

Review

Cancer-related hair loss: a selective review of the alopecia research literature

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Abstract

Objective: Alopecia is a common side effect of cancer treatment, affecting approximately 65% of patients. Healthcare providers and allied staff recognize that alopecia is distressing for people with cancer; however, they are often unaware of the extent of distress or the great efforts expended by patients to cope with hair loss. This study reviews the existing literature regarding the psychosocial impact of alopecia on cancer survivors and the coping strategies they use to manage hair loss.

Methods: We searched for studies examining the psychosocial effects of alopecia on cancer survivors using PubMed and PsycInfo databases and Google Scholar.

Results: A total of 36 peer-reviewed articles were deemed relevant to be included in this review. In this review, alopecia was consistently ranked as one of the most distressing side effects of cancer treatment. Survivors report that hair loss disrupts how they experience their bodies, interact with others, and conceptualize their body image beyond treatment. Although upsetting for both genders, the scarce literature that exists suggests that there may be some gender-specific aspects of experiencing cancer-related hair loss. Cancer survivors cope with alopecia in numerous ways and often rely on strategies such as concealment, social support, social avoidance, information seeking, and behavioral rehearsal.

Conclusions: Treatment-induced alopecia negatively affects millions of survivors each year in unique and nuanced ways. We hope that survivors' healthcare providers and loved ones may better appreciate the psychosocial challenges they experience related to hair loss, as well as the strategies they use to cope. Further research is much needed to better understand cancer-related alopecia.

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Introduction

Cancer patients experience multiple physical changes that may affect their attitudes towards their identity, body image, and interactions with others [1–4]. There has been increasing recognition of the impact of cancer-related hair loss on the lives of individuals with cancer [5–7], particularly women [8–10]. Existing research suggests that alopecia is regarded as the most traumatic side effect of cancer treatment [2]. This paper provides a selected review of the alopecia literature, focusing on the psychological impact on cancer survivors, and is unique from existing literature reviews because it places greater emphasis on the social implications of alopecia in cancer patients by focusing on the link between appearance and identity. Cancer-related alopecia not only affects how individuals perceive themselves but also how they are perceived by others.

Methods

We conducted a literature review using PubMed and PsycInfo databases, and Google Scholar. Standardized terms and keywords were combined in the search for the following concepts: oncology/cancer, alopecia/chemotherapy-induced alopecia/hair loss, identity, appearance, body image, psychological impact, quality of life, depression, and anxiety. All searches were completed between March and May 2014 and limited to English language articles examining alopecia in humans with cancer. The primary author reviewed the titles and abstracts of the literature search for potential inclusion. If a determination about inclusion could not be made from the title and/or abstract, the full article was obtained and reviewed. Duplicates were identified and removed. The references of selected articles were searched for any additional relevant articles.

Cause of alopecia

There are multiple classes of anti-cancer drugs that can induce alopecia, and combination therapy (consisting of two or more agents) usually produces higher incidence of more severe hair loss when compared with monotherapy [11]. Chemotherapy-induced hair loss is a consequence of direct toxic insult on the rapidly dividing cells of the hair follicle [12]. Hair loss can be diffuse or patchy, involve scalp and body hair or just scalp hair, and may occur suddenly or gradually over time depending on the individual and type of treatment [12]. Chemotherapy-induced alopecia typically occurs within 3 weeks of the first chemotherapy exposure [13]. For some individuals, complete hair loss may occur within 2 to 3 months. Generally, hair loss is reversible, with hair regrowth typically occurring after a delay of 3 to 6 months after the completion of chemotherapy. In some patients, the new growth is different in color and/or texture.

Impact of alopecia on the individual

Trauma associated with alopecia

For many individuals, alopecia is a traumatic experience that can be stigmatizing and may result in feelings such as anger, embarrassment, sadness, shame, helplessness, and fear [2,5,14,15]. Although little systematic research has been performed to fully measure the psychological effects of alopecia, it has been associated with anxiety, low self-esteem, depression, and loss of sense of self in cancer patients [16]. In a study of nearly 300 individuals with non-cancer-related alopecia, psychiatric disorders were significantly more common than in the general population; thus, people with alopecia may be at higher risk for developing major depression or an anxiety disorder [17]. Alopecia can represent a loss of vitality, health, and physical strength [18]. It is a visual symbol of cancer identity and treatment [2,15,19,20], which can heighten an individual's awareness that they have a life-threatening illness [16,17,21]. Alopecia can be suggestive of cancer, even when an individual wears a wig as hair pieces is sometimes obvious to others (e.g., when they do not fit exactly or do not match one's skin tone).

Social context of appearance

Appearance is an important part of how people view themselves because it allows people to tell others who they are as individuals and impact how they want others to perceive them [22–24]. Specifically, facial features and hair are critical aspects of appearance that facilitate recognition and allow individuals to be categorized as female or male, young or old, and healthy or unhealthy. The process of categorization influences how individuals behave in a social context as well as how others will interact with them. Individuals often have heightened awareness of

their bodies during social interactions when there are noticeable changes in appearance such as alopecia. As Ucock explains, it is through 'the responses of others to our bodily presence in social interaction we find out about the social meanings of our bodies, get used to them (even to the degree of being attached to them) and make them a part of ourselves' [10, p. 304]. Because appearance reflects important aspects of identity, managing one's appearance allows one to control the perceptions that others have about them [22]. For example, a cancer patient with alopecia may decide to wear a wig (i.e., control their appearance) so that others do not realize their cancer status (i.e., to claim a healthy identity). Appearance plays a key role in how individuals define themselves and are defined/perceived by others.

Concerns/distress about appearance

Individuals may become alienated from their bodies and personal identity if alopecia disrupts the way they experience their bodies (i.e., their hair grows back differently, etc.). This difference from their past or ideal body may make individuals feel increasingly self-conscious [25]. According to a study examining the frequency of appearance-related symptoms and distress in 638 cancer patients receiving chemotherapy, 86.6% of female patients were concerned about some aspect of their appearance [26]. Similarly, in a study of 37 male and female cancer patients, researchers found that although 80% of participants were concerned about their appearance, women reported greater appearance-related distress than men [24]. The analysis of adolescent female cancer patients of Wallace *et al.* [27] found that appearance concerns were a significant part of the cancer experience and endorsed as the 'worst' part of treatment. Participants dealt with these concerns by restricting social activities and refusing to go out in public without having their head covered.

Body image

Alopecia may be the one of the most difficult corporeal features of cancer due to the impact it has on body image [15,16,20,28,29]. Body image is composed of appearance (dis)satisfaction, appearance investment, appearance behavior, and emotions related to appearance [30]. Appearance investment is composed of the following: (1) self-evaluative salience, which is the importance one places on physical appearance in defining self-worth and self-concept and (2) motivational salience, which refers to one's efforts to engage in appearance management behaviors to improve attractiveness. Moreira and Canavarró [30] found that higher levels of self-evaluative salience predicted lower psychological and social quality of life, higher levels of depression, and increased fear of others' negative evaluations in cancer patients. Higher levels of motivational salience protected against these factors. According to Can *et al.* [5], body image is poorer in younger cancer patients than older

patients, patients with lower income than those with moderate income, and patients with breast cancer than those with other types of cancer.

Psychological reactions to appearance changes

Patients may experience negative thoughts and feelings about their appearance that last well beyond treatment [25]. Frith *et al.* [8] found that body image was poorer during treatment and did not return to pre-treatment levels when hair returned. Moreira and Canavaro [3] compared newly diagnosed breast cancer patients and survivors on levels of self-consciousness about appearance and appearance investment as well as how appearance investment moderated the relationship between psychological adjustment and appearance self-consciousness. While newly diagnosed women were significantly more anxious than longer term survivors, their increase in self-consciousness about appearance was related to an increase in depression and anxiety as well as a decrease in psychological quality of life regardless of their level of appearance investment. For longer term survivors, an increase in self-consciousness about appearance was only associated with an increase in depression if the survivor was highly invested in their appearance as a component of self-worth.

Gender identity and gender differences

Perceptions of appearance are an important aspect of gender identity, particularly within a societal context. In a review of children's books about alopecia, Coles [31] found that books for girls portray alopecia as a difficult, scary, and traumatic experience; hair loss may affect girls' social identity because of others' confusion about their gender, leading to identity loss, fear, and sadness. On the other hand, books directed at boys, depicted alopecia as part of cancer treatment that could be a positive experience, allowing boys to explore identity, challenge appearance norms, and show their uniqueness or individual strength. Moreover, adults who hold traditional gender roles and attitudes may be more self-conscious and pay more attention to gender-specific aspects of appearance. This may lead to body shame and lower quality of life because they are more likely to internalize societal appearance norms and invest in their appearance [32].

There are very few studies examining gender differences in the way that cancer patients react to hair loss. A 2008 study comparing men's and women's experiences of alopecia found that both men and women expressed negative and often similar feelings about hair loss [24]. Alternatively, another study found that women with alopecia experience significantly more distress, self-consciousness, social anxiety, dissatisfaction with appearance, and overall life dissatisfaction compared with men [23]. Similarly, a study examining how 35 cancer patients coped with hair loss found that male participants were more likely to view

hair loss as a normal and inevitable side effect of treatment, while women were more self-conscious about their appearance [18]. The generalizability of the latter finding is limited because of the small sample size.

Women with alopecia may experience a loss of sense of femininity, sexuality, attractiveness, self-confidence, and womanhood [9,14–16,20]. They may have lower social, physical, and total well-being than female patients without alopecia [20]. In a study reported by Roark [33] of 'Look Good Feel Better' (a psychoeducational intervention designed to boost self-esteem and quality of life) participants, 79% of women reported that cancer treatment had a somewhat negative or greatly negative impact on their psychosocial well-being, and 83% reported that their quality of life was impacted by treatment. Can *et al.* [5] found that women with any form of alopecia reported lower psychological well-being than men. Their study also found women with complete alopecia reported lower social, physical, and general well-being than men with complete alopecia. In contrast, other research indicates that survivors may come to accept and view their changed bodies as a sign of strength [25]. They learn that they can rely on their bodies to withstand the effects of cancer treatment.

Coping strategies

Existing research demonstrates that alopecia is a stressor for cancer patients [1,16]. Cancer patients use a variety of strategies to cope with alopecia such as social avoidance, concealment, social support, information seeking, and behavioral rehearsal. These strategies are not mutually exclusive and may be used by individuals at different times.

Research suggests that some patients with alopecia may use social avoidance or minimize social activities because they are worried that others will treat them differently because of their appearance [2,14,16,20,25]. In a study of 23 Danish cancer survivors, Rasmussen *et al.* [4] found that survivors were more likely to be concerned with how visible bodily changes such as alopecia affected social interaction. Seventy-five percent of participants reported experiencing silent stares from others and attributed such stares to their 'cancer appearance', for example, one participant, who worked as a teacher, recounted an experience when a pupil's parent crossed the road to avoid talking to her. Study participants also believed that their altered appearance was what others focused on and reported that people they knew tended to avoid public contact with them regardless of whether changes in appearance were readily visible to others. This occurred even with those who knew about their diagnosis. As a result of feeling 'different', participants may choose to avoid or minimize socializing with others.

Another coping strategy used frequently by cancer patients with alopecia is concealment, reflecting how society

perceives illness and disability in general – as conditions that should be hidden by individuals and societies visually and verbally. Williamson *et al.* [7] argue that the teasing, staring, questioning, and avoiding by peers experienced by adolescents with cancer reflected the important psychosocial consequences of ‘looking different’. Adolescents reported trying to maintain a normal appearance in order to distract others and themselves from appearance changes, reject a cancer/illness identity, and avoid sympathy or unwanted attention [7]. Adolescents may exhibit greater concern about appearance changes related to alopecia because they are already paying more attention to their bodies; thus, adolescents who look different may be more vulnerable to low self-esteem and ridicule from peers.

In her analysis of adult cancer patients in France, Rosman [18] found that men were more likely to put their baldness forward as a banality and not protect others from it. Other studies have found that women were more likely to be encouraged by others to cover their hair loss [24,26]. Hiding hair loss allows women to avoid being pitied by others and simultaneously (re)affirms that in a healthy society, people must ‘look right’ [34]. Although using wigs and other forms of headwear may be beneficial for some women because it allows them to individualize their appearance and regain control over it [20], such strategies may make their cancer status more visible to others because these items are symbolic of cancer treatment [20]. Interestingly, in a study of breast cancer patients by Kim *et al.* [2], none of the patients planned ahead for alopecia but opted to purchase wigs or hats once they began losing their hair. It is unclear whether this reflects optimism, denial, or avoidance.

Social support may help cancer patients cope with alopecia. The analysis by Williamson *et al.* [7] of adolescent cancer patients found that their friends and family members offered support, reassurance, and acceptance for their altered appearance by giving compliments, comparing teens to positive role models, protecting and shielding them from negative reactions, and helping them manage change in general. Adolescents were also able to manage the reactions of others by assessing social events, particularly contextually, to determine if/when it was safe to reveal their altered appearance to others as well as warning others of any appearance changes prior to interaction. In a qualitative study of 21 adult breast cancer patients by Kim *et al.* [2], patients reported less distress if they had emotional support from family.

Previous research has suggested that cancer patients felt that they were not given adequate information about how to prepare for or manage life with cancer-related hair loss [2]. Female cancer patients can turn to programs that teach women how to use makeup, wigs, scarves, and hats to hide the effects of chemotherapy, such as ‘Look Good Feel Better’ [10,35]. There are mixed findings about whether or not these programs are effective in helping

women cope with hair loss [23,36]. Some studies have found that participating in such programs may help women cope with alopecia and other appearance changes by distracting them from treatment, providing psychosocial support, and helping them feel better about themselves [14,25]. In contrast, Taggart [36] found that although program participants reported statistically significant improvements in self-image and reduced anxiety because they looked and felt more normal, participants did not receive as much social support as they had anticipated prior to beginning the program. Others have suggested that programs like ‘Look Good Feel Better’ are too limited in the coping strategies presented [23], particularly in terms of embracing baldness [37].

Cancer patients may choose to adapt to alopecia through behavioral rehearsal, such as trying out new hairstyles or preparing others [15]. A 2007 study by Frith *et al.* [8] found that the coping process for breast cancer patients expecting to lose their hair consisted of the following potential stages: anticipating, coming to terms with, becoming ready for, and taking control of the change in their appearance. Women became ready for the onset of alopecia by trying out and/or purchasing wigs or scarves. This allowed them to prepare themselves and others for their new appearance and to manage anxiety. Finally, women took control of their experience by proactively cutting their hair or shaving their head so that they could decide when and how hair loss happened, perhaps with the expectation that taking control of the process would make it easier to bear [see also 21, 24].

Psychological interventions that may be helpful for patients with alopecia include discussion about previous successful coping, both to remind them that they have coped with previous stressors, as well as to explore potential coping strategies familiar to the patient that can be incorporated into their efforts to cope with hair loss [38,39]. In addition, normalizing the patient’s experience and putting it into context [40] can support their self-concept and sense of self-efficacy. Finally, mindfulness and acceptance-based interventions can help patients with alopecia to acknowledge and observe unpleasant thoughts and feelings about their hair loss while supporting engagement in meaningful and valued life activities [41].

Lessons learned

There are several lessons that can be learned from existing research in this area. First, there may be some perceived benefits associated with hair loss. For example, Williamson *et al.* [7] report that individuals believed that alopecia had given them a new perspective and appreciation of personal qualities not associated with appearance. Similarly, Kim *et al.* [2] found that individuals believed that they had a better understanding of others in similar situations, appreciated small things that they previously took for granted, and became more considerate after experiencing

alopecia. They perceived new hair/the return of hair as representing hope, life, and renewal. Some individuals may come to realize the importance of defining themselves and others in ways unrelated to appearance. Second, studies have shown that there is a demand for more information and support for how to prepare for and manage alopecia [2,10]. Although some respondents preferred to get this information and support from clinicians, others preferred to receive it from experienced patients or survivors so they could learn more about how to manage and/or conceal appearance changes in their daily lives. Aside from support, appearance-focused programs give women a sense of control over their appearance by providing them a set of resources they can use to deal with appearance changes. However, it is unclear if these programs facilitate women psychologically coping with such changes or if they present baldness as an equally viable option for appearance.

Implications for future research

Existing research shows that alopecia is a traumatic, distressing experience for individuals. The experience tends to be more difficult for women although the reasons for this are hard to discern because most of the studies in this area focus on women. None of the studies of alopecia focus solely on men, so the few studies that focus on gender differences are the only source of information about what the experience is like for men.

There are many gaps in the existing literature. There is little research that explores the racial, ethnic, or cultural differences in how individuals experience and cope with cancer-related alopecia. Relatedly, it would be useful to examine if coping strategies vary by age or are there a set of universal strategies that people use when coping with alopecia?

There is a lack of research focused on resilience in cancer patients with alopecia, particularly in regard to who is resilient in coping with it or how distress can be eased [8,28]. It would be useful to explore if and why certain individuals with alopecia display greater resilience than others as well as identify potential psychological strategies for easing alopecia distress. Also, future research could examine how individuals adjust to and cope with hair regrowth. Do individuals continue concealing their hair loss until their hair returns to its previous state, or do they stop concealment before then? Similarly, how do individuals cope with hair regrowth that is different than before (i.e., color, texture, etc.)? Are they more likely to adjust to and/or accept their new appearance because they are grateful to have hair again, or do they try to change their hair so that they can reclaim the appearance they had before they had alopecia? Perhaps, further investigation could help to determine whether there are particular approaches to coping that are more likely to yield resilient outcomes.

Conclusions

Alopecia is a traumatic experience for many cancer survivors. The change in appearance caused by alopecia may lead some survivors to experience a sense of identity loss and distress because they have difficulty accepting their altered appearance. These appearance changes may lead survivors to be recognized as cancer patients because alopecia is a well-known indicator of cancer status. Individuals, particularly women, may find alopecia distressing or may have difficulty coping with it. Survivors cope with alopecia by social avoidance, behavioral rehearsal, information seeking, and social support. Healthcare providers will benefit from having a greater appreciation for difficulties survivors with alopecia may have in coping with appearance changes.

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