Anticipating an altered appearance: Women undergoing chemotherapy treatment for breast cancer

Hannah Fritha,*, Diana Harcourtb, Anna Fussellc

aBristol Doctorate in Clinical Psychology, 29 Park Row, Bristol, BS1 5NB, UK
bSchool of Psychology, University of the West of England, Coldharbour Lane, Bristol, BS16 1QY, UK
cOutlook Psychosocial Support Service, North Bristol NHS Trust, Bristol, UK

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Summary
Chemotherapy treatment for cancer can have a profound impact on appearance, and is often experienced as distressing. Few qualitative studies explore experiences of chemotherapy, and seldom focus on the process of anticipation and preparation for an altered appearance. We report findings from an interview study of 19 women which explored their expectations of chemotherapy-induced hair loss, their anticipated reactions to hair loss and how women intend to prepare for an altered appearance. The results demonstrate that women are active in anticipating hair loss and adopt a range of different strategies to manage their alopecia—even before it has occurred. Four key themes were identified: (a) anticipating hair loss, (b) coming to terms with the inevitability of hair loss, (c) becoming ready, and (d) taking control. We argue that this can be seen as a form of anticipatory coping, which involves affective and behavioural rehearsal so that women can feel more in control of their experience of the side effects of chemotherapy treatment for cancer. We suggest seeing these activities as a form of anticipatory coping, and understanding the psychological reasons why women engage in these activities, may help nursing professionals to better support women through this often traumatic time.

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Zusammenfassung
Chemotherapien können das äußere Erscheinungsbild von Krebspatienten erheblich verändern und werden auch aus diesem Grunde häufig als sehr belastend empfunden. Bislang existieren nur wenige qualitative Studien, in denen untersucht wurde, wie Krebspatienten ihre Chemotherapien wahrnehmen. Nur selten steht in diesen Studien der Prozess der Antizipation und der Vorbereitung auf ein verändertes Erscheinungsbild im Vordergrund. Wir berichten über die Ergebnisse einer Interviewstudie, in der die Erwartungen von 19 Frauen im Hinblick auf einen chemotherapiebedingten Haarverlust sowie die antizipatorischen Reaktionen dieser Probandinnen auf den Haarverlust untersucht wurden; ferner wurden die Probandinnen gefragt, wie sie sich auf die Veränderungen ihres körperlichen Erscheinungsbildes vorzubereiten gedachten. Die Ergebnisse zeigen, dass sich die Frauen aktiv auf den erwarteten Haarverlust vorbereiten

*Corresponding author. Tel.: +44 0117 3315020; fax: +44 0117 3315035.
E-mail address: hannah.frith@bristol.ac.uk (H. Frith).

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Introduction

Treatments for cancer can have a profound impact on patients’ appearance and body image (Runsey and Harcourt, 2006). Yet in comparison to the relative wealth of research into the impact of surgery on body image (see Moyer, 1997 for an overview), the psychosocial impact of chemotherapy has received relatively little attention.

Chemotherapy is recognized as having a range of side effects (including nausea, fatigue, hair loss, ulcers), which often make patients feel ill in a way that the actual disease does not (Fall-Dickson and Rose, 1999). Alopecia or hair loss is often rated as one of the most common, feared, and traumatic aspects of chemotherapy (see Batchelor, 2001; Cull, 1990; Münstedt et al., 1997), and may even be considered emblematic of the treatment and of cancer itself (Harcourt et al., 2006). Although mechanisms for preventing or reducing hair loss (such as scalp tourniquets or scalp-cooling devices) have been developed, their effectiveness is contested (see Batchelor, 2001 and Hesketh et al., 2004 for overviews), and hair loss is, for many patients, currently an unavoidable aspect of their chemotherapy treatment.

Understanding more about the experience of chemotherapy-induced hair loss enables us to inform healthcare practices and to better support patients. Two different literatures currently inform our understanding: quantitative research that attempts to establish the incidence and severity of different side effects from chemotherapy, and to assess the impact of these on psychosocial outcomes such as self-esteem, body image, and distress; and qualitative studies that aim to explore the experience of chemotherapy (including hair loss) for women themselves. These literatures, which we briefly review, tell us little about how women prepare for hair loss before it occurs.

Quantitative studies of hair loss

Most studies within the nursing field have been concerned with documenting the incidence and severity of side effects, the onset and duration of symptoms, and the extent to which these are perceived as distressing or difficult. Alopecia is typically ranked as one of the most troublesome side effects of chemotherapy along with nausea and fatigue (e.g. Griffin et al., 1996; Lindley et al., 1999). Some studies suggest that the experienced side effects are not as difficult or distressing as patients anticipate (Lindley et al., 1999 see also Tierney et al., 1992), and this knowledge might go some way to reassure those receiving chemotherapy for the first time. Nonetheless, substantial numbers of patients undergoing chemotherapy find hair loss difficult or distressing.

Little research has explored the psychosocial impact of these side effects on self-esteem, depression, and body image. Carpenter and Brockopp (1994) found that women rated their self-esteem as significantly lower at the time of alopecia, although this did not necessarily mean that they had low self-esteem overall. A prospective longitudinal study that explored 29 patients’ self-concept and body image before treatment, during complete hair loss, and after hair re-growth, found that self-concept and body image were poorer during treatment and did not improve or return to pre-treatment levels when hair began to re-grow (Münstedt et al., 1997). While it is difficult to tease out whether differences in body image, self-esteem, or self-concept result from alopecia specifically, or more general adjustment to a cancer diagnosis and chemotherapy treatment, they do suggest that many women experience a range of distressing side effects from chemotherapy treatment, including alopecia, which has a significant impact on their psychosocial well-being. Further research is needed to explore the psychosocial impact of chemotherapy side effects, and how cancer patients cope with these changes.

Qualitative studies of hair loss

A few qualitative studies have explored cancer patients’ (predominantly women) experiences of chemotherapy, including the meaning of hair loss (Gallagher, 1997); the social and cultural aspects of hair loss (Freedman, 1994); the experience of hair loss and re-growth (Williams et al., 1999); the meaning of chemotherapy treatment (Richer and Ezer, 2002); and experiences of fatigue (Rosman, 2004). Although not all of these studies focused specifically on hair loss, collectively they have identified a number of key elements in the experience of chemotherapy-induced alopecia.

Studies that provide descriptive accounts of the process of hair loss suggest that for many women this is traumatic. Patients describe having hair fall out in clumps, on pillows...
and sticking to the body in the shower or clogging up the plug hole (Gallagher, 1997). They are shocked when hair loss occurs and they are confronted by their baldness. Only two studies explicitly (but briefly) examined how women prepared for treatment side effects. In one, patients prepared by gathering information from others (people they have known, nurses, internet, etc.), going to hairdressers, shaving their hair, and buying wigs and hats—but even those who engaged in these activities still felt unprepared (Williams et al., 1999).

In order to manage or cope with alopecia, patients disguise or camouflage hair loss through the use of wigs, hats, and scarves. Rosman (2004) describes how some women engage in total camouflage where a wig is worn “always and everywhere” and partial camouflage when they decide not to wear a wig in the presence of some people (usually when at home). Looking ‘normal’ is something that takes effort, and is done for the benefit of self and the protection of others (Rosman, 2004; Williams et al., 1999). Some studies describe the problems associated with wig use, such as finding them uncomfortable, as signalling a denial of the disease, and perpetuating a feeling of being abnormal, and some women were relieved when these efforts could be abandoned and the wig discarded (Williams et al., 1999).

Studies that focus on the meaning of hair loss suggest that this can represent a visible reminder of the illness, women look like a ‘cancer patient’ and can be recognized as such by others (Freedman, 1994; Harcourt et al., 2006; Richer and Ezer, 2002; Rosman, 2004; Williams et al., 1999). Hair loss can also create a loss of self or identity, as the person in the mirror no longer looks or feels like ‘me as I normally am’ (Freedman, 1994; Williams et al., 1999). However, for some women hair loss was accepted as an inevitable consequence of treatment—part of the “price one pays for having treatment”—a temporary and manageable aspect of treatment which one just has to get through, and which can be taken as evidence of the effectiveness or strength of the treatment (Rosman, 2004).

These qualitative studies have been extremely useful for illuminating women’s experiences of hair loss. Despite the small sample sizes, there is some coherence between the themes being described across these studies. However, they rarely focus specifically on the process of preparing for hair loss. Where studies do address the anticipation or preparation for hair loss this is often one among many themes, and focus on this theme in detail is sacrificed in favour of providing an overview of the chemotherapy experience (e.g. Gallagher, 1997; Williams et al., 1999). Consequently, despite the utility of these studies, we still know very little about how women prepare for the effects of chemotherapy treatment, and how this preparation might be supported by healthcare workers.

In summary, hair loss is often an unavoidable side effect of undergoing chemotherapy treatment for cancer, and it is often experienced as distressing or traumatic. Research suggests that hair loss may also have a psychosocial impact on patients self-esteem, body image, and self-concept, but little is known about which patients might be more vulnerable or resilient to these effects, and what factors might ameliorate this distress. Preparing patients for hair loss is a significant challenge for nurses and physicians, and yet little is known about the process of preparing from the perspective of women themselves. Since preparation for hair loss has been identified as a key role for healthcare professionals, understanding more about this crucial period may enhance our ability to support cancer patients through this potentially difficult time. In this paper we use data from interviews with women prior to commencing chemotherapy treatment to explore the process of anticipating and preparing for hair loss.

Method

The data in this paper forms part of a larger study exploring women’s experiences of chemotherapy. In the wider study nineteen women were recruited on a volunteer basis from an Oncology Centre in a large city in the South West of England. The study was scrutinized and given approval both by the University of the West of England and by the South West Local Regional Ethics Committee. Details of the study were introduced by the consultant and specialist nurses during a consultation prior to chemotherapy treatment. An initial interview was arranged by telephone, and formal written consent was obtained during the first interview. All women had diagnoses of breast cancer and all were receiving chemotherapy (although there were a variety of treatment regimes being used). Some had previously undergone surgery to remove some or all of the breast tissue, some were to undergo radiotherapy after the chemotherapy, and some were expecting to have surgery at a later date. For all (but one) of the women this was their first experience of chemotherapy. The women were aged between 35 and 68, all were in heterosexual relationships (12 were married) with the exception of one who identified as lesbian. We recognize the limits of a volunteer sample and recognize that such a small sample will represent only a select set of experiences. However, our aim was to identify a number of key aspects of preparing for chemotherapy treatment and explore these in depth. Women were interviewed before or at the beginning of treatment, and again after their course of chemotherapy had been completed. In this paper, we focus on the analysis of the initial interviews from the 19 women in which they talked about their expectations about the chemotherapy treatment and how they thought they would respond to changes in their appearance. Semi-structured interviews were conducted by the authors in the participants’ own homes (with the exception of two women who preferred to be interviewed in a hospital setting), were tape-recorded, and lasted approximately one hour. Women were interviewed prior to commencing treatment about their expectations and concerns about chemotherapy (e.g. What do you understand by the term ‘chemotherapy’? How do you feel about having chemotherapy?), and about how they thought this might impact on appearance (e.g. Do you anticipate that the chemotherapy will change your physical appearance or your feelings about your body? How? In what ways?). Other questions in the initial interview focused on women’s views of creating a photographic record of their experiences and are not discussed here.

The resultant data were analyzed by adopting the widely used, but seldom acknowledged method of thematic analysis which is used to identify, analyze and report patterns or
themes that reoccur across a data set (Boyatzis, 1998). Thematic analysis has much in common with other forms of analysis (such as interpretative phenomenological analysis or grounded theory) which search for patterns or themes across a data set, but is not wedded to a pre-existing theoretical framework which means that it can be used flexibly (see Braun and Clarke, 2006 for an accessible discussion of thematic analysis). In the current study, thematic analysis was used to identify recurrent patterns in women's experiences of preparing for the side effects of chemotherapy treatment. The analysis proceeded through a number of stages. Firstly, the data was transcribed and two researchers read and re-read the transcripts and noted initial observations. Secondly, these initial observations were reviewed to develop initial codes, which were then systematically applied to the data set to identify all data extracts associated with this code. These codes were reviewed for consistency with the data extracts (i.e. were all the data extracts coherent and related and did they collectively represent the theme) and for validity in relation to the whole data set (i.e. did the themes identified accurately represent the data as a whole). Finally, the theme is given a final definition and a name that reflects its content. Three key themes were identified and these are discussed below.

**Results and discussion**

For many of the women in this study, like those in other studies, chemotherapy was often seen as synonymous with hair loss. Many women found the thought of hair loss distressing but even those who seemed less distressed or anxious about losing their hair still put a great deal of thought into anticipating how they would manage and cope with hair loss. The analysis revealed three key themes: coming to terms with hair loss, becoming ready, and taking control. Each of these themes is discussed in turn.

**Anticipating hair loss**

These women, like those in other qualitative studies, reported that one of their first reactions to being told that they would need chemotherapy was distress and anxiety about the side effects of chemotherapy treatment. The analysis revealed a number of stages. Firstly, the data was transcribed and two researchers read and re-read the transcripts and noted initial observations. Secondly, these initial observations were reviewed to develop initial codes, which were then systematically applied to the data set to identify all data extracts associated with this code. These codes were reviewed for consistency with the data extracts (i.e. were all the data extracts coherent and related and did they collectively represent the theme) and for validity in relation to the whole data set (i.e. did the themes identified accurately represent the data as a whole). Finally, the theme is given a final definition and a name that reflects its content. Three key themes were identified and these are discussed below.

**Coming to terms with the inevitability of hair loss**

This theme describes the process of coming to accept that hair loss is likely or inevitable, and letting go of the often unrealistic hope that hair might be retained. Fear of hair loss meant some women were initially reluctant to engage with the treatment ("I didn't want to have it [chemotherapy]. Didn't want to lose my hair did I"). Others hoped that they would be one of the ‘lucky few’ who will avoid hair loss ("at the back of your mind you’re hoping you’ll be the one person it doesn’t happen to"). Medical research allows healthcare professionals to predict with a fair amount of certainty which drugs and treatment regimens produce the greatest likelihood of hair loss, and when this loss will occur. Women's uncertainty, and the oscillation between fear and hope, ends when this news is delivered. For example, one woman described how friends had tried to comfort her with stories about others who had undergone chemotherapy but had not experienced hair loss, but then her consultant told her that she would definitely lose her own hair:

... he actually sat down in front of me and said [name] you're going to lose your hair’ then I came to terms with it a bit more, I think I almost had this thought in my head, ‘well maybe I won’t, not everybody does, perhaps I might be lucky, perhaps it might only go thin’ but when he actually looked at me and he said ‘you're going to lose your hair, you might keep your eyebrows but you’re going to lose your hair’, then I started to come to terms with it, because I thought now I can take steps to be positive and do something about it.

Although often seen as upsetting news, this nevertheless allows women to accept that they will lose their hair and to start focusing on how to prepare, manage, and cope with this event.

**Becoming ready**

This theme describes the time, energy, and emotional resources which women invest in exploring how to manage hair loss before it has occurred so that they can feel ‘ready’. Chemotherapy-induced hair loss is an expected and anticipated event. The women we interviewed were keen to tell
us about the hats, scarves, and wigs that they had obtained in preparation for hair loss, (“I’ve already set myself up with one wig and I have another one in the pipeline coming along”) and about the straight-forward information about the availability of wigs and other head-coverings they received from nurses and physicians. While other studies have noted that women cut their hair or purchase wigs (e.g. Williams et al., 1999; Gallagher, 1997), they do not really explore why women engage in these activities and what it means to them. For the women in this study, these purchases were proudly presented as evidence that they were coming to terms with the inevitability of hair loss, and were actively engaged in preparing for the process. Trying on wigs, hats, and scarves was seen as a way of becoming ‘ready’ for hair loss and gathering resources which could be used when hair loss finally happens:

... when I went to my first chemo session I said ‘where’s the wig lady, I want to see the wig lady’. And they said ‘oh you’ll see her at your next one’, and I said ‘no I won’t, I want to see her today’. I was absolutely adamant, I knew I wouldn’t cope for three weeks thinking ‘my hair’s going to fall out and I’ve got no backup’. So she came to see me and we ordered it then and there, went through all the colors and it was great, and I felt really happy then.... she said ‘yeah it’s brilliant it’s just like your hair’. [...] so that was good and I bought some scarves which I consequently hate, but I needed them, I just needed to be ready really.

For some, simply having the wig and the scarves is enough to help them to feel ready for hair loss, but others may want to ‘try out’ their ‘camouflage’ to ensure that it actually works:

... in actual fact I’ve just had a test run. I did put [my wig] on, ooh about four days ago, I went up the shops and nobody looked at me twice. Nobody looked at me twice. And I thought this is going to be brilliant because I’m gonna feel really comfortable. [...] That’s good because when my hair has gone I’ll be fine.

Building on the notion of ‘affective rehearsal’, this could be seen as a kind of ‘behavioural rehearsal’ where they gather resources and practice strategies to manage hair loss. A second form of behavioural rehearsal was to cut hair shorter in anticipation of its loss:

I don’t really want to wake up one morning and find a load of hair on my pillow and stuff like that. I think I’d get really upset then. Um, whereas it’s very short, um, I don’t think I’d notice it so much, I’ll do it gradually.

Having a shorter haircut was also a way of preparing others (work colleagues, spouses and children) so that it “won’t be such a great shock when it actually happens”, and so that it is a “slow process ... rather than suddenly shaving it off”. This process of behavioural rehearsal, then, allows some women to manage their anxieties about hair loss (e.g. about loss of privacy), to practice their strategies for camouflaging or disguising hair loss, to reassure themselves that they have the material (and emotional) resources to cope with hair loss when it happens, and to prepare others for their altered appearance.

Taking control

This theme captures the way in which women talked about engaging in strategies to feel more in control of their hair loss. Despite the range of information available to patients (e.g. at what point in treatment hair loss might be expected to occur, advice about wearing hats to ‘catch’ lost hair, etc.), women still perceive the timing and nature of hair loss to be uncertain, since they cannot know for sure how it will be for them until it happens. Shaving their hair, rather than waiting for it to fall out, was seen as a way of exerting some control over this process:

... I’m starting to think I might take it all off before I start, rather than wait, [...] the thought of waking up one morning and finding a great clump on the pillow or, in the shower or whatever, I think that would be more distressing than doing it at a time I chose.

Being in control of hair loss, being able to decide when and where it will occur was seen as important, especially when so many aspects of the disease, the treatment and its side effects seem outside of personal control (see Brennan, 2001):

Yeah, it [shaving hair] is control, definitely about the control aspect, ‘cos I won’t be able to control how I feel internally, if I feel sick I’m gonna feel sick, there’s nothing I can do about it. Tiredness is the other thing, but that is one thing, I can decide when it [hair] goes, what I do about it, whether I hide it with a wig, whether I wear a hat or a scarf or whatever, you know.

These women are thinking carefully not only about how to control the process of hair loss, but also about how to control and manage their own emotional reactions. Recognizing that hair loss may be distressing or frightening, they are actively engaged in finding ways to alleviate their distress in order to deal with their loss. Shaving hair is seen as a proactive step, something which the individual decides to do, to let go of the hair rather than to lose it.

Yeah, it’s my way of getting back at cancer as well. Chemo’s not going to take my hair, if anyone is going to have anything to do with my hair loss, I will do it myself.

Hair loss is re-conceptualized as a process which can be actively precipitated rather than passively awaited, as something which is within their control.

General discussion

Anticipatory coping

We argue that this preparation could be seen as a form of anticipatory coping—coping which involves the preparation for managing the stressful consequences of an upcoming event which is likely or certain to occur (Aspinwall and Taylor, 1997). Anticipatory coping has received relatively little research attention but it is likely to involve some of the same activities as proactive coping (coping efforts to prevent potentially stressful events) but targeted towards an anticipated event. These activities include: resource accumulation (information etc.), initial appraisal
and coping (Walker, 2001), but few studies explore the psychological theories of emotional well-being, adjustment control over their situation. Control is a central concept in our research demonstrates that many of the activities described are similarly useful in enabling them to deal with the stress of losing their hair as well as avoiding problematic interactions and helping to manage the emotional consequences of hair loss. Somerfield (1997) has argued that coping research needs to focus on a particular stressor (in this case hair loss rather than the broader ‘coping with chemotherapy’ or ‘coping with cancer diagnosis’), and that descriptive research such as the one presented here can inform the selection of relevant variables for more streamlined, theory-guided research. We argue that a focus on anticipatory coping could be a useful starting point for exploring further individual differences in the efficacy of coping efforts (i.e. do women who engage in more, or more elaborate, anticipatory coping experience less stress and anxiety when their hair actually falls out?), and that affective rehearsal and behavioural rehearsal could be important elements in anticipatory coping.

Control

Our research demonstrates that many of the activities women engage in to manage and cope with their impending hair loss are valued because they allow women to gain control over their situation. Control is a central concept in psychological theories of emotional well-being, adjustment and coping (Walker, 2001), but few studies explore the myriad of different strategies that individual cancer patients might use in order to compensate for lack of control. One exception is Thompson et al.’s (1993) study with cancer patients with a range of different diagnoses. They found that although there was a strong relationship between perceptions of control and successful adjustment, the arena for control was important. Perceived control over daily emotions and physical symptoms was more important than controlling the disease, relationships or medical care. The women in this study may have no control over their cancer or the side effects of their treatment, but they find ways of gaining control by shaving their hair before it falls out, by cutting it short to emotionally ‘prepare’ themselves and others for seeing them without hair, and by practicing wearing wigs and scarves. It is important to them, as it was to the participants in Thompson et al.’s study, to have perceived control over the more mundane, day-to-day problems. Self-generated feelings of control like these have been found to be associated with successful coping, better emotional adjustment and improved performance (Thompson and Spacapan, 1991). Understanding that women use anticipatory coping strategies to enhance their sense of perceived control may be an important resource for physicians and nurses.

There is much existing good practice in the provision of information about the side effects of treatment (such as leaflets produced by charities such as Breast Cancer Care1), and the provision of wigs.2 Indeed, innovative developments, such as the use of computerized hair imaging software which allows women to see themselves with a new hairstyle/without hair prior to change and promotes self-acceptance (McGarvey et al., 2001), continue to extend the availability of useful resources. However, most information leaflets and recommendations focus on the physical side effects rather than on the emotional or psychosocial impact of the treatment. For example, in her review if this area, Batchelor (2001) recommends that health care professionals encourage women to shave their heads once hair loss becomes pronounced because this is associated with less pain or discomfort, and because it promotes quicker regrowth. Similarly, women with long hair should be encouraged to have their hair cut shorter to “disguise thinning and also minimize the problem of shedding long hair, which may create anxiety” (p. 157). Our research suggests that cutting and shaving hair may serve a multitude of additional functions (to prepare self and others for the loss of hair, to gain control over the timing of hair loss, to feel proactive). By failing to consider some of the psychological motivations behind particular practices and strategies, healthcare professionals may miss the opportunity to help patients to enhance their feelings of control. We suggest that nurses and healthcare practitioners could consider ways of helping patients to perceive control over day-to-day issues, and use the language of control in their information leaflets and interactions with patients. In this paper, we have focused specifically on coping with one particular aspect of chemotherapy treatment—hair loss—and have identified a range of different strategies that people adopt, but more than this we have revealed something about why people adopt these different strategies (such as to gain control). If this information were shared with other patients they would have a better understanding of the benefits to be gained by adopting different strategies as well as an understanding of the range of different strategies available. A clear understanding of the psychosocial impact of an altered appearance due to chemotherapy treatment, by health care professionals and patients alike, would aid the process of anticipatory coping and would provide patients with a wider range of resources and

1Breast Cancer Care is the UK’s leading provider of information, practical assistance and emotional support for people affected by breast cancer—www.breastcancercare.org.

2The UK’s National Health Service provides a free wig for all patients who are likely to lose their hair as a result of chemotherapy treatment.
strategies for altered appearance. We recommend the development of explicit guidance for healthcare professionals, and the adaption of patient information to better reflect these psychosocial concerns.

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References