Clinical review

The psychological impact of alopecia

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Alopecia is a chronic dermatological disorder in which people lose some or all of the hair on their head and sometimes on their body as well. It is a chronic inflammatory disease that affects the hair follicles. It is neither life threatening nor painful, though there can be irritation of the skin, as well as physical problems resulting from the loss of eyelashes and eyebrows. The aetiology and subsequent development of alopecia is not fully understood, but it is an autoimmune disorder that arises from a combination of genetic and environmental influences.[1] We have included alopecia secondary to chemotherapy in the current review as, although there are fundamental aetiological differences, they may share similarities—for example, anxiety arising from the alopecia and the psychological impact relating to identity.

Alopecia has few physically harmful effects, but may lead to psychological consequences, including high levels of anxiety and depression. Medical treatment for the disorder has limited effectiveness, and the failure to find a cure can leave patients very distressed. This article reviews the research into the psychological impact of alopecia.

Summary points

- Little systematic research has examined the psychological effects of alopecia
- Alopecia can be associated with serious psychological consequences, particularly in relation to anxiety and depression
- Alopecia is a form of disfigurement that can affect a person's sense of self and identity
- No randomised control trials have explored the effectiveness of psychological treatment for alopecia
- Alopecia can be caused by traumatic events
- Alopecia after a traumatic event can make dealing with that event difficult

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Sources and selection criteria

We conducted the searches for this clinical review in September 2005 through Ovid, focusing particularly on Medline, PsycINFO, ScienceDirect, the Cochrane Library, and the Web of Science. Searches went as far back as 1980. The main terms used were: alopecia, stress, psychology, treatment, anxiety, depression, and trauma. We also examined the reference lists of articles found. We included all studies that focused on the psychological consequences of alopecia, irrespective of method used. Studies were excluded if they focused on androgenetic alopecia. We included studies relating to hair loss from chemotherapy, as some of the evidence shows that such hair loss can be psychologically damaging beyond the impact of the chemotherapy. We included a total of 34 studies in the analysis (table).

Prevalence and clinical features

Alopecia is a common disorder, with an estimated lifetime prevalence of 1.7%,[2] though this figure is not a reliable estimate, as few epidemiological studies have been published[3] owing partly to under-reporting. We cannot break this figure down further to explore the frequency of alopecia by sex or age as much alopecia goes unreported.

Different types of alopecia may be qualitatively different. Alopecia areata involves the loss of patches of hair from the head, varying in size from about 1 cm to relatively large areas. Individuals with limited hair loss are more able to cover the loss with remaining hair and so are less likely to experience psychological problems such as post-traumatic stress disorder (with alopecia as the distressing traumatic event), anxiety, or depression. Small patches of hair loss are relatively common in pregnant women.

People with alopecia areata may have spontaneous remission but may also have repeated episodes. The hair that grows back is not always of the same type, colour, and texture as it was before. Alopecia areata is sometimes responsive to medical treatment, though the effectiveness of such treatment is unclear.[4]

Alopecia totalis involves the loss of all hair on the head, and alopecia universalis involves the loss of all head and body hair. These two forms of alopecia are far less responsive than alopecia areata to treatment, and the patient is much less likely to experience substantial regrowth. Alopecia totalis and alopecia universalis are estimated to account for 7% to 30% of all alopecia cases.

Alopecia is also caused by chemotherapy. Once chemotherapy is stopped, the hair tends to grow back, but as with other types of alopecia (such as areata, totalis, and universalis) it may not be the same as before.

Type of studies included in analysis of the psychological impact of alopecia

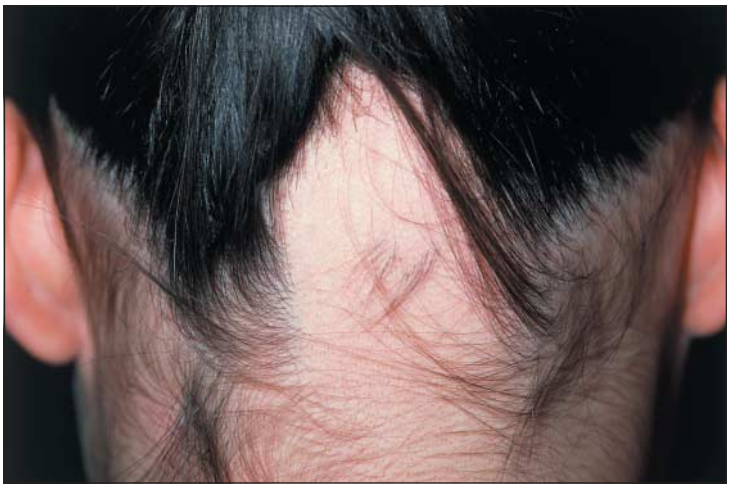
Type of study	No of studies included
Controlled	17
Before and after treatment	3
Assessment of patients at clinic	4
Quantitative self report measures or assessment by psychiatrist	4
Qualitative	4
Case study	2

Psychological problems associated with alopecia

Research into the associated psychological problems relating to alopecia has often not been thorough and systematic. Such research is often secondary to another aim of the research (for example, effects of a treatment). Such evidence as exists supports the view that the experience of alopecia is psychologically damaging, causes intense emotional suffering, and leads to personal, social, and work related problems.[5] There is an important link between hair and identity, especially for women.[6] About 40% of women with alopecia have had marital problems as a consequence, and about 63% claim to have had career related problems.[7] The extent of alopecia is one of the predictors of psychological distress. People with severe hair loss are more likely to experience psychological distress.

Some studies do not fully support the notion that alopecia is distressing,[8] though these often still show that people with alopecia have more problems than controls. Several decades ago, alopecia was considered to be a psychosomatic disorder, but the limited research was associated with serious methodological problems, such as poor psychiatric evaluation instruments, poor diagnostic criteria, and inadequate classification systems.[9]

Psychiatric disorders are more common in people with alopecia than in the general population, suggesting that those with alopecia may be at higher risk for developing a serious depressive episode, anxiety disorder, social phobia, or paranoid disorder.[10] In another study some alopecia patients experienced an ongoing feeling of loss, showing that for some individuals, coping with alopecia may be equated with grieving after bereavement.[11]



Head of a 22 year old woman showing area of hair loss due to alopecia areata

Most of the research shows that people with alopecia have higher levels of anxiety and depression than controls. They also experience lower self esteem, poorer quality of life, and poorer body image.[12] Those who lose eyebrows and eyelashes may also have problems with identity and identity change,[13] as these features help to define a person's face.

Hair loss may be seen in terms of abnormality and as a failure to conform to the norms of physical appearance in society, which has the potential to set people apart in their own estimation and in the estimation of others. People can have serious problems with self esteem.[14] One limitation of the research is that the association between alopecia and depression or anxiety may be confounded by stressful life events, which may trigger both the alopecia and the depression or anxiety.

Alopecia and women

Hair is essential to the identity of many women. Femininity, sexuality, attractiveness, and personality are symbolically linked to a woman's hair, more so than for a man.[15] Hair loss can therefore seriously affect self esteem and body image. In a study of cancer patients with and without alopecia, those with alopecia had a poorer body image. Furthermore, women's self concept worsened after hair loss.[16]

Stressful life events have an important role in triggering some episodes of alopecia.[17] Women with high stress levels are 11 times more likely to experience hair loss than those without.[18]

One study followed a group of women who experienced hair loss after chemotherapy and found four reactions common to most of the group: not prepared; shocked; embarrassed; and felt a loss of a sense of self.[12] Hair loss is symbolic of major cultural beliefs and values, and for some women the loss of hair is reported as being psychologically more difficult than the loss of a breast through breast cancer.[19]

Alopecia and children

Children may also experience psychological problems as a result of alopecia. In one study the children with alopecia areata had more psychological problems than the controls, who visited a paediatrician for a "mild skin condition." In particular, they were more anxious, depressed, withdrawn, aggressive, or delinquent. Girls were more affected than boys.[20] In another study, seven of 12 children with alopecia areata met the criteria for anxiety disorders.[21]

Psychological treatment of alopecia

Very little research has examined the effectiveness of psychological treatment as a means of enabling people with alopecia to cope with the psychological consequences of the disorder. The research has not been systematic and has not included any randomised control trials. It has focused on general issues of coping rather than on specific psychological treatment strategies.

One study described the benefits (reducing psychological problems) of using a support group to help people with alopecia to cope with the disorder.[22] This describes a patient led group, with nurses, doctors,

and other healthcare workers as guest speakers, but it presents no evidence on the efficacy of these groups.

Dealing with alopecia patients

Recognition of possible psychological problems accompanying alopecia is important, and such problems need to be dealt with carefully. Given that medical treatment for the more severe forms of alopecia is largely ineffective, it is critical that the person is helped to learn to live with the disorder and dissuaded from searching fruitlessly for a "cure." This may mean referral to psychological services.

Future research

Research needs to examine the effectiveness of psychological treatments for patients with alopecia and to develop means of helping people to cope with the psychological consequences of the disorder. Broader issues involving the impact on the family—for example, the use of family therapy or relationship counselling—should also be considered.

Epidemiological research needs to establish the prevalence of alopecia and determine geographical and population bias—for example, circumstantial evidence suggests that alopecia is more common in war zones and in refugee populations. This research will also determine the extent of the various types of alopecia.

Research should also identify the individual factors that predict the onset and course of alopecia and consequent psychological (and comorbid medical) problems. These factors may include personality, prior experience, coping styles and social support, and age and sex.

Conclusions

Doctors should be aware of the psychological impact of alopecia, especially as current treatments have limited effectiveness. Providing treatment that is unlikely to be effective may do more psychological harm than medical good. Doctors also need to help the patient to understand their alopecia and their psychological responses to the disorder. They can do this partly by providing appropriate information (including about changing one's appearance through, for example, wigs and tattoos). Although few psychologists or psychiatrists specialise in the psychological problems associated with alopecia, GPs may refer serious cases to clinical psychology or psychiatric services, as the psychological symptoms experienced are common and have recommended treatment strategies.

A patient's perspective

A 27 year old man lost his hair after his best friend was killed. This immediately added to his distress and was exacerbated by his partner also experiencing problems because of the alopecia. She could no longer bear to look at him. When he was first sent to a dermatologist he went in wearing a cap. He had only recently lost all his hair, and the thought of being seen in public with no hair was unbearable. He was very self conscious, and his problem was not the alopecia, but coping with his new appearance. The dermatologist, a traditional doctor in his 50s and a white coat, greeted him curtly and ripped off his hat without permission, exposing his hairless head in a way he was not ready for. This was the point at which he realised that doctors were not going to help him.

Additional educational resources

The European Hair Research Society (www.ehrs.org/siteindex.htm)
Promotes the research of hair biology and hair disease

Keratin.com (www.keratin.com/siteindex.shtml)
Provides a comprehensive guide to alopecia and other hair disorders; publishes reviews, and guidelines, and provides links to other websites

Information resources for patients
Alopecia UK Online (www.alopeciaonline.org.uk/)

Hairline International (www.hairlineinternational.com/) (for United Kingdom)

National Alopecia Areata Foundation (www.naaf.org/) (for United States)

Outlook (www.nbt.nhs.uk/depts/SurgicalServices/Outlook/)
Outlook is a psychological support service for anyone affected by a disfigurement or visible difference

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