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The Lived Experience of Alopecia Areata: A Qualitative Study (Word Count: 7014)

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Abstract

This study explored experiences of individuals living with alopecia areata (AA) and alopecia universalis (AU) and investigated their accounts of adjusting to, and coping with, such conditions. Whilst previous research has primarily focused on the adverse psychosocial impact of alopecia, this investigation used Interpretive Phenomenological Analysis to provide a more holistic perspective. Biographical interviews were undertaken with 12 respondents (7 women; 5 men) diagnosed with alopecia for periods ranging between 2-49 years. Results revealed the strategies respondents used evolved over time and that there were clear gender differences. In the early stages, respondents did not want to contemplate that their hair loss would be lasting and managed the condition via concealment. Later coping strategies reflected an embodied acceptance with respondents managing the effects of AA/AU and becoming more optimistic about living with the condition. Limitations of the study are discussed as well as implications for patient care.

Keywords

Alopecia, Body Image, Coping Strategies, Facial Appearance
Alopecia is a Greek word meaning hair loss or baldness. The reasons for its onset are not known, but it has been suggested that psychological stress, physical trauma, and genetic predisposition may well be associated (Green & Sinclair, 2000). There are many different types of alopecia including alopecia areata (AA), alopecia totalis (AT), and alopecia universalis (AU). In AA, hair loss occurs in patches on the head, face, and/or body. Patches can range from around one centimetre which may be easily hidden, to quite large areas which may be more distinctive and noticeable. In AT, total hair loss occurs on the head, and AU is the complete loss of hair on the body as well as on the head (including eyelashes and eyebrows). According to a recent study 34-50% of AA patients will recover some or all of their hair within one year of onset whereas 15-25% will progress to AT or AU (Tosti, Bellavista, & Lorizzo, 2006). However, due to the unpredictable nature of this condition, hair loss may not necessarily develop in sequence from AA-AT-AU. For example, it is possible to develop AU without AA or AT being present beforehand.

Hair loss can be a distinctive facial appearance changing condition and people, particularly those with AA, may experience erratic episodes of hair loss sometimes followed by re-growth. Alopecia “accounts for about two per cent of new dermatology outpatient attendances” (Hunt & McHale, 2004, p. 1) and can happen to anyone regardless of age, gender, or ethnicity. Onset, severity, and re-growth can be very unpredictable. Papadopolous and Bor (1999) suggest that when dermatological conditions are unpredictable, individuals are likely to be anxious because they do not know when episodes will occur, and this could impact on how they cope with the condition. In the context of AA, the size and location of patches of hair loss could also impact on how people experience the episode(s).
This study focused on the lived experiences of people whose AA/AU was ongoing and explored the ways in which they coped with the uncertainties of their condition. It began by considering possible social and psychological implications of appearance disturbance such as negative body image and lack of confidence. Treatments and interventions were examined before assessing the impact of hair loss and the ways in which people adapted to these conditions.

In western societies there seems to be significant emphasis placed on physical appearance and attractiveness (Gilbert & Thompson, 2002). According to Jackson (2002), if a culture values attractiveness in people then “individuals will value attractiveness in themselves and others” (p. 13). Social representations of attractiveness are heavily influenced by appearance, facial appearance in particular, which may affect people’s opinions of individuals with a visible facial appearance altering condition.

Hair is a distinctive and valued facial characteristic for both men and women and when hair loss is experienced, the ability to manipulate and improve appearance may become uncertain and out of one’s control (Cash, 1999; 2001). Although men can find hair loss distressing, Cash suggests that a woman’s self-worth is “usually more invested in physical appearance and adverse appearance-altering conditions can be more troubling to women” (p. 162). In a study on androgenetic alopecia (male/female-pattern baldness) by Cash, Price, and Savin (1993), it was revealed that women in particular suffered from more negative psychological effects of hair loss. This suggests that it is not necessarily the type of hair loss or type of alopecia that creates the distress, but perhaps the visibility and altered image that hair loss in general can bring about.

Although there have been various medical interventions developed for people with alopecia, such as steroid creams or injections, Hunt and McHale (2004) conclude that
“evidence for their effectiveness is rather weak” (p. 4). Therefore the assistance that health care providers offer should perhaps be focused on providing psychological and social support (Elgin, Hilker, & Drabman 2006). Although a psychosocial approach acknowledges factors that could influence ways in which a patient perceives and experiences a visible disfigurement (Wade & Halligan, 2004), studies have shown that many medical practitioners fail to recognise or offer support with respect to the psychosocial aspects of hair loss (Hunt & McHale, 2005; Papadopoulous & Bor, 1999).

Beneficial outcomes for AA patients receiving psychotherapy were reported in the 1960s. Reinhold (1960) found hair re-growth in 35 out of 52 patients following psychotherapy but information such as type of therapy, duration, and frequency of sessions was not mentioned. And in a single case study carried out by Sanduk (1964) it was found that after 3 months of individual and group therapy, though no re-growth had occurred, the patient was adjusting to his condition. But as with Reinhold, no information was given with regards to type of therapy, duration, and frequency of sessions.

More recently, Willemsen, Vanderlinden, Deconinck, and Roseeuw (2006) investigated the effectiveness of hypnotherapy on the psychological well-being of 21 AA patients. Although this was a preliminary study with a small number of patients, some relatively positive outcomes were reported. After a 5 year period it was found that all 21 patients had significantly lower scores for anxiety and depression and hair re-growth was found in 12 patients. However, since 10 of those patients were receiving additional treatments (such as corticotherapy & immunotherapy) hair re-growth cannot be linked directly to the hypnotherapy. Furthermore, no control group was used to compare samples and re-growth could have occurred regardless of treatment.
Since prospective studies about the impact of hair loss are impossible to implement, it is difficult to say whether any negative psychological effects arise directly as a result of the condition. Some insights could be gained from examining the impact of hair loss which occurs as a result of chemotherapy, although findings must be generalised with caution. Münstedt, Manthey, Sachsse, and Vahrson (1997) investigated the self-concept and body image of 29 patients who underwent hair loss inducing chemotherapy. They found that 73% of the patients were not as self-confident as they were before treatment commenced and 46% of patients considered hair loss to be the most traumatic side effect of chemotherapy.

It can be difficult to come to terms with the diagnosis of alopecia and the realisation that there is no present cure could be very difficult to come to terms with. Papadopolous and Bor (1999) suggest that “personality traits, severity of the condition, and the length of time a person has lived with it are all considered with regard to the adaptation process” (p. 23). They also note that mourning for one’s “normal” appearance may be part of that adaptation and coping process. This suggests that individuals may need to go through a series of psychological adjustments in order to become reconciled with their changeable appearance.

Social support, self perceptions, optimism, and coping styles are some more variables that have been related to an individual’s adaptation to altered appearance. For individuals with hair loss, the anticipated fear of social situations may well create avoidance which could in turn possibly create more fear. It could be argued that the actual fear of confronting one’s condition could create more anxiety than the confrontation itself (Newell, 1999). Rumsey, Clarke, White, Wyn-Williams, and Garlick (2004) investigated appearance-related concerns of people with a visible disfigurement. They found that “coping strategies such as engaging in social activities with close friends or family are effective, and the lowered threat that this produces is likely to encourage repeated exposure and reduce social avoidance” (p. 450).
Thompson, Kent, and Smith (2002) suggest that the process of adjusting to, and living with, an appearance altering condition is unlikely to be a linear, incremental one. More recently Cash, Santos, and Williams (2005) have discussed three aspects of body image coping namely; avoidance, appearance fixing, and positive rational acceptance. They suggest that such strategies are applicable to acquired conditions that threaten or alter an individual’s body image. They also note that further research is required to explore coping strategies amongst people with appearance related conditions.

Previous research on the psychosocial implications of hair loss has identified specific psychological correlates related to the condition. Much of this portrays hair loss as distressing where sufferers experience negative outcomes. However, there has been little research that tries to take a more holistic perspective or which seeks to capture respondents’ ongoing lived experience of their condition. This study employed biographical interviews with people who had experienced ongoing AA and AU to discover the ways they have been affected by the condition and the strategies they used for managing their often unpredictable appearance. Interpretive Phenomenological Analysis was used to explore the meanings and understandings that underpinned respondents’ experiences of living with AA/AU.

Method

Participants

A purposive volunteer sample was recruited. It was essential that respondents had received a formal diagnosis of alopecia for a minimum of six months in order to explore “lived experiences” of the condition. It was also important that volunteers with other forms of alopecia (such as androgenetic or chemotherapy induced alopecia) were excluded as those forms often progress in a more predictable manner.
Following University ethical approval 12 adult respondents volunteered to take part in this study. Most had been diagnosed with AA (7 women; 4 men), and 1 man was diagnosed with AU. Respondents were aged between 31 and 59 years with an average age of 37 for women, and 45 for men. Six women and 3 men were married or lived with a partner and 10 were parents (6 women; 4 men). Respondents’ duration of experiencing AA or AU ranged from 2-49 years. Women’s mean duration = 20.7 yrs; $SD = 13.8$, and men’s mean duration = 14.6 yrs; $SD = 18.11$. Only 1 respondent reported having attended professional counselling sessions. Volunteers were recruited via news items placed in the Alopecia UK newsletter and also in a local newspaper, which explained the study.
The study was guided by Interpretive Phenomenological Analysis and designed to elicit individuals’ reflections about living with alopecia. Biographical semi-structured interviews were used in order to “try to enter the psychological and social world of the respondent” (Smith, 1995, p. 55). The interview schedule was devised by the researcher, a trainee counselling psychologist with clinical interviewing experience. The schedule was structured to explore respondents’ recollections about the onset of AA/AU, how they were affected by it, and their subsequent experience of living with their condition up to the present day. Topic areas were informed by relevant literature and questions were refined through discussion with colleagues and through feedback from a pilot interview conducted with a colleague who had knowledge of this condition. The interviews focused on each person’s understanding about the impact of alopecia and attempted to provide an environment that would draw out their personal viewpoint, with the researcher taking care to check or clarify the meaning of any points that were unclear.

Procedure

An interview room at the University was used to conduct most of the individual interviews although some respondents preferred to be interviewed in more conveniently located settings, such as a quiet cafe. Respondents were briefed about the purpose of the study and signed a consent form giving their permission to participate. Each person took part in a 30-60 minute audio tape recorded interview. Following the interview, respondents were debriefed and informed of their right to withdraw their data. Due to the sensitive nature of this topic respondents were given details of a local alopecia support group.
Analysis

Each interview was transcribed verbatim and was analysed following Smith and Osborn (2003). The researcher began by immersing herself in the data from one selected interview, noting significant comments followed by critical reflection, re-reading, and the generation of emergent thematic phrases. This process continued for the subsequent interviews with themes from the initial interview used as tentative reference points. Regular cross-checking with the interview transcripts were maintained in order so that themes were grounded in the text. This also enabled the researcher to identify convergence and divergence across participant accounts. Member checks were performed with respondents to ensure analysis was accurate and the researcher’s supervisor was also involved in checking that themes clearly linked to the transcripts. Finally, the lists of themes from all interviews were reviewed and from this, superordinate and sub-themes were produced. All respondents were allocated pseudonyms and any personally identifying information was excluded from illustrative quotes.

Results

Interpretive Phenomenological Analysis generated two superordinate themes and six sub-themes which are listed below:

Superordinate Theme 1: Coping with the initial impact of alopecia.
Sub-themes: Pragmatic coping 1; social dimensions; treatments and social support.

Superordinate Theme 2: Living with the unpredictability of alopecia.
Sub-themes: Time to adjust; pragmatic coping 2; putting things into perspective and positive thinking.

Unless otherwise indicated, via the annotation (AU) all quotations are from respondents with AA.
Coping with the Initial Impact of Alopecia

This theme considers the ways in which respondents tried to adjust following their onset of AA/AU. Existing research suggests that the ways in which people cope with hair loss, and other forms of visible impairment, can depend upon individual characteristics, specific coping strategies and psychosocial support (Horing & Gieler, 2002; Papadopolous & Bor, 1999).

Pragmatic coping 1. Most respondents recalled trying to hide their hair loss following their initial episode of AA/AU. Strategies to conceal were often used before people gained formal diagnostic confirmation of their condition. All seven women respondents and three of the men spoke about trying to hide patches by wearing scarves, hats, headbands, using sprays, and also by covering patches with remaining hair. Other ways of covering patches included colouring them with make up and keeping the hair flat using hairspray:

   Deb: “I was wearing bandanas, headbands and scarves”.

   Jane: “I was colouring my scalp, you know with eyebrow pencils and brown eye shadow, and that was fine on a day when there was no wind”.

   These strategies were relatively effective in concealing smaller AA patches and were used by respondents as short to medium term solutions. However, they had to be changed or abandoned if the hair loss became more extensive or occurred on particular areas of the scalp. During early episodes of AA most respondents noted that they rejected the possibility of wig use. Although wigs seemingly offer a practical way to conceal hair loss, their use was ruled out because it also signified that the AA/AU would be lasting. Interestingly, the only male participant who chose to wear a wig initially found it to be helpful:

   Barry: “It was at this time that I got my first wig. This gave me more confidence to go out and I returned to work as a fully qualified television engineer”.
However this solution was not one that he felt comfortable with. He later abandoned the wig and adopted a similar solution to the other men which was to shave off his hair:

Barry: “I wore the wig until my late thirties, even though I hated it, and eventually I had the courage to stop wearing it, which was a great relief and I wish that I had done it years earlier”.

*Social dimensions.* A visible difference can affect how a person communicates and interacts with others. Interactions may not only be affected by the reactions of others but also by the altered behaviour of the individuals themselves (Rumsey & Harcourt, 2004). The unexpected onset of AA/AU meant that many respondents were not only trying to cope with their own reactions to their hair loss but, given its visibility, they were aware that their appearance could attract (unwanted) attention from others:

Keith: “As soon as you go out or the wind starts blowing or you comb your hair and you can’t see it at the back.... You can feel people looking at you, you know”.

Nathan (AU): “Shortly after the hair loss I was asked to be an usher at a good friend’s wedding, I felt I had to turn it down because I wasn’t ready to be seen in public”.

Some respondents in this study feared that they may be rejected or stigmatised by others because of their visible difference. They initially believed that having AA/AU would prevent them from participating in normal social interactions:

Jane: “I felt quite odd you know, I was very ashamed really.... I think with alopecia you think, ‘Why are you a freak?’”.

Fortunately, for those who did withdraw from social contact, this was relatively short lived and most respondents found that their condition was not as socially limiting as they had perhaps initially feared. Male respondents talked about feeling self-conscious over their hair
loss but also were mindful that norms for masculinity discouraged their expression of distress about it:

Keith: “If I go into a pub or anything like that I do sometimes feel embarrassed about the alopecia, you know. You get some comments which can be funny and you try to take it as a bit of fun... But deep down it can be hurtful”.

For women, it appeared that hair loss was initially associated with feelings of great distress and a perception that a key signifier of their femininity was compromised. One mentioned that she felt sorry that she could no longer dress herself up:

Marie: “I do miss using my hairdryer and my straighteners. Well it’s a girlie thing really, getting ready and styling your hair”.

Other women talked about initially trying to compensate for their hair loss by trying to enhance their social self-presentation:

Kim: “I just felt that I had to overcompensate with my personality for my lack of hair, always trying to be extra funny and going and buying lots of nice clothes”.

*Treatments.* All respondents commented on the treatments they had been subject to as a means to try to cure AA/AU or restore hair. Most were prescribed by medical practitioners and included shampoos, tablets, creams, and liquids. When these did not produce significant improvement steroid creams or injections were likely to be offered as a final resort. Nine respondents reported undergoing steroid treatments:

Jane: “I was having dermajets into my patches every 3 weeks and that just got very painful, and I’d get puffy eyes with that. And I started to think, steroids injected into my scalp I know it’s meant to be only absorbed to that area but I’m a bit suspicious about steroids”.
As this example shows, procedures could be painful, and respondents in this study did not find any noticeable or lasting improvements after undergoing treatment. Some respondents reported trying alternative therapies including heat treatment, herbal remedies, and acupuncture. Nathan (AU) had tried almost everything, again without success:

“I searched everywhere for a cure, from dermatology to counselling to acupressure to homeopathy”.

Treatment regimes seemed to be an inevitable, yet unsatisfactory, rite of passage that respondents experienced as they were coming to terms with their AA/AU. Most respondents finally decided to step off the treatment cycle and accept that a permanent cure was unlikely, although some still continued to hope that a cure could be found.

Social support. All respondents spoke about the support received from family, partners, and friends, and some mentioned attending support groups. One important aspect of this support was that respondents felt accepted for who they were, irrespective of changes in their appearance:

Marie: “It doesn’t even need to be explained, I can just walk about without my hair band and he (her husband) just doesn’t say anything at all. He is very positive”.

However, some respondents did not receive such support in the early stages of their hair loss. This was illustrated through the account of one woman participant who felt she was left on her own to cope with, and understand, the nature of her condition:

Val: “Throughout the time that I really needed my mam (her mother) she was never there for me and I remember coming in crying one day from school and she walked away and said, ‘Just ignore them’. And I always remember I wanted someone else’s mam (mother)”.


Such comments provide vivid illustration of the distress caused by the absence of support particularly when it involves support from those who are expected to be relied upon. Fortunately, in all cases, respondents eventually found supportive individuals who accepted them and their condition:

Val: “I got lots more support from my work friends than from anyone else really and that helped a lot”.

It has been suggested that support groups can play an important role in assisting patients with hair loss (Prickitt, McMichael, Gallagher, Kalabokes, & Boeck, 2004). Support groups are intended to empower members and meeting others who have similar experiences can be beneficial and uplifting. Of the seven women respondents, five spoke about support groups with both negative and positive experiences:

Jane: “I tried going to a support group but found it depressing and suppressive. It was a lot of people sitting around a table in a hospital meeting room and it wasn’t very positive”.

Gabrielle: “I find the support group much more helpful than any treatment I could have”.

Respondent comments suggest that small, user-led groups may be more successful in meeting the needs of their members than perhaps those organised within health care settings. Male respondents did not report use of support groups.

Living with the Unpredictability of Alopecia

The second theme considers how respondents have continued to live with their AA/AU over the longer term. Living with AA/AU appeared to lead to pragmatic changes in the way that respondents managed their appearance and their embodied experience of the condition.
Time to adjust. All respondents reported that, over time, their coping strategies had improved. According to Folkman and Moskowitz (2000) it is possible to experience control in a seemingly uncontrollable situation, although this may require time and experience in order to develop a sense of confidence. Many respondents mentioned feeling distressed and overwhelmed by their early episodes of hair loss but they reported that time, age, and having other priorities enabled them to move forward positively and manage their condition:

Marie: “I think I do cope better now the older I’ve got. It’s not as important, if you’ve got children and you get to your thirties and think, its nothing really, I think I have got better with it, definitely”.

Barry: “I eventually gained enough confidence to join a band”.

Others felt that, while they had gained confidence about their appearance and how they managed it, they looked forward to the time when they would develop sufficient confidence to not be concerned about reactions from other people:

Jane: “Hopefully one day I will have the confidence to go out without my wig on and just think, ‘Well if you don’t like it then don’t look’, really”.

Although the hair loss could be unpredictable, most respondents mentioned how they had taken charge over how they respond to it. They could still feel angry or stressed by particular episodes of hair loss (with AA), but as their experience increased, it allowed them to keep the impact of episodes in proportion.

Pragmatic coping 2. All of the women reported that over time they made a decision to buy and use wigs. Some wore them almost continually, whereas others would use them alongside other types of head covering. These accounts could suggest that wearing a wig signified respondents accepting and taking charge of their appearance, rather than avoiding the fact of their hair loss:
Val: “I mostly wear a bandana during the day but if I have an evening out and decide to wear my wig then I will do, but if I decide that I don’t want to wear it then I won’t”.

Jane: “I feel more in control, I will act on it now, getting a wig rather than desperately trying to cover patches. I’m possibly a bit more blasé as I’ve gotten older and care less what people may think of me”.

As noted earlier, most male respondents chose not to wear wigs. Their strategy for taking control was through shaving off their remaining hair. Most talked about reaching a point of self-acceptance:

Nathan (AU): “One hot summer’s day I went to the bank and I decided to take my cap off, then I walked out of the bank and up the crowded road which was so hard for me because I really did think that people were looking at me and thinking I was a freak. But I did it, and when I did I was really pleased with myself because it meant that I could re-join the world properly rather than just hiding away and having a cap on”.

Barry: “Now, at the age of 56 I am totally bald.... But for the first time in my life I am comfortable with my appearance”.
"Putting things into perspective and positive thinking." Although respondents noted that AA/AU made a visible difference to their appearance and created a significant impact on their self image and sense of well-being, they also reported how it was important to maintain a sense of perspective. An interesting finding to emerge from respondent accounts was that many of them made comparisons to more serious conditions. For example, they emphasised that AA/AU posed no threat to their health, and comparisons were made with people who experienced hair loss as a result of treatments for cancer:

Jane: “I just feel really sorry for the people that are going for wigs when they are having chemotherapy. And I think my god, you know, we’ve got no reason to complain at all”.

Having a determined and positive outlook appeared to help some respondents to stop ruminating about why AA/AU had happened to them:

Kim: “Yes, I do have my moments and do have times where I think it’s unfair and have a sad day but I generally try and give myself a kick up the backside as there are many worse things that you can get”.

Most of the women spoke about positive aspects of AA. For example, some mentioned being able to get ready quicker as they did not have to style their hair, and others said that having a selection of wigs gave them more choice over their appearance. One woman talked about friends and colleagues commenting on whether different lengths, styles or colours of wig suited her:

Sarah: “If I change my style or I go different colours my friends say, ‘I like that or I don’t like that’. At one point I was really jet black and dark and everybody told me that they hated it but when I was married I was blonde, so I do change my hair quite often”.


Another woman set up her own wig company as a result of living with AA. She talked about meeting new people through her business and the benefits she gained from helping others:

Marie: “I would like my hair to grow back but I’ve met so many nice people and set up my own business because of it. So to me it’s been a good thing in a bizarre way, I feel as if I’ve helped people”.

In reflecting on their lived experience, respondents emphasised that having AA/AU had helped them value many of the “ordinary” aspects and activities within their lives. They talked about the positive aspects of life such as the importance of families, children, having a good social life, work, and hobbies.

Discussion

A qualitative approach to this study explored the phenomenon of AA/AU and found that adjustment was related to a range of psychosocial factors. Although this volunteer sample may typify people who were successfully managing to live with AA and AU, their accounts illustrate the complexity of the adjustment process.

In accordance with Papadopolous and Bor (1999), it was found that coping techniques did indeed change and improve with time. One noticeable finding was the way that respondents identified different challenges, priorities, and coping strategies as they moved from experiencing AA/AU as a temporary anomaly, to an embodied acceptance of the enduring and often unpredictable reality of the condition.

Respondents appeared to go through specific stages whilst adjusting to their hair loss such as avoidance, appearance fixing, and positive rational acceptance. This is consistent with the three-pattern framework of body image coping (Cash et al., 2005). Initial strategies involved concealment of the AA/AU. Pragmatic coping at this point avoided
acknowledgement that the AA/AU could be ongoing, or that it would re-occur. What emerges from respondent accounts as they describe their experiences over the longer term, are references to appearance fixing strategies that enable them to get on with their lives. Choices could still be influenced by the position or amount of hair loss, but strategies reflected acquired expertise, personal preference, and situational factors such as being at work or having an evening out. It became evident that the pragmatic strategies that developed in the longer term were associated with experiencing control and being relatively comfortable with their appearance. This could be an illustration of positive rational acceptance. Respondents actively experimented with techniques to manage their social self-presentation. Refining, eliminating, or changing techniques in order to achieve a personally acceptable image allowed respondents to feel they had achieved some control over the effects of their condition (Lamb, Fried, & Feldman, 2004).

Respondents initially discussed the disruptive impact of AA/AU on their self-image and self-esteem, but here too they actively tried to make sense of their reactions and their interactions with others. Some individuals, who did not receive the initial support they had hoped for, reported trying to avoid social situations but, over time, respondents had a supportive network of family and/or friends who helped to restore confidence and encouraged social participation (Rumsey & Harcourt, 2004). Respondents also developed an appropriate perspective about their hair loss through deliberate positive, acceptance-oriented thinking, and many made comparisons with people living with more severe health conditions or impairments. Making such social comparisons could give people a sense of perspective about the impact of hair loss and helped them focus on getting on with their lives (Buunk, Collins, Taylor, VanYperen, & Dakof, 1990).
Another finding observed in this study concerned the gendered experience of adjusting to, and living with, hair loss. For women, hair is often talked about as their “crowning glory” therefore practical choices over hair management could be linked to wider gendered expectations. Men, on the other hand, were expected to be less concerned over their appearance than women (Pope, Phillips, & Olivardia, 2000). Whilst all respondents spoke about the distress associated with the initial onset of AA/AU, there appeared to be more acknowledgement of the suffering it could cause women. This is consistent with previous research on the psychological effects of androgenetic alopecia which also found that, whilst hair loss was a traumatic experience for both men and women, it was “substantially more distressing for women” (Cash et al., 1993, p.568), suggesting that distressing reactions can occur regardless of the type of hair loss. Cash (1999; 2001) also found that although men regard hair loss as unwanted and report feelings of embarrassment, they can generally cope and maintain integrity of their body image because male baldness is relatively common and accepted in today’s society. During the course of their AA the men managed their appearance by shaving off their remaining hair whereas the women eventually all wore wigs. The decision to wear a wig, shave one’s hair, or wear a cap/bandana, was seen to be about balancing benefits and limitations in order to meet individual appearance requirements, and not about avoiding the reality of AA/AU.

Another gendered difference in coping was that women reported using support groups whereas men did not. This could be linked to the fact that women experienced more distress about their hair loss. However, it could also be because men may have found it more difficult to engage in help seeking, which is consistent with previous research that men are less likely than women to use this kind of support network (Kiss & Meryn, 2001).
A particular challenge for many people with alopecia, AA in particular, is living with the unpredictable loss of hair. The fact that there is currently no cure may become particularly anxiety provoking. Despite poor treatment outcomes reported by most respondents they continued on a “revolving door” of medical consultations and appeared to work through a range of lotions, pills, and injections until all options were exhausted. However, Papadopolous and Bor (1999) suggest that in time, people’s anxiety associated with the uncertainty over their appearance diminishes. This study appears to support such findings.

Hair is such a distinctive aspect of a person’s appearance and the way that it is styled, coloured, and worn helps to define one’s self concept (Thompson & Shapiro, 1996). It has been found that, compared to controls, people with hair loss are more depressed with lower self-esteem, reduced quality of life, and poorer body image (Hunt & McHale, 2005). As noted, respondents had lived with AA/AU for a number of years and their experiences indicated that the treatment offered by health services were exclusively bio-medically focused whereas the challenges they faced were psychosocially based. Therefore health practitioners may need to recognise such requirements in order to focus on facilitating patient psychological well being.

Psychosocial interventions have shown some beneficial outcomes for people living with hair loss. For example, reductions in anxiety and depression as well as improvements in adjusting to AA (Reinhold, 1960; Sandok, 1964). Hypnotherapy has also been shown to reduce anxiety and depression levels of people with AA, AT, and AU (Willemsen et al., 2006). Also Kleve, Rumsey, Wyn-Williams, and White (2002) carried out a study on the effectiveness of cognitive behavioural therapy (CBT) with 36 participants. Of those participants 27 had facial disfigurements and 9 had bodily disfigurements. After 3-6 sessions it was found that participants improved significantly in social anxiety, appearance-related
distress, general anxiety, and depression. Results were also maintained at a six month follow up. Jarry and Berardi (2004) reviewed the literature exploring body image therapy, and from the 18 studies reviewed, they found that “stand-alone body image therapy based on cognitive-behavioural principles is highly effective” (p. 328). Whilst the studies that they reviewed did not apply specifically to hair loss, body image CBT has been proven to be an effective therapy for body image disturbances (Cash, 2008). Since hair loss has adverse effects on one’s body image, CBT interventions could be adapted to meet the needs of this condition too.

The findings from the present study clearly demonstrate lived experiences of AA/AU and Interpretive Phenomenological Analysis was a suitable methodology to provide a critical, insider-focused exploration. However there were some limitations that may have affected results. Most respondents suffered from AA and only one experienced AU. Also, the duration and severity of AA/AU differed across the sample and so respondents may have been at different stages of coping or acceptance of the condition, which could have affected results. As the study used a volunteer sample, respondents who agreed to participate may have developed beneficial coping strategies. The variability in time since diagnosis of AA/AU amongst participants may have influenced recollections and constructed meanings about the initial impact of this condition. Furthermore, age at diagnosis of AA ranged from 7 to 56 years of age and emergence during particular lifespan periods may also be related to respondents’ views about its initial impact. Therefore, it is important to recognise that this particular sample cannot be seen to represent the population of people with AA or AU. Nevertheless, despite variations in the duration, type, and severity of hair loss, respondents still faced common barriers and feelings of distress over the changes to their appearance.
Accounts also revealed that respondents became much more skilled in managing the effects of their hair loss and more optimistic about continuing to live with it.

Future research could use a larger sample of respondents and focus on each particular sub-type of alopecia so that possible divergence of lived experience between different types of alopecia can be explored. Also, given the gendered experience of alopecia, it would be appropriate for future research to explore how psychosocial interventions can be developed to respond to men and women’s embodiment of this condition. From the findings in this study it is sufficient to state that implications for patient care are vital when treating people with hair loss. The physical aspect of hair loss could initially diminish a person’s sense of self and create distress on a psychological level. This must be acknowledged in order for the effective psychological interventions mentioned in this study to become more established within health care settings.
References


