maidenhead: Open University Press.
- Tate, H., & George, R. (2001). The effect of weight loss on body image in HIV-positive gay men. *Aids Care, 13*(2), 163–169.
- White, C. A. (2000). Body image dimensions and cancer: A heuristic cognitive behavioural model. *Psycho-Oncology, 9*, 183–193.
- Williams, J., Wood, C., & Cunningham-Warburton, P. (1999). A narrative study of chemotherapy-induced alopecia. *Oncology Nursing Forum, 26*, 1463–1468.

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