

Living with alopecia areata: An online qualitative survey study

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Abstract

Background

Living with alopecia areata, totalis and universalis (collectively referred to here as AA) involves unpredictable, sometimes rapid hair loss. There is currently no effective treatment and patients describe feelings of shock, loss, trauma and disrupted identity. Cultural meanings attached to hair and hair loss, including associations between hair and femininity, and hair loss and cancer may exacerbate distress. Consequently, wigs and make-up are frequently used as camouflage, but this can produce feelings of inauthenticity, shame and anxiety.

Objectives

To explore how meanings associated with hair and hair loss influence experiences of living with AA. To identify how this understanding might inform practice by healthcare professionals to best support patients to cope with the condition.

Methods

Ninety-five participants with AA completed an online qualitative survey about their experiences of living with the condition. Data were subjected to thematic analysis within a critical realist theoretical framework.

Results

Four themes were identified: It's (not) just hair; A restricted life; Abandon hope all ye who lose their hair; and Seeking support in "a highly personal journey".

Conclusions

Findings suggest that negative cultural meanings of hair and hair loss are pervasive and may drive social avoidance and camouflage behaviours in people with AA. Normalising social interactions with healthcare practitioners, significant others and peers were cited as pivotal

to positive adjustment. Support groups and online forums were highly valued particularly as few had been offered specialist psychological support. Future research should develop and evaluate psychological support to address the specific challenges of living with AA.

What's already known about this topic?

- AA is a common autoimmune hair loss condition characterised by unpredictable hair loss.
- Physical discomfort caused by AA is limited but it is associated with high levels of depression and anxiety, low self-esteem and lower quality of life.
- People with AA often struggle to develop effective coping strategies.

What does this study add?

- Supportive and normalising social interaction with healthcare practitioners, family, acquaintances and others who have AA is a key factor in the development of effective coping strategies.
- Support groups and online forums are highly valued sources of support. Consistent signposting to these by doctors would improve care for people with AA.
- Psychological intervention should be offered early and ideally by practitioners with specialist understanding of appearance related distress.

Introduction

Alopecia areata (AA) is a common autoimmune hair loss condition¹ with a lifetime risk of 2%². It is characterised by patchy hair loss and an unpredictable trajectory. Permanent spontaneous regrowth is common; however, periods of remission may be followed by further hair loss, including, in severe cases, loss of all head hair (alopecia totalis) or loss of all head, face and body hair (alopecia universalis)³. Physical discomfort associated with AA is limited but the psychological impact is significant; studies have reported high levels of depression and anxiety, and lower quality of life (QoL) in people with this form of hair loss⁴⁵. Current treatments have limited efficacy and potentially serious side-effects, and hair loss usually resumes once intervention ends⁶. Consequently, the British Association of Dermatologists (BAD) has recommended that “not treating is the best option in many cases”

and that psychological interventions should be considered⁷. However, no guidance is available on what forms of psychological support may be helpful or on referral pathways, and specialist psychodermatology services are rare.⁸

The provision of effective support for people with AA requires an understanding of what it is like to live with the condition. Few qualitative or mixed methods studies have explored the psychological impact of AA, but what literature does exist highlights the distress and threats to identity associated with unpredictable, often rapid hair loss^{9 10 11 12 13}. Feelings of shame and isolation have been reported^{14 15} alongside struggles to develop effective coping strategies^{16 17}. It has been suggested that good social support may help to ameliorate the psychological impact of AA,¹⁸ but this can be difficult to access since AA is associated with impaired social functioning,¹⁹ and unsupportive responses from doctors have been reported²⁰. Wigs and make-up are commonly used to conceal hair loss, but the psychological effects of such practices are complex; masking of hair loss can increase self-confidence but concerns about wigs being noticed or coming off can simultaneously increase anxiety, create feelings of inauthenticity and affect interactions with others, leading to avoidance of social activities^{21 22}. Social context may therefore be significant in understanding both distress and coping in people with AA.

This qualitative online survey study uses a critical realist framework to investigate people's experiences of living with AA. It develops existing qualitative literature on AA by attending to the social context in which experiences occur and the cultural meanings attached to hair and hair loss. Given that the distress experienced by people with AA is arguably at least in part created by these meanings and the wider social context of hair loss, it is important for healthcare practitioners to understand how this may affect their interactions with patients who are seeking help for the condition.

Method

The sample was a convenience/volunteer sample with participants recruited primarily online using email, social media, and the charity Alopecia UK's online newsletter. Inclusion criteria were that participants should be aged over eighteen, UK resident and identify as having alopecia areata, totalis or universalis, with first hair loss at least one year previously. Ninety-five eligible participants completed the survey, the majority identified as female (N=84) and white (N=76) (see Table 1). Six participants answered 'no' to the question about

diagnosis but were included in the analysis because their experiences were not qualitatively different from those of other participants. Furthermore, exclusion would raise ethical questions given that they gave time to write these personal accounts, and self-identification is common in qualitative research²³.

Qualitative data were collected and collated using the *Qualtrics* online survey software. Participants answered the questions in their own words in as much depth as they chose (see Table 2), resulting in 63 pages (51,467 words) of single-spaced qualitative data. Online surveys are unusual amongst qualitative methods in allowing for the collection of data from a large geographically dispersed sample²⁴ with a high degree of anonymity²⁵. They are therefore an ideal tool for studying little understood and sensitive topics such as living with hair loss²⁶. The depth offered by qualitative methods is retained while voice is given to a relatively large number of people, including those who might otherwise be unable to participate due to location, or work and family commitments. Importantly, this wide-angle lens extends to those who struggle with social situations or are concerned about public exposure, as is frequently the case for people with a visible difference²⁷.

Data were analysed using thematic analysis (TA)^{28 29} within a critical realist framework, which views meaning and experience as subjective and attends to the social and cultural context in which they are produced³⁰ (see Table 3). The study identified patterns in people's experiences of living with AA, and the ways they seek to manage distressing meanings, including the resources they draw upon to cope. In line with standards for quality in the reporting of qualitative research³¹, it is important to disclose that the first author's interest in this topic was prompted by the experiences of someone close to her who lives with the condition.

The study was approved by the Health and Applied Sciences Faculty Research Ethics Committee of the University of the West of England.

Results

A striking feature of the data was the varied, often contradictory ways in which people made sense of their experiences of AA and developed strategies to cope with it. This complexity is captured in the four themes identified.

Theme 1: It's (not) only hair

Hair loss was emotionally devastating for many, and could lead to depression, anxiety and, in some instances, suicidal thoughts. The pace and unpredictability of hair loss were often mentioned as particularly disturbing and shocking. Hair loss was frequently likened to bereavement or loss of a limb, emphasising that impact extends beyond the physical body to self-confidence, self-esteem and identity. References to symbolic and cultural meanings attached to hair were common; monsters, aliens and bald evil characters were mentioned such as Voldemort from the Harry Potter books and films, and some women likened hair loss to mastectomy since both breasts and hair signify femininity. Many considered themselves ugly, unattractive and shameful, beliefs contributed to by distressing recent or past behaviours from other people including shouting or staring in the street, and bullying at school. Yet alongside this, was the contradictory sense of not being entitled to distress or sympathy because hair loss is not “life threatening” (e.g. P10, female; P87, male) unlike the cancer suffered by the chemotherapy patients for whom they were often mistaken. Many described being told it is “only hair” (e.g. P47, female) by healthcare professionals, which deepened distress; not only were feelings of loss, grief and emotional devastation not acknowledged, the sense of not being entitled to those feelings or to support was reinforced. For a few participants it *was* only hair, and others strived for this position, describing a process in which the shallowness of an appearance-obsessed culture could be rejected by valuing the inner self and accepting the outer self. See Table 4 for illustrative quotations.

Theme 2: A restricted life

People struggled with or avoided activities ranging from sport and exercise, to shopping, socialising and simply leaving the house because of anxiety that their hair loss would be noticed or exposed. Wigs and make-up were helpful tools in managing such fears, yet simultaneously contributed to feelings of anxiety because of concerns about being ‘fake’ (e.g. P64, female); both hair loss itself and attempts to hide it were deemed shameful. Feelings of self-consciousness and inauthenticity were particularly salient in both new and existing relationships with acquaintances, friends, family and intimate partners. People described concealing their baldness or patchy hair loss from even close friends, and feeling unable to be bald at home because of fears that their partner would find their appearance disturbing or unattractive. They also described anxiety about if or when to reveal hair loss to

new people. Some believed they would never be able to have an intimate relationship because “who wants to be with a bald woman” (P84, female) and hair loss means “feeling sexy is virtually impossible” (P75, female). Anxiety about managing hair loss in new contexts with new people also restricted career decisions; some chose roles that felt less visible and exposed, others stopped working altogether. The time, financial cost and physical discomfort involved in concealing hair loss with wigs, make-up or scarves before facing people were also restrictive. People described worries about sweating or touching their face for fear of smudging make-up, the itchiness and discomfort of wigs, particularly in hot weather, and difficulty deciding what to wear” because nothing looks right with a bald head” (P73, female). Yet alongside this heightened investment in appearance management, many felt loss and longing for the pleasures of ordinary grooming such as visits to the hairdresser and bonding with friends through getting ready together before going out. A few claimed liberation from the restrictions of hair loss by going ‘bald and proud’, a position admired by others but which many saw as unattainable for themselves. See Table 5 for illustrative quotations.

Theme 3: Abandon hope all ye who lose their hair

Experiences of hopes raised and dashed were common in the data, shaped by the unpredictable pattern of regrowth and further hair loss that characterises areata and can occur with totalis and universalis. People described managing their relationship with their hair, trying not to become emotionally attached to it in order to cope with ever-present anxiety that regrowth would be followed by further or worse hair loss. Feelings of hope and hopelessness were also generated by seeking and trying out treatments that proved ineffective, had unpleasant side-effects, or only worked while being taken. For some this was worsened by a sense of being exploited by businesses that raised hopes selling expensive treatments that turned out to be useless. Dismissive or insensitive encounters with GPs and dermatologists were also experienced as reinforcing or contributing to feelings of hopelessness. Where the psychological impact was acknowledged by healthcare professionals this was valued. However, few mentioned positive encounters and there were accounts of even counsellors and psychological practitioners showing poor insight and lack of empathy around the distress involved with hair loss, thus exacerbating the very feelings of hopelessness that help was being sought for. Running through the data is a sense that

only by abandoning hope that hair will regrow can acceptance begin to become possible. However, this process of working towards self-acceptance was presented as a long struggle and often felt incomplete with many describing exceptions or conditions to self-acceptance that seemed indicative of continued upset. See Table 6 for illustrative quotations.

Theme 4: Seeking support in “a highly personal journey”

Many people described social, emotional, and cosmetic resources that helped them to cope with their hair loss. The development of coping strategies was “highly personal” (P34, female) yet strongly influenced by social factors and there was a sense that the processes involved were often unnecessarily long and lonely. Many expressed anger and frustration that healthcare professionals and the NHS more widely, failed to offer care, information or resources that could help. Social support from family and friends was seen as facilitating the development of self-acceptance and adjustment. Contact with others living with AA was also important to many, although for a few it made things worse, for example by serving as a reminder that full recovery is unlikely. Online forums, the Alopecia UK website, and support groups were frequently mentioned as crucial sources of reassurance and information, offering validating access to shared emotional experiences, and tips for successfully camouflaging hair loss. However, people were rarely signposted to these by doctors, having instead to seek them out themselves. Many were unable to access prescription wigs, and the quality of products and fitting experiences were often poor for those who did receive this assistance. Likewise, few were offered NHS counselling or psychological support; many felt that it would be helpful but only if offered early and long waiting lists put people off. For those who did access psychological therapy, experiences were varied, but when positive it was seen as contributing to coping, acceptance and wider personal development. Accounts that conveyed more developed acceptance and coping included a sense of post-traumatic growth; people described becoming “more compassionate” (e.g. P14, female), less likely to make “snap judgements on others” (P3, female). Some people reported making positive new life choices such as retraining in hairdressing or psychology, or setting up support groups, thus sharing the learning of their personal journey and supporting others to acquire the tools to cope. See Table 7 for illustrative quotations.

Discussion

People's experiences of living with AA are complex and deeply personal, fraught with contradictions and instability as they navigate cycles of hope and hopelessness, and the restrictions created by this unpredictable hair loss condition. In the participants' accounts, the distress they experienced was shaped and contextualised by complex cultural meanings such as the role of hair loss as a signifier of illness. Accurately identified by others as having a disease, participants nonetheless felt unentitled to the sympathy offered, or to their own distressing feelings, because AA is a disease of 'just hair' unlike the 'life-threatening' cancer so frequently assumed by sympathisers. As found in previous studies^{32 33}, the use of wigs and other products to camouflage hair loss often exacerbated feelings of inauthenticity, leading to anxiety that this 'fraud' (e.g. P77, female) would be exposed. Other symbolic meanings that presented distressing challenges to identity, included the association between hair and femininity which could lead participants to believe that they were shameful as women so should not leave the house and would never have an intimate relationship.

Importantly, the study shows how distressing meanings are frequently reinforced by encounters with the GPs, dermatologists, and psychological therapists from whom help is sought. Given that healthcare professionals are subject to the same social and cultural discourses of hair as their patients and the wider public, this is unsurprising. Thus, the contradictory 'just hair' theme plays out in consultations as doctors and psychological practitioners dismiss AA as just cosmetic, yet simultaneously reinforce the significance of hair loss by, for example, referring to cancer or staring. Although participants' accounts demonstrate how lack of effective medical interventions can create feelings of hopelessness, they also indicate important ways in which doctors can meet the needs of their patients. By reflecting critically on the meanings attached to hair, such as associations with femininity, or cultural representations of monsters as bald, practitioners can better recognise the nature of psychological difficulties experienced by patients with AA. This can inform insightful communication, producing the supportive social interaction that appears to be key to enabling people to cope. Training to develop dermatologists' sensitivity to the psychological impact of skin conditions has been called for³⁴ and the current findings indicate that this could improve the experiences of people with AA, particularly if it included attention to the meanings that can affect patients' social interactions.

Just as experiences of negative social encounters such as bullying, staring or dismissing can produce and reinforce negative meanings for people with a visible difference³⁵, this study suggests that positive, normalising interactions can facilitate self-acceptance and even access to new identities. The therapeutic benefits of contact with others who have AA has previously been noted³⁶, including its potential for promoting wellbeing and support within the wider family context³⁷. However, further research is needed to explore how best to facilitate such interactions and whether a variety of approaches is required to meet individual needs. A pilot study into the benefits of a mindfulness-based group intervention for people with AA yielded promising results³⁸; it would be interesting to explore whether the supportive function of being with others with the condition contributed to the outcomes, including the possible role of this contextual factor in aiding the cultivation of mindfulness. In the meantime, doctors can meaningfully support patients by signposting to charities such as Alopecia UK, explaining that many people find support groups and forums to be helpful sources of practical information around managing hair loss, and emotional reassurance that can make the experience of living with AA less lonely.

The data also indicate that counselling and psychological interventions can be helpful for people with AA, but few participants reported being offered an NHS referral and experiences of both NHS and private practitioners were varied. Given the lack of specialist psychodermatology provision, Talking Therapies services may present the most accessible referral pathway. However, practitioners in such services are unlikely to have expertise in working with appearance related distress. There are very few studies into the provision of psychological support for people with AA^{39 40} and the need for further research has been highlighted⁴¹. However, the findings presented here can helpfully inform practice across therapeutic modalities. Specifically, they demonstrate how people who seem to develop more effective coping strategies are often engaged in acknowledging and challenging the meanings associated with hair loss. For some this extends to working towards an identity in which an appearance-obsessed culture is rejected and a valued inner self embraced, suggesting the kind of personal transformation through struggle with adversity that has been defined as post-traumatic growth.⁴² It has been suggested that social support and focussed cognitive processing are both key factors in facilitating such growth; the chance to talk in a validating space can allow the person to grieve a lost identity and develop new

narratives in which some sense is made of the adversity suffered, even if it is ongoing. One task of psychological intervention may therefore be to help the patient explore the meanings of hair that are shaping their experience, and to support them to develop alternative, less distressing meanings⁴³. Through this, patients may be able to make sense of the trauma and loss referenced so frequently in the data presented here, helping them to develop self-acceptance and a positive identity. Future research could explore how best to provide this support in a medium acceptable to patients. Given the enthusiasm for online support from participants in this study, online programmes might appropriately offer one way to help address the difficulties of accessing support across the UK.

The principal limitation to this study is the predominance of white women among the participants. This is particularly important to note given that meanings attached to hair are influenced by gender and ethnicity^{44 45 46 47 48}, and thought needs to be given in future studies as to how to reach more diverse participants. The survey link for this study was circulated via Alopecia UK and the authors' online networks. Initial responses were predominantly from white women which may reflect Alopecia UK's membership and the online contacts of the researchers who are all white women. Attempts were made to find additional channels with broader reach; paper information about the study was distributed to barbers and hairdressers, particularly in areas with large non-white populations. When approached, staff expressed interest in the study and enthusiasm for circulating the information, sharing stories about the difficulties described by customers with AA. However, this was not followed by responses from more men or people of colour. It may be that people are more likely to access the survey when presented with the link electronically, suggesting the need to identify relevant online channels to generate a more diverse sample. Additionally, the online written method of responding to questions about difficult personal experiences may feel uncomfortable or inaccessible to some people, and it does not allow the researcher to probe participants answers⁴⁹. However, the accounts given in this survey were rich, detailed and intimate, with high emotional content. Participants included people who described severe social anxiety and many responses were submitted late at night or early in the morning demonstrating that this method gives voice to people who might not otherwise be able to participate in qualitative research.

In conclusion, the themes identified demonstrate how the cultural context and meanings of hair and hair loss shape the experiences of people with AA, including their interactions with healthcare professionals. Practitioners can improve the quality of these interactions and support people to cope by acknowledging the distress produced by hair loss, signposting patients to Alopecia UK, and offering early referral for psychological support.

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Table 1: Participant demographics (N=95)

Diagnosis	Alopecia universalis – 38 Alopecia areata – 35 Alopecia totalis – 16 No formal diagnosis – 6 (these participants indicated with * in Tables 4-7)
Source of diagnosis	Dermatologist – 62 GP – 29 No diagnosis - 2 Clinic doctor – 1 Self – 1
Age range	18-79 (mean=44; median =45)
Range of age at first hair loss	1-69 (mean=27; median=24)
Range of number of years since first hair loss	1-50 (mean=17 years ago; median = 15)
Sex	Female 84 Male 11
Sexuality	Heterosexual – 89 Bisexual – 3 Gay - 2 Lesbian - 1
Ethnic Identity	White – 76 British – 11 Scottish – 2 British Asian – 2 South Asian – 1 Black British – 1 Middle Eastern – 1 British Welsh - 1
Disability	Yes - 9 No – 85

	No data - 1
Social class	<p>Middle class – 42</p> <p>Working class – 33</p> <p>Blank - 7</p> <p>No class – 8</p> <p>Other – 4</p> <p>Lower class – 2</p>
Occupation	<p>Full-time employed -46</p> <p>Part-time employed – 15</p> <p>Retired – 8</p> <p>Unemployed – 7</p> <p>Self-employed – 6</p> <p>Full-time student – 5</p> <p>Part-time student – 5</p> <p>Carer -5</p>
Current relationship status	<p>Married -45</p> <p>Single - 24</p> <p>Partnered – 17</p> <p>Divorced/civil partnership dissolved – 7</p> <p>Civil Partnership – 2</p>

Table 2: The Living With Alopecia Areata, Totalis and Universalis Survey

1. Please tell me about your experience of starting to lose your hair
2. How does having alopecia affect your day to day life?
3. How do you think other people perceive you?
4. In what ways, if any, does having alopecia affect your sense of who you are as a person?
5. In what ways, if any, does having alopecia affect your identity as a woman/man?
6. Has your experience of living with alopecia changed over time?
7. What is your experience of seeking information and help (including pharmaceutical and cosmetic products) around your hair loss?
8. Have you ever been offered counselling or psychological support to help you cope with having alopecia? If yes: When was this offered and what kind of support was it? Can you tell me about the experience, including what, if anything was helpful or unhelpful? If no: Is counselling or psychological support something that you would like? Can you tell me why you would or would not like to be offered counselling or psychological support?
9. What do you think counsellors and psychologists should know about your condition and how it affects you?
10. Is there anything else that you think it is important for me to know about what it is like for you to live with alopecia? Please include anything that feels relevant or significant to you.

Table 3: Thematic analysis process based on the procedures outlined by Braun and Clarke (2006)

<p>Braun and Clarke describe their approach to thematic analysis as ‘reflexive’ because it provides an analytic technique situated within a qualitative philosophy or paradigm, and emphasises the researcher’s active role in data interpretation and theme generation⁵⁰. They outline a 15-point checklist⁵¹ for good quality thematic analysis, which emphasises rigorous and systematic coding, researcher reflexivity, and theoretical knowingness rather than the use of multiple independent coders and coder agreement as hallmarks of quality. Because thematic analysis is a theoretically flexible method researchers should specify their theoretical assumptions and data orientation. The use of thematic analysis in this study was broadly critical realist, inductive and descriptive, and sought to ‘stay close’ to participants’ reported experiences.</p>		
Phase	Process	Author involvement
Phase 1: Data familiarisation	The researcher reads and re-reads the data making a note of any initial impressions or insights. Familiarisation facilitates a rich and complex account of the data.	All authors engaged in data familiarisation and met to discuss their initial impressions.
Phase 2: Coding	The researcher systematically codes the data. Coding is not fixed, but an organic and evolving process. Coding can be at both the semantic (data surface) and latent (underlying assumptions) level.	LD and VC coded the data separately, focusing primarily on semantic meaning and staying close to the participants’ accounts.
Phase 3: Generating initial themes	The researcher generates initial themes from the codes and coded data. This typically involves clustering together similar or related codes.	LD and VC generated initial themes separately.
Phase 4: Reviewing and refining theme	The researcher reviews the initial themes, first in relation to the coded data and second in relation to the entire data set. Themes are reworked or even discarded until there is a final set of themes that provide a good ‘fit’ with the data.	All authors met to review the coding and initial themes and agree 4 themes that best ‘fit’ the data for further development. LD and VC reviewed the themes against the coded data and entire dataset.
Phase 5: Defining and naming themes	The ‘story’ of each theme is refined and developed through finalising theme names and writing theme definitions.	All authors finalised the theme names and wrote theme definitions that formed the basis of the written report.
Phase 6: Producing the report	Producing the report constitutes the final analytic stage, with further opportunities for refinement of themes.	LD and VC selected the illustrative extracts, all authors reviewed and agreed. All authors were involved in writing the paper, led by LD.

Table 4: Illustrative data extracts for theme 1: It's (not) only hair

<p>Hair loss is emotionally devastating</p>	<p>"People often say 'it is only hair', 'it is not a life-threatening condition' but personally I do not think that anyone can appreciate just how massive losing your hair is unless or until it happens to you. They need to understand how massive it is and how the condition often brings feelings of huge depression and suicidal thoughts" (P56, female)</p> <p>"every day is a struggle, that gets worse and worse, the more my hair falls out, the more my hairline recedes, the bigger my bald patch grows. The more I die inside." (P74, female*)</p> <p>"it's emotionally damaging. It has the potential to destroy your self-confidence, self-esteem and your self-worth, which is so wrong because at the end of the day, all it is, is hair. Humans are so much more than their hair." (P19, female)</p> <p>"Dealing with the loss of identity and the feeling of watching it slowly slip away everyday your hair thinning the patches getting bigger is heart breaking." (P12, female)</p>
<p>Pace and unpredictability of hair loss</p>	<p>"Finding handfuls of hair on my pillow every morning was extremely distressing. Washing my hair and finding the plug hole blocked with hair was alarming." (P57, female)</p> <p>"Because it happened quite rapidly, it was very difficult to decide how to manage it (by covering it up) and to get used to it." (P39, female)</p>
<p>Hair loss is like a bereavement</p>	<p>"it must be treated like grief. The psychological impact is all encompassing and never seems to diminish. It is extremely lonely and isolating." (P73, female)</p> <p>"losing hair is a grieving process and the emotions felt mirror those experienced by those suffering a bereavement." (P3, female)</p>
<p>Hair loss is like losing a limb, a breast, or part of the self</p>	<p>"It's like losing a piece of you. Nothing makes sense and you cannot recognise yourself." (P34, female)</p> <p>"it's a deeply personal feeling, and at times akin to women who have had a mastectomy and feel that something that made them a woman has been taken away from them." (P49, female*)</p> <p>"I miss my hair it's like a strange amputation I wake up in the morning sometimes and feel my hair 'argh where's my hair!'" (P90, female)</p> <p>"It's not just 'hair'. It goes much deeper than that. I'd rather be seen naked in public than without my wig and makeup." (P14, female)</p> <p>"it isn't just cosmetic and it can affect people deeply it is like losing a limb, and you have to adjust." (P10, female)</p> <p>"I don't feel like alopecia is any different to losing something else you love or having another physical change (such as scaring of amputation)- it's just adjusting, accepting and trying to move on." (P1, female)</p>

	<p>"Leaves you feeling you are not the same person, people say it's only hair. Yes it is, but when you lose eyebrows, lashes, facial hair and look in the mirror - not a good look you just want to fit in like everybody else not to be stared at." (P58, male)</p>
<p>Feeling or looking monstrous or alien</p>	<p>"Also having to draw on eyebrows & eye liner or face looking like an alien." (P75)</p> <p>"I get quite upset when I see myself bald. There is a reason monsters are portrayed bald. In Lord of the Rings when Gollum was a hobbit he had hair when he turned evil - bald. Then of course there is Nosferatu, Voldemort, Trolls and Orcs." (P61, female)</p> <p>"I don't like being bald and I hate looking in the mirror. When I lost my eyebrows I looked like Voldemort out of Harry Potter. I do feel a bit of a freak sometimes, especially with no make-up." (P11, female)</p> <p>"it makes you feel like a monster. It is like mad scientists are portrayed with thick pebble glasses, villains have scars and monsters are bald." (P61, female)</p>
<p>Feeling ugly and unfeminine</p>	<p>"feeling like an amorphous blob." (P20, female)</p> <p>"Hair is always used to exemplify femininity and good looks. It is almost revered. In literature it is often the hair of a female character which is described and it is that which defines her." (P66, female)</p> <p>"having no eyebrows or eye lashes makes me feel like I'm no longer a woman as I don't have the womanly face anymore, it's just a blank canvas with no features at all now." (P55, female)</p> <p>"I have particularly low self-esteem when I consider the way I look, especially as a woman. I feel rather ugly when I'm not wearing my wig and it makes it difficult for me to feel that men would find me attractive (even with my wig on)." (P17, female)</p> <p>"I feel unfeminine and do not feel like a woman at all more androgynous." (P77, female)</p> <p>"I don't feel like a woman. I feel like a man stuck in a woman's body. I.e. Has lady parts but with something that is perceived only men have issues with. - hair loss." (P74, female*)</p>
<p>Being bullied</p>	<p>"I was teased, bullied and beaten up [in school] because I didn't have hair. I was called so many names - alien, cancer girl, freak etc - I had my bandannas and hats ripped off my head in the yard, I was beaten multiple times to the point of having to be taken home from school to have my injuries assessed medically. I had my head flushed in a toilet, I had food mushed into my head, I had chemicals tipped on me in science class, I had my jumper set on fire by another student with a cigarette lighter, and I had metal shavings rubbed into my remaining hair on one occasion... I have always felt different, that there was something wrong with me, that I was ugly and worthless etc." (P2)</p>

	<p>"I've lost my hair at various life stages. Initially as a teen I was bullied at school and stared at and shouted at in the street by strangers." (P67)</p> <p>"I lost my hair at the top of my head when I was 25. I was clubbing dating girls and loving life. Alopecia knocked the wind out of my sails at the time. Men tend to say the worst things to one another, no man wants to go grey let alone lose their hair so I had to bear a lot of verbal abuse which really bothered me inside although I never let it show personally." (P87 male)</p>
<p>Significance of hair loss dismissed by healthcare professionals</p>	<p>"The consultant was totally obnoxious and made me cry – his attitude was, it's only hair." (P47, female)</p> <p>"Usual view is it is caused by the alopecia sufferer's reaction to stress e.g. you're responsible as you can't cope with life. Also, it's cosmetic so wear a wig and get on with it. When I was 12 I used to wish I had cancer so there would be a greater understanding towards my hair loss." (P67, female)</p> <p>"I feel doctors turn a blind eye, and shrug." (P94, male)</p>
<p>Not entitled to be upset</p>	<p>"It does cause insecurities but then almost everyone has something that does. I'm just very glad it's not life threatening although I do sometimes worry about passing it on to my children. When I first got it at university it did have a significant emotional impact and made me quite depressed." (P50, female)</p> <p>"we need to be told it's ok to feel a bit rubbish about it, even though we are not ill. Based on my limited experience of meeting with other people with alopecia we tend to have the feeling that because we don't have cancer we should somehow be grateful. Of course we're glad we haven't had to have chemo and we're not ill, but we don't need those feelings to be belittled and then feel guilty for feeling bad about it." (P28, female)</p> <p>"It is an isolating disease that seems to receive little attention. I feel blessed that I don't suffer from a more damaging auto immune disease. I suffer no pain or discomfort. It is, however, so very visible and that is the difficulty for me." (P25, female)</p>

Table 5: Illustrative data extracts for theme 2: A restricted life

<p>Unable to participate in leisure activities, exercise and playing sports</p>	<p>"I used to love swimming, but stopped, ditto running, sailing and exercise generally, you can't really take part when you're wearing a hat." (P57)</p> <p>"It affects just about everything I do. Don't want to do exercise as it's too hot wearing a wig. Terrified to hold my little grandson in case he pulls my scarf or wig off in front of people." (P45, female)</p> <p>"I stopped doing activities I enjoyed like swimming and cycling. I would avoid all situations where a discussion on hair might take place or where there might be adverse conditions for someone wearing a wig e.g. windy." (P56)</p> <p>"At first, I didn't know how I could carry on living and felt worthless. I was bound by the constraints of cheap wigs, such as not being able to go swimming, afraid to walk outside in the rain, afraid that any gust of wind might whip it off my head at any moment." (P30, female)</p>
<p>Avoiding leaving the house and socialising</p>	<p>"My alopecia now is a lot worse. I seldom leave my home and if I have to go shopping I leave early as less people about. I also lost my eyelashes and eyebrows" (P65, male)</p> <p>"I avoid situations where I won't be sleeping at home. E.g. staying over at friends' houses." (P34, female)</p> <p>"I try to avoid conversation with people and never make eye contact." (P65, male)</p> <p>"I don't like to go to social events and when I do, I find a corner to sit in so no one can stand behind me and then can see my attempt to cover my baldness." (P74, female*)</p> <p>"As my alopecia has progressed, it has had a greater impact on how I feel about myself, my confidence to put myself forward or in the public arena. I have shrunk away from dating, going out and work." (P77, female, female)</p>
<p>Affecting career choice or feeling able to work</p>	<p>"In my mid 20's it drove my career choices and made me shut down from the corporate world and retreat to a safer & less threatening role. As a new parent I struggled with making new friends." (P67, female)</p> <p>"For the first 2 years I was devastated gave up my job and didn't want to go out, then got used to it." (P63, female)</p> <p>"I suffered depression for just under a year, which I took time off work for." (P40, female)</p>
<p>Costs of concealment</p>	<p>"Hot weather is a nuisance as my head sweats in the wig... Windy weather is also a pain. I now make sure I have an umbrella with me all the time and lots of hats for the winter to keep the rain off. I carry a hat and umbrella in the car and always have wet wipes with me to wipe my head off if it gets sweaty." (P72, female)</p>

	<p>"Always have to make sure face is fully made up 24-7 otherwise look seriously ill. Have eyebrows tattooed every year. Having to wear wig when going out but it's hot, sweaty, itchy, annoying. When home just wear headscarves. Can no longer go swimming. Too much hassle. Feel conspicuous." (P84, female)</p> <p>"I worry when it's windy in case my wig gets blown off." (P22, female)</p> <p>"Wearing a wig is uncomfortable and not like my own hair which is annoying and expensive. I don't like wearing eyelashes so wear more eyeshadow and liner than I used to and miss my lashes." (P1, female)</p> <p>At first I wore acrylic wigs but since I've started wearing vacuum ones it's been much easier to cope. They are very expensive (£1,900) and I need a new one every 3 or so years so it's a significant financial burden but since I wear it every day it's one I save for. I've also had temporary tattoos regularly for my eyebrows and eyeliner. The latter I gave up because it didn't last very long and it was really unpleasant as well as expensive. I've also tried microblading. (P50, female)</p>
<p>Concealment and inauthenticity in relationships</p>	<p>"I wear a wig every day and do not tell anyone about the fact that I wear a wig. Even my closest friend doesn't know." (P48, female)</p> <p>"It's hard telling my brain that people can't see through the wig. I don't like meeting new people because I feel like I'm lying to them before they even get to know me. It makes me very anxious. To the point that I don't leave my house on some days." (P17, female)</p>
<p>Restricted opportunities for and in intimate relationships</p>	<p>"I feel "who wants to be with a bald woman". (P84, female)</p> <p>"Feeling sexy is virtually impossible, although this is my paranoia not from my husband as he is brilliant and doesn't care at all." (P75, female)</p> <p>"I think I would struggle trying to explain my hair loss to a new man." (P72, female)</p> <p>"Hair is important to women, and not having any, especially when first dating someone can feel difficult and awkward. (P69, female)"</p> <p>"On the bad days I feel less of a woman. That men wouldn't be interested in dating me because of it." (P54, female)</p> <p>"I have also secretly wondered how my husband would feel about it despite his sincere assurances he doesn't care" (P49, female*)</p> <p>"Can't get too close to people as don't want to have the conversation about my hair." (P57, female)</p> <p>"I'm not sure why it bothers me so much about meeting a new partner and having to tell them. I get really worked up and will avoid seeing them or staying over, all things I want to do but my alopecia stops me." (P24, female)</p>
<p>Loss of the mundane</p>	<p>"You no longer have the enjoyment of going to the hairdresser - especially before a special event." (P56, female)</p>

<p>pleasures of femininity (gendered grooming)</p>	<p>"I feel excluded from so many conversations - women seem to talk about hair a lot... Some dating sites have no option for no hair. It makes you feel like you do not belong in the category female sometimes. But you don't get the benefits of being male - and you still get raped." (P20, , female)</p> <p>"I feel hair is such an important part of making you feel feminine, so it affects me heaps, i.e. not having my own hair to brush, style, wash and cut!" (P89, female)</p> <p>"Its silly things like not being able to put your hair up for nights outs or occasions, not being able to curl it always having your hair in the same style always looking the same. When my eye brows fell out and eye brows are a big thing for females my age, I felt I looked so different to everyone. When I lost my eye lashes it was the same all these things other females spend so much time on I didn't have." (P60, female)</p> <p>"I don't feel as girly anymore, because I can't do my hair and makeup the same way I did before. I can't take part in those hair and makeup preparation routines with friends or family anymore which can feel deflating sometimes." (P39, female)</p>
<p>The ultimate freedom is being 'bald and proud', and authentic, in public</p>	<p>"I still wear wigs however I would like to ditch them and embrace the real me." (P14, female)</p> <p>"I was bound by the constraints of cheap wigs, such as not being able to go swimming, afraid to walk outside in the rain, afraid that any gust of wind might whip it off my head at any moment. It was 6 years ago, that I took my wigs off and went bald in public. That feeling was liberating." (P30, female)</p> <p>"I'm out and proud with my baldness." (P11, female)</p>

Table 6: Illustrative data extracts for theme 3: Abandon hope all ye who lose their hair

<p>Even if my hair grows back, I fear losing it again</p>	<p>"another concern is if my hair should grow back again I'm worried that it may fall our again." (P43, female)</p> <p>"It grows back then falls out again. I have no emotional relationship with my hair as I never know if it will be there for long." (P4, female)</p>
<p>(False) hope of treatment</p>	<p>"After many trips to the doctor and being referred to hospital, creams, steroid injections, my hair sometimes grew back a little but always fell out again. I realised very little help was available so stopped looking." (P31, female)</p> <p>"There is nothing by false hope from pharmaceutical or medical professionals." (P73, female)</p> <p>"Dermatologists see us as a waste of time because there is no treatment or else guinea pigs for trials. some of which have horrible side effects or give false hope because as soon as the treatment stops the hair falls out again" (P86, female)</p> <p>"I am now treating the disease, which may be working (beard and eyebrow are starting to re-grow) - so I am in a new phase now of hopeful optimism, tempered with the acknowledgement that I have a 50:50 chance of losing it all again once off the meds." (P82, male)</p> <p>"I have visited many dermatologists, doctors and naturopaths to help with my condition. Each has given me hope in a new treatment that could cure my hair loss. None have worked" (P95, female)</p>
<p>Exploitative businesses</p>	<p>"I have my wigs through the NHS but my first wig I bought in a hairdresser's and they just wanted to sell me expensive products - when I still had some hair it was £20.00 shampoo when my hair grew again £16.00 thickener. They wear also did not like me getting my wigs via the hospital. I felt like a cash cow!" (P61, female)</p> <p>"A herbalist took a lot of money off of me for treatment that they knew wouldn't work, but you try anything!! (P10, female)</p>
<p>Dismissive or insensitive doctors</p>	<p>"my GP is as helpful as a refrigerator at the North Pole!" (P46, female)</p> <p>"I get a lot of pity- even a GP I saw for the first time straight away asked how far into chemo I was without looking at my records which would have stated I had the all clear. Even after I told her I had Alopecia she persisted in asking 'how far into your chemo are you?' This made me very cross. If even a GP won't listen and continues making upsetting assumptions what on earth must other people think?!" (P9, female)</p> <p>"Well the GP didn't give a hoot, the skin specialist didn't either, the trichologist is an expensive waste of time... if there was a cure, there would be no bald people about" (P86, female)</p> <p>"It is important that this secret and embarrassing condition is recognised and given the attention it deserves from GPS who in my experience are not interested whatsoever." (P51, female)</p>

	<p>"I do not visit the GP unless I really have to. I did however, ask on a routine visit if there had been any progress in treatment. The GP said no "but at least you won't go grey". She had very grey hair and although I now she meant this as a joke, it was rather insensitive." (P66, female)</p> <p>"even a GP I saw for the first time straight away asked how far into chemo I was without looking at my records which would have stated I had the all clear. Even after I told her I had Alopecia she persisted in asking 'how far into your chemo are you?' This made me very cross. If even a GP won't listen and continues making upsetting assumptions what on earth must other people think?!" (P9, female)</p>
<p>Lack of insight or empathy from counsellors and psychologists</p>	<p>"In terms of psychological help, there was none. I had general counselling, but none of the counsellors knew what alopecia was nor did they understand the impact that alopecia can have on someone's life. I was never offered counselling, my parents had to look for counselling help on their own." (P2, female)</p> <p>"First counsellor basically told me to get over it later counsellors have helped me with other aspects of my self-esteem which has helped me to become more accepting of my alopecia and to get on with life despite it" (P77, female)</p> <p>"The counsellor asked me what was the worst thing about it and I said that it was people staring at me. She stared at me for 2 sessions and it totally freaked me out. So she did exactly the things which I had told her was the worst thing. The counsellor had told me that she had never come across anyone with alopecia." (P29, female)</p>
<p>There is no option but to get on with life</p>	<p>"in the end you have to resign yourself to the fact that this is it and you have to deal with it and get on with it." (P42, female)</p>

Table 7: Illustrative data extracts for theme 4: Seeking support in “a highly personal journey”

<p>An individual journey towards coping and acceptance</p>	<p>“It's a highly personal journey which has to be taken at an individual pace.” (P34, female)</p> <p>“When I was younger It was devastating. Now I'm middle aged it has less of a detrimental impact. Hair does not complete me. My personality does.” (P4, female)</p> <p>"I've become more oblivious to it as time has gone on but it still does get me down and have moments where I'm so insecure I won't leave the house." (P13, female)</p> <p>“I've learnt to accept it over the years. When growing up the slightest look or comment made me burst into tears straight away but now it doesn't bother me. I always think there's always someone worse off than myself and it's only hair right?! It doesn't change me as a person. I still lead a normal life and enjoy activities that the next person enjoys.” (P27, female)</p> <p>“To those who only know me for what I look like today only some realise I have no eyelashes or eyebrows but having had Alopecia for so long I no longer care about how I am perceived based on how I look.” (P87, male)</p> <p>“I struggled at first - was hyper aware of my patches in public. I now don't think about it and have accepted my condition. I would love to wear my hair down again and not have to think about it.” (P91, female)</p> <p>“I do not want to look strange - this has affected my sense of how I appear, but I am trying very hard to ensure this will actually have a positive impact on my sense of who I am as a person - As it appears I will be permanently affected by this disease - I am now trying to force myself to view my alopecia in a certain way - 'it doesn't matter', 'as long as I am healthy, I should be happy'. I want to be able to confidently talk about it, I want people to ask me about it, I want feel like I have accepted it and that it is just a part of me.” (P82, male)</p> <p>“It seems the world is generations behind in terms of understanding the condition. The focus now is so heavily on one’s external appearance that you almost have to live on a different plane of understanding in trying to live with your appearance.” (P73, female)</p>
<p>Anger and frustration at lack of signposting to psychological and peer</p>	<p>“I've found out more on the internet and forums than I have from medical professionals. My Doctors don't even have a leaflet on alopecia. We are not kept up to date on new</p>

<p>support in medical contexts</p>	<p>discoveries, I know more about it than the majority of medical professionals I have met, including dermatologists” (P47, female)</p> <p>“There needs to be more help and support right at the beginning of diagnosis. GPs need to be giving out more information especially on support. If this does not happen you feel you are drowning under the condition and there doesn't seem to be a way out. “ (P56, female”</p> <p>"GP not interested. Dermatologist - nothing we can do - no information supplied. Just want me off their list." (P84, female)</p> <p>“It was definitely a case of seeking help rather than any help being offered!! Offered no counselling from doctor (even though I asked), no signposting to support organisations, limited treatment options offered (given advanced nature of hair loss by the time I saw a dermatologist - only topical steroid cream offered), knew nothing of semi-permanent make up options. Everything I've discovered, I've had to discover for myself. Nothing was made easy for me when I lost my hair 7 years ago. I have 'stumbled across' things myself including Alopecia UK.” (P3, female)</p>
<p>Counselling or psychological therapy needs to be offered early on and therapists need to understand what it's like to live with alopecia</p>	<p>“Maybe if I had had help sooner or help from a counsellor who knew about alopecia or understood the effect it can have, I would not have suffered so much. Unfortunately, I was never offered counselling or psychological support. My parents found a counsellor, but they did not understand and the support that they were able to provide was limited.” (P2, female)</p> <p>“Much too late now may have been beneficial when first lost my hair, but too much time passed now and feel cope fairly well now”. (P64, female)</p> <p>“Too late now but it might have been helpful during initial hair loss which was traumatic.” (P53, female)</p> <p>“I think counselling would have helped me to come to terms with my loss. Also maybe helped me find ways to deal with society & being accepted” (P35, female)</p> <p>“Due to the long time that had elapsed by that time I had had to survive through my period of low esteem and suicidal thoughts and I felt it was too late to feel I had the need of counselling so I did not accept the offer - also there was a long waiting list so I would have had to wait 3-6 more months before I would have actually seen a counsellor. I had needed help at the beginning of my experience not once I had learned how to cope by myself” (P56, female)</p>

<p>Counselling and psychological therapy help</p>	<p>“Just having space to talk about the experience was good.” (P32, female)</p> <p>“I think just speaking to a professional who has the time and tools has helped me become more positive.” (P60, female)</p> <p>“The best thing my GP provided for me was counselling.”</p> <p>“I think I am a strong individual not because of my hair loss but because I have used counselling to discover who I am and what I really feel and think without all of life experiences impacting on my chosen survival strategies.” (P38, female)</p>
<p>Support from family and friends helps coping and self-acceptance</p>	<p>“I am lucky that my husband is extremely supportive and he says that I'm the same woman he married, it's just that now I'm bald.” (P11, female)</p> <p>“The love and strength of my family and friends have got me to where I am today I will not let alopecia rule my world it will not bring me down.” (P16, female)</p> <p>“I have been married to a lovely man for 30 years and he has always said and acted as if alopecia didn't matter and this has helped me to heal and grow very much and thus to accept myself better as a woman.” (P71, female)</p>
<p>Learning from others with alopecia how to manage hair loss</p>	<p>“Once you meet others especially ones who have lived with the condition for longer than you for me this made all the difference as to how I could cope. At this very moment I am trying to be optimistic that I will not start losing my hair again. However at least I know that if I do I already have the information/support at my finger tips which will make the journey so much easier - no less devastating but hopefully one I can cope with from the beginning.” (P56, female)</p> <p>“By searching online myself I found the Alopecia UK charity website and was put in contact with their local support group has been a lifeline as far as products/recommendations etc are concerned I also researched other wig suppliers that I could go to and try on alternative wigs. My NHS referral took 9 months but again offered no help” (P56, female)</p>
<p>Contact with others who have alopecia helps coping and self-acceptance</p>	<p>“I had a real identity crisis and hated the way I looked so my confidence went out of the window very horrid and felt alone and nobody was listening until I joined Alopecia UK and started meeting others, I then set up the * branch so helping others as well as me.” (P90, female)</p> <p>“Support from others in the same position far outweighs a sympathetic haired person.” (P75, female)</p> <p>“My experience is that as a person living with alopecia, those experiencing hair loss do relate very well to someone who</p>

	<p>truly understands what it's like to be in their dark place.” (P52, female)</p>
<p>Hearing other peoples’ experiences of alopecia makes things worse</p>	<p>“articles by celebrities who willingly shave off their hair and talk about how it has affected them make me extremely cross. They don't also lose their eyebrows, eyelashes etc and I see them as revoltingly self-indulgent”. (P57, female)</p> <p>“I can look at other women and see how beautiful they are living with alopecia, how brave they are not hiding behind scarfs, wigs, hair pieces etc. How confident they come across. Not me, every day it's a struggle, that gets worse and worse the more my hair falls out, the more my hair line reseeds, the bigger my bald patch grows. The more I die inside”. (P74, female*)</p>
<p>Post traumatic growth</p>	<p>“I am studying hairdressing level 3, Wig making level 2 and braising and weaving courses so I can make mend cut and colour my own wigs and hopefully help others from becoming frustrated when buying human hair wigs. So I guess it’s something I strive everyday with to help others with Alopecia make informed choices.” (P38, female)</p> <p>“For many years I was very self conscious and lacking in self esteem and in self confidence. Then I have studied psychology and meditation and have worked in these fields all my life. Alopecia made me compassionate and able to understand others suffering - it also made me develop a sense of who I was inside . I feel that my physical body is not who I am deep down ...so I have grown confident and self accepting from inside out.” (P71, female)</p> <p>“I definitely think it has made me a nicer person! It has been a great teacher for not judging people on appearances for example. And made me more compassionate towards others, especially those who feel/look different. It has made me stronger too. Even though I felt like hiding away I quickly realised life goes on and I was determined to live mine to the full.” (P14,female)</p> <p>“Alopecia has definitely made me a more compassionate and accepting human being. In the past, I may have been guilty of making snap judgements on others based on their visible appearance only. I no longer do that. I also think alopecia has probably made me less sensitive to judgements about my own appearance.” (P3, female)</p>

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