Chemotherapy-induced alopecia: a phenomenological study

Breast cancer accounts for 16 per cent of all cancers in females. The treatment regimen is complex and almost half of all women with breast cancer undergo alopecia-inducing chemotherapy. The aim of this study was to explore the lived experience of chemotherapy-induced alopecia and its effects on women with breast cancer. Five women who had experienced chemotherapy-induced alopecia in the past 12 months were interviewed, revealing four main and four sub-themes. The findings have implications for health professionals, patients and for oncology nursing practice. Chemotherapy-induced alopecia affects each individual differently. The provision of practical information to patients in a caring and sensitive manner is important, even following re-growth of hair.

Quantitative studies demonstrate the effectiveness of chemotherapy in treating women with stage I and stage II breast cancer (Pasacreta 1997, Walker et al 1999). Despite the effectiveness of chemotherapy in the treatment of primary breast cancer, a number of descriptive studies have identified a range of side effects associated with treatment, including nausea, fatigue, alopecia and stomatitis (Carelle et al 2002, De Jong et al 2002, Jordan et al 2007).

Alopecia is one of the most distressing and visually noticeable effects of cancer treatment. For some patients, the fear of treatment-induced alopecia is so significant that some women may refuse potentially curative chemotherapy (Tierney and Taylor 1991, Pruzinsky 2004). In 2005, 2,379 women were diagnosed with breast cancer in Ireland, meaning that breast cancer accounts for 16 per cent of all female cancers in the country, and as many as 40 per cent of women with breast cancer undergo alopecia-inducing chemotherapy (National Cancer Registry 2006).

For more than 30 years, researchers have tried to find ways to prevent treatment-induced alopecia. Perhaps the most predominant technique is scalp cooling. This method causes vasoconstriction of the blood vessels in the scalp, which reduces the uptake of drugs into hair follicles, thus decreasing the amount of hair loss (Randall and Ream 2005). Patients are often willing to endure the uncomfortable side effects associated with scalp cooling, such as headaches, nausea or sensations of severe coldness, in an effort to avoid chemotherapy-induced alopecia (Peck et al 2000, Massey 2004, Dougherty 2006).

Hair plays a pivotal role in a person’s outward presentation and social interaction (Cash 2001). Hair serves as a social signal of gender, age, status and group membership (Pickard-Holley 1995). For women, in particular, it is an important indicator of attractiveness, femininity and body image (Rosman 2004). It is perhaps not surprising that chemotherapy-induced alopecia has traditionally been associated with loss of individuality, unattractiveness...
and a state of disgrace and illness (Freedman 1994, Batchelor 2001).
Chemotherapy-induced alopecia poses a significant threat to body-image and self-esteem. Despite its prevalence, a literature search revealed just five studies specific to the problem (Freedman 1994, Carpenter and Brokopp 1994, Munstedt et al 1997, Williams et al 1999, Rosman 2004). Findings from these studies illustrate that age or degree of hair loss do not differentially affect levels of self-esteem, which further supports the subjective nature of body image. Participants felt unprepared for hair loss; their self-confidence and body-image were adversely affected even following hair re-growth.
Freedman (1994) was the only researcher to explore chemotherapy-induced alopecia for breast cancer patients – Munstedt et al (1997) looked at gynaecological cancers and Williams’ team (1999) looked at men and women with different cancers. While Freedman’s study claimed to explore the social and cultural dimensions of hair loss for women with breast cancer, the interviews were focused on the meaning of being a woman with breast cancer.
Despite the fact that these interviews were not directly focused on treatment-induced hair loss, 46 per cent of participants felt that alopecia resulting from chemotherapy was more significant than the loss or partial loss of a breast. This suggests there is a need for further studies of women’s experiences of chemotherapy-induced alopecia.
In 2006, I conducted a phenomenological study to explore the experience of women with breast cancer with regard to chemotherapy-induced alopecia.

Methodology
Phenomenology is a philosophical movement dedicated to describing the structures of experience as they present themselves to consciousness, without recourse to theory, deduction, or assumptions from other disciplines such as the natural sciences. The purpose of phenomenological research is to describe experiences as they are lived, that is to capture the ‘lived experience’.
Philosophers who developed the phenomenology theory include Edmund Husserl, Søren Aabye Kierkegaard, Martin Heidegger and Jean Paul Sartre. Phenomenologists view the person as integral to the environment and they examine how a person interprets their experiences.
Phenomenologists agree that each individual has his or her own reality. However, the positions taken by these pioneers in phenomenology are different from those found in nursing today and may be difficult to understand.
A Heideggerian approach using a purposive sample was chosen to enable interpretation and understanding of women’s experiences of living with treatment-induced alopecia. Ethical permission to conduct the study was obtained from the ethics committee of the hospital in question.
Five women with breast cancer who had experienced chemotherapy-induced alopecia in the past 12 months gave informed consent to participate in the study.

Table 1. Degree of hair loss and length of time since completion of treatment (at time of interview)

<table>
<thead>
<tr>
<th>Participant</th>
<th>Degree of hair loss</th>
<th>Time since completion of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Partial</td>
<td>7 weeks</td>
</tr>
<tr>
<td>2</td>
<td>Complete</td>
<td>2 months</td>
</tr>
<tr>
<td>3</td>
<td>Partial</td>
<td>1 month</td>
</tr>
<tr>
<td>4</td>
<td>Complete</td>
<td>3 months</td>
</tr>
<tr>
<td>5</td>
<td>Partial</td>
<td>6 months</td>
</tr>
</tbody>
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Table 2. Demographic data

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. 1</td>
<td>56 years</td>
<td>Worked in the home</td>
</tr>
<tr>
<td>No. 2</td>
<td>55 years</td>
<td>Professional</td>
</tr>
<tr>
<td>No. 3</td>
<td>41 years</td>
<td>Worked in the home</td>
</tr>
<tr>
<td>No. 4</td>
<td>37 years</td>
<td>Professional</td>
</tr>
<tr>
<td>No. 5</td>
<td>48 years</td>
<td>Worked in the home</td>
</tr>
</tbody>
</table>
analysis, the data were returned to participants for further verification of the emergent themes. Table 1 details the degree of alopecia experienced and the length of time since completion of treatment. The demographic data of participants is detailed in Table 2.

Findings
Four main themes emerged following data analysis and four sub-themes were also identified (Table 3).

Themes
1. Importance of hair
The importance of hair was discussed by all participants. Three did not appreciate the significance of their hair until they lost it. The following statements portray the trauma associated with losing hair:

‘It hit me with a bang. I am not too sure if losing the breast affected me as badly, I actually couldn’t get over [the hair loss]. Your confidence is taken away without your hair.’

‘When I was first diagnosed and when I was told I’d be having chemotherapy, I thought that the hair loss would be the least of my worries when I heard about all the other side effects – like the nausea and that. [Hair loss] was a shock to me.’

‘Our hair is important to us. I wanted to hide [the hair loss] from my friends.’

‘It is the feminine side of somebody. If your hair is washed and shiny, no matter how bad you feel, you feel good. For a lot of people their hair is everything. People spend money on their hair.’

‘I mourned the loss of my hair. I suppose that is another thing about it. I’d go up to the bathroom and look at myself and say: “Will I ever get back to myself?”’

2. Threat to body image
Chemotherapy-induced alopecia poses a serious threat to body image (Munstedt et al 1997, Carpenter and Brockopp 1994, Rosman 2004). My study findings support this. For some, the threat to body image continues following the re-growth of hair. This suggests that hair loss has a long-term effect on body image and self-perception.

‘I mourned the loss of my hair. I suppose that is another thing about it. I’d go up to the bathroom, look at myself and say: “Will I ever get back to myself?”’

It is important to remember that treatment-induced hair loss not only involves the loss of scalp hair, but also hair from other parts of the body. The statements below show that some of the women who were interviewed felt unprepared for the loss of scalp and pubic hair. One woman stated that the loss of her pubic hair posed a serious threat to her sexuality and femininity.

‘It is not just your head hair, it’s everywhere. Don’t know if I should mention this, but the loss of pubic hair was also a shock to me. I felt really weird without it you know. I almost felt like a baby.’

Table 3. Themes and sub-themes

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Sub-themes</th>
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</thead>
<tbody>
<tr>
<td>Importance of hair</td>
<td>Living with the wig</td>
</tr>
<tr>
<td>Protecting loved ones</td>
<td>Feeling different</td>
</tr>
<tr>
<td>Threat to body image</td>
<td>Feelings of shame/lack of confidence</td>
</tr>
<tr>
<td>Thoughts on the future</td>
<td>Support</td>
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</tbody>
</table>

References


4. Thoughts on the future
All participants in this study spoke of their thoughts on the future. Many spoke about support, which is an important sub-theme. All considered formal and informal support to be important in helping them to cope with their hair loss. For some of the women interviewed, the re-growth of hair symbolised a return to normality; for others it was a source of anxiety. For one participant, hair re-growth promoted feelings of optimism. But for two women, their levels of confidence and self-esteem did not return to normal, even following re-growth of hair. All participants dealt with hair loss in different ways, reinforcing the idea that coping with chemotherapy-induced alopecia is a subjective experience.

‘My hair is coming back now. It is brilliant. I’m looking forward to the summer and leaving the wig off. The colour – you can get all types of hair dyes now – herbal colours and everything.’

‘I’m doing well now, it’s not such a big ordeal anymore – the hair – but I was thinking about it growing back again. It is probably going to grow back grey. That in itself is a bit of a trauma.’

‘Psychologically, I probably feel at my worst now than when I was going through the chemotherapy. I feel the future is out there somewhere and I have to deal with it. I suppose I don’t feel well enough yet to deal with all this change.’

Sub-theme
Living with the wig
The literature search did not reveal the concept of living with a wig to be an important issue for patients. However, ‘living with the wig’ did emerge as an important sub-theme in my study. All participants spoke of their relationship with the wig, especially the fact that it was uncomfortable and was associated with feelings of awkwardness. Despite their negative feelings toward the wig, participants were willing to endure the discomfort of wearing it in an effort to be accepted in society. All participants stressed the importance of taking the time to choose a suitable wig.

‘Initially, I would have said I wouldn’t bother (getting the wig), but definitely, you need the wig. Over the few months, you’re bound to go somewhere socially – somewhere you’ll need to dress up.’

‘If you weren’t feeling up to it, you might just buy in the first place you go to. I was lucky. I had one friend who insisted on dragging me around to all of the places.’

Conclusion
It is important that healthcare professionals adopt an individualised approach to educating patients about hair loss. As such an approach is vital, implementing a general check-list for educating all patients about hair loss would be beneficial. As a follow on to the findings of this study, I am involved in a working group on chemotherapy-induced alopecia. The group liaises with the Irish Cancer Society. Its aim is to standardise information to patients.

Implications for practice
When discussing treatment-induced hair loss with patients it is essential that healthcare professionals are aware of the social significance of hair. Only then can the issue be addressed in a sensitive and practical manner. The wig plays a significant role in allowing patients to continue with social interactions. Therefore, providing practical information on the fitting, cost and choice of a suitable wig is important to patients. Healthcare professionals should provide patients with a list of reputable wig suppliers in their area.

Patients need to feel comfortable addressing the issue of hair loss with family members, especially children. Information on how to approach the topic is essential to avoid unnecessary distress. The threat to body image and self-esteem posed by treatment-induced alopecia must also be acknowledged when educating patients. Programmes such as the ‘Look good-feel better programme’ should be made readily available in an effort to improve self-confidence and self-perception. Loss of hair other than scalp hair emerged as a source of distress for some participants in this study. Much of this distress was due to the lack of information provided to patients by healthcare professionals, who need to address the loss of body hair when talking about hair loss.

Healthcare professionals need to be aware that patients need support even following hair re-growth. Information on support groups such as Reach to Recovery should be readily available. While peer support from individuals or cancer support houses can be beneficial, healthcare professionals must also acknowledge that informal support from close family members and friends is beneficial to patients and should be discussed when educating them about chemotherapy.

In summary, written and verbal information on the physical and psychological impact of hair loss needs to be provided before starting chemotherapy. Reliable and up-to-date information on coping with chemotherapy-induced hair loss is available on websites such as CancerBackup (www.cancerbackup.org.uk/Home) and on the Irish Cancer Society’s website (www.cancer.ie/news/ronnie_drew_song.php).