Anticipatory Coping: Taking Control of Hair Loss

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Many women consider hair loss to be one of the most difficult and feared side effects of chemotherapy treatments. On learning they will likely lose their hair, women immediately begin anticipating the event and its impact on themselves and others. Anticipation of an unwanted event can lead to greater anxiety, fear, or depression, particularly if women see or find no options for gaining some sense of control. Anticipatory coping is the process of anticipation and preparation for an expected altered appearance. By researching options, making deliberate choices, and taking specific actions to determine their appearance without hair, women gain a greater sense of control of their changing appearance. This greater sense of control may ease or lessen feelings of fear and depression and help women to take control of other aspects of their lives that contribute to a greater quality of life during cancer treatment. Oncology nurses are in a unique position to help women turn their anxiety about hair loss into an anticipatory coping process, one that increases women’s sense of control over some of the outward changes taking place in their bodies and empowers them to make proactive choices regarding their overall response to cancer.

Which is more difficult, an unwelcome event or the anticipation of that event? In the process of anticipating events in life that trigger emotions such as reluctance, fear, or uncertainty, people often tend to envision the worst-case scenarios, possibly making the anticipation more difficult than the event itself. In the context of cancer and chemotherapy, many women anticipate and worry about the potential appearance changes that will result from treatment. Among women losing their hair because of breast cancer treatment, many indicate that coping with hair loss is more difficult than the loss of their breast because it is outwardly visible to others, affects their femininity, and is a constant reminder of their treatment (Benjamin, Ziginskas, Harmon, & Meakin, 2002; Kaderman, Kaderman, & Toonkel, 1999). Feeling helpless in anticipation of a negative or unwanted event may compound feelings of reluctance, fear, and depression. Just as anticipation of a hurricane stirs its potential victims to take action to protect themselves from the worst forces of the storm, so may anticipation of a major appearance change, such as chemotherapy-induced hair loss, propel women into actions intended to help them cope with their hair loss. The purpose of this article is to emphasize the emotional significance of chemotherapy-induced hair loss and the important potential role of oncology nurses in helping women turn their fear and anticipation of hair loss into proactive actions intended to increase their sense of control over their changing appearance.

At a Glance
- Hair loss can significantly impact a woman’s perceived quality of life during cancer treatment. As an oncology nurse, providing information and self-care strategies aimed at coping with alopecia in the care plan is important.
- Helping women turn their anticipation of hair loss into a proactive preparatory process may help to reduce their anxiety and give them a greater sense of control over their changing appearance.
- Women who feel more in control may be more likely to take other actions that can improve their overall quality of life during cancer treatment.

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Anticipatory coping, defined as the process of anticipation and preparation for an altered appearance (Frith, Harcourt, & Fussell, 2007), may play a key role in helping women to not just cope, but to rise above the assault to their self-image and self-esteem posed by sudden hair loss. Giving women the information and resources they need to turn anticipation of hair loss into proactive action is gaining attention in some cancer treatment programs, but more is needed.

As awareness of the relationship between emotional well-being and physical healing grows, cancer care is expanding to include emotional and appearance support. An increasing number of cancer treatment centers offer programs, such as the American Cancer Society’s ‘Look Good Feel Better’ program, which was designed to help individuals with cancer learn how to address appearance issues from the cancer and its treatment, improve their self-esteem, and manage their treatment and recovery with greater confidence. However, very little real understanding of, or attention to, the emotional impact of medical hair loss exists (McGarvey, Baum, Pinkerton, & Rogers, 2001).

Emotionally, when patients experience hair loss, they experience feelings such as anger, sadness, embarrassment, and fear of rejection (Batchelor, 2001). Despite this, some feel that the medical profession still tends to underestimate just how big an impact hair loss has on patients’ everyday lives (Rosman, 2004).

In the context of cancer treatment, alopecia is most often caused by certain cytotoxic drugs, but site-specific hair loss also may be associated with radiation treatment to the head. The likelihood of alopecia is related to the type of drug used and its schedule of administration (Lemieux, Maunsell, & Provencher, 2008). The emotional impact of hair loss may be underestimated because chemotherapy-induced hair loss is expected to be temporary.

Oncology nurses may become accustomed to seeing patients who have lost their hair and must ensure they do not become complacent regarding the patient’s emotional experience related to alopecia (Dougherty, 2007). Although the hair loss itself may be temporary, the negative emotional repercussions may be long lasting. Even after finishing treatment and regrowing hair, many women will continue to feel self-conscious and experience a persisting negative self-image. Rosman (2004) conducted a study (N = 35) exploring women’s experiences with chemotherapy-induced alopecia and highlighted the following reactions as those experienced by most of the study group: (a) not feeling prepared, (b) shock, (c) personal embarrassment, and (d) loss of a sense of self. The loss in self-confidence experienced by many women in the course of chemotherapy-induced hair loss often persisted even after the hair had grown back (Münstedt, Manthey, Sachsse, & Vahrson, 1997; Rosman, 2004). Among Münstedt et al.’s (1997) study participants (N = 29), 73% of the patients did not feel as self-confident as they did before cancer treatment. Apart from the initial diagnosis of cancer, alopecia often is characterized as the most traumatic disease-related event that patients with cancer will experience (Baxley, Erdmann, Henry, & Roof, 1984), as debilitating as the disease itself (Ucok, 2005), and is a constant reminder to patients of their disease. Münstedt et al. (1997) summarized this by saying,

In contrast to our expectations and the hypotheses in the literature, we were unable to detect any improvement after the chemotherapy was completed and patients had experienced hair re-growth and, presumably, undergone the suggested time-dependent adaptation processes during which physical characteristics were thought to become less important as measures of value while living itself was thought to become more important (p. 142).

The Power of Hair

Next to communication of the diagnosis, the start of hair loss is an important moment in becoming aware of the cancer (Rosman, 2004). Alopecia often is rated as one of the most common, feared, and traumatic aspects of chemotherapy (Münstedt et al., 1997), and may even be considered emblematic of the treatment and of cancer itself (Frith et al., 2007). Freedman (1994) stated that,

Embodied in the symbolism of hair is a concept of the whole self, a completed person, who has the possibility of expressing individualism through the design of her hair. The loss of hair is an extremely traumatic experience precisely because it is the symbolic precursor to the loss of self (p. 336).

Women’s hair is used as an indicator of personality, attractiveness, sexuality, and femininity. The symbolic power of women’s hair seems particularly evident when one considers the common practice of covering a woman’s hair among more modest cultures or religions. In present day mainstream American culture, it seems as if no amount of hair is enough hair for appearance-conscious women, evidenced by the popularity of hair volume products such as hair extensions, volumizing shampoos and sprays, and hair accessories designed to give the appearance of more hair. In this context, the fact that chemotherapy-induced hair loss has been characterized as a significant psychosocial stressor is not surprising (Hesketh et al., 2004).

Without hair, many women may find their identity and femininity altered, and find it even more difficult to maintain the sense of optimism that can help them cope and to maintain hope. These women need options and resources for turning their fear and anticipation into actions that reinforce their sense of control, boost their self-esteem, and give them courage to take other actions that may help improve their quality of life during cancer treatment, such as maintaining social relationships, exercising, and remaining open to joyful experiences.

Anticipatory Coping

Frith et al. (2007) used an interview-based study of 19 women to identify four key themes in women’s anticipatory coping.
mechanisms: (a) anticipating hair loss, (b) coming to terms with the inevitability of hair loss, (c) becoming ready, and (d) taking control. Frith et al. (2007) referred to this form of anticipatory coping as a process of thought and behavior rehearsal that women employ in an effort to feel more in control of their experience of the side effects of chemotherapy. Some women’s attempts to “take control” include actions intended to prevent hair loss, such as cold cap treatments or choosing chemotherapy drugs that are less likely to cause hair loss. For many women, though, hair loss is an unavoidable side effect of their treatment. Among Frith et al.’s (2007) study participants, even those women 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. In studying a woman’s emotional experience of her symptoms, focusing on the patient’s perception is important because the intensity of symptoms may not reflect amount of distress (Boehmke & Dickerson, 2005). Image-related issues may be secondary to survival issues, but the suffering because of a loss of control of one’s bodily appearance and self-presentation may be significant and, for some women, as debilitating as the illness itself (Ucok, 2005).

Behavior rehearsal, in which a woman imagines herself without hair and practices preparing herself for public outings, allows some women to manage anxiety about hair loss. Through behavior rehearsal, women learn to master new styling or dressing techniques and, in the process, reassure themselves that they have the material and emotional resources to cope with hair loss when it happens. It also may be an opportunity to prepare others for their altered appearance. According to Frith et al. (2007), women anticipate their hair loss and try out different emotional reactions, testing the opinions of others in advance of actual hair loss. Aspinwall and Taylor (1997) highlighted the following activities as part of an anticipatory coping process: resource accumulation, initial appraisal of the impact of the event, initial coping efforts (activities to prevent or minimize the event), and elicitation and use of feedback.

Being in control of hair loss, such as deciding when and where it will occur, is important to many women, particularly when so many aspects of the disease, the treatment, and its side effects seem outside of personal control. McGarvey et al. (2001) referred to this as a problem-focused coping strategy employed because, while the event itself (alopecia) is not changeable, a woman’s outward appearance can be managed. Despite this, a prevalent assumption exists among well-meaning medical professionals and cancer care support staff that women undergoing cancer treatment are unwilling or unable to put effort, thought, or significant financial resources into finding or purchasing medical headwear. Such presumptions may stem from a lack of understanding of the potential for unique, fashionable, and high-quality headwear products to help improve a woman’s self-image. In addition, these sorts of presumptions may reinforce feelings of guilt experienced by women who privately feel ashamed and self-critical for being “vain” for caring about their appearance in the context of a life-threatening illness (Gallagher, 1997). It may be that a preparation process that includes searching, considering multiple options, and selecting headwear items that increase a woman’s comfort level with her changing appearance are behaviors that reduce anxiety and increase sense of control over changing appearance. By failing to consider some of the psychological motivations behind particular practices and strategies, healthcare professionals may miss the opportunity to help patients enhance feelings of control (Frith et al., 2007). During the anticipation phase, adaptive self-care strategies to prepare for and cope with chemotherapy-induced hair loss should be encouraged (Hesketh et al., 2004). This means going beyond simply informing a patient that she will lose her hair, as knowing hair loss will occur does not necessarily prepare a patient for the experience (Dougherty, 2007).

Preparation

Oncology nurses can help prepare women for the emotions they and their loved ones may experience as a result of chemotherapy-induced alopecia. Prechemotherapy teaching to address chemotherapy-induced alopecia is a perfect time to begin to educate the patient with written and verbal explanations. Conducting an initial conversation with the patient regarding her past experiences with illness, treatment, and hair loss is an important starting point for teaching self-care strategies related to alopecia. Listening to a patient verbalize what hair loss will mean to her and her significant other, with attention to the amount of perceived support that is available to the patient, will help to individualize self-care strategies. Being proactive and addressing concerns helps in formulating a care plan. By using the face-to-face time to prepare the patient, oncology nurses can play an important role in helping to minimize and manage the patient’s emotional distress as she deals with the hair loss at home. Oncology nurses can teach their patients skills for optimizing appearance during cancer treatment by talking about available choices for head coverings, encouraging patients to experiment with different looks through behavior rehearsal, or by referring them to appearance support programs. This is akin to the role of nurses in “hope instillation” intended to “expand the patient’s repertoire of coping mechanisms” (Dougherty, 2007, p. 146).

Oncology nurses can teach their patients skills for managing their emotions and appearance during cancer treatment by talking about strategies for reducing anxiety and grief, such as cutting or shaving the hair before it falls out, talking about available choices for head coverings, encouraging patients to experiment with different looks through behavior rehearsal, or by referring them to appearance support programs. In addition, oncology nurses can help patients regain some sense of control over their changing appearance by teaching them what to expect and helping them develop a plan for managing some of the most emotionally challenging side effects. A cancer diagnosis usually translates to a loss of control of one’s life in many ways. When oncology nurses acknowledge the disturbing impact chemotherapy-induced alopecia has on their patients and play an active role in providing women with information and tools to help them cope, patients can more easily move through this challenging time to a renewed sense of well-being (Batchelor, 2001) and improved quality of life (McGarvey et al., 2001).

Findings

4Women.com, Inc., which helps women and young girls cope with the emotional upheaval of medical hair loss by providing
appearance solutions and by advocating for greater awareness of
the emotional impact of medical hair loss, conducted an online
survey exploring women’s anticipatory coping strategies and
the significance of hair loss as a side effect of chemotherapy. An
e-newsletter was sent to 1,322 women who are cancer survivors,
women currently battling cancer, and a small number of women
diagnosed with cancer who had not started their treatment. The
online survey consisted of six questions, some multiple choice
and some open-ended, created by the second author of this
article. All questions offered a space for respondents to provide
additional comments. The survey was voluntary and anony-
mous. Three hundred
and nineteen women
(24%) responded and
completed the survey.

The response rate may
have been affected by
using a Web-based
methodology because
the study participants
to have access to
a computer as well as
some degree of com-
puter literacy. In addition, women had to demonstrate enough
interest in their hair loss to open and read the e-newsletter and,
subsequently, complete the survey. Women who were very ill
were possibly less likely to participate.

For the question “What, if anything, did you do that helped
you to manage your anxiety about hair loss?”, 83% of respondents
indicated shopping for headwear items prior to losing hair, 40%
talked to other women who had gone through chemotherapy and
lost their hair, and 23% talked to their doctor, nurse navigator, or
other cancer care team member.

When asked to rate the importance of feeling some sense of
control over a changing appearance in the context of cancer
treatment, 70% of respondents indicated extremely important,
27% indicated it was one of many important issues, and 2%
indicated it was not important (1% gave no response). Some of
the participants elaborated on the answers given.

We survive by not just feeling in control, but by actually
being in control. There are many choices out there, every
woman needs access to and to know all their choices so
they can choose for themselves. For women with breast

cancer, hair loss will be only one of many other ways her
appearance will change with treatments. With that part
under control, one burden will be lifted and we can move
on to others with less load.

I still wanted to “fit in” and not have others treat me other-
wise. As long as possible it is important for the quality of
life, even when your quantity of life may be shorter.

During this period of uncertainty and fear, being able to
grasp even the smallest sense of control is very empowering.

I think it is so important that it even determines the out-
come of their treatment.

This last sentiment exemplifies what Holland and Lewis
(2000) refer to as the “tyranny of positive thinking.” Patients
are led to believe that if they fail to keep a positive attitude they
can prevent their own healing or, worse, cause their tumor to
grow faster. Holland and Lewis (2000) devoted a chapter in their
book to demonstrating, through case study conversations with
patients, just how the tyranny of positive thinking invalidates
people’s natural and understandable reactions to a threat to
their lives.

According to the survey respondents, the most common form
of information provided by cancer care staff to help women
identify or take actions to increase their sense of control over
hair loss were resource options for scarves, wigs, or hats. One
respondent shared,

My surgeon knew no resources and yelled at me for bothering
him, but with my insistence, my oncologist added wig/
scarves [information] to the drug/side effects packets they
give out before chemo[therapy].

Another respondent wrote,

They didn’t even tell me about Look Good, Feel Better in
the very same hospital I was getting chemo[therapy]. I
found that on my own!

Although many women are benefitting from resource informa-
tion provided by cancer care professionals, a disconnect still
exists between those treating the disease and those focused on
healing the patient, even when such programs and profession-
als work side by side in the same medical care facility. Directly
touching upon the importance of anticipatory coping for an
optimistic attitude, one respondent wrote,

I cannot stress enough the importance of taking control
of your changing appearance. I got used to new looks and
make-up before my hair fell out. I was ready for it . . . and
my attitude was, “Bring it on.”

In response to the open-ended question, “What would you
advise other women anticipating chemotherapy-induced hair
loss to do to ease their own anxiety and increase their sense of
control over the appearance changes they are facing?”, many
women listed getting a short haircut prior to initiating che-
motherapy and shaving their head once hair loss began as the
most important actions they took or regretted not taking in an
attempt to maintain a greater sense of control over their chang-
ing appearance. A number of women also described the painful
scalp sensations that accompanied their hair loss, explaining
that they received no prior information preparing them for it
and that the pain made it much more difficult to find options
that helped them maintain some sense of normalcy in their ap-
pearance without adding to their pain or discomfort.

Many survey respondents pointed out the very individual and
personal nature of how one reacts to the medical hair loss that
accompanies many chemotherapy treatments. For some women,
the fear of death is extreme and largely separate from the more
physical manifestations of the disease or its treatment. Similar
to the work of Lemieux et al. (2008), who found a minority
of women for whom alopecia is perceived as a sign of the efficacy
of chemotherapy, comments were made by the respondents
characterizing alopecia as a reassuring side effect.

For many women, going about life as if all is normal is of
primary importance. Hair loss becomes a major visual obstacle
to maintaining focus on day-to-day life, rather than the disease.
For some women, wigs are essential to their sense of confidence in public. Although many women are advised to purchase at least one wig before their hair falls out, a number of survey respondents commented that they regretted having purchased wigs early on as they were expensive and, ultimately, something they did not wear, either because they were uncomfortable or because they made them feel more self-conscious. One survey respondent said, “It takes time to find your own style during this time of transition. Being prepared with as many options as you can gives you a sense of control. Even if you never wear your wig or the scarves or the hats, it is empowering to have options readily available.

Although giving women tools and resources to foster some sense of control over chemotherapy-induced appearance changes may not determine the outcome of their treatment, helping women feel better about themselves in the face of cancer can both raise their self-esteem and help them to feel that they are facing cancer with a more positive outlook; again easing some of the burden they feel about managing or controlling their responses to cancer.

Conclusions

Chemotherapy-induced hair loss poses significant emotional challenges to women wishing to maintain a sense of normalcy, their self-esteem, and a high quality of life despite cancer treatment. Many women begin anticipating this unwanted side effect almost immediately upon learning they will need chemotherapy. During this period of anticipation, women can benefit greatly by exploring head wear and appearance-enhancement options and by taking actions that help them feel prepared for their hair loss. Rather than minimize hair loss as a temporary or merely external side effect of chemotherapy, oncology nurses can play an important role in helping women turn their anticipations into a proactive coping process by discussing options and providing patients with the informational resources that will enable them to make proactive choices. Helping women facing cancer proactively prepare for their appearance changes that will accompany chemotherapy is a necessary element of medical care geared toward treating the whole patient. As programs and counseling approaches spread, attention to the role of anticipatory coping mechanisms will hopefully spread with them.

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