

The psychological impact of alopecia

HAIR loss is usually thought of as something men start worrying about as they get older. But there are various forms of hair loss, often extensive and sudden, which can impact on anyone – male or female – at any time.

There are three main forms, distinguished largely by the extent of the loss: *alopecia areata*, referring to the partial loss of hair from the head, usually patchy rather than general thinning; *alopecia totalis*, which is the loss of all head hair; and *alopecia universalis*, the loss of all head and body hair. We will refer to these three as ‘alopecia’ in this article, and while some of the issues may also relate to male pattern baldness (*alopecia androgenetica*), we are not specifically concerned with this.

Psychologists have largely neglected alopecia. There has been very little research carried out specifically by psychologists; dermatologists and other medical practitioners have conducted most of it. Our aim is to describe the disorder, outline the psychological research that has been carried out, and provide some questions that researchers and practitioners might wish to address.

The extent of the problem

Alopecia is a chronic inflammatory disease that affects the hair follicles, and it can affect men, women or children at any age. The aetiology and subsequent development of alopecia is not fully understood, but it is an autoimmune disorder that arises as a combination of genetic and environmental



NIGEL HUNT and SUE MCHALE

on the limited research and the need for more.

influences (Madani & Shapiro, 2000). The hair follicles in the anagen stage of development (growth phase) become the target for immune cell attack. Why they are attacked is – again – not fully understood, but it appears to be a complex relationship between individual characteristics (e.g. immune system problems, personality, coping styles) and the environment (e.g. a stressful situation).

There is an estimated lifetime risk of alopecia of 1.7 per cent (Kalish & Gilhar, 2003), though the actual figure is unknown because many people with alopecia do not present to the medical community. If the figure is accurate, that would indicate that around one million people suffer from alopecia in the UK at some point in their life. There is controversy over the rate at which alopecia is expressed as alopecia totalis or alopecia universalis. The extent of the more severe forms of alopecia is disputed, as there have been no relevant epidemiological studies; figures from 7 per cent to 30 per cent have been suggested.

Alopecia is neither life-threatening nor painful, though there can be irritation of the skin, weakness of the fingernails, and physical problems resulting from the loss of eyelashes and eyebrows. Eyelashes and

brows are surprisingly effective against the rain, and eyelashes help turn the eyelid outwards. Without eyelashes the lids turn in and irritate the cornea, similar to constantly having grit in the eye.

There is a relationship between the extent of hair loss and the chances of it growing back again. The more hair is lost, the lower the likelihood of regrowth. If the hair does grow back, there may be repeated episodes of hair loss. The hair which grows back may be different in terms of colour and texture.

Treating alopecia

There is a range of medical treatments for alopecia, but unfortunately there is no good evidence that they have more than limited long-term effectiveness. Treatment is generally ineffective for the more serious types of alopecia (totalis and universalis), while the evidence relating to alopecia areata is less clear. In many cases the problem resolves itself, and any treatment can take three to six months to be effective. Topical application of corticosteroids is a common treatment for alopecia, though if they are taken for prolonged periods of time there are potentially serious side effects. Diphenylcyclopropenone (DPCP) is also used, with varying results – while there is initially some success, there is a high relapse rate (Aghaei, 2005). Minoxidil is also used; again it has limited effectiveness for alopecia areata, though it is the only treatment recommended for use by women with hair loss (Messenger & Rundegren, 2004).

Dobbins *et al.* (2003), currently conducting a Cochrane systematic review of treatments, have found no good clinical evidence for the effectiveness of any of the treatments for alopecia. While some studies show that there is regrowth, spontaneous regrowth does occur without treatment, particularly with patchy hair loss (alopecia areata), and the studies that have been carried out do not account for this with

CASE STUDY

I used to be very proud of my hair. It was almost black, and went down to my waist. Everyone told me how nice it looked. I didn't think about it at the time, but it somehow made me the person I was. After my accident my hair fell out very quickly – it was gone within a few weeks. When I looked in the mirror the person I saw looking back was not me. It was someone else. It is very difficult to describe when I mean by that, but simply because I do not have any hair I am now a different person; and I behave differently with people. Inside I still remember who I was, but in everything I do, I think I am someone else.

Helen, quoted in Hunt & McHale (2004)



suitable controls. Furthermore, the treatments can be lengthy and painful, and cease to be effective when stopped.

Clearly, while alopecia can be psychosocially damaging, there may also be psychological consequences resulting from the treatment itself. If it is prolonged and of limited effectiveness, this may impact on the person's psychological well-being. Also, knowing that medical treatments have limited effectiveness will impact on the way a psychologist deals with alopecia because it is often a matter of helping the person learn to live with alopecia rather than seek a means of enabling the hair to regrow.

Psychology and alopecia

Alopecia can have serious psychosocial consequences, causing intense emotional suffering, and personal, social and work-related problems. Surveys have shown that around 40 per cent of women with alopecia have had marital problems, and around 63 per cent claimed to have career-related problems (Hunt & McHale, 2004).

Alopecia also leads to depression, anxiety and social phobia in a number of sufferers. This relationship between alopecia and psychosocial consequences can be complicated, in that alopecia can result from a stressful experience, and then itself lead to further distress. Limited research has been carried out in the area.

There is evidence that stressful life events have an important role in triggering some episodes of alopecia (Garcia-Hernandez *et al.*, 1999). Women who experience high stress are 11 times more likely to experience hair loss than those who do not report high stress (York *et al.*, 1998). Compared with the general population, increased prevalence rates of psychiatric disorders are associated with alopecia (Koo *et al.*, 1994) suggesting that people with alopecia may be at higher risk for development of a major depressive episode, anxiety disorder, social phobia or paranoid disorder. Egele and Tauschke (1987) identified a group of alopecia patients with an ongoing feeling of loss, suggesting that for some individuals the process of coping with alopecia may be equated with the grieving process following bereavement.

Furthermore, alopecia is a disfiguring disorder and therefore there are also issues relating to self and identity. The loss of hair, particularly the eyelashes and brows which help to define a person's face, means that a person looks very different. Hair loss

TABLE 1: Summary of themes and subcategories

Theme	Subcategory	Examples
Personal	Physical effects Causes Psychological distress	Eyes dry and sore Times of stress I fell over and was knocked unconscious Distressing condition I seriously considered suicide Difficult to come to terms with Don't have to visit the hairdresser
Identity	Coping	I deliberately set about changing how I viewed my life Profound effect on my life
Social	Social Work Relationships Sex differences Children and adolescents Social support	I am more reclusive I do think people make comments and I feel humiliated Off work with stress... couldn't perform my job to the best of my ability I felt sensitive to student comment [Family] cannot comprehend the significance of the loss Never seen a bald woman out shopping Losing one's hair affects men as much as women Not much fun being a bald teenager Embarrassing at that age I was teased a lot Great support from husband Extremely difficult to adjust to her baldness A bald child is handy for getting rid of unwanted visitors
Medical	Treatment Doctors' attitudes	Travelled the country to find a cure I only wish there was a miracle cure Scalp always sore Large water blisters, headaches Consultants not interested in your psychological well-being No help, support or advice... hospital very dismissive and unhelpful It is dismissed by doctors as being trivial... 'it is only your pride that is hurt' said one doctor

may be seen as a failure to conform to the norms of physical appearance within society, a situation which has the potential to set people apart in their own estimation and in the estimation of others.

Overall, there has been little systematic research into alopecia's psychological consequences (Hunt & McHale, 2005a).

Our research

We have used a variety of methods, questionnaires and interviews, to examine the relationship between alopecia and psychological factors (Hunt & McHale, 2005b). We have also reviewed the literature relating to psychological consequences of alopecia. What follows is a brief synopsis of our findings so far.

We collected questionnaires and e-mail interviews with individuals with alopecia, ranging in age from 12 to 93 years. There is no claim here that the sample is representative of people with alopecia. As is often the case, those with no problems and those with the most extreme problems are probably less likely to volunteer to take part. In fact, the majority of our sample were women. While we suspect that alopecia is not more common in women, there are a number of reasons why they may be more likely to volunteer. Women are more likely to want to talk about their alopecia because the disorder can be more difficult for them. Put simply, in our culture a bald man is socially acceptable, a bald woman is not.

The analysis of the qualitative data proved most interesting, generating a number of themes (Hunt & McHale, 2005b). The examples in Table 1 are illustrative of the kinds of quotations we obtained. Many of the participants desperately wanted to find out why they had alopecia, and searched everywhere for a cure. Others had issues regarding their relationships, with some spouses being very supportive, and in some cases the alopecia was the catalyst to end a relationship.

Some people could not go outside or go to work for fear of being mocked. Women in particular described having problems, perhaps because of the importance of hair to a woman's notion of self and identity. Children and adolescents had problems, not just because they might be bullied at school, but because they are the ones going through the stages of establishing identity. If one's physical appearance changes abruptly at this point, then this can have catastrophic consequences.

These issues surrounding relationships demonstrate the importance of identity and selfhood, and how one's identity is not just personal, but bound up in the physical and social worlds. These findings are similar to those obtained for other types of

Regrowth of hair after alopecia totalis

fundamental appearance change or physical disfigurement, which often have profound psychosocial effects (e.g. Rumsey & Harcourt, 2005). Visible skin disorders having social anxiety and social avoidance implications simply because they are visible, irrespective of any physical problems associated with the disorder.

Further research needed

We are currently undertaking further research relating to the psychosocial consequences of alopecia. There is a lot to be done. One important psychological issue involves establishing the role of physical appearance in defining identity. Previous research has examined identity construction generally, but people with alopecia are a population for whom physical appearance is heightened. Their experiences, particularly when eyebrows and lashes are affected, may be compared with others who experience facial disfigurement. It is likely that there is a differential impact on men, women and children.

The role of psychological trauma as

both a precursor and a consequence of alopecia should be examined. There is a need to examine the role of coping and social support, the latter being seriously affected by the change in appearance of the individual with alopecia. The role of personality and individual differences should be examined, as it is possible that particular types of people are more prone to alopecia.

It is also important to establish links between psychological and physiological mechanisms. The evidence points to the importance of the interaction between individual characteristics and the environment. For instance, some theories of stress propose that self-efficacy is a powerful factor in mediating stress. Bandura *et al.* (1982) suggested that self-efficacy may moderate immuno-suppression, and this may be relevant to the course of alopecia.

A strong theoretical understanding of the psychological impact of alopecia is required. This will involve carrying out research drawing together our understanding of the immune system, the stress response, and psychological responses. A psychoneuroimmunological understanding of alopecia should be developed, as there is a strong interaction between physiological and psychological responses.

Finally, it is critical that psychologists are able to provide appropriate treatment for people who are severely psychologically affected by their hair loss. Appropriate treatment strategies and regimes should be established and disseminated among therapists and others responsible for the care of people with alopecia.

Hair loss has profound social implications. Within the general population people ascribe great importance to physical appearance. Social relationships and social support severely impact upon coping with changes in appearance, which may lead to identity change. From the limited evidence that is available we can see that alopecia can have profound effects on an individual's life. There is a strong need for further research leading towards a fuller psychological understanding of the implications of alopecia.

■ *Dr Nigel Hunt is at the Institute of Work, Health & Organisations, the University of Nottingham. E-mail: nigel.hunt@nottingham.ac.uk.*

■ *Dr Sue McHale is at Sheffield Hallam University. E-mail: s.l.mchale@shu.ac.uk.*

WEBLINKS

Alopecia UK: www.alopeciaonline.org.uk
Information and links: www.keratin.com/index.shtml

References

Aghaei, S. (2005). Topical immunotherapy of severe alopecia areata with diphenylcyclopropenone (DPCP): Experience in an Iranian population. *BMC Dermatology*, 5, 6.

Bandura, A., Reese, L. & Adams, N.E. (1982). Micro-analysis of action and fear arousal as a function of differential levels of perceived self-efficacy. *Journal of Personality and Social Psychology*, 43, 5–21.

Dobbins, H.M., Delamere, F.M., Sladden, M.J. & Sinclair, R. (2003). Interventions for alopecia areata. (Protocol) *Cochrane Database of Systematic Reviews*, Issue 4.

Egele, U.T. & Tauschke, E. (1987). Die Alopecie: Ein psychosomatisches Krankheitsbild. *Psychoter Psychosomatic Medical Psychology*, 37, 31–35.

Garcia-Hernandez, M.J., Ruiz-Doblado, S., Rodriguez-Pichardo, A. & Camacho, F. (1999). Alopecia areata: Stress and psychiatric disorders: A review. *The Journal of Dermatology*, 26, 625–632.

Hunt, N. & McHale, S. (2004). *Coping with alopecia*. London: Sheldon Press.

Hunt, N. & McHale, S. (2005a). Clinical review: The psychological impact of alopecia. *British Medical Journal*, 331, 951–953.

Hunt, N. & McHale, S. (2005b). Reported experiences of persons with alopecia areata. *Journal of Loss and Trauma*, 10, 33–50.

Kalish, R.S. & Gilhar, A. (2003). Alopecia areata: Autoimmunity – evidence is compelling. *Journal of Investigative Dermatology*, 8, 164–167.

Koo, J.Y., Shellow, W.V., Hallman, C.P. & Edwards, J.E. (1994). Alopecia areata and increased prevalence of psychiatric disorders. *International Journal of Dermatology*, 33, 849–850.

Madani, S. & Shapiro, J. (2000). Alopecia areata update. *Journal of the American Academy of Dermatology*, 42, 549–566.

Messenger, A.G. & Rundegren, J. (2004). Minoxidil: Mechanisms of action on hair growth. *British Journal of Dermatology*, 150, 186–194.

Rumsey, N. & Harcourt, D. (2005). *The psychology of appearance*. Maidenhead: Open University Press.

York, J., Nicholson, T. & Minors, P. (1998). Stressful life events and loss of hair among adult women: A case-control study. *Psychological Reports*, 82, 1044–1046.