

**The lived experience of adults with anagen syndrome: an interpretative
phenomenological analysis**

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Abstract

Introduction: Currently there are no studies within the academic literature which document the lived experiences of those who have Anagen Syndrome (AS). AS is a benign condition which impacts head hair growth. There are two known phenotypes, Loose Anagen Hair Syndrome which is a condition that makes anagen hair easily and painlessly fall out, and Short Anagen Syndrome, which results in a short anagen hair growth rate. The study aimed to investigate the psychological and social factors the condition brings for those who have it.

Method: The participants were recruited from a Facebook support group for the condition. A sample of seven white adult females who self-identified as having Anagen Syndrome were interviewed using a semi-structured interview. The data from the interview was transcribed and the transcripts were individually and group wide analysed using interpretative phenomenological analysis.

Results: Three master themes and nine superordinate themes were developed to describe the experiences of living with AS. The master themes are “feeling imperfect”, “I’m more than my hair” and “Nobody understands me”. Participants described two distinct time periods: before finding out about what AS was which left them feeling different and ‘feeling imperfect; and after finding out about the condition which is outlined in “I’m more than my hair”. Participants also reported feeling misunderstood throughout both of these time periods which is reflected in “Nobody understands”.

Discussion: The findings are compared to existing relevant psychological theory and literature. A critical evaluation of the study is presented as well as potential future research within the area and implications of the research.

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Abbreviations

AS	Anagen Syndrome
SAS	Short Anagen Syndrome
LAS	Loose Anagen Syndrome
CBT	Cognitive Behavioural Therapy
GT	Grounded Theory
DA	Discourse Analysis
IPA	Interpretative Phenomenological Analysis

Introduction

Introduction to the study

The aim of this study is to investigate the lived experience of people with Anagen Hair Syndrome, a condition which affects the sufferers, length, condition and texture of their head hair. There are two documented forms of Anagen Syndrome: Short Anagen Syndrome; (Oberlin, Maddy, Martínez-Velasco, Vázquez-Herrera, Schachner, and Tosti; 2018) and Loose Anagen Syndrome; (Swink & Castelo-Soccio, 2016), each of which will be explored in detail towards the end of the literature review below. This paper will refer to the combined conditions as Anagen Syndrome (AS) unless otherwise stated. The condition is considered benign. However, since it influences appearance, it is believed to have psychosocial implications, which will be discussed when reviewing the condition below. I developed a strong interest in the condition as soon as I became aware of it as I recognise I have it. I was frustrated by the lack of rigorous scientific literature on the condition, with only a few short papers documenting its existence, diagnostic procedures and potential treatment options. Most information found in relation to the condition came from an internet support site which, whilst interesting, are anecdotal accounts and unscientific. The small amount of literature there is in this area has tended to focus on children, with adults' experiences being largely neglected. This study aims to rectify this by providing evidence for the psychological implications of living with AS as an adult.

Literature review

This chapter will present an overview of the current literature in this area. The phenomena of Short Anagen Syndrome (SAS) and Loose Anagen Syndrome (LAS) have been neglected within the academic arena. Despite a comprehensive search of the literature no qualitative research has been found. A search was completed in Medline, PsycInfo and Ovid using the

terms Loose Anagen Hair Syndrome and Short Anagen Hair Syndrome. As there is limited research investigating AS, and none to my knowledge which investigates the psychological consequences of having the condition, literature of similar conditions have been compiled. Acquired physical deformities such as burns or facial disfigurements have not been included as they are likely to be a different experience than those who have had a condition from birth. The social context of physical attractiveness in society has been presented to demonstrate how individuals interact within their environment and are influenced by their social circumstance. The psychological effects of conditions that impact on appearance will be reviewed to address the experiences people with such conditions face. Specific conditions that result in atypical hair will be outlined as a basis for comparison with AS. Then the literature on psychological interventions for people living with hair loss will be reviewed to demonstrate the potential utility of such approaches that could be adapted for those with AS. Finally, the hair growth cycle will be outlined with a detailed investigation of both SAS and LAS and how the conditions are represented in the literature.

Physical Attractiveness in Society

Appearance and the importance of being attractive within society is frequently pervasive (Rusmey & Harcourt, 2004). This leads to people feeling concerned about how they appear to others in social settings, with a substantial number of people having some degree of concern about their physical appearance (Gilbert & Thomas, 2002; Grogan, 1999; Rumsey & Harcourt, 2005). The research indicates the lacuna between those who are deemed attractive and those that are not is wide ranging (Becker, 1994; Goldin & Katz, 1999; Hamermesh & Abrevaya, 2013). In addition, this demonstrates how important and valued beauty and looks are in Western society. This is further supported by the millions of pounds spent worldwide on beauty related products, procedures and advertising. However, Talamas, Mavor and Perret (2016) criticise the methodological limitations surrounding research on attractiveness. They

claim it is plagued by small sample sizes, research design flaws and highlight the inaccuracies with regards to definitions of attractiveness.

Popular sayings such as ‘don’t judge a book by its cover’ and ‘beauty is only skin deep’ are warnings to not use attractiveness as the only way of judging or valuing someone. It highlights how people often have a tendency to overly value attractiveness within Western society over personality traits (Langlois, Kalakanis, Rubenstein, Larson, Hallam, and Smart, 2000). Despite such warnings, society often idolises looks (Langlois et al., 2000). This can lead to individuals feeling dislocated, in that society has mixed messages regarding the importance of attractiveness. It is portrayed as both important and equally not important. This can lead to those with a condition that affects their looks feeling shamed for valuing their appearance, despite society pressurising people to value it (Vangeel, Vandebosch, & Eggermont, 2018). This concern is exacerbated for those who have a medical condition which affects their appearance (Rusmey & Harcourt, 2004). Since AS is a condition which affects hair, and therefore appearance, the significance of hair within society will now be addressed.

Social significance of hair

Whilst the main function of hair is to help regulate body temperature and provide some degree of protection, it also plays an integral part in human identity (Freedman, 1994). Literature suggests that hair plays a significant role in physical attractiveness and personal expression (Dogruk Kacar, Ozuguz, Bagcioglu, Coskun, Polat, Karaca, & Ozbulut, 2016; Nolte, Donnelly, Kelly, Conley, & Cobb, 2006). From an evolutionary perspective, Muscarella and Cunningham (1996) state that hair is frequently a prominent factor for both sexes when choosing a partner, as it is seen as a sign of youthfulness and reproductive fitness.

Hair is often referred to as a woman's 'crowning glory' (Cash, 2001). In wider society, fashion influences all areas of physical appearance, with modern styles frequently favouring women with longer hair than men. Weitz (2004) suggests that women are taught to value their hair from a young age. The importance of hair is emphasised throughout Western society, none more so than in the mass media. This is demonstrated by the dominant media attention that is aroused when a female celebrity changes her hairstyle. This is particularly the case when a female celebrity shaves her head for a role in a film or shaves her head in what is represented within the media narrative as an emotional breakdown (Williamson, 2010).

Women are reported to spend significantly more time and money on hair maintenance than their male counterparts (Weitz, 2004). From a young age, hairstyles in the Western world are used to help us to identify cues for gender: "women with shorter hair are often perceived as more masculine than women with long hair" (Manning, 2010, p. 35). Brebner, Martin, and Macrae (2009) found that a person's hairstyle is the most predominantly used facial cue for determining sex. They argue this becomes problematic if a person does not adopt a hairstyle that is congruent with their sex; such a person is more likely to be 'misgendered'. Terry and Krantz (1993) looked at perceived attractiveness and found that women with longer hair were deemed more youthful and attractive and less demanding. Swami, Furnham, and Joshi (2008) acknowledge that more research is required surrounding styles of hair and perceptions of physical attractiveness. Given the prominent influence of attractiveness in society and the affect that hair plays on a person's appearance, it is therefore evident that appearance and having a condition that impacts on appearance will have a psychological effect on the sufferer.

The psychological effects of conditions that impact on appearance

Those with visible differences frequently report suffering with numerous psychological distresses (Papadopoulos, Bor & Legg, 1999; Rumsey & Harcourt, 2005). The psychological consequences of looking differently can often be seen as trivial in comparison to the physical concerns of conditions within the medical arena (Papadopoulos et al. 1999). However, psychological implications are frequently severe and widespread, with 30-50% of people treated in hospital for facial disfigurement reporting significant psychological distress in relation to their appearance (Rumsey & Harcourt, 2005). Jowett and Ryan (1985) completed an investigation of a dermatology outpatient clinic and found that 61% of patients surveyed reported high levels of anxiety and 33% reported clinical-level depression, attributed directly to their skin condition. It is important to highlight that those who were interviewed discussed additional adverse effects of having a skin condition, such as itching and irritation as well as effect on employment, social life and clothing. However, 80% of the sample reported the worst aspect of having the condition was shame and embarrassment. Rumsey, Clarke, and Musa (2002) conducted an investigation with 650 outpatients who had a range of dermatological conditions, all of which affected their facial appearance. They found that 48% had levels of anxiety significant enough to be of clinical concern and 27.5% had clinical level depression reported to be a result of their skin disfigurement. Rapp, Exum, Reboussin, Feldman, Fleischer and Clark (1997) looked at the multidimensional consequences of psoriasis and found negative psychological implications to be significant; 25% of their sample of 317 people had considered suicide, while eight per cent reported that life was not currently worth living as a direct result of their psoriasis. These results are supported elsewhere in the literature (Weiss, Kimball, Liewehr, Blauvelt, Turner, and Emanuel, 2002; Krueger, Koo, Lebwohl, Menter, Stern, Rolstand, 2001; Gupta & Gupta, 1998). Thus, the research demonstrates that conditions that affect appearance and attractiveness can have such negative consequences on people's self-esteem it can lead to suicidal ideation.

“Self-esteem is the positive or negative evaluation of the self” (Smith, Mackie, & Claypool, 2014, p. 107). However, Moss and Carr (2004) suggest that self-esteem is only affected if a high value is placed on appearance. They argue, those who value appearance highly are more likely to have lower rates of self-esteem if they have a condition which affects their appearance. However, Jackson (2002) reports this is dependent on social factors, in cultures where physical attractiveness is valued highly, individuals are more likely to rate physical appearance as an important attribute and will therefore have lower rates of self-esteem if they have a condition which affects their appearance. However, in cultures which place less value on physical attractiveness, such conditions do not have the same effect on self-esteem (Jackson, 2002). Rumsey (2002) argues that resilience and coping mechanisms aid people to maintain self-esteem when living with conditions that affect their appearance. They found that a number of individuals in such circumstances have developed coping strategies that reduce the negative psychological burdens. Meyerson (2001) suggests that such coping strategies include religious beliefs, family, humour, social aptitude and fortitude. Coping strategies specific to alopecia will be explored in more detail in the psychological interventions section of this introduction chapter. Thus personality, support systems, values and culture all collectively affect the self-esteem of a person living with a condition which affects visible difference. Conditions which effect hair, resulting in uncommon hairstyles will now be addressed to determine the implications for sufferers with hair conditions.

Conditions which result in atypical hair

Historically, hair has had cultural and social importance (Freedman, 1994). While fashions change in regard to hairstyles, the dominant discourse in Western society is that women should have hair (Weitz, 2004). The negative impact of not being able to grow hair into a style that fits the social norm can be substantial (Weitz, 2004). As already highlighted, there is no research to date that documents the experience of those living with AS. I have therefore

reviewed the literature of other hair conditions, predominantly alopecia areata. I acknowledge that the findings cannot be directly applied to AS but they may provide valuable insights into the implications of having a hair condition which can then be applied to AS. The key differences between the conditions is those with alopecia lose their hair and therefore face a loss, while those with AS have predominately had their hair difficulties from birth. Additionally, alopecia is a recognised condition that is commonly understood and AS is not recognised or understood.

Alopecia areata

Alopecia areata is an autoimmune chronic condition that results in hair loss (Hunt & McHale, 2005). Alopecia is the umbrella term used to describe hair loss. However, there are three subtypes: alopecia areata, which refers to patches of hair loss from the scalp; alopecia totalis, which refers to the total loss of all hair on the head; and alopecia universalis, which refers to a complete loss of all hair on the body (Hunt & McHale, 2005). The psychological consequences of losing hair are pervasive and well documented (Hunt & McHale, 2007). Cash, Price, and Savin (1993) found that women in particular suffer negative psychological effects as a result of undesirable hair. They stated that women with alopecia were considerably more likely to report social anxiety as well as poorer self-esteem and psychosocial well-being and a less satisfying quality of life in comparison to males with alopecia. They also found that women were twice as likely to report being very upset by their hair loss than males, suggesting that women may place a higher value on hair than men (Cash, Price, & Savin, 1993).

Van der Donk, Hunfield, Passchier, Knecht-Junk, and Nieboer (1994) found that 75% of their sample of women with alopecia had poor self-esteem. Rumsey and Harcourt (2005) found that people with alopecia avoided social interactions if they did not have an existing strong

social support network. Buunk, Collins, Taylour, VanYperen, and Dakof (1990) found that people with alopecia could gain both comfort and distress from making social comparisons to others. Those who compared the condition to more severe health conditions were able to gain a sense of perspective and comfort, although this left some with a sense of guilt and shame. In contrast, those who compared themselves to those with no visible difference felt a high degree of distress. Carr, Harris, and James (2000) found that the biggest consequence of having alopecia was on identity. Hunt and McHale (2005a) support this notion, stating that alopecia was particularly damaging to participants' identity through its impact on their emotional management and relational experiences.

Layegh, Arshadi, Shahriari, Pezeshkpour, & Nahidi, (2010) looked at the rate of depression and suicidal ideation for patients with a range of dermatological conditions. They found patients with alopecia had the highest rates of depression and suicidal ideation when compared to other dermatological conditions such as acne, psoriasis and vitiligo. They also found that those with alopecia universalis and diffuse alopecia areata had the highest rates of suicidal attempts. This study took place in Iran and had a higher proportion of males (n= 193) than females (n=107) in their sample. They reported that females had a higher rate of depression than males but there was no difference between the sexes for suicidal ideation. They also evidenced that younger participants had higher rates of depression. We need to be cautious of these results as the sample in the current study only includes people from western cultures. However, Gupta and Gupta (1998) who completed a similar comparison study reported that those with alopecia had the lowest rates of depression and suicidal ideation in comparison to other dermatological skin conditions such as acne or vitiligo. This may suggest a cultural difference as Gupta and Gupta's study was conducted in Canada. Additionally, they also used a range of both inpatient and outpatient participants whereas Layegh, et al. (2010) only included outpatients in their sample. It may be reasonable to assume the difference

between inpatient and outpatient participants is significant, with those who are on an inpatient ward being more likely to have severe forms of the conditions and it also having a larger effect on their lives which is likely to affect their mental health. This increase in suicidal ideation amongst those with visible differences has also been replicated amongst those suffering from cleft-lip (Herskind, Christensen, Juel and Fogh-Anderson, 1993), acne (Hull & D'Arcy, 2005; Purvis, Robinson, Merry, & Watson, 2006; Gupta & Gupta, 1998) and atopic dermatitis (Dieris-Hirche, Gieler, Kupfer, & Milch, 2009).

Most health services exclusively offer bio-medically focused provisions and neglect the psychological needs of their patients; despite the wide range of psychological difficulties the condition is known to cause (Welsh & Guy, 2009). This can increase the guilt, shame and embarrassment patients experience for being concerned about their appearance (Bates & Cleese, 2001; Kent, 2002; Harcourt & Griffiths, 2003; Frith & Gleeson, 2004). Hunt and McHale (2005) found that those with alopecia are more likely to be depressed, have low self-esteem, a poor self-image and reduced quality of life in comparison to matched controls. Despite this, studies show medical practitioners who work with people with hair related conditions can often neglect the detrimental psychosocial impact of undesirable changes in hair (Welsh & Guy, 2009; Hunt & McHale, 2005; Papadopolous & Bor, 1999).

Chemotherapy induced alopecia

Chemotherapy in cancer treatment can lead to a range of iatrogenic conditions, one of which is hair loss. Williamson, Harcourt, Halliwell, Frith & Wallace (2010) found that the loss of hair was the most disturbing change for adolescents with cancer. They monitored this through a series of case studies, where participants completed diary entries monitoring their mood as well as completing semi-structured interviews. This was supported by Wallace, Harcourt, Rumsey and Foot (2007), Enskär, Carlsson, Golsäter, and Hamrin (1997) and Hedström, Skolin and von Essen (2004), who also found that adolescents with cancer reported losing

their hair had been the most distressing aspect of their treatment. Such results demonstrate how much adolescence value their hair. Hopwood and Maguire (1988) report that adult cancer patients also frequently feel high levels of distress by how the disease has altered their appearance specifically their hair, weight and facial shape. They report that patients feel unable to report this distress to their doctors as they feel guilty for focusing on anything other than survival. Buunk, Collins, Taylor, VanYperen, and Dakof, (1990) conducted a clinical study that looked at a sample of 55 cancer patients (30 women, 25 men) with a mean age of 54. They also supported the assertions that cancer induced alopecia patients reported feeling guilty for having concerns about their looks, especially when making comparisons to others with more severe or life-threatening strains of the disease. Choi and Koo (2003) state that the psychological impact of psoriasis is deemed to be substantially harder to live with than the physical aspects of the condition. Papadopoulos and Bor (1999) also found that patients living with skin conditions find the psychological distress caused by a change to their appearance harder to manage than the physical complications of the condition. Despite this, psychological factors are frequently trivialised by healthcare professionals with medical interventions taking a priority, resulting in further distress for patients with such conditions (Papadopoulos, Bor, & Legg, 1999).

Studies have documented numerous cases where people (mostly women) have refused life-saving cancer treatment because of the possibility they may lose their hair, the prospect of which they find too traumatising to face (Fawzy, Secher, Evans, & Guliano, 1995; Lemieux, Maunsell, & Provencher, 2008). As highlighted above, a number of studies present the view that for adolescents with cancer, hair loss was reported to be the most distressing aspect of having the illness for many of those interviewed. Batchelor (2001) also found that hair loss is the most feared side effect of chemotherapy for many adult patients. However, they acknowledge that this can depend on the individual, with many reporting survival as their

main concern. Lemieux et al. (2008) challenge the results of Batchelor (2001), as they documented a number of women who had chemotherapy-induced alopecia and who experienced hair loss positively, as they associated it with a sign their treatment was working. Kaderman, Kaderman, and Toonkel (1999) explored the experiences of female cancer patients who have had a mastectomy procedure (complete removal of the breast tissue) and reported hair loss was more disturbing than breast loss for these women. This demonstrates the considerable importance that some women place on their hair as well as why neglecting or trivialising its impact can intensify their psychological distress. The high degrees of distress evidently caused by hair conditions presents a clear need for psychological interventions.

Psychological Interventions for people living with hair loss

Successful psychological interventions for supporting and empowering people living with hair loss have been documented in the literature. The benefits of treatment for anxiety and depression as a result of disfigurement using Cognitive Behavioural Therapy (CBT) have been evidenced, with effects still apparent at six month follow up (Kleve, Rumsey, Wyn-Williams, & White, 2002). Cash (2008) found that CBT had a longitudinal positive impact on anxiety, depression, self-image and empowerment for individuals living with hair loss. Whilst hypnotherapy's efficacy remains controversial, Willemsen, Vanderlinden, Deconinck and Roseeuw (2006) completed a five-year study on the treatment's effectiveness on clinical outcomes and psychological well-being for 28 patients with alopecia areata. They documented significant improvements in scores of anxiety and depression. However, all participants continued with other treatments including therapy and antidepressants as well as the hypnotherapy and a number noted an increase in hair growth, which may have affected

their mood scores. These results suggest that those with atypical hair can be responsive to psychological interventions to aid with mental wellbeing.

Coping strategies

Drawing from the alopecia literature, participants who experience hair loss can demonstrate resilience and an adaptive coping style over time. Welsh and Guy (2009) conducted 12 interviews, seven of whom were women and five of whom were men using Interpretative Phenomenological Analysis. They found that three distinct stages of adjustment were present for participants: avoidance, appearance fixing and positive rational acceptance. Participants initially described wanting to hide the condition from others and not acknowledge it. As time progressed, participants made references to appearance-fixing strategies and processes that enabled them to move forward with their lives. This often reflected an increase in knowledge and resilience, such as returning to work or engaging in social activities. After this, participants' accounts began to emerge into a final stage of positive rational acceptance of the condition. Participants discussed achieving an acceptance of their appearance, as well as experiencing a higher degree of perceived control. Cash, Santos and Fleming-Williams (2005) also support these three distinct stages of adjustment in their development of the Body Image Coping Strategies Inventory (BICS). The BICS is a 29 item measure consisting of three internally consistent body-image coping factors; avoidance, appearance fixing and positive rational acceptance. Cash, et al (2005) sample included 603 volunteer American college students, 468 were women (with a mean age of 20.6 years) and 135 men (with a mean age of 20.4). They found that women predominantly used all three of these coping strategies, especially focusing on the appearance-fixing strategy. This is in comparison to the males in this sample who reported low levels on appearance-fixing strategy. They also acknowledge that women experienced more threats to their body image compared to males and they felt more pressure from society to alter their appearance in pursuit of social ideals. However, as they normed this measure on American college students and not

people with dermatological conditions. This three-stage framework is consistent with the notion that coping strategies and resilience change over time as outlined by Papadopolous & Bor (1999). It may be reasonable to assume that people living with AS might go through similar stages of adjustment as the conditions outlined above.

Hair growth cycle

This thesis focuses on the psychological implications of AS and does not aim to expand on the pathological processes described by other papers (Swink & Castelo-Soccia, 2016; Olsen, Bettencourt, & Coté, 1999; Giacomini, Starace, & Tosti, 2011). However, a brief explanation of the process of hair growth is warranted to enable a more thorough understanding of the condition. Human hair has three distinct hair phases: the anagen (growth) phase, the catagen phase (a transitional period of renewal) and the telogen phase (a rest phase prior to hair falling out). Each individual hair goes through each of these phases independently at different times so each isolated hair can be at a different phase to other hairs at any one time (Araújo, Fernandes, Cavaco-Paulo, & Gomes, 2010). Those with SAS have a shorter anagen phase than is typical, meaning their hair does not grow for a long period before it reaches the telogen phase.

Short Anagen Syndrome

Clinical features, aetiology, diagnosis and prevalence

Whitmore (1999) was first credited with identifying AS in the academic literature. Despite the condition being recognised in 1999, little is known about it, including what causes it and its prevalence rates. The condition is deemed to be uncommon but potentially underreported (Antaya et al., 2005; Alaimo, Sorce, & Bongiorne, 2016). However, a small number of case studies have been published on how to diagnose the disorder (Whitmore & Tausk, 1999; Antaya, Sideridou, & Olsen, 2005; Avashia, Woolery-Lloyd, Tasti & Romanelli, 2010;

Giacomini, Starace, & Tosti, 2010; Barraud-Klenovsek & Truelo, 2000; Thai & Sinclair, 2003; Jung, Kim, & Kang, 2011).

SAS refers to an idiopathic anomaly in head hair growth. The condition's distinctive features are not widely recognised and its aetiology remains an enigma. The primary characteristic of SAS is not being able to grow long hair. This is due to an unknown short anagen phase in the hair growth cycle (Giacomini, Starace, & Tosti, 2011). Hair is of typical appearance but the anagen (growing) phase is considerably shorter, with reports suggesting the duration is just 4 to 13 months in comparison to the expected 2 to 6 years (Antaya, Sideridou, & Olsen, 2005). In order to receive a diagnosis of SAS, the hair must have a slow growth rate. This is assessed by shaving a small patch of hair at the back of the head and leaving it to grow for four weeks. Those with SAS also have a higher proportion of telogen hair, which is determined under microscopic investigation (Barraud-Klenovsek, & Trüeb, 2000).

Treatment

Presently, there is no uniformly accepted treatment for SAS. There have been a number of case reports that document successful treatment of the condition using topical minoxidil (Van Egmond, Hoedemaker & Sinclair, 2007; Cheng, Chen, Lin, Hsiao, Chiu & Chan, 2016; Giacomini, Starace, & Tosti, 2011). However, the definition of successful treatment is poorly outlined. Cheng et al. (2016) state that hair density was reported to improve from observation pre-post treatment, but not the length or calibre of growth. Sinclair (2007) documented a successful treatment using minoxidil for a child of four years of age. Treatment using minoxidil is controversial. The mechanism behind the treatment is unknown and queries have arisen in relation to potential side effects. Furthermore, its effectiveness has been questioned (Olsen et al., 2005). The onset of puberty appears to resolve the condition for some people (Cheng et al., 2016), although this is not the case for everyone (Dhepe & Naik, 2012). There

has been a documented case of using a combination of topical minoxidil and oral cyclosporine to treat the condition (Jung, Kim, & Kong, 2011). Whilst this is positive, the length the hair had grown was not reported, which makes the treatment's efficacy difficult to establish.

Loose Anagen Syndrome

Clinical features and prevalence

Loose Anagen Syndrome is a benign condition of abnormal hair in which anagen hairs can be easily and painlessly removed from the head. People with LAS frequently describe their hair as 'unmanageable' (Cantatore-Francis & Orlow, 2009). It is often uneven in length and does not grow longer than the nape of the neck (Swink et al., 2016). Additionally, people with LAS frequently have hair which is high in porosity, meaning the hair has holes in the cuticle which let in and easily lose an excessive amount of moisture (Hessefort, Holland, & Cloud, 2008). LAS is an umbrella term for three different categorisations of the condition. LAS type A is thin hair that does not grow, LAS type B is patchy hair that is unruly, and LAS type C primarily affects adults and results in a 'normal appearance with disproportionate shedding of loose anagen hairs' (Olsen, Bettencourt, & Coté, 1999; Swink & Castelo-Soccio, 2016). Throughout this thesis all three categories of the condition will be referred to as LAS.

LAS is thought to be extremely rare and hence there is a large gap in the literature. However, Sinclair, Cargnello and Chow (1999) report the condition is more common than is documented, this they believe is due to the lack of knowledge about LAS and its clinical features. Based on the number of people they have seen with the condition in their skin and cancer clinic in Melbourne in 1999 the occurrence rate is estimated to be 2 to 2.5 cases per million per year. It is also suspected that this is an underrepresentation as many people have the condition without seeking a diagnosis or reporting it, additionally this paper is now ten years old. The

condition frequently manifests in families, indicating an autosomal dominant inheritance pattern (Baden, Kvedar, & Magro, 1992). LAS is predominantly reported to occur in white females aged between two and nine years old before spontaneous recovery occurs when at puberty (Dhurat, & Deshpande, 2010). However, there are reported cases of boys with the condition (Hamm & Traupe, 1989; Pham & Krejci-Manwaring, 2010).

Due to its inheritance pattern, the condition should manifest equally between the sexes. However, the sex ratio is currently reported to be six males to 37 females (Sinalair, Cargnell, & Chow, 1999). It is believed that the condition is underdiagnosed in boys due to differences in hairstyles between the sexes, with boys often keeping their hair shorter, meaning the condition is less apparent (Pham & Krejci-Manwaring, 2010). There are also documented adult cases (Chapalain et al., 2002; Price & Gummer, 1989). The literature on the condition is sparse, with the majority being single case studies with white girls of pre-pubescent age (Cheng & Bayliss, 2008; Price & Gummer 1989; Mirmirani, Uno, & Price, 2011). Whilst literature on LAS overall is limited, the literature for adults is particularly minimal, with more case studies focusing on children being published.

Aetiology

The exact aetiology of LAS is unknown. Tosti and Piraccini (2002) and Chapalain et al. (2002) hypothesise that LAS is a keratin defect which results in a weakened adhesion between the inner root sheath and the cuticle of the hair shaft, although they acknowledge that further genetic investigation is required.

Diagnosis

Diagnosis for LAS is based on clinical features and reported history from the patient alongside a 'pull test'. This involves a gentle tug of a small section of hair to determine whether the hair can be removed easily and painlessly. It will then be investigated under a

microscope. LAS hair comprises of at least 70% anagen hair without sheaths, as well as misshapen bulbs and ruffled cuticles on its proximal portion (Tosti & Piraccini, 2002).

Treatment

There are more cases of LAS within the literature than SAS. Despite this, there are still limited empirically supported treatment modalities. Observation, which involves watchful waiting with no active treatment, is the most prominent treatment of choice since LAS is expected to rectify itself with the onset of puberty (Tosti & Piraccini, 2002). There are also a small number of documented cases of successful treatment using topical minoxidil (Anouar, Hjira, & Boui, 2019; Cantatore-Francis & Orlow, 2009, Chapalain et al., 2002). However, these successful cases are again simply described as a ‘marked improvement’ and have no definitive data to support them. Swink and Castelo-Soccio (2016) recommend the use of biotin supplements for their sample of participants. This is a popular supplement discussed and utilised within support groups on online forums, although it has not been empirically tested (Rushton, 2002; Swink et al., 2016; Oberlin et al., 2018). In summary, evidence for the empirical treatment of the condition is weak and mostly comes from case studies. Further research in this area is evidently required.

Representation of SAS and LAS in the literature

There are some documented ambiguities between professionals distinguishing between the two conditions in the literature (Weedon, 2009). This is despite studies which highlight the conditions’ differing characteristics (Oberlin et al., 2018, Vujovic, Andre, & Stene, 2016; Antaya et al., 2005). Based on the informal review of the main themes discussed on the support forum, the distinction between the two phenotypes is not often spoken about and at times the two conditions are described as being one. It is believed that both SAS and LAS have no long-term serious health ramifications and the conditions are neither life-threatening

nor painful. This may provide an explanation as to why research has neglected the conditions. It has also been suggested that the reliance on peoples personal historical accounts on how their hair has grown throughout their lives may have also reduced the representation of the condition in the literature (Antaya et al. 2005). Research that has been published on the disorder has primarily been case studies that centre on dermatological aspects of diagnosis. The psychological effects of the condition are beginning to be acknowledged within the literature but have not yet been investigated in any depth (Antaya, Sideridou, & Olsen, 2005).

Purpose of this Research

AS is a condition that is believed to cause distress for sufferers, although this has yet to be evidenced, therefore it was important to gain a more thorough understanding of this distress. As previously highlighted AS had not been investigated in detail before, with most existing research focusing on diagnosis and small scale case studies documenting the condition. This study is therefore important to highlight the psychological and social significance of AS. It was also important to gain an understanding of the experiences of those with this condition and how their experiences with the condition have changed over time. As the study aimed to gain an understanding of people's experiences of the condition, the use of IPA was the best suited methodological approach for this study. It was hoped this research will increase knowledge of the condition amongst both researchers and the general public.

Research Questions

1. How do adult females describe their experience of having Anagen Syndrome?
2. How do they make sense of their experience of having Anagen Syndrome?
3. How has this experience changed and developed over time?

Methodology

This chapter describes the methodological approach that this project took. The study's method, design, sampling, recruitment procedure, and ethical considerations will be outlined with a detailed explanation provided for each. Finally, an account of the data analysis, the quality checks used within the data analysis process and a reflective statement will be presented.

Methodological Approach

Qualitative methodology was selected for this study as it was the most appropriate methodology to answer the research questions the study set out to answer. Qualitative research answers different questions than quantitative research, it also uncovers a depth of understanding not possible with quantitative research. "Qualitative research opens a space inside psychology to do something radically different, to link human experience with social action" (Parker, 2005, p.1). As with all methodological approaches, there are weaknesses associated with qualitative research. This includes the caution that needs to be applied when generalising the findings, due to the unique and limited sample they often employ. Johnson & Onwuegbuzie (2004) also recognise researchers bring their life experiences, opinions, expectations and views to their work. They highlight the importance of being transparent with these viewpoints so as to enable the reader to assess if the data has been assessed openly or if their personal bias has infiltrated the data; this will be addressed in more detail below in the Hermeneutics paragraph. Qualitative research can generate hypotheses and parameters of the innovative topic, laying a foundation for further work to expand on. Qualitative research is becoming increasingly valued within healthcare settings particularly when its focus is on the experiences of patients (Department of Health, 2006).

Alternative methods considered

The following section will present the two other methodological approaches that were considered and finally a justification of why IPA was selected.

Grounded Theory (GT) (Glaser & Strauss, 1967)

GT is the method aimed at discovering patterns within data and developing theories from these patterns (Walsh, Holton, Bailyn, Fernandez, Levina & Glaser, 2015). This approach aims to develop categories and concepts from social interactions which the researcher will be able to identify through repeated analysis and theory development. GT aims to create a theory and an understanding to the phenomena as a whole. I did not aim to devise a theory in order to answer my research question and I was predominantly interested in gaining an understanding of the individual's lived experience of AS. I therefore rejected GT for the current study.

Discourse Analysis (DA) (Potter & Wetherell, 1987)

DA is concerned with how language constructs our reality. It focuses on gaining a more comprehensive understanding of the social occurrences that are fluid and ever changing by exploring social interactions that take place between people. Potter and Wetherell (1987) are first credited with the development of this approach within psychology. Parker & Burman (1993) argue that DA is interested in '*how people use language to construct versions of their worlds and what they gain from these constructs*' (p.100). This approach would be able to highlight how the language that is used constructs reality or meaning for those with AS. As I was more interested in participants' internal cognitions and the sense that is derived from these experiences, IPA is a more appropriate methodology.

Interpretative Phenomenological Analysis (IPA) (Smith, 1996).

IPA aims to focus on a person's experience of a given phenomenon but also how they understand their experiences and so each individual will have their own unique account. The

approach therefore recognises that people's lives and understandings are shaped by assumptions and prior experiences. This is closely associated with social constructionism. Social constructionism views peoples' individual experiences as "being only one way of seeing the world amongst many potential ways it can be seen" (Burr, 1995, p7). Burr (1995) advocates that people's assumptions, understanding and knowledge of the world are shaped by their personal history. These are grounded in culturally specific language, social interpretations and culturally specific phenomenon. IPAs theoretical underpinnings comprise of three components; phenomenology, hermeneutics and idiography (Pietkiewicz & Smith, 2014).

Phenomenology is the philosophical study of understanding experience. Husserl (1927) (as cited in Smith, Flowers, and Larkin, 2009) pioneered the importance of reflecting on one's experience and Smith, Flowers, and Larkin (2009) brought its relevance to the psychological literature. The subsequent work of Heidegger (1962), Merleau- Ponty (1962) and Sartre (1956) (as cited in Smith et al., 2009) highlighted the importance of acknowledging the complex environment the individuals having the experiences exist within. They argued that the individual is affected by cultural experiences, language, relationships and bidirectional projections (Smith, Flowers, and Larkin, 2009). Langdrige (2004) argues that whilst these factors play an important role in an individual's experience, they can never be comprehensively acknowledged by the individual as some of these processes will be unconscious to the individual. Phenomenology in IPA is gaining an understanding of the participant's experience of a given phenomenon.

Hermeneutics is the theory of interpretation. People regularly interpret and attempt to make sense of their own experiences. They also attempt to interpret other people's experiences to increase their understanding of those around them. Whilst completing IPA the researcher is engaged in double hermeneutics as they are "trying to make sense of the participant, who is

trying to make sense of what is happening to them” (Smith, Flowers and Larkin, 2009, pp. 3). As such the researcher’s own experiences inevitably impact the analysis (Willig, 2013). Therefore, Smith, Flower, and Larkin (2009) suggests that IPA aims to acknowledge the key role the interviewer plays in this methodology. Smith, Flower, and Larkin (2009) also argue for the importance of documenting the researcher’s influence on the data. They advocate the use of reflexivity by the researcher to acknowledge their personal position throughout. They hope this transparency will acknowledge the potential effect of the researcher’s influence on the participant’s data.

Idiography is concerned with the study of the individual at a specific and detailed level (Larkin, Watts & Clifton, 2006). Larkin et al. (2006) advocate intensive and detailed analysis at the individual level initially, and then for this analysis to be completed at a group level, and finally that such results can never be applied to the nomothetic level. As such idiography in IPA focuses in detail on understanding one subjects experience in context at a time making conclusions about the individual before examining across cases.

Justification of approach

Kelle (2006) advocates the methodology employed should predominantly focus on how the research question will be best answered. As such IPA (Smith, 2004), which focuses on understanding peoples’ experiences and how they make sense of this experience, was considered the most appropriate qualitative methodology for these research question. Furthermore, Smith, and Osborn (2008) advocate the use of IPA when a topic is both novel and complex. Given this topic has not been previously researched, IPA was deemed the most appropriate methodology to investigate the study’s research questions.

Data Collection

IPA is designed to provide a first-person account of individual experience. It requires exploration of rich and detailed data in order for the researcher to delve into the participant's world. Participants need to be able to talk freely and openly and not be restricted by closed questions; as such semi-structured one-to-one interviews are deemed the most appropriate methodology for collecting such data. This facilitated the opportunity for a "conversation with a purpose to occur" (Smith, Flower, and Larkin, 2009, pp. 57).

A semi-structured interview is when respondents are asked a number of open ended questions that are based on a semi-structured interview guide (Smith, Flowers, and Larkin, 2009). A semi-structured interview is a list of important questions or topics that need to be covered within the interview (Jamshed, 2014) and so provides a clear framework and guidance for the interview. However, it also enables flexibility so that nuance and interesting topics of conversation, that cannot be anticipated, can also be captured (Jamshed, 2014). The use of semi-structured interviews has been criticised previously for its lack of credibility in terms of reliability and validity (Brink, 1991; Diefenbach, 2009). Potter and Hepburn (2005) document a number of critiques of the "taken for granted position of the open-ended interview as the method of choice in modern qualitative psychology" (Potter & Hepburn, 2005, p. 282).

Despite the critique of semi-structured interviews they also offer a number of advantages. They are flexible in they allow the researcher to follow interesting trajectories if they materialise, whilst also covering the important topics that are required. A semi-structured interview also allows for the space and time for a strong rapport to be developed between the interviewer and the participant, all of which can aid the participant to feel comfortable and open (Smith, Flowers & Larkin, 2009). The approach also allows rich data to be generated as participants are open and free to talk about the topic without any restrictions or limitations.

Semi-structured interviews were the method of data collection choice for a number of reasons. It was an approach that enabled the collection of rich data on the topic. I have experience of conducting semi-structured interviews and it allowed me to use my clinical skills to develop a good relationships with the participants, an area I felt comfortable with. It was deemed the best way for me to get data in regards to participants lived experiences. Finally, it was an approach that was easily organised within the stringent time limits of this research project.

Method

Design

A qualitative design using semi-structured interviews was employed to explore the experiences of people with AS. The interviews were all transcribed verbatim and then analysed using Interpretative Phenomenological Analysis (IPA) to highlight the experiential themes. Initially analysis was conducted for each of the individual participants and then analysis was completed at the group level to identify the master and superordinate themes.

Participants

Setting the context

All participants were recruited from the Facebook support group, Short Anagen & Loose Anagen Syndrome (SAS & LAD) - Hair Disorders group. It was set up for advice and support for those with SAS/LAS or with a close family member with the condition. The site is used globally by people from all over the world and has 2,407 members and is regularly used by a large number of people with regular posts being posted daily. The forum is a closed internet based support group via Facebook (https://www.facebook.com/groups/saslas/?multi_permalinks=10155434131052981¬if_id

[=1513572914529482¬if t=group highlights](#)). Members can only join after undergoing a brief security and purpose check via members of the administration team who run the group.

I completed an informal review of the main themes discussed on the Facebook support group. This was completed to provide a brief understanding of how people primarily use the group. There were six prominent categories of topics that posts on the group fell within; pictures of peoples hair with progress reports on their hair growth (this is predominantly pictures of children), discussions about products, hypothesis for causes of the condition, stories of hope for others, stories of difficult experiences that people have encountered, and request for help and support. Whilst the group does give the impression it provides a positive space for people with the condition it does appear to have more posts which reflect negative aspects of having the condition. This did make me consider if my sample may also have similar perception of the condition.

Sampling

Smith, Flowers and Larkin (2009) advise that a total of six to eight participants are sufficient for a successful doctorate study. Turpin, Barley, Beail, Scaife, Slade, Smith, and Walsh (1997) advice that for UK clinical psychology doctorate programmes, specifically, a sample size of between six to eight participants are recommended. I therefore set out to collect a sample size of eight. However, only seven participants were recruited that met the criteria and agreed to participate in the research. They were aged 27-64 years of age. This number allowed me to complete an in depth exploration of a person's individualised lived experience prior to looking at the collective experiences.

Inclusion and exclusion criteria

This section now outlines the Inclusion and exclusion criteria with justification for each.

The Inclusion criteria:

- Aged 18 years of age or older.

As highlighted in the introduction section AS is prominently reported to be a condition experienced by young children who grow out of it during puberty. However, there are numerous adults who reported not growing out of AS and continue to have it as adults, on the support group, whose experience has not yet been acknowledged. The age of 18 was chosen as I was interested in understanding how AS was experienced by adults with the condition, this also ensured the participants had experienced the chronic nature of the condition (with the expectation that they will have lived with it for the minimum of 18 years). It also ensured they could consent to taking part in the research independently. An upper age limit was not placed on the study to ensure for the possibility of recruitment of enough participants.

- Identified as having either loose AS or short AS.

This was the primary focus of the study and was an essential criterion to gain insight into peoples' experience of the disorder. This was ensured by asking potential participants if they identified with having the disorder. It was not be a requirement of the study to have a formal diagnosis. This is because frequently no formal diagnosis is sought by those with the condition. This is for a number of reasons. The condition presently is unrecognised, rare and not yet established within both the general population and medical settings. Sufferers have been left isolated or unaware that there is a medical explanation for the condition. Additionally due to limited treatment options available adults often do not seek out a diagnosis after living with it for all of their lives. Diagnosis is only recently beginning to be pursued for young children. The participants of the study were asked simply to describe their hairs presentation over their lifetime instead of the specific phenotype of AS they had. This was because the majority of the sample did not have a formal diagnosis to establish if they had SAS or LAS. The specific type of AS also was not required to know the impact their hair had had on their experience of the condition.

- Be able to converse clearly in English

The subject needed to be able to converse clearly in English, and also have a good knowledge and understanding of the English language. This is imperative for the successful use of IPA which uses language as a vehicle to portray understanding.

The Exclusion criteria for participants in the study were as follows:

- Anyone under the age of 18 years of age (this is justified by the reasons stipulated above).

- Anyone who does not identify as having either LAS or SAS, as this is the primary focus of the study.

- Anyone who does not consent to be recorded as this is essential for the analysis

- Anyone who feels they will not be able to discuss the topic without becoming overly distressed, as based on the information sheet

- Anyone who has a comorbid hair condition other than LAS or SAS. This was imperative to exclude the possibility that other factors could have influenced the participant's lived experience of their hair.

Recruitment Procedure

Due to the rarity of the condition I posted an initial post on the online support forum to scope potential participants for the project. This was to identify if it was viable to complete the study, 133 potential participants expressed an interest in taking part in the study; which demonstrated a strong likelihood in meeting the sample numbers required. It is important to highlight however, the inclusion and exclusion criteria were not stipulated at this time point. An official advertisement post was later posted on the site for recruitment of the study, after ethical approval was gained, with further details including inclusion and exclusion criteria,

from which all participants were recruited for the study (please see Figure 1 below for recruitment flowchart).

Final Sample

The final sample was seven female White participants who met all the inclusion criteria stipulated above.

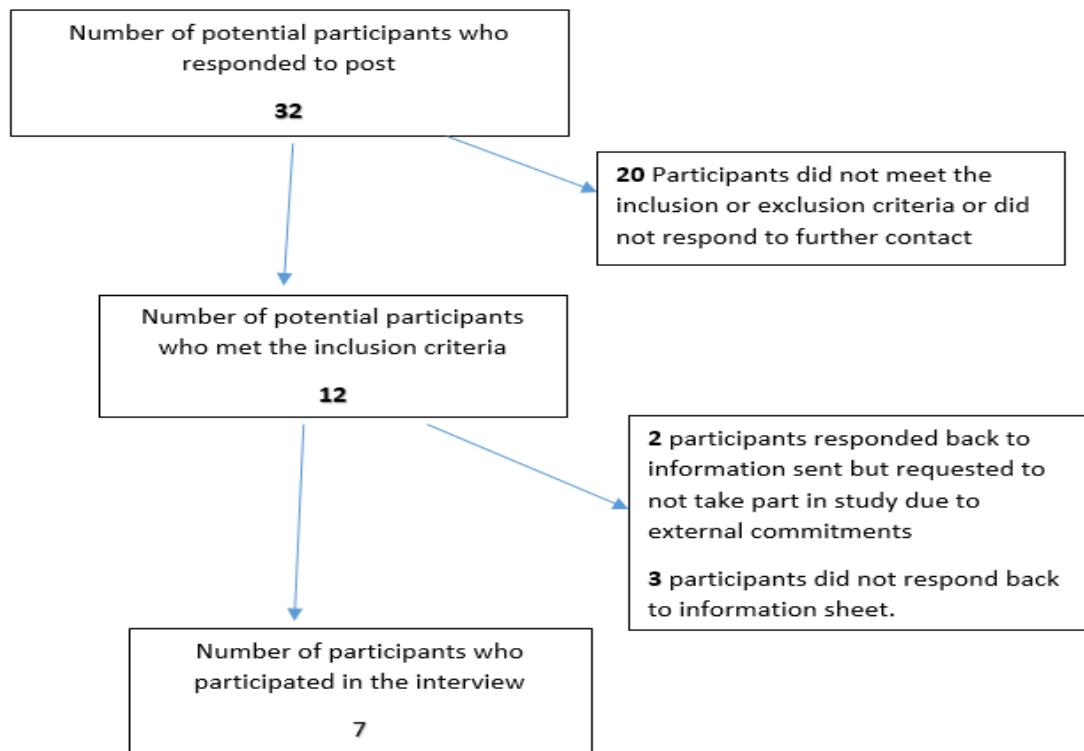


Figure 1: Recruitment Flow Chart

Interviews

The interviews were arranged to accommodate each person's individual requirements. Three of the interviews were completed at participant's homes whilst the remaining four were conducted via the telephone. The interviews lasted between twenty six minutes and sixty one minutes. All interviews were audio recorded and later transcribed. As soon as the interviews

were completed I made a note of my reflections. I transcribed three of the interviews myself in order to familiarise myself with the process and immerse myself with the data and the remaining four interviews were transcribed by a university approved transcriber. After each transcript was completed I listened to the audio recording whilst reading the transcript to ensure for accuracy and to ensure non-verbal communication and pauses were highlighted and then made any amendments that were required.

Interview Schedule

In order to gain a rich and thorough account of the participants' experiences, a semi-structured interview schedule was devised. As Jamshed (2014) highlighted an interview schedule is simply a guide and was not to dictate the interview; it was simply a '*visual map*' (Smith et al., 2009, p.59). In regards to the literature on interview schedules Hollway and Jefferson (2000) suggest that the type of questions that are asked influence the stories participants give. They advocate for the importance of using participant's own words as this elicits more depth whenever possible. As such, interviews were individualised and adapted as the interview took place. Despite this, the schedule guided the interview with topics that were to be covered. It also included open-ended interview questions and helpful prompts that were there to gain more depth about people's experiences.

There were a number of processes that influenced the development of the interview schedule; the research questions, pre-existing literature on similar conditions, and the results of an informal review of the main themes of the topics most frequently discussed on the Facebook support group (this will be discussed in more detail in the participants section). After it was devised it was then taken to an IPA workshop where feedback was given from both the organisers and my peers. In line with this feedback I made some revisions to the order of my questions, ensuring the first question was broader to allow participants to open up and give

them space to discuss the topic more widely. I then shared it with my supervision team who reviewed it and made suggestions. Finally, I completed a pilot interview with a peer to test out the interview schedule and to ensure it allowed for the utmost engagement of the participants. This resulted in no changes and ensured I was confident with my interview schedule.

The Interview schedule is as follows:

Interview Topic Guide

What follows is a guide to the topics that are likely to be covered in the interviews with participants in order to explore their experiences of having Anagen Syndrome (Short Anagen Syndrome and Loose Anagen Syndrome). Some topics may emerge spontaneously and so the order of the questions and the exact content may vary as the interview develops.

Individual experience of having Anagen Syndrome

1. *What does SAS/LAS mean to you?*

Probe for:

- Symptoms (*what do you experience? What is it like for you to live with these symptoms?*)

2. *In what ways 'if at all' has the condition featured in your life?*

Probe for:

- Impact on life domains e.g. mood, emotional well-being, self-concept

3. *Can you tell me how you experienced the condition as a child?*

4. *Has your experience of the condition changed at all over time? What factors 'if any' influenced this change? How do you see the condition influencing you in the future?*

5. *What are the most challenging factors 'if any' about having the condition? Why? How do you get through a bad day with the condition?*

6. *What advice would you give to someone with the condition? And why do you consider this important?*

7. *What would you be prepared to give up to have the hair you would really want?*

8. *Have there been any occasions which the condition has brought positive experiences to your life? (Can you tell me about these and the impacts they have on you and your thoughts on the condition?).*

9. *Is there anything that you expected me to ask you to talk about today which we have not covered that you would like to talk about?*

Depth prompts

How do you feel about that?

What was going through your mind at the time?

Why was this?

Can you tell me more about that?

Ethical considerations

Ethical approval for this research was granted by the School of Medicine Research Ethics Committee at the University of Leeds on the 24th July 2018 (see Appendix 2).

Participants

The interview, naturally, generated conversations about participants' experiences of having a condition which impacts on their appearance and this may have triggered emotional reactions for those involved. Whilst it was not the aim of the study to cause participants distress, it was acknowledged that it may evoke topics that cause participants to feel distress. I did adhere to the BPS guidelines on this matter "the risk of harm must be no greater than that encountered in ordinary life" (British Psychological society, 2014, pp11). Participants were given a detailed information sheet that was sent to them by email that documented everything that the study would involve (Appendix 3). Despite this, participants might have found talking through their experiences may have brought back painful memories or reflections. If participants became distressed the plan was to stop the interview and provide immediate support before full termination of the interview if I felt they were not able to continue. They would have then been signposted to gain support from the online forum, the Samaritans and their local GP. Fortunately, this did not occur in any of the interviews, with only one participant becoming openly distressed but she felt able to continue with the interview after a short break. After each interview a full debrief was completed to ascertain whether elements

of the discussion had brought about emotions the participant felt unable to manage (McMahon & Winch, 2018).

Researcher

As I have the condition it was possible that I could have been exposing myself to emotionally distressing material. To guarantee the success of the overall project I ensured that I protected my own wellbeing throughout the completion of the study. I used my supervisors and peer group to support me with this. I had regular meetings and contact with the team, to allow me to reflect on the experience. I also completed a reflective diary and regularly updated this throughout the process, paying particular attention to my own wellbeing and reflections throughout.

Maintaining anonymity and confidentiality

Prospective participants were informed that all potentially identifiable information would be removed or anonymised in the final report. This was discussed prior to the participants agreeing to take part in the study and signing the consent form. Pseudonyms were allocated to all participants and any places mentioned in order to maintain the human element of the study, which is important in qualitative research. If any information was deemed to be potentially identifiable some details were changed without distracting from the data to protect the participant. Participants were also advised prior to taking part to only share what they felt comfortable disclosing, and they had the right to decline to answer any questions they felt they were unable to answer. They were also informed that anonymised direct quotes of their words would be used within the report. All electronic data were stored securely on the university system in accordance with the University's Data Protection Policy. I also recorded the interviews using an encrypted electronic recording device. The data was then transferred to a secure university computer and deleted as soon as transcription was completed. A

university approved transcriber was utilised to transcribe four of the seven interviews after signing a confidentiality agreement (Appendix 4).

Managing Informed Consent

All potential participants were given a detailed information sheet (see Appendix 3) prior to taking part which outlined the nature of the study, what it involved and potential topics that may arise within the interview, as well as areas they may find distressing. They were also sent an electronic consent form (Appendix 5) and required to sign it and email it back to me prior to taking part in the study. They were given a week to read over this information and the opportunity to ask questions over email before agreeing to take part. Prior to the interview they were again asked if they fully understood the nature of the study and were happy to participate.

Managing withdrawal from the research

Participants were informed, prior to them taking part in the interview, that they had a one week period in which they had the right to withdraw their interview from the study. They were informed they did not need to provide a reason if they did wish to withdraw. However, after this one week period data transcription and analysis would be taking place and so they would not be able to withdraw from the study after this time point. No requests to withdraw from the study were made.

Data Analysis

Each participants' interview was individually analysed using a combination of the guidelines set out by Smith et al. (2009) as well as two additional IPA workshops that I attended to support me with my analysis. The process that I followed is set out below in Table 1 including explanations of why each process was completed. Smith et al. (2009) outline six identifiable steps for analysis and I have nine. The first three stages I completed were

additional and were added after attending the University of Derby’s analysis support day, explanations for each step is provided in the Table 1 below.

Table 1

Stages of Data Analysis.

Stage	Process	Description
1	Initial Reflections	I made a note of my initial reflections after each interview. This included how I made sense of their interview and any prominent feelings that arose for me. This was completed to document my initial thoughts and aid the reflexive position that I took.
2	Audio Reflections	I then listened to the audio recording of the interview and made further reflections. I also made a note of any changes I would like to make in regards to my interview approach for the next interview. This was to add to my initial reflections and ensure that I had an in depth reflexive account prior to beginning the analysis.
3	Summary	I then made a summary of the interview with all the key elements that stood out for me at this point in time. This was completed to capture my thoughts and understandings to aid the individual analysis as well as to draft the first version of the pen portraits.
4	Reading and re-reading transcript	After each interview was transcribed I listened to the audio again to check the transcript was accurate. I then read and re-read the transcript several times to really familiarise myself with the data. This was to immerse myself in the data
5	Initial noting	<p>I then began the process of line by line analysis of the text. I made detailed comments by hand on the right hand side of the transcript, paying particular attention to any comments that highlight participant’s experiences. I then left the text for a period of a week and then started a fresh copy of the interview transcript and started the process again.</p> <p>I then got a third fresh copy of the interview transcript and noted any significant descriptions, linguistic comments or conceptual comments that stood out to me. This was all completed in different coloured ink to help it stand out for me. This initial noting was to further immerse myself in the data, developing a comprehensive understanding as well as beginning the initial level of the analysis. An example of this can be seen in Appendix 6 and 7.</p>
6	Developing Emerging themes	<p>I then brought all the data together (both the transcripts and all the comments that I had made). I then incorporated these into emergent themes and wrote them in the left hand column of the original transcript.</p> <p>I then re-read the transcript whilst listening to the audio recording to check that the themes were an accurate reflection and made any changes I felt were necessary.</p> <p>At this point in time I took sections of my transcripts to the IPA</p>

		<p>support group to ensure others agreed with my emergent themes. Any amendments were then made in line with this.</p> <p>I then typed the themes into a word document with the corresponding extracts. I then took these to supervision and had in depth conversations with my supervisor's to ensure they were robust.</p> <p>This process was completed to attempt to produce clear but concise themes that reflect a strong essence of the experiences they are aiming to capture.</p>
7	Searching for connections across emergent themes	<p>I then printed off and cut out all of these themes and clustered them together in regards to connections or links (both those with similar connections and oppositional connections). I took a photograph of these to recall how I had organised them and then repeated the process once more. Then I compared the two groupings together to ensure I was happy with the outcome.</p> <p>I then copied and pasted these groupings together into a separate word document and gave them master and superordinate theme names. I then shared them with both my supervisors and my IPA support group for quality checks.</p> <p>I then took an A3 paper and wrote out all of the master and superordinate themes with post it notes of the subordinate themes underneath. Using the audio recording and my original plotted summary I checked they represented the essence of the interview. At this point I wrote a draft pen portrait for the participant.</p> <p>This stage was completed to marry the themes together and map out the prominent themes that capture the essence of the participant's experience.</p>
8	Moving to the next case	I then repeated this process again for the next participant's interview, until I had completed them all.
9	Looking for patterns across cases	<p>I then produced an excel spreadsheet with all the master, superordinate themes and subthemes and looked for connections across cases.</p> <p>I then produced new names for the clusters of themes that I felt captured their essence. I completed a table noting which participant experienced which theme. Again this was discussed on numerous occasions with both my supervisors and my IPA support group to ensure I had developed them thoroughly.</p> <p>This stage was completed to develop a comprehensive and clear group analysis.</p>

Quality Checks

It is vital that all qualitative research is held up to high standards of reliability and validity to ensure the highest possible data quality. With regards to holding myself accountable for

methodological rigour I have highlighted two key frameworks to work from Elliott, Fischer and Rennie (1999) and Yardley (2000, 2008). Elliott et al. (1999) developed guidelines and recommendations for completing high quality qualitative research. These comprise of “owning one’s perspective”, “Situating the sample”, “Grounding in examples”, “Providing credibility checks”, “Coherence” “Accomplishing general versus specific research tasks”, and “Resonance with readers”. Additionally, Yardley (2000, 2008) also documented a framework for completing rigorous qualitative research which highlights four key dimensions including “Sensitivity to context”, “Commitment and rigor”, “Transparency and coherence” and “Impact and importance”. With this in mind I completed the following steps:

- I read and re-read my data on numerous occasions, including allowing time to pass between reads to try and come back to the data with a clear mind. This was to ensure that I had attempted to consider alternative perspectives.
- To safeguard the quality of my data I regularly met with my supervision team who received anonymised extracts of my transcripts and tables of emergent themes with verbatim extracts. This allowed them to see the themes that my analysis had highlighted. We discussed these in detail to ensure that I had considered all perspectives. After each supervision session I would refine my themes until I felt confident in my analysis.
- I attended an IPA analysis course at The University of Derby. The day was designed to instruct us in completing the highest level of analysis for our data. We reviewed anonymised extracts of our data and our analysis were looked at within the group and on an individual level with the instructors. Discussions were had about the emergent themes from the data which again widened the lens I approached the data with.

- In addition, a small research group of those completing IPA studies from the University of Leeds Doctorate in Clinical Psychology was set up. This was to provide mutual support and feedback throughout the process but chiefly to guide each other to meet the relevant quality criteria set out by Yardley (2008) and Elliott et al. (1999). This also enabled me to gain different perspectives on the data and themes and supported me to refine my approach to the data.
- Throughout the process I kept a detailed reflective diary to document and identify any biases that I become actively aware of. In order to make my personal stance transparent I had regularly included reflective comments throughout the thesis and I read back over my diary regularly to check to see if my thinking had changed. This was particularly important as I am also a sufferer of the condition, to ensure for transparency.

Reflexivity in IPA

Integral to the process of analysis using IPA is the researcher's ability to reflect on how their own life experiences may impact on the way they view the data. This is crucial in the double hermeneutic process as documented in Smith and Osborn (2003). Therefore, the experiences that I, as a researcher, have had to date play an integral role within the analysis process. Yardley (2008) highlights that it is not possible to remove subjectivity from a researcher's view point and so therefore this should not be attempted. Instead, the researcher's perspective should be made transparent within the process. Therefore, in order to ensure the data is not constructed through an overly subjective lens the researcher is required to keep a reflexive and open-mind throughout the process.

The following section will outline my personal experiences and perceptions connected to the research. As a person with the condition I came to the research with a personal understanding

of it. It was therefore vitally important to acknowledge the position this brought to my research. Stringent quality checks and comprehensive reflexivity was vital to ensure the robustness of my data highlighted above. I also interviewed my parents to gain their experience of me having the condition to gain a different perspective of my experience. Finally I regularly utilised the Leeds Doctorate Clinical Psychology IPA support group, which was made up of those within my year three cohort who were completing IPA thesis projects, to quality check my work.

Initial reflexive position

My initial experience of the condition

Throughout my life my hair has never grown and has been extremely unruly and hard to manage. I had never understood this and at times found it frustrating. I was initially alerted to the condition of AS a few years ago. A close friend of mine was working in a paediatric health services in London and had a child present with the condition at her clinic. She informed me of the condition, knowing that I had experienced similar symptoms all my life. On hearing about it I felt a wave of relief and empowerment as I instantly identified with having the condition. This led me to conduct some research which highlighted how little there was known about the condition within the literature. It also brought me to the Facebook support group which depicted how many people were experiencing it and how isolated and distressed some people reported to be feeling about having it. I became extremely motivated to conduct research on AS to promote knowledge and awareness of the condition. When given the opportunity to do such research I approached one of my supervisors to inquire about investigating AS.

Upon becoming aware of AS I felt I had already come to a period of acceptance with my hair. In early periods of my life I had felt a great source of emotional pain in relation to my hair; it

had been a source of shame for me which led me to, at times, feel insecure about my appearance. Most people in my life had been positive about my hair, with very few negative comments that I can recall ever being made about it. I have always been a confident person in all areas of my life with the only exception being my hair, which had brought me some sadness. However, with age and maturity I had felt that I had begun to accept it as a part of me. Therefore, when I began this research I did not feel the condition would be emotionally taxing for me and I was motivated and excited to begin the process. I did however, inevitably, come to the research with some strongly held biases. I expected the condition would likely to have impacted others in a similar way as I had experienced it. I expected people to discuss feeling different from others and feeling insecure because of it but despite this thinking their personality had always made up for what they lacked in hair. I did also acknowledge that others may have had different journeys to mine and was interested and open to hear how others had experienced it. I was also very interested to hear how it had manifested and impacted on others as they grew older to see how it impacts on people at different ages.

Reflexivity during the Research Process

I began to find it hard when people would ask me about my research and how I had known about AS in social situations and settings that I had not expected to talk about the condition in. I started to feel an internal pressure to 'out myself' as a person with the condition more regularly than I would have expected or wished to. I was also thinking and reading about hair more than I ever had done previously which at times became difficult for me and I noticed that my relationship with my own hair started to deteriorate as a result. This was not something that I had expected prior to starting on the research process. Due to this I completed a reflexive interview with a peer and realised after this that I still had some way to go before I had accepted my hair fully. This interview however did assist me in enabling me to bracket off my experiences to aid in the analysis stage. I also made a note of these

reflections and read them again prior to each interview to help me to remain as objective as possible.

Reflexivity After the interviews

I had noted that I had not found most of the interviews taxing, but some were emotional and required the support of my supervision team and friends around me. After completing the interviews it was apparent to me how different one of the participant's experiences was from the others. She reported that the physical symptoms of the condition only began when she was an adult. Collectively, the other participants appeared to have difficulties with the condition from being a young age with most having experienced emotional pain as a result of it. In order to assess my own experiences and test out my own biases, I conducted an interview with my parents on how they recalled my experiences of the condition as a child. This process highlighted to me how much my adult bias had influenced my lifelong view of the condition. My parents reported that I had not been influenced or upset by my hair as a child and it was only when I became an adult, of roughly seventeen years of age, that it had started to affect me. They both recalled times I had been a child and mistaken for a boy because of my short hair and I had confidently corrected people and not appeared to have been impacted by it, despite my parents finding it 'heart breaking'. I noticed how I had hardly any recollections about this. I considered how many mums of daughters on the Facebook support group have expressed similar stories and reported feeling very emotional for the pain their daughters may feel in such situations.

There was certain occasions when I was a child that we could all recall me being upset by my hair, such as when I was a bridesmaid for my cousin's wedding and a school event I could not comply with the dress code for because of the length of my hair. Despite these specific upsetting events, my parents reflected that overall I had mostly been accepting of my hair as a

child. I had neglected this, thinking that I had always had concerns about my hair. I also considered how most of the participants in their interviews had been unable to acknowledge any periods where they may have been satisfied with their hair too, which I found interesting. However, I could not assume that they may have had positive periods in their lives regarding their hair as it had not been expressed in their interviews. I continued the reflective journal throughout the research process to aid in my transparency in my analysis.

Results

The following chapter will document the results of the interpretative phenomenological analysis of the lived experiences of people with AS. Initially I will present a pen portrait for each participant, briefly describing them and their experiences of having the condition. I will then address the group analysis. A thematic representation of the themes will be presented and then a table presenting the major and subordinate themes, followed by a detailed description of each. Finally I will present my reflections on the process.

Pen Portraits

In this section a pen portrait will be present for each participant. I will briefly outline each of their experiences of having AS, my reflections and any significant points that I had noted from the interviews. This has been included to present my participants' individual stories as well as to give context to the group analysis. All participants were White and from countries in which English is the first language. Six of the seven participants did not have a diagnosis but all confidently self-identified as having AS. They reported not being officially diagnosed with the condition as they could see no advantage in gaining one, with there being no treatment available. Additionally, not all participants lived in a country that offers free health care which was an additional deterrent for gaining a diagnosis. All participants reported being motivated to complete the research as they wanted more people to be aware of AS and they hope for more research to be completed on the condition in the future. The pen portraits have been ordered in age; starting with the youngest and ending with the oldest to provide a clear distinction between the younger and older participants.

Table 2:

Table of Demographics

Pseudonym	Age category (in decade)	Location of interview	Condition presentation	Do they have children/grandchildren with the condition	Length of interview
Darcy	20	Participant's home	From birth never grew long	No	44mins
Nat	20	Participant's home	From birth never grew long	No	28mins
Alison	30	Telephone	From birth never grew long	Yes (Children)	61mins
Lucy	40	Telephone	From birth but gradually grew after puberty	Yes (children)	41mins
Hayley	40	Telephone	Developed in twenties still cannot grow long	No	53mins
Jenna	50	Telephone	From birth	No	26mins

			never grew long		
Tina	60	Participant's home	From birth never grew long	Yes (Grandchildren)	33mins

Darcy

Darcy identified as coming from a middle class family that valued education and did not value appearance. She lived with her mum dad and younger sister when she was growing up. Darcy described thinking that she was different from a young age which she attributes to having to wear glasses, wearing different style clothes from her peers and having short hair that was thin and would not grow. She reported that her parents would regularly dress her in second hand clothes and at times this would be embarrassing for her amongst her peers and she was targeted by bullies because of her appearance in school. She reported being envious of her sisters long thick hair. She described thinking this was not fair as she was younger and her own hair should be longer. Darcy also described growing up in a multi-cultural environment and being around a number of girls from different cultures who had different hair types than her own. This all contributed to her having a sense that she was different from others.

Darcy reported having no awareness of her hair being different from others when she was a young child. She would regularly try different styles she had seen in children's magazines and would be confused as to why they did not look the same as in the magazine. She did not recall being self-conscious of this at the time. Darcy found her hair more challenging when she was a teenager when she began to become self-conscious about it. She described not

being able to express herself as easily as others could and she wished she could have changed her hairstyle and colour.

Darcy found out about the condition from a friend, which led to her researching it online and identifying with having the condition. Gaining an awareness of the condition was validating for her. It made her recognise that she was not on her own with it, which she had felt previously. She reported that she knows her hair is delicate and so she is careful and cautious about how she manages and styles it but even though she is careful with it, it is still thin and falls out easily.

Darcy reported feeling fearful of the future; she fears she may go bald as she gets older. Darcy did express some positive aspects of having AS. She reflected on how much pressure there is in society to look good and be attractive and how hard it is to not feel this pressure. She felt AS had aided her to not overvalue appearance, which she thinks she may have done without having AS, but despite this she did continue to feel the pressure to look attractive. This was frequently frustrating for her as she recognised herself as someone who had more to offer than just what she looks like. She described having supportive friends and family and her boyfriend always highlighted how much he liked her hair which helped her to feel better about herself.

Darcy's interview flowed well and she gave long, detailed, expressive and emotional responses to each question asked. I reflected on how well Darcy had made sense of things and expressed her experiences. Darcy confidently directed the conversation which made for an easy and interesting interview as a result. I came away from this interview excited about the data that the interview generated. Darcy presented as confident throughout the interview, and was comfortable discussing her vulnerabilities which made for powerful data. I thought Darcy was strong and independent and appeared to know herself well. She reported that she

had found the interview cathartic, as she had never before been able to talk for that length of time about her hair with someone just listening to her.

Nat

Nat described her family as middle class. She reported they valued appearance and advocated always looking your best. She described having always been conscious of what others thought of her, a value that she felt had been installed in her by her parents. She had two older sisters that were both significantly older than her, she reported she had never lived with them and so growing up it had just been her mum and dad in her house.

Nat reported her hair had never grown long. The longest it had ever grown had been to her shoulders, which had been extremely distressing for her when she was growing up. She thought it had impacted on her self-esteem and self-confidence. Whilst Nat was aware that her hair did not grow, she had only become aware of having AS in the last few years, when she was researching it online. She reported that prior to finding out about the condition she was always trying different products in the hope they would resolve her “problems with her hair”. Nat found it reassuring to finally know why her hair did not grow but equally she found it disheartening there was no cure for this condition.

Nat described still wishing for a cure in the future and she regularly searched for different products to improve her hair. Nat reported finding the Facebook support group beneficial but she had also found it frustrating that it was mostly mums who had daughters with the condition that post on it. This left her feeling that very few adults were affected by AS; making her feel more isolated.

Whilst Nat reported continuing to feel distressed about how much hair she lost daily through simple tasks, such as brushing it, she reported feeling that the condition no longer impacted on her self-confidence as much as it once had. Nat believed this was down to maturity but she

acknowledged that at times it continued to make her feel insecure about her appearance. She reported this was particularly prominent when she was attending special occasions as she felt it was important she looked her best at these events.

Nat was the first participant that I interviewed. The responses she gave to most of the questions were short and direct and she required a lot of encouragement to give more in depth responses. I reflected on whether I had given enough information on the expectations of the interview beforehand, potentially she may have been unsure as to the detail that she was expected to give. However, she gradually began to give more detailed responses as the interview progressed and the relationship developed. Nat appeared to be quite shy and she reported that her self-esteem and confidence had been deeply affected by having the condition. When prompted she was able to recall significant events that impacted on her life with this condition and connect with the emotional experiences of having AS. At times she was contradictory in her experiences. An example of this was when she reported that she thought that no one on social media has the condition and how other conditions are widely promoted on such platforms, forgetting that the Facebook site was how she was recruited.

Nat appeared to be reluctant to discuss how AS had impacted on her relationships with others, even when directly asked. Whenever Nat did speak about others they appeared to only be used as a marker to compare herself unfavourably against. It is important to highlight that she did only speak about her friends from school when she was younger and people she follows on Instagram (hair models). She indicated that she felt guilty for still caring about her hair as she thinks at her age she should no longer be focused on her appearance. She gave me the impression that she felt shame in admitting this is something that she valued.

After the interview I had thought that I had not got the best account of her experiences and that she had appeared to be holding back something from me. We are similar in ages and

from the same part of the country and I did wonder if this may have been a challenging factor for her. Despite this, she did give valuable insights into her experiences of having AS. She reported that she had found it useful to think about her hair in such detail and reflect on how far she had come with the condition.

Alison

Alison did not disclose much information about her upbringing, although she did report that her mum's response to her hair had been painful for her growing up. Her mum would frequently make jokes about her hair when she was younger and Alison found this very distressing. She also reported that she had found managing her hair the most challenging when she was a young teenager and when she had to move schools. This had been really difficult for her as it was at a point in her life where she was feeling the most insecure about her hair; it resulted in her feeling different and isolated.

Alison had been aware of her hair not growing since she was a young child. She reported that this was the "*most traumatic experience she had as a child*". It had been deeply frustrating for her; with her often trying different things to help it grow that were not successful. Alison found other people's negative reactions to her hair particularly upsetting. She described becoming less upset about it as she matured. She thought she had reached a place of acceptance with her hair before she found out about the condition. However, when she found out she was pregnant with a little girl she became anxious that her daughter would have the same hair as her. This made her realise she still had some difficult emotions connected with her hair.

She became aware of AS after researching on the internet why her hair would not grow. Alison reported that she was overjoyed when she found out about AS and she thought having this understanding aided her to accept herself. She also claimed that it had been restorative

for her relationship with her mum, as it had facilitated them to discuss her mum's management of her hair when she was a child, which they had never addressed before. It also allowed her to think about how best to approach it with her own daughter's (who also have the condition). She was grateful to now have a support system of other mothers with children who have AS. This is something she acknowledged that her mum did not have access to. Despite this she was still anxious for her daughter's future with the condition as she thought that society has now become more focused on appearance than it had been when she was younger, so she is concerned it may be more difficult for her daughter.

Alison reported being comfortable with the way she managed her hair. She described being able to style it in a way that made it look thicker when she wears it up. This has aided her to feel more comfortable with her hair and herself. However, she reported she still becomes nervous when she has to go to the hairdressers and her hair does occasionally upset her. She reported her daughter's hair is now more distressing for her. She wants to protect her daughter from any hardship it may cause her. Alison expressed having strong desires to advocate for those with the condition and to promote knowledge about it, in the hope this would prevent other people having some of the experiences that she had when she was younger.

Alison was articulate and clear throughout and gave detailed responses to all questions. The interview flowed well, she often gave emotional and comprehensive answers to all topics covered and I did not feel the need to prompt her for more detail in her responses. Alison was softly spoken but was confident in her approach and I thought that we developed a good rapport quickly. She had her two young daughters with her during the interview. This did not appear to disrupt the interview until the end when her youngest daughter became distressed. However, by this point the interview had come towards a natural conclusion.

I was excited by Alison's interview. Her detailed and emotive responses made me enthusiastic to start analysing her data. There were times during this interview when she talked about painful memories that led to her becoming visibly upset. I felt very in tune with her emotionally and thought she had been brave in telling her story. I really wanted to do her story justice and capture it the best I could. I did feel a great sympathy for her and frustration with how people around her had managed the condition, although it was clear it had not been their intention to cause her deliberate distress. This interview reinforced the emotional cost that AS can have on people and how important this research is. Alison said she had found the interview enjoyable and was really interested to hear about others experiences with AS.

Lucy

Lucy grew up with her mum, dad and sister. She was envious of her sister's long princess hair. She described herself as being a "tomboy" growing up which she attributes to her hairs length. Lucy recalled a number of incidents when her hair had caused her significant distress. She reflected on how her parents had always supported her with this by not making a "*big thing of it*". She also thought that at that period in time people did not focus as much on hair as they do now. When Lucy hit puberty her hair started to grow longer and she felt that she fitted the typical pattern of someone who only has this condition as a child, which she was grateful for.

Lucy recalled regularly being mistaken for a boy when she was a child because her hairs length, which she found distressing. She described a number of emotive accounts when this had happened to her as a young child. Lucy battled with the concept that her hair had impacted on her identity and personality; believing that she was a tomboy because she had short hair. Despite this, she had always secretly wished that she was a princess with long hair. As an adult she questioned if she acted like a tomboy as a child to protect her self-esteem as

she was not able to look very feminine. Lucy recounted that her hair did begin to grow “slowly” after “*puberty had kicked in*” and she was then, understandably, less distressed by it.

She was first made aware of the condition when she began to research why her daughters’ hair was not growing. Lucy reported feeling happy with her hair now but she felt this was only because her hair did eventually grow and she would feel quite differently if it had not grown. Lucy also thought that her priorities and values had changed since she had become a mother and she placed less value on her appearance now than when she was younger.

Lucy was the only participant who reported that she now really appreciates her hair. Despite her being able to grow her hair longer she keeps it at shoulder length which she thinks is more manageable and suits her better. She reported appreciating that it grows slowly, as it requires fewer haircuts and so is cheaper for her than her friends with faster growing hair. However, she reported still having an entrenched fear of hairdressers that started in childhood because of her experiences. She recognised that if she had a “*bad haircut*” she is stuck with this for a long period of time and she struggle to trust hairdressers as a result.

Lucy’s main source of current distress with the condition comes from being a mother to three young daughters with the condition. She believes attitudes and styles have changed from when she was younger and there is immense pressure on her daughters to have long hair. Lucy recounted that her daughters are the only ones in their large school with short hair. She described incidents where they were victimised and humiliated in school because they did not have long hair. This had left her feeling powerless. It also brought back memories of her own difficult experiences with her hair when she was younger. She expressed her frustration at how children’s female role models all have long hair, which does not help girls with short hair to feel good about themselves. She acknowledged that more is being done to promote the abolishment of gender roles, but it angers her that she thinks society still expects females to

conform to look a certain way if they are to fit in. She wished that Disney would have a princess with short hair instead of them always having long hair. She thinks female cartoon characters always have long hair also. This is something she reported she would like society to address.

Lucy was able to formulate and expresses herself well and she gave rich and detailed responses to all the questions which provided me with a real insight into her experiences of having the condition. She presented confidently and appeared to have a firm understanding of both herself and how the condition had impacted on her. This allowed the interview to flow like a conversation and I felt I had a firm understanding of what the condition had been like for Lucy. I did feel that at times, particularly towards the end of the interview, Lucy was focused more on her daughters' experiences of the condition, which whilst insightful was not the focus of my research. I had noted a real sense of frustration when she spoke about her young daughters being bullied and victimised in school because of their hair. I felt a great deal of sympathy for her daughters and for Lucy in how powerless she must have felt in relation to these situations. I felt I had developed a good rapport with Lucy and she also reported having enjoyed the interview.

Hayley

Hayley grew up in a middle class family with her mum, dad and sister. She reported her hair had grown at a normal rate till she was eighteen, when she cut it short and it never grew back. Hayley's sister is a hairdresser and she thought this encouraged them both to be experimental with their hair. Her hair had been her main way of expressing her personality. Hayley reported she was primarily motivated to take part in the research in the hope she would gain more information about AS. When I informed her that I was unable to give her any further

information on the condition she said she was still motivated to still be part of the research in the hope it could generate more research in the future.

As highlighted above Hayley reported that her hair had grown at a normal rate until she was eighteen when she cut it short. However, prior to her cutting it she reported that her sister had told her not to cut her long fringe as it was her “*protection*”. This made me wonder if there had been some issues with her hair before this time point. After cutting her hair short it never grew back. This account is in contrast to all of the other participants and people who have posted about the condition on the forum, with them all having had the condition since birth.

Hayley’s initially blamed herself for her hair’s lack of growth. She thought she was the one causing the problem with her hair and she was left feeling hopeless. She described it as “*the most depressing thing that has ever happened*”. She desperately wanted the longer hair she had once had. At this point Hayley began a long quest to attempt to understand why her hair would not grow. She described trying several different products and began going to a number of different professionals in an attempt to rectify the problem. She described numerous negative experiences with a number of different professionals, none of which helped her or gave her any indication as to why her hair would not grow. These experiences left her feeling misunderstood and at times financially exploited.

Hayley eventually visited a trichologist who diagnosed her with LAS. Hayley was the only participant with a formal diagnosis. She reported initially feeling a large sense of relief from receiving the diagnosis. She was relieved to finally have an answer and to know she was not doing anything that was causing her hair difficulties. This had been a large fear of hers despite believing that she had not done anything that could be causing this difficulty. After the relief of finding out about the condition she expressed feeling depressed that there was no

cure. Hayley's trichologist had suggested an expensive treatment but she was unsure if she should pursue it as it was new and there was no evidence for its effectiveness.

It was clear from the start of the interview that Hayley was still extremely distressed by her hair. She described feeling isolated with the condition and feeling she was unable to go out when she thought it looked bad. She described thinking her difficulties were unacknowledged by those around her. She relied on having hair extensions, which she describes as being her only way of feeling able to go out of the house. Hayley reported being so motivated to get longer hair she said she would do anything including "*swopping her car or her expensive watch*" to get the hair that she wants. She considered it to have had an extremely detrimental impact on her self-esteem and confidence.

At first Hayley appeared anxious during the interview as she spoke at a fast pace and switched topic of conversation suddenly and frequently. I thought this may have been due to nerves. I attempted to slow Hayley down by speaking slowly and in a calm tone; this did not appear to impact effect Hayley's responses. I was really struck by the desperation she had felt and how she was urgently still seeking a cure. She had spent a significant amount of money in the hope something would work. This made me feel extremely torn ethically. I knew that my position was to be a researcher and not to provide advice but I felt very uneasy knowing that she was doing something that was at a great financial expense to her that had no proven utility.

I was also very interested in how different her experiences were in comparison to others with the condition. She appeared to develop the condition as an adult and had not struggled with it as a child. This, whilst anecdotal, appears to be very rare, with no other reports of this clinical presentation.

I felt a great deal of sympathy for Hayley. She reported feeling isolated and not heard by those around her. She had missed social events because of how much her hair had affected her mood making her feel she could not leave the house.

Jenna

Jenna said little about her upbringing other than she identified as being working class and her mum also had AS. Jenna described her mum having a more severe form of the condition as her hair was very short, not growing past her ears. She described how her hair had never grown but it had never concerned her. She had a son and a daughter, both of whom did not appear to have the condition. Jenna stated she had never valued looks as her mum had always installed this in her. She reported that her son had mental health difficulties which had been concerning for her, her son's health problems reinforced for her that appearance is not something to value.

Jenna reported that her hair did not grow and she was unable to style it. However, this had never felt detrimental to her and she had only considered it "*annoying*". Though she did become more conscious of it on special occasions, as she wished she could style it to look different then. She described it as always "*looking a mess*". Whilst she reported that her hair did not impact on her and that she had accepted it, she reported frequently being envious of others hair. Jenna described the biggest difficulty of having AS had been how it had limited her ability to express herself. Despite this, she did not consider this important, with other problems in her life surpassed her hair difficulties.

Jenna reported that she had only found out that it was a condition in the last couple of months when an acquaintance told her about it, before this she had believed she just had "*weak hair*". She then investigated the condition and self-identified as having AS. Jenna stated that whilst

finding out about the condition had been interesting for her and gave her an understanding of her hair, it did not change anything for her.

Jenna reported being accepting of her hair and comfortable with it. She dyes it blond and the length is just below her shoulders. She said even if there was treatment for it she would not pursue this, which she thinks she may have done when she was younger. Jenna emphasized that she does not value looks and “*at her age*” is more concerned with her health. Jenna’s interview was different from all the other interviews. She did not appear to be distressed at all by the condition. I was surprised at her not only taking part in the research, but also being a member of the support group. I recognised that was my biased view of who might use such support groups.

Jenna said she was nervous about the interview, being unsure as to what I would ask her and if she would be able to answer the questions. Her responses to all the questions were short and direct. I had to give her a number of prompts to enable her to expand on her responses. This was mostly because Jenna reported the condition having had very little affected on her, meaning there was not many accounts and experiences to explore. This interview was less of a conversation in comparison to the other interviews. Afterwards I was left querying how well it had gone and I was concerned about how much depth I had captured for the analysis. When I asked Jenna how the interview had gone for her she said “*I hope that was okay for you*” and did not reflect on her own experience, even when being given an additional prompt which left me unsure as to how she had felt about it.

Tina

Tina described herself as being from a middle class family and grew up with her mum and dad; she did not mention having any siblings. Her best friend, who lived next door to her growing up, had long hair and she would regularly compare herself negatively to her. Her

parents had always gave her encouragement that she was “*beautiful*” but despite this she had always felt insecure about her appearance, thinking her hair contributed to her being ugly and no one would ever find her attractive.

Tina described her hair as being uncontrollable, hard to manage and very short. She found this very challenging when she was growing up. She reported that she had been targeted and humiliated by people when she was in school because of her short hair. Tina believed that her hair would eventually grow. She held onto this belief until she was in her twenties when she then realised that this was now unlikely. Tina stated that most people who knew her accepted her hair as it was. She mostly only got negative remarks from strangers, which she found hard to manage. However, she did describe being targeted by one girl in her secondary school who would regularly bully her and call her a man because of her short her. This contributed to her feeling insecure about her looks. She described thinking that to be feminine she must have long hair. She described how hard it had felt for her as a young girl that all the Disney princesses had long hair, something she was not able to emulate.

Tina reported that when she met her husband and they got married she began to feel more comfortable with herself and accepting of her hair. She described knowing someone found her attractive made her feel more secure in herself. She thinks that it was at this point in time that she stopped seeking answers about why her hair did not grow. Tina’s styled her hair into a short style that she liked as she thought it kept it in good condition. She described it as getting frizzy the longer it got. Tina reported still feeling insecure about her hair at times but she was now mostly accepting of it.

Tina found out about AS only a few years ago when she was in her late fifties. She was relieved to finally know why her hair did not grow. She had begun to research the condition when her granddaughter was born with the same problem.

Tina reported feeling that she had no control over how she styled her hair and she disliked not being able to follow hair fashions and change her hairstyle like others can. However, she was happy with her current hairstyle, believing she has found a style that suited her and her hair no longer distressed her like it had done. She also reported that now her physical health is more important to her than how she looks. This is because she now has other health concerns which helped her to put her hair into perspective. Despite this, she was happy to know about AS as she had found it hard to not understand her hair and it had been challenging when she was younger, thinking she was the only one with the condition. She now found it more distressing that her granddaughter had the condition and she had less concern for herself. Her granddaughter is extremely distressed by her hair not growing and Tina discussed how hard it is to reassure her. She felt that society had changed to overvalue appearance, which was not the case when she was younger. She does think it is helpful for her granddaughter that she has short hair so she can be a role model for her, as this was something she did not have when she was younger. Tina thought there needs to be more short haired role models in wider society and she felt this directly contributed to females with the condition feeling inadequate.

Tina's interview took place at her home and it was my first interview. When I arrived she had a large collection of photographs she had ready for the interview, which naturally led to us talking about them and her hair prior to the interview beginning. We spoke for approximately fifteen minutes before the interview started about a range of hair related and miscellaneous topics. I was very conscious of this at the time and asked Tina if we could start the interview so that I could capture these important stories in the interview. I felt a real warmth and connection with Tina. After the interview in my reflexive account I made a note of what we had discussed prior to the interview to aid my memory and to provide context to the analysis. Tina's interview was thirty-three minutes long although this was spread out over an hour and twenty minutes. This was because Tina had a health condition which left her requiring a

number of breaks and pauses throughout the interview. This was necessary, but they did naturally disrupt the flow of the interview. She was clear throughout the interview but she did not appear to be able to give a great depth to her account, despite my prompts to encourage this. However, she did describe the emotional implications of her story. Tina appeared as a shy and anxious lady. This led me to ask the questions tentatively and delicately so as to not overwhelm her. It was clear towards the end of the interview that Tina was tired and ready for the interview to end. I did however find it interesting that when I began the analysis I recognised that she had given me more depth than I had first realised. I wondered if at the time I had felt so protective of her that I had neglected to see her strength and resilience. At the end of the interview I felt a real connection with Tina. Tina reported that she had enjoyed the interview process but it had made her feel very tired.

Group Analysis

Whilst participants had their own unique journey with AS the group analysis highlighted three master themes: “Feeling imperfect”, “I’m more than my hair”, and “Nobody understands”. The participants' themes accounted for two distinct time periods: their feelings before becoming aware AS and how they felt after finding out about the condition. The master theme, “Nobody understands”, was present for participants both before and after finding out about their condition.

Figure 2 depicts a thematic map of these themes and demonstrates how they are connected. Table 3 is a ‘who said what’ table which outlines which participants described each theme. In this write up if more than one participant has reflected an idea of a theme this has been highlighted in the text but only a few quotes have been represented. It therefore gives the reader an idea of which participants described experiencing each theme.

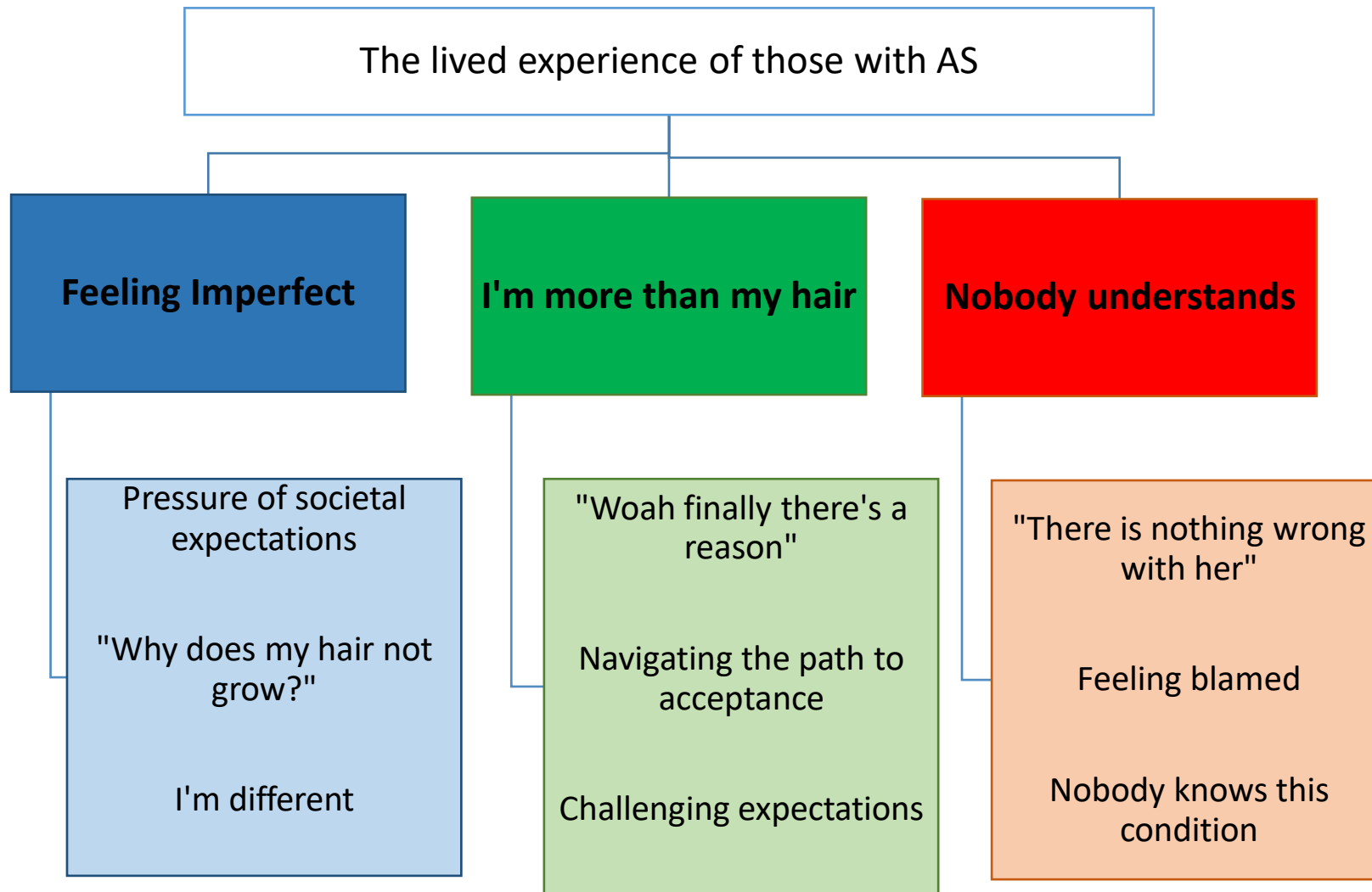


Figure 2: Thematic Map of Themes

Table 3:

Who Said What Table

Theme	Hayley	Darcy	Tina	Nat	Jenna	Alison	Lucy
Master Theme: Feeling Imperfect Superordinate Themes: i. Pressure of societal expectations ii. <i>“Why does my hair not grow?”</i> iii. I’m different	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓	✓ ✓	✓ ✓	✓ ✓ ✓	✓ ✓ ✓
Master Theme: I’m More than my hair Superordinate Themes: i. <i>“Woah Finally there is a reason”</i> ii. Navigating the path to acceptance iii. Challenging expectations	✓ ✓	✓ ✓	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓
Master Theme: “Nobody understands” Superordinate themes: i. <i>“There is nothing wrong with her”</i> ii. Feeling blamed iii. Nobody knows the condition	✓ ✓ ✓	✓	✓ ✓	✓ ✓ ✓	✓ ✓	✓ ✓ ✓	✓ ✓ ✓

*The themes in quotes and italics are direct quotes of participants.

Feeling Imperfect

The master theme "feeling imperfect" denotes the time period before participants had knowledge of AS. It reflects how participants recognised that there was an ideal way for them to have their hair. They felt they were unable to even have normal hair, let alone ideal hair. The ideal way to have hair was suggested by how others communicated and acted towards them based on their hair. These interactions often felt humiliating and antagonistic, which was both distressing and painful. The three superordinate themes are "pressure of societal expectations", "I'm different", and "why does my hair not grow?"

Pressure of societal expectations

This theme refers to the societal pressure participants felt the need to live up to regarding their hair. Other people had highlighted to them how different their hair was in a number of ways, both intentionally and unintentionally. This was often a painful experience for participants; it reminded them their hair was flawed. Hayley reported feeling unattractive as a result of her hair which was reinforced by her hairdresser who was discussing her hair's condition with her: *"At one point, she-she kind of said something, 'Oh your hair! It's terrible' and I said, 'Well how would you feel if you were me?' And she went, 'If I was you I would not go out'".* Hayley felt shame and humiliation from this encounter, leaving her questioning whether she should be out in public given her hair. This was also experienced by Darcy who felt that being on the wrong side of society's standards caused her to feel ostracised: *"So I think like the hair sorta added to me looking a little bit different. So I think it is, so I don't think it was the reason I got bullied but I think it was part of it".* Such social interactions reinforced the expected standards for hair, and how others will react to them when they do not adhere to these standards.

The majority of participants reflected on the frequency in which they had been mistaken for boys when they were younger because their hair did not match what was expected for girls.

Alison and Lucy reflected on how prominent these memories were for them as children:

“just the fact that I was being mistaken for a boy so often when I was a younger child, when I was older I was very, um – and I was, I was never gender confused or anything like that [I: Yeah] um - but, yeah, it bothered me a lot to, um – especially because I had – I wanted to look like my mom”. (Alison).

“I remember being called a boy all the time. All the time...I do, I remember crying about that awfully.... And I remember crying about that instance. And of course I would have been [sighs] what, six, seven or eight. But I still vividly remember that one specific time. Umm, but there would’ve been-I know there were hundreds more. Hundreds more; so maybe . . . Didn’t my face, ‘can’t you see that I’m a girl?’ I don’t, you know I am a girl. Everything about me felt like a girl; My hair being short doesn’t make me not a girl. (Lucy).

These encounters were painful for these participants given that they strongly aligned to being female. To them their femininity was attacked. Tina recounted a time when she felt attacked and bullied for having short hair: *“These boys came along and said you’re a boy aren’t you. You have got boys hair.”* Having boys’ hair was a vicious insult for Tina. This was more distressing for her as it was out of her control and she wished she could have the long hair society expected her to have. As a result of this, Tina questioned how others see her: *“I really think about that at times. Well I used to think about it as you know with someone saying that it made me think that that is what people think of me.”* She felt she was an outsider in society.

Reflexivity (from interviewing my parents and recalling events from my past)

I was not surprised by the number of participants reporting that they had been mistaken for boys when they were younger. However, I was surprised by how distressing this experience had been for people. Whilst I recall it being mildly distressing for me on occasions, my parents reported they had found it more distressing but they had protected me from their distress. On reflecting back on this as an adult I do think of them as upsetting but not traumatic or influential, perhaps because they only ever took place with strangers. When I originally completed the analysis I had initially downplayed the distress this caused participants. It was only after I discussed my transcripts with others that I recognised the pain that these experiences caused my participants. I therefore re-analysed my data and recognised the difficulties that I had initially minimised. From seeing how difficult others had found such situations made me consider how I had made the assumption that others had the same feelings about this as I did. It therefore opened me up to the possibility that people may have found different aspects of AS challenging than I personally had experienced or expected.

Another experience that one participant described was people mistaking her for being unwell because of her hair. Hayley described a time when a new hairdresser had made the incorrect assumption that she had cancer because of her hair. This demonstrates the depth of society's pressure for women to have long hair, it was assumed she was unwell if she did not adhere to this:

“One of her stylist said to me, ‘Can I ask when you stopped your chemotherapy’ I was like, ohhhh, I thought please just ground open up, swallow me now because this is the worst thing anybody’s ever said to me in my life. I was like . . . ‘I haven’t had any.’ She went, ‘Have you been very ill then?’ ‘No . . .’ you know? ‘Oh my God, this is awful!’ I never went back, as you can imagine”.

In conclusion, participants described feeling that society expects females to have long hair and when they do not conform to this standard people make assumptions about them being different, being male or being sick. The pain of such judgements from others is compounded for participants as they desperately wish they could conform: *“all I really wanted was long hair”* (Tina).

“Why does my hair not grow?”

This theme refers to yearning and searching for an answer as to why their hair does not grow. All participants described questioning why their hair would not grow. Whilst this lack of knowledge was a shared experience it was not felt the same way by all.

Participants described having had a strong desire to find out why their hair would not grow. Some participants expressed this as a challenging quest for them: *“you know that constantly trying to find the reason why it was happening and the amount of money that I had spent is for us to tally up we’d probably both fall over.”* (Hayley). Both the financial and emotional consequences of not knowing or having a diagnosis were large for Hayley. Some participants assumed they were personally responsible for their hair when they were not aware of AS: *“But it’s been pretty much nine years of me thinking that I was doing something wrong. I was the person that was doing this to my hair”*. (Hayley). This extract captures the deep frustration Hayley felt at not knowing the reason behind why her hair would not grow. Lucy reflected on how painful she had found the period of time before she had gained awareness about her hair condition: *“I, I wanted hair; I desperately-I remember crying with my Mum, ‘Why doesn’t my hair grow?’”*. The desperation participants felt in being left in the dark about their hair not growing, left them feeling as if they had no hope.

Prior to having a definitive explanation and understanding as to why their hair does not grow, participants described developed their own narratives to explain this: *“Erm so yeah I just thought, I just thought I had thin hair”* (Darcy). Hayley held a belief that she was responsible for her hair’s condition given what others said to her: *“And [hairdresser] always said to me it was hair breakage with me, you know. Breaking, that’s what it was; me blow-drying it. And it was always me-me-me. I was doing all these things. ‘And you need to stop.’”* This led her to feel confused as to what she was doing that was causing her hair not to grow. This was deeply unsettling and upsetting for her. However, this was not a universal experience with some participants reflecting how they knew it was not their fault: *“because it is not my fault*

that I am bald you know, that I was bald as a baby, you know but it never was.” ... “it is not like I did something wrong that made me not have any hair” (Alison). Alison had always suspected she had an unknown condition that had not yet been diagnosed, which prevented her from blaming herself. This led to a higher yearning to find out what the condition was that was preventing her hair from growing.

Jenna believed that she had been unlucky with her genetics. She therefore did not feel the need to search for answers as to why her hair would not grow. She described having a long standing joke with her mum about her hair. She reported having joke conversations with her mum where she held her responsible for her hair: *“Yeah, it’s all your fault I’ve got hair like this. I’d rather have hair like me dad”*. Whilst Jenna described this in a humorous tone, she appeared to be masking a feeling of anger. The use of humor may have enabled her to live with the anger and uncertainty.

Participants had their own personal beliefs to explain to themselves why their hair would not grow, but without them having definitive answers it left the majority of them open to doubt these explanations. Thus, they continued to yearn to know why their hair would not grow and to have a definitive explanation.

I’m different

This superordinate theme captures how an internal pressure to be perfect develops within participants. This is based on them feeling the societal expectations to have long hair and recognising their hair is different. They then judged themselves negatively for not being able to match this standard. Judging themselves on how they match or differ on society’s standards has had a large impact on their self-worth, anxiety levels and self-esteem. Participants reported two distinct time frames with these judgments; how they once judged themselves when they were younger and how they now judge themselves. For Nat her hair

had led to her feeling insecure when she was younger: *“I think particularly when I was younger my emotional wellbeing like [pause] it made me so insecure and like probably issues with my self-esteem.”* Participants felt insecure as they judged themselves unfavourably for not being the apparent ideal. Tina reflected on how she had once felt no one would find her attractive because of her hair and thus it would make her unlovable: *“You know like no one would want me with my horrible hair. I thought how everyone thought that I was ugly and just ugly freckly curly and short hair”*. This reflected the extent to how much she felt she was outside of society’s perimeters of acceptability.

For some participants their negative judgments of themselves led to them feeling traumatised. Alison reflected on how challenging she had found having the condition: *I didn’t have a terrible childhood, as far as my childhood traumas that was pretty up there as far as traumatic because my hair was awful”*. This demonstrates the emotional experience Alison felt in relation to AS forcing her to not be able to comply with society’s expectations.

Being the same as others felt vital for the majority of participants when they were younger: *“I wanted to be like everyone else and wanted you know the same as them”* (Tina). The desire to be the same as your friends is greater during adolescence (Brown, Eicher & Petrie, 1986). When participants were not able to fit in with their friends this led to them feeling inferior. Whilst fitting in was important when they were younger, it felt less important as they grew older; this will be discussed further in the ‘I’m more than my hair’ major theme.

The influence of hairstyle fashion affected how participants felt about themselves. Whilst fashion is an external pressure, participants frequently described the internal pressure they placed on themselves to follow it. Darcy encapsulates this when she discussed the pain of comparing herself to those who influence fashion, which led to her feeling imperfect:

“It is quite a hyper-feminised look is really in fashion and sorta really long hair and really curvey. So like the Kardashian’s is really like they all have really long hair and

I think as I don't have that much of a curvey figure either so it is just one more thing that makes me worried about how I look and I don't fit in with the current beauty trends".

Darcy compared herself and judged herself against fashion standards, which made her feel insecure and also led her to worry about how others would perceive her: *"People who don't not know about it but might just think I have got like a really shit hair style and that I have got like a bad style"*. Participants reflected this was often a concern, with them worrying that others would think they had chosen their hairstyle. Thoughts of being different and how others would judge them for being different had a large impact on participants' self-esteem. Nat also judged herself for not having long hair: *"erm it is rubbish (laughter) erm because you think that is socially acceptable and you're not fitting that socially acceptable norm I suppose."* Jenna highlighted the concept of her hair not being the way she had wished it would be, led to her feeling disgust: *"I tell everybody that, 'Oh yeah. Yeah, gorgeous when it was done. Look at state of it"*. She negatively judged herself for not meeting the standard that society expected of her. This internal pressure is so great that Hayley highlighted that she would give up any of her expensive material possessions to have the hair she wished for so as to not be different. This was expressed when she was discussing how important her hair was for her and what she would have been prepared to give up to have the hair she wished for: *"Can I have your car and umm, you know you can have this lovely long hair I've got.' I'd be like, 'Yeah. There you go. There's the keys. See you later.' Definitely. Mm-huh"*.

An additional area that participants felt different from others was how they judged their judgments. Participants described how they had judged themselves for having such strong concerns about a condition that could be considered trivial in comparison to conditions which are life threatening or physically disabling. Nat recognised that it was her own ideas of how her hair should be that led her to feel negatively about herself:

“It is your mind that is telling you that it is not happy with it. Like your body, it’s not an issue necessarily for your body that you have got the condition with your hair. It doesn’t make much difference in that sense it is all mental.”

Additionally Darcy also criticised herself for prioritising society’s expectations:

“I feel like it is quite shallow and that I shouldn’t care and then I get quite frustrated with myself being upset.....you get upset because I think that is something that I think society does as well it sorta praises how people look that is like really important as a woman but if you care too much about it you are punished so you can’t win either way”.

Participants reflected how isolated they felt about having this condition, which made them feel so different from others. The isolation it had caused people had been painful and it had left people with a feeling of being deeply different: *“even though other people might not necessarily realise you are any different you know it inside”*. (Nat). This deep rooted feeling of isolation left some people emotionally scarred. Alison demonstrates the emotion this evoked for her:

“You know, that sense of oddity that I’ve always had, not fitting in and oddity and otherness, like, that – I was like: “What am I doing bringing another odd person into the world? Like, she’s gonna suffer the same way that I have and –“Um, so just that (.) um - sorry I’m really emotional”.

Alison did not want to inflict the emotional pain of isolation onto her daughter, demonstrating how difficult this feeling was for her. Participants attributed their hair as the key factor in why they felt different from others.

In conclusion, this theme of 'I'm different' demonstrated how participants judged themselves negatively for not being perfect and being different from others.

I’m more than my hair

The master theme *‘I’m more than my hair’* refers to the time period after finding out about AS and reflects how participants recognise that whilst they have AS, the condition does not define them. It conceptualises participant's move away from the all-encompassing pain that their hair had once brought them and redefined their relationship with it. The first

superordinate theme is “*Woah finally there’s a reason*” which indicates the relief participants felt in finding out there is a reason for their hair being the way it is. After gaining knowledge of AS, all participants demonstrated they were negotiating their journey towards acceptance. Some participants indicated they felt more acceptance of their hair than others, and this journey was unique for all so this superordinate theme is called ‘*Navigating the path to acceptance*’. Finally, participants expressed a desire to reject and challenge society’s expectations regarding the need for females to have long hair, thus this superordinate theme has been called “*challenging expectation*”.

“*WOAH, finally there’s a reason*”

All participants acknowledged a relief in finding out about AS. The majority of participants revealed the internet had been a source of enlightenment for them with the condition:

“I just Googled it; there’s more access to the internet than there was, you know if you had a problem with your body you know in the 1970s it was all to the doctors and a doctor’s not going to talk to you about your hair not growing.” (Lucy)

Lucy, who now has young daughters with AS, reflected on the comparison between when she was younger with the condition and how it is now. She revealed how she had a sense when she was younger that appearance was not important and as the condition is not life-threatening and only affects her appearance, it would not warrant medical attention. Her hair caused her great distress but she thought this would not have been considered to be important by her doctor. This emergent awareness was euphoric for some: ““*WOAH, finally there’s a reason!* “ *I mean, we don’t know what causes it but, like, I’m not alone, I’m not just some random freak out there who didn’t have hair as a kid, you know?”* (Alison). “*Just acknowledging that there is a condition and a reason for why I don’t. I can’t even come to terms with why knowing that it is a condition makes such a difference* (Alison). This experience brought order to the chaos that she had previously felt when she was uninformed about why her hair would not grow. For Hayley finding this answer meant that she was no

longer lost in the unknown and it was an extremely emotional experience “*looking at some of the wee girls pictures on that, that Facebook page . . . that is my hair*”.

Knowing they had a condition legitimised their experience and finally gave them an explanation.

Navigating the path towards acceptance

Navigating the path towards acceptance referred to participants' current relationships with their hair, from turbulence to gradual acceptance. The intensity of pain they had once felt in relation to their hair had decreased as they began to feel more comfortable with themselves. Participants highlighted they had begun to recognise there are more important things in life than their hair as their values evolved. They identified as still having both good and bad moments with their hair and their acceptance did not reflect a purely positive experience. They highlighted the reality of not being able to alter their hair as they wished they could and thus accept the style they are forced to have. Whilst some participants described feeling more comfortable with their hair than others, all participants still reported having some painful emotions connected with their hair. For some participants employing a routine management strategy with their hair e.g. wearing it up in a bobble enabled them to have a degree of acceptance. Whilst some participants expressed being more in tune with their more painful emotions connected with their hair, they still expressed having made some tentative steps towards acceptance. Hayley reflected how she was reluctant to accept her hair but would have to face accepting it if there was no other option for her:

“If I know this is never gonna grow, d’you know what, then I need to just deal with that and admit defeat and just go. I’m always gonna have shorter. I’m gonna have to get kinda a really short cut and try and make the best of it . . . because it’ll be better than chasing this whole nonsense of people telling me that it’s my fault”

For all participants, acceptance was a journey they had to work towards, and not something that came easily for them, as Alison highlights:

“So it took me a long time for me to feel like I was pretty, and to feel like – to feel recognised and accept compliments about my appearance and feeling pretty and have that confidence of: “I am – “ you know “ – pretty. I can be attractive.” Like: “I don’t look like a boy.”

Tina, when reflecting on her experiences of having AS during her lifetime, credits maturity with her ability to accept her hair for how it now is:

“Yes I do. I think as you gradually have got older you know and come to terms with it and having it cut shorter you think well I am never going to have long hair so I am not going to worry about it anymore. I think that is how it became just how I am.”

This acceptance had gradually emerged and evolved as she aged. Participants also expressed how their appearance become less important for them as they aged. Nat considered society’s expectations of her appearance had altered as she had aged: *“but when you get older people can look past that”*. Her hair became less of a priority for her as she got older as she no longer felt society emphasized the importance of her appearance, making her relationship with her hair easier to accept. Nat’s maturity appeared to bring about an independence that allowed her to feel resilient: *“It got to a point where I thought I don’t care about other people’s opinions anymore”*. For some participants a change in priorities as a result of maturity had resulted in them redefining their relationship with their hair:

“How I feel about my body has changed as well as my hair, in my mid-forties to how I did in my twenties, when obviously I wanted to be skinny and I wanted to have long hair and I wanted to kind of . . . be that where I’m definitely a mother now in your priorities”. (Lucy).

This change in relationship between participants’ and their hair documented a shift in values. For some participants, putting their hair in perspective of other life events aided them on their journey towards acceptance. Hayley used her work to help ground her:

“I actually work with people who are terminally ill; so, I think that keeps me kind of grounded in the fact that as I said to you, I can’t get really pissed off. I can have a good bubble, you know, ‘There’s nothing . . .’ you know at the end of the day it is just hair, right. I need to keep remembering that because I am in and out of people’s houses that they are dealing with real . . . real, real stuff. And, you know I sometimes do feel, ‘God! You’re whinging about stupid hair!’ you know, ‘Put a hat on and shut up.’”

Whilst this demonstrated that participants had an understanding about their hair not being an all-encompassing entity in their life, it also acknowledges the emotional peaks and troughs that can occur as a result of having AS. Acceptance of their hair was not a linear process and having difficult emotional days was to be expected. Darcy emulated the jolting back to emotional pain from a position of acceptance:

“In general I do have a really good life and I am able to feel ok about myself I can sorta you know I know that I am not just my hair and I know there is a lot more important things than hair but I would also say that it is ok to get upset about it sometimes as well”.

This quote encapsulated the challenges of accepting AS. It can feel as if acceptance has been gained and then the rug can be pulled from under your feet as if from nowhere:

“I think that was my worst, um, moment of dealing with it, um, and it was at a point where I had thought that I had come to terms with it already and then here I was realising that I was having a little girl and that – that overwhelming thought of: “What if she’s just like me?”. (Alison).

Whilst Alison had felt she had reached a level of acceptance with her hair, she was able to acknowledge the painful journey the condition had brought her during her life. This pain was not something that she would want for her daughter.

Participants journey towards acceptance enabled them to recognised and accept the limitations that their hair brought them. The most common limitation discussed was how their hair restricted their ability to express themselves. Darcy recognised the importance of protecting her hair: *“But now I sort of have it quite basic don’t dye it try and like keep it as healthy as possible. It is boring as well”.* Darcy felt unable to change her hair colour as it may damage her hair. For Darcy having to ensure her hair remained healthy was more

important than being able to express herself through dying it. Describing her hair as “boring” reflected her disappointment in not being able to have the hair that she would like, but also reflected an embodied acceptance she had reached with her hair. It had once been something that was highly distressing for her, but she had now reached a point where she described it as “*boring*” which hinted at her accepting the limitations of her hair. The majority of participants also expressed feeling distressed at not being able to express themselves as they wished they could:

“The most challenging factor is that you know that you can’t have all the different styles that other people can have; and you think, ‘Argh, I’d love to be able to have my hair like that.’” (Jenna),

“I look at other people with – and they try out these funky haircuts and, you know, if they don’t like it it’s gone in a couple of months, whereas, like, it takes forever for a bad haircut to grow” (Alison).

Participants expressed having to be careful and protective of their hair. They therefore outlined that their current hairstyles, whilst limiting the expression of their personalities, felt more acceptable to them than taking the risk with a more flamboyant style which may have long term consequences. However, whilst this was challenging they had all found a style they felt was acceptable, but not ideal, which indicated a reluctant acceptance they had reached with their hair.

Whilst participants highlighted difficult times they have had in relation to accepting their hair, some participants reflected on the positive aspects of having the condition: “*you know the one cut a year or one cut every year and a half isn’t a major dilemma. It’s easier.*” (Lucy). She identified that it was easier and cheaper to only get her haircut once a year in comparison to her friends whose hair grows quickly. She discussed this when she was reflecting on the positive aspects of having AS. This demonstrates that social comparisons, which had once been so problematic for participants, can now be advantageous. Nat also recognised the positive facets of having AS as it aided her to embrace her individuality:

“Being different is better than being the same as everyone else”. Embracing her individuality and rejecting the societal expectations she had once felt dominated by propelled her on her journey towards acceptance.

Challenging expectations

As participants reached a stage of acceptance with their hair they began to challenge societal expectations. The process of reaching acceptance and then beginning to challenge society was not always linear, with some participants describing challenging expectations before they reached acceptance of their hair. However, it was mostly described as acceptance being reached first. They recognised the pain they had once felt had been unnecessary and questioned it. Darcy expressed a desire to rise above the pressure to look good:

“So I have this little phrase that I say to myself and it is “I’m not an ornament, I’m not here to just look good” erm (laughter) I am not a model and I don’t have to be. Just because I am a woman doesn’t mean that I am here for people to look at and enjoy. I am not a sculpture do you know what I mean? I am existing in the world and feel like the way that women are treating and set up sorta like it is our jobs to be beautiful for men to be beautiful. That is not my job. I have a job!”

Darcy is rejecting the role she feels society imposes on her the most because of her gender. Whilst she spoke about her desire to challenge society’s expectations she had not yet felt able to act on her desires and still openly values being seen as attractive, and thus valuing her appearance. She is hopeful that in time she will be able to break away from the expected mould she felt as a female and place less value on her appearance: *“hopefully my hope for my future is going to be this more bad ass older woman who wears whatever”*. Darcy believes her strength will come as she ages. Believing that as she gets older she will then be able to defy society by wearing whatever she wants. By being free from society’s restraints she thinks she will inadvertently challenge them.

Others express their defiance of society in different ways. For example, Tina recognized the impact of role models on challenging society’s standards: *“It is all about looks isn’t it and*

you see it on the television princesses all have long hair and why? Princess Diana didn't have long hair she had short hair." Having a prominent role model break the mould for females and still be valued, appeared to enable Tina to question and break the rules herself:

"Why don't they make dolls with short hair? For girls. You know. Silly isn't it?" "I actually cut one of the dolls we have got upstairs you know a Barbie. I cut her hair for Hannah so that Hannah would see one with the short hair and she always plays with that one."

In cutting the Barbie's hair Tina altered the reality of her granddaughter by provided her with two short haired role models, both herself as her grandmother and the Barbie doll with short hair. This empowered Tina and made her feel that she was supporting her granddaughter the way she wished she had been supported as a little girl.

The desire to change reality for others by making the world a more accepting place for those with the condition was highlighted by a number of participants. For example, Alison felt passionate about challenging expectations by increasing knowledge of AS: *"And not only informing people about my hair but through the experiences that I've had, I kind of feel almost like an ambassador for SAS and for curly hair"*. By providing others with knowledge about the condition she was aiming to directly challenge society's attitude towards hair.

Lucy rejected the over inflated value of hair within modern society. Whilst she does not overtly call for a change in society her message encompasses the desperate desire to challenge the current status quo of hair for women:

"It is cosmetic but cosmetic means a hell of a lot in our, in our, I don't know, society now, well I suppose always, always has. Does that make sense?" (breaths out) "er, it's annoying . . . umm, it very annoying cause you just kinda think, 'Argh, come on it's not everything, it's hair.'"

In voicing her annoyance about how much society values hair, it is evident that she is equally angry with herself for also having placed value in it. She has therefore judged herself for placing value in what society says she should. This judgment of herself is different from the individuals discussed above, who judge themselves for not looking a certain way. This

judgment is about adhering to what society enforces without an obvious justifiable reason. All participants expressed a desire to challenge and change society's expectations which demonstrated how they had all recognised the pain it causes when people are not able to adhere to them.

Nobody understands

The final master theme "*Nobody understands*" referred to the way AS shapes participants relationships with others. These relational issues were consistent throughout their lives as they felt their experiences were not understood by others. The first superordinate theme highlights how participants described the condition as being minimised by others and was called "*There is nothing wrong with her*". The next superordinate theme "*feeling blamed*" reflects how participants felt that others blamed them for their hair condition. The final superordinate theme denotes participants feeling that "*Nobody knows this condition*".

"There is nothing wrong with her"

Participants expressed how challenging it was when others did not acknowledge how hard it is to live with their hair. This superordinate theme reflects two distinct categories; people who do not believe it is a condition and people who do not believe it is as bad as the participants consider it to be.

Participants expressed how hard they found it when the condition was not acknowledged or believed. This difficulty was exasperated when it was reflected by medical professionals. Tina recounted her mother taking her to the doctors about her hair when she was a child (over forty years ago), prior to her knowing about the condition. She recalled the doctor stating: "*look she has only got short hair there is nothing wrong with her medically*". This had been an invalidating experience for her and it had left her feeling dismissed and not believed. For

Hayley she felt totally unheard by her doctor, who did not recognise the emotional severity of her situation:

“Can’t keep going to my GP. My GP was not interested – still to this day is not that interested, to be honest; would not refer me onto a dermatologist. Wouldn’t do it. Just point blank, ‘No. you’re not bald.’ Umm, and his advice was to get a haircut like his”.

Hayley’s interactions with her GP made her feel misunderstood and discounted. Additionally it made her think the condition which is causing her great distress is not legitimate. This led to her thinking that others also did not consider it important:

“there’s not a lot of people that actually believes this exist, I don’t think; or, or they just don’t really care or it’s something that only wee, tiny kids get and, you know don’t even worry about that cause they’ll grow out of it.” (Hayley)

Participants reflected on how people would also minimise their experiences by saying the condition was not as bad as they thought it was. This led to them again feeling that others did not think there was anything wrong with them and left them feeling misunderstood. Participants reflected on how those around them would frequently minimize their experiences. Hayley reported that frequently her friends and family would attempt to encourage her to feel better about herself by reflecting that it was not as bad as she considered it to be: *““you know your pals go, ‘You’re imagining it, you know it’s not as bad as you think, you know. Don’t be silly, you look great.”* However, this left her feeling belittled and demoralised. Darcy also recognised how there were times when comments from her friends and family had led to her thinking that others did not recognise her hair condition:

“So I am quite jealous and she sorta moans about it like saying “you wouldn’t want hair like this as it is uncomfortable and it is really hard to manage”. I find that is what a lot of people tend to say when I am like moaning to them about their hair or they will sorta shrug it off and say oh but your hair is fine or just it looks fine it is just your hair. But I guess it is different when you are actually living with it”.

Darcy acknowledged that others also do not like their own hair but she continues to long for the hair they have. However, she equally does not appear to acknowledge the negatives that

they see in their own hair. Despite this, it is clear that she feels those around her downplay her experiences with her hair. Her friends and family, at times, did not acknowledge the condition and did not recognise the pain and hurt it caused her which resulted in an alienating experience.

Feeling blamed

Participants expressed how painful it was when they were blamed for their hair's condition. This was with people believing they were not looking after it properly which resulted in it being in poor condition. This was particularly difficult when they knew they were not responsible. This was often expressed in accounts of interactions with hairdressers. All participants expressed anxieties and trepidations about going to the hairdressers, as they often felt blamed by them for their hair's condition. Hayley reported having experienced a number of difficulties with hairdressers where she felt misunderstood and blamed:

“Come on. You use, it's these box dyes, isn't it?” And I was like, ‘I, I've not used the box dyes since 16 probably, you know. I've got a sister who's a hairdresser. Never done my own colour in my life; everything's done professionally or, you know I spent a bloody fortune to look this bad.’ And she actually put a thing on Twitter, which was ‘Wh-when a new client comes in and, you know her hair is breaking after years and years of box dyes’I did have words with her. Umm, ‘I told you I'd never done that.’ ‘Ah, I know but come on. You have haven't ya? I mean look at the breakage at the top,’ you know, ‘that is not bloody breakage!’ So that's my experience with hairdressers and . . . it's been awful”.

The pain of being held responsible and not being believed exaggerated her grief. However, feeling publically targeted in such a way was further degrading for Hayley. Alison also reported feeling that she was blamed for her hair by her hairdresser: *“I've had numerous hair stylists saying: ‘Have you ever had your hair thinned? You know you shouldn't do that.’ I'm like: ‘No, I have never once had my hair thinned thank you very much!’”* This resulted in Alison feeling belittled, angry and at fault because of her hair. Having others blame them for their hair was a painful experience, particularly as they knew they were not responsible and

were being misunderstood. This resulted in participants recognising how hard it is to have a condition that nobody knows.

Reflexivity

I was fascinated by the majority of participants reflecting on the difficult experiences they have had with hairdressers. Even those who were the most accepting of their hair still reported experiencing a feeling of dread when going to get their hair cut. My experience with hairdressers has always been a positive one. I had initially made the assumption that as the participants had wanted their hair to grow, having it cut may have been difficult for them. This may have led to them finding the experience of going to the hairdressers a more challenging than it really was. My colleagues in the IPA support group highlighted that my assumptions may have been tainting my view of their experiences. I re-evaluated the data and realised that people did genuinely have traumatic experiences going to the hairdressers and I was the exception in finding it a positive experience. This assumption resulted in me being more explicit with myself in my assumptions and how they were impacting on my analysis of the data. By being extra cautious of this I began to be more present and curious with the data.

Nobody knows this condition

All the participants recognised that the condition was not well known. Nat found this one of the most challenging aspects of having the condition: “*if you said to somebody that didn’t have it they wouldn’t have a clue what it was*”. This led to her feeling invalidated and that she was the only person to know what it means to have AS. Lucy found this equally taxing: “*the fact you have to explain it every time*”. The frequency of how often they had to explain the condition to people highlighted to participants how rare the condition is and how misunderstood their experiences are.

Participants also expressed frustration in not understanding the condition completely themselves: *“I mean, we don’t know what causes it”* (Alison). Thus, whilst she knows about AS she does not fully understand it herself and so nobody knows this condition.

Discovering the condition for some participants had been a lightbulb moment in their relationships with others. Having an understanding of AS enabled them to share this knowledge with others and the difficulty of having the condition. Alison highlighted how having a firm understanding of AS was restorative for her relationship with her mother. She had experienced difficult times with her mum due to her hair. This was due to her mum’s lack of understanding about Alison’s hair and the emotional difficulties that it triggered for her:

“erm I guess in a way when I became aware of SAS and the condition and that’s why I had the lack of hair that was a positive break through moment for me and erm and a repairing moment for me and my mom in our relationship.”

Having an explanation as to why her hair did not grow enabled them to build a bridge of understanding and strengthened and improved their current relationship: *“We’ve talked about it since, and she feels bad that she made me feel bad”* (Alison). Participants reflected on how living with the condition would be easier for those who have it, if more people understood about the condition: *“more social awareness and niceness about something, would be lovely.”* (Lucy).

The desire to make more people aware of AS resulted in participants wanting to advocate for the condition. Alison expressed a wish to spread knowledge about AS to help people to understand it: *“not only informing people about my hair but through the experiences that I’ve had, I kind of feel almost like an ambassador for SAS”*. All participants had expressed how they wanted more people to know about the condition, which had been a motivating factor for them to take part in the research.

Discussion

This chapter will summarise the main findings of this study. In order to explore this topic, the following research questions will be discussed:

1. How do adult females describe their experience of having Anagen Syndrome?
2. How do they make sense of their experience of having Anagen Syndrome?
3. How has this experience changed and developed over time?

The findings of the study will be discussed and consideration given to how these findings fit with the existing wider psychological literature. Then a critical evaluation of the study will be presented alongside the implications of this project and potential future research. Finally, a conclusion will be provided.

Summary of main findings

The results of the analysis elicited three master themes and nine superordinate themes. The participants themes reflected two distinct time periods: before becoming aware of the condition, which is outlined in “*Feeling imperfect*”; and after finding out about the condition which is outlined in “*I’m more than my hair*”. Participants also reflected feeling misunderstood throughout both of these time periods which is reflected in “*Nobody understands*”. Each of these themes will be outlined in more detail below. These results are novel findings as AS has not been researched before.

Feeling Imperfect

The master theme “*Feeling imperfect*” denotes the time period before participants had knowledge of AS but they recognised they had different hair from others. It reflected how participants felt imperfect in how they looked based on their hair being different from others.

The first superordinate theme was “*Pressure of societal expectations*” which referred to how participants recognised a pressure to have long hair based on society’s standards. Participants then described how they judged themselves for not meeting these societal expectations and they began to question “*Why does my hair not grow?*” which reflected a deep yearning desire to know the reason behind their hair’s presentation. Feeling different was a deeply painful experience that caused them to feel inadequate and imperfect and has been depicted in the theme “*I’m different*”.

I’m more than my hair

The master theme “*I’m more than my hair*” referred to the time period when participants had gained awareness of AS and so they finally had an explanation as to why their hair would not grow. It reflected how participants recognised that whilst they have AS, life continues for them. The first superordinate theme was “*Woah, finally there’s a reason*” which indicated the relief participants felt in gaining an awareness of AS and finally having answers as to why their hair does not grow. This knowledge enabled them to begin to process how the condition has impacted on them in their life and it allowed them to progress to “*Navigating the path to acceptance*”. Accepting AS included coming to terms with the condition and accepting themselves with the condition but also having both bad and good moments with their hair. Finally, participants described thinking how unnecessary the pain they had experienced as a result of their hair had been, and how the pressure society imposes on people had caused this distress. This led to them “*Challenging expectation*”. Participants expressed no longer questioning themselves but questioning society.

Nobody understands

The final master theme “*Nobody understands*” refers to how participants feel others do not understand what it feels like to have AS. Participants experienced this feeling throughout their lives, both before and after finding out about AS. Participants discussed how hard it is that so few people know about AS. Prior to finding out about the condition they had felt isolated, as if they were the only ones whose hair does not grow. The first superordinate theme alludes to participants feeling the condition was minimised or trivialised by others and was called “*There is nothing wrong with her*”. It referred to how participants felt that people did not consider the condition serious or important, despite them personally feeling deeply affected by the condition. The next superordinate theme refers to the deep rooted frustration participants felt when people blamed them for their hair and was titled “*Feeling blamed*”. Being blamed was challenging for people and left them feeling confused and doubting themselves. The final superordinate theme has been named “*Nobody knows this condition*”. It refers to how unknown the condition is and how frustrating and upsetting it can be having a condition that is not understood.

Comparing results to wider literature

This section will now compare the current study’s results to the wider literature, with the aim of developing a deeper understanding of how people experience AS. These comparisons are necessary for the reader to determine how useful the results of this thesis are. The results of the study generated comparisons to a range of psychological theories and models which will now be addressed.

Societal pressure

All participants in this study highlighted they had felt pressure to have hair in a specific way because of their perceptions of society’s expectations. Participants also reported receiving

conflicting messages from society, with some participants describing feelings of guilt for valuing their appearance, as society also portrays those that value their appearance are deemed to be shallow: “*You can’t care for how you look too much*” (Darcy), “*at the end of the day it is only hair*” (Jenna). Vangeel et al (2018) who looked at the five year impact of self-objectification (specifically the internalization of the media’s appearance ideals, valuing appearance over skills and capabilities, and body scrutiny) on 400 adolescents and early adults (54.5% were female). They also found participants felt guilty for caring about their appearance, believing it to be vain to value it. Some participants in this study also thought the condition was not worthy of medical support as it only impacted on appearance and so would not be taken seriously: “*a doctor is not going to talk to you about your hair*” (Lucy). This is similar to Buunk et al (1990) who demonstrated that cancer patients also felt unable to tell their doctor how much they were struggling psychologically with the change in their appearance since getting cancer, thinking this was not deemed important by medics. People appear to hold beliefs that medical professionals are not able to support them with appearance related concerns, as it is not deemed worthy enough of medical attention.

Social Comparisons

Social Comparison Theory (Festinger, 1954) proposes that we learn about ourselves by engaging in a series of social comparisons with others, which makes us feel either positive or negative about ourselves. This is referred to as either positive or negative affect (Dijkstra, Gibbons and Buunk, 2010). When the individual compares themselves to another they determine if they are worse or better off (Festinger, 1954; Dijkstra et al, 2010). If they are worse off than the individual is left feeling negative emotions such as; frustrated, sad, resentment etc. which causes negative affect (Dijkstra et al, 2010). However, if they determine themselves to be better off they feel positive emotions such as; pride, happiness,

relief etc. These positive emotions lead to positive affect (Dijkstra et al, 2010). Participants in the current study frequently described engaging in social comparisons with others and determining they were worse off. They felt those who had desirable hair were better off than they were. Engaging in such social comparisons frequently appeared to leave participants with negative affect.

Increased use of social media increases negative affect and reduction in positive affect (Appel, Gerlach, and Crusius, 2016). Negative affect results in a negative impact on their emotional wellbeing, leading individuals to feel bad about themselves (Feinstein, Hershenberg, Bhatia, Latack, Meuwly, and Davila, 2013). A high number of the younger participants in this study reported that whenever they used social media they would feel worse about themselves and their hair: *“Sometimes I get into a thing of looking at pictures on social media and I know exactly what it is going to do I know it is going to make me feel shit”* (Darcy). The following studies are all completed on individuals with no reported health conditions or conditions known to impact on appearance. Haferkamp and Krämer (2011) conducted both a small scale qualitative interview (n=6) and an online experiment (n= 91). Participants had a mean age of 22.5 years. In the interview participants did not describe having been affected by profiles of others. However, the experiment demonstrated that people had a higher rate of negative affect after viewing physically attractive people’s profiles in comparison to viewing unattractive people’s profiles. However, de Vries, Möller, Wieringa, Eigenraam, and Hamelink (2018) who conducted an experiment with 130 college students investigating the effect of individual difference on social comparison, found that individuals who frequently compare themselves to others feel more negative affect after viewing posts of others doing something desirable than those who do not. Those who do not have a tendency to compare themselves to others feel positive affect after being exposed to others desirable posts. This indicates that individual differences affects the impact of social comparison with

others. It is important to acknowledge this was a small scale sample using exclusively only college students. Therefore this sample is not representative of the current study's sample. Not all participants in the current study reported being negatively affected by social media, but all did report to using it, it may be possible this could be explained by individual difference, or it could be that this did not come up in the interview for some participants.

Studies have also investigated how people with health conditions make social comparisons to others. Buunk et al (1990) interviewed fifty-five cancer patients, 30 women and 25 men aged between thirty and sixty-six years with a mean age of fifty-four, about their health experiences and the social comparison they have made since gaining a cancer diagnosis. They had found those who had lost their hair (alopecia areata) due to their cancer treatment gained both comfort and distress from making social comparisons with others who also had cancer. The majority of participants in the current study only reported making negative social comparisons to others which caused them distress. They recognised the pain of comparing themselves to people they see on social media and other mass media platforms like beauty magazines and television "*You see all these perfect people with their perfect hair on Instagram, erm... they are all hair models almost how can I be like that*" (Alison). Some participants recognised that a lot of these images they are comparing themselves to are fake and unattainable "*their hair is probably all fake but it makes me think that's what I should have*" (Nat). It may be hypothesised that participants in Buunk's et al (1990) study consider themselves to have an 'illness' and so alopecia areata feels easier to manage in comparison to more life limiting illnesses such as Cancer. Whereas, AS is not considered an illness, it may be hypothesised that people with the condition do not make such positive comparisons. Although one participant (Jenna) did make a positive social comparison between AS and mental health difficulties. She reported that she would rather have AS than a mental health difficulty. Additionally, from the informal review of the topics discussed that I completed of

the Facebook support group, a number of people regularly report being grateful for having AS over having other conditions which may be more life altering. This therefore may suggest that people with this condition also experience this positive social comparison but it was not expressed in this study.

Femininity Ideals

The results of this study demonstrated the powerful impact femininity and seeking to be the 'ideal female' had on the majority of the participants in this sample. From a young age girls are socialised to value their appearance (Rumsey and Harcourt, 2005). Hair is described as being a woman's "Crowning glory" (Welsh and Guy, 2009, p199) highlighting the gendered expectations of hair. Fairy tales and children's cartoons such as Disney princesses reinforce the importance of being beautiful to young girls with all their main characters described as being beautiful and having long hair. These characters reinforce pre-existing stereotypes about the importance of being beautiful to young girls and beautiful characters frequently have long hair (Rumsey and Harcourt, 2005). It is not just children who are influenced by characters they see on television and other forms of mass media. Thompson and Van den Berg (2002) completed a survey of 3,452 women and found that 23% had reported that celebrities had influenced their body image aspirations and made them feel inadequate. Western societies have seen an epidemic number of people in recent years report they have concerns about their physical appearance (Grogan, 1999; Rumsey and Harcourt, 2005). Social media and mass media are the commonly used means to communicate the standards of attractiveness that people are expected to live up to (Hari, 2003). With the increase use of social media platforms like Instagram and Facebook, where there is a heavy reliance on appearance, people are increasingly exposed to beauty standards they feel they should live up to (Jan, Soomro & Ahmad, 2017; Vogel, Rose, Roberts and Eckles, 2014; Baker, Ferszt and

Breines, 2019). However, with the increase in technological advancements where images can be manipulated and ‘touched up’ to improve their aesthetics, the blur between truth and reality becomes distorted, and people become unaware that the standards that they are comparing themselves against are unattainable (Lakoff and Scherr, 1984).

The majority of participants reflected on how their internalised self-view had been impacted by role models. This was particularly the case when they were young children. Disney princesses with their long hair had caused a high degree of emotional pain for most as children who could not have the hair they had: “*every princess has long hair; every cartoon character...the cartoons obviously crazy hair that’s, you know down to their feet and flying in the wind*” (Lucy). This study demonstrates that people with AS feel unable to live up to the beauty standards society imposes.

Stigmatisation

The results of this study highlight how people with AS expressed feeling stigmatised as a result of their hair. Goffman (1963) highlights how certain groups of individuals are discredited by society which in results in them feeling shame and stigmatised. Goffman highlights this stigma can be both internal and external, as in the individual can also stigmatise themselves as a result of this devalued characteristic as well as being denounced by others. This internal stigma is connected with anxiety about acceptance. Scambler and Hopkins (1986) believe that children from a young age are schooled by their parents about appearance and acceptance in society and those children who have a condition with a visual difference may be unintentionally taught by their parents that they will be stigmatised by society for their appearance.

Goffman (1963) highlighted the negative implications that result from stigmatisation which impacts on the individual's physical and mental health as well as self-esteem and general status within society. Goffman's definition of stigma was broad, he included three predominant categories of stigma including tribal stigmas (which included devalued races, ethnicities or religions), physical deformities (which included differences that manifest themselves physically such as impairment of vision or mobility) and blemishes of character (this was, at the time, deemed personality choices or options which defied the society norms such as imprisonment or addiction). Goffman argued that stigmatised individuals often face the same social constraints, irrelevant of the factor surrounding their stigma. Link and Phelan (2001) focused on Goffman's work on stigma whilst also incorporating social power and influence. They argue that all stigma processes through four distinct phases: labelling human differences, stereotyping such differences, separating individuals into those labelled 'us' and those labelled 'them', and status loss and discrimination against those labelled. The results of this study highlight how the majority of participants have gone through this process internally against themselves, with some individuals also suggesting they have also experienced this socially with others.

Lamont, Silva, Welburn, Guetzkow, Mizrahi, Herzog & Reis (2016) documented the consequences of stigma on population-level health discrepancies. They highlighted how it often brings groups of stigmatised individuals together in social movements which can result in society level transformation such as changes in law and societal attitudes. A number of participants in this study highlighted they felt stigmatised and isolated by the condition. A number also highlighted the need for advocacy for the condition and how often conditions of stigmatised individuals with other conditions have raised awareness of these conditions with great success. They highlighted how frustrating this is that AS has not been given the same

treatment and how further isolated and stigmatised they feel increasing their level of shame for their hair.

Psychological Distress

The results of this study provide further support for the existing literature that people experience psychological distress when they have visible conditions such as, dermatological conditions, alopecia etc. Cash and Grant (1996). claim that people develop image related schema as a result of interactions with others. Such interactions and socializations enables the individual to develop a scheme of the ideal way to be. Cash and Grant suggest individuals then engage in an evaluation of themselves and the ideal, with those who have a larger discrepancy between their own physical characteristics and the ideal feeling a higher degree of dissatisfaction in their appearance. However, Cash and Grant acknowledge that people place varying degrees of importance on their appearance. Not everyone will value their appearance highly and so the extent of this discrepancy between the proposed ideal and the self will not result in distress for all. However, for many having a high discrepancy between the self and the schema of the 'ideal' will result in distress.

Rumsey, Bull and Gahagan (1986). put forward the suggestion that those with visible difference often exhibit poor social skills for a variety of reasons, including the expectation they will be rejected, social anxiety, and self-consciousness. Once poor social skills have been displayed others often respond poorly towards them and a self-fulfilling prophecy exhumed. Rumsey et al. (1986). argues that those who exhibit positive social skills can diminish the social impact of their disfigurement. Whilst this study did not investigate the impact of participant's social skills it may be reasonable to assume that those who have a higher degree of distress and trepidation about their hair may have higher degrees of anxiety about social interactions.

This study also provides support for the proposal that those with a condition which impacts on their hair will have a heightened degree of emotional distress in comparison to conditions which impact on other areas of aesthetics (Wallace et al, 2007; Enskar, 1997; Hedstron and Von Essen, 2004). Wallace et al (2007) who interviewed six female adolescents with cancer and analysed the data using IPA also documented that participants placed high value on their appearance during treatment, with their loss of hair being a constant reminder that they are different and a marker of their illness to others. They did however demonstrate a shift in views and values after treatment. After their hair had grown back they reported to place less value on their hair and their appearance overall. The results of the current study demonstrate that people with AS report feeling psychologically distressed by their hair not being 'normal' and feeling different from others but they do also appear to develop a shift in values over time reaching a level of reluctant acceptance, with less value being placed on appearance despite their hair not growing back as documented in Wallace et al (2007) study. Whilst participants report feeling a higher level of acceptance of their hair over time some participants reported continuing to feel a high level of distress with AS. These results demonstrate that people feel psychological distress even in light of having a condition which may be less noticeable than significant skin conditions and facial disfigurements as highlighted by Papadopolous et al (1999) and Rusmey and Harcourt (2005). In comparing these results it may suggest the severity of the disfigurement does not correlate with degrees of distress but in comparing themselves to the 'ideal' they feel they should be that results in increased feelings of distress.

As previously highlighted there has been no research on the implications of having AS to date. Therefore the condition of alopecia areata, which has been extensively investigated, was the condition that was most closely linked to AS, due to it being a benign condition which impacts on hair. The results of this study provide similar findings to studies investigating the

psychological implications of alopecia areata. Carr et al (2000) and Hunt and McHale (2005) reported that alopecia areata caused an alteration in their participant's identity. The majority of participants in this study also attributed AS as having an impact on their personal identities, they indicated they had felt inhibited by their hair in being able to express themselves. This provides support for the claims made by Nolte et al (2006) who completed a randomised control trial on chemotherapy induced alopecia on the effects of hair loss on body satisfaction scores. They documented that hair loss significantly reduced women's body satisfaction and also had a negative impact on their ability to personally express themselves.

Coping strategies

Thompson (1998). suggests that people with visual differences employ either emotional-focused or problem-focused coping strategies. Lazarus. (1993). first outlined these approaches that aim to either 'protect the self' or a form of 'presenting the self' a certain way. These strategies are those that aim to bolster the individual's self-esteem against negative reactions from others so they are often cognitive or behavioural approaches. They could involve not leaving the house to avoid others' negative comments on their hair or using hair extensions so as to conceal the length of their hair. Evidence indicates that the distress of adjusting to visual difference is often associated with attempts to conceal the difference (Root, Kent and Al-Abadie. (1994). The results of this study may support this assertion, with those participants who were most focused on masking their hair presenting a higher degree of distress than those who embraced their hair difficulties.

This study demonstrated that participants' ability to cope with their hair and the strategies they employed to manage their hair evolved over time. Welsh and Guy (2009) who completed an IPA study on the lived experience of people with alopecia areata found that people with alopecia go through three distinct phases of coping when they develop the

condition; avoidance, appearance fixing and positive rational acceptance. Participants in the current study appeared to go through stages of avoidance with their hair: *“It was awful at that stage...I mean awful. I used to just put it up and ignore it”* (Alison), *“I used to just try and not think about it and get on with my day”* (Nat), *“I just never think about it”* (Jenna). Additionally, some participants did describe expecting their hair would spontaneously start to grow at some point in the future, which may reflect further aspect of avoidance in acknowledging the chronic nature of the condition. Participants also documented having tried numerous ways to make their hair grow: *“I’ve tried everything to make it better, every thickening shampoo, nothing works”* (Jenna), *“the amount of money I have spent trying to fix my hair would make us both fall over”*. (Hayley). *“I’m always trying different products to help but nothing ever works”* (Nat). The majority of participants also documented eventually having feelings of positive rational acceptance, similar to Welsh and Guy. *“I just accept it for how it is now”* (Jenna), *“I do quite like my hair now, it is nice hair”* (Lucy), *“I no longer care what others think about me now so I am okay with my hair now”* (Nat). This evidences that those with AS also transition through an avoidance, appearance fixing phase and rational acceptance similar to the one described by Welsh and Guy (2009).

This study highlighted how participants with AS’s relationship with their hair changed over time. They all developed effective coping strategies that enabled them to feel comfortable with their hair on a day to day basis. These included masking their hair by using hair extensions, wearing it in a style they suited or keeping it short. This is similar to findings from Papadopolous and Bor (1999) who found that people with significant skin conditions and facial deformities coping strategies evolved over time.

Model of Loss

The results of this study appear to demonstrate that participants with AS go through distinct phases with the condition. They appear to have similar trajectories as those who have experienced loss. Bowlby's model of loss has been presented to demonstrate the 'typical' process a person goes through when facing grief. They outline a number of stages that people need to navigate when facing a grief (Bowlby, 1980). Whilst there are multiple types of loss, the majority of models of loss primarily focus on stages of bereavement that takes place when a loved one dies. However, participant's accounts appear to fit with stages of grief and so Bowlby's model has been applied to offer a theoretical understanding of this process. There are a number of models of loss within the academic literature but Bowlby's model of loss appears to have the best fit with those with AS. The phases that participants described in this study fit well with Bowlby's model.

Bowlby's four phase model of mourning outlines four sequences of grief; shock and numbness- where there is a recognition there has been a loss, yearning and searching- where the loss is attempted to be undone, despair and disorganisation- where it is accepted that the loss is irreversible, and reorganisation and recovery- where life's investments are reorganised. This model will now be applied to the results of this study. All participants in this study identified that something was wrong with their hair prior to them spending time researching it or considering what was causing their hair not to grow. It may be reasonable to assume the interim period between them recognising there is something wrong with their hair and doing this research may be a self-protection or numbness, as indicated by Bowlby. Participants described having a strong feeling of yearning and searching, with all participants documenting this stage before knowing about AS: "*you know that constantly trying to find the reason why it was happening*" (Hayley). Some participants reported still having the feeling of yearning and searching even after finding out about the condition as they were looking for potential treatment options and management strategies: "*I'm always trying*

different products erm in the hope it works” (Nat). The majority of participants also reported having feelings of despair after they had accepted the condition and their hair was not going to change “*Nothing works. And I think that for me is the annoying thing*” (Jenna). It had led to them feeling hopeless and disorganised for a period of time. All participants reported having started the reorganisation process on the path to recovery and acceptance; they had begun to recognise they can live their life with AS: “*I absolutely think that you can have a good life with it*” (Darcy). Bowlby’s model highlights this stage does not mean the grief is fully resolved, it is still ever present, it just has been reorganised with less focus than it once had held for the individual. This also fits with how participants in the current study reported feeling with regards to navigating the path to acceptance. Silverman and Klass (1996) also support the notion that bereavement is never fully resolved, a complete closure and recovery is never achieved for the majority of people who are bereaved. They propose it is simply a process of negotiating and renegotiating the meaning of the loss over time which participants in the current study indicated they do also.

Participants in the current study described feeling differently about their hair over time, and their journey with the condition had evolved. Small, Hockey and Katz (2009) criticise Bowlby’s model of grief for his linear time assumptions. They argue that grief is not a straightforward time process like a “blueprint of grief” (Small, Hocket and Kratz, 2009 in Earle, Lomarmy and Batholomew, 2009 p154). They argue that grief disrupts the experience of time and so people do not go through successive stages of grief as Bowlby outlined. They advocate that people move between stages at different time points. The data from this study would support this notion, with participants appearing to switch between the different stages frequently.

Psychosocial Theory of Development

The results of this study demonstrated that people had different experiences and stories of how AS affected them at different time periods of their lives. The data captured in this study demonstrated that participants described having different perspectives and priorities surrounding their hair at different stages of their life. Erikson's psychosocial theory of development (Erikson, 1968) is a theory that proposes a person's personality and identity is shaped by a series of staged crisis that materialise over their lifetime. He puts forward eight developmental stages, each with a focus on a specific skill that aids the individual to function fully within their environment. It also allows the individual to gain a greater sense of their identity if the crisis is successfully resolved. However, if the crisis is not resolved they will have a weaker concept of their identity (Shaffer and Kipp, 2010). Each of these stages/dilemmas will occur at certain phases of life but they are interconnected and each dilemma continues to influence and shape the other stages (Feist and Feist, 2006). Erikson proposes that people focus on different challenges and issues at different times in their lives and so their understandings, experiences, and reactions will be different based on the phase they are currently operating at. Once they have progressed with the life goal it may be likely to become less of a focus for the individual. The four stages applicable to these findings are stage four industry vs inferiority (5-13 years old), stage five identity vs role confusion (13-21 years old), stage six intimacy vs isolation (21-39 years old), and stage seven generativity vs stagnation (40-65 years old).

Participants described feeling imperfect as a result of their hair when they were children (stage 4). This was predominantly in relation to being aware of the difference between their hair and their peers. Some participants also described accounts of being bullied or targeted because of their hair at this stage. According to Erikson's model children at this phase frequently value approval of their peers and engage in activities which facilitate this approval. If they are able to gain approval from their peers at this stage they are able to feel competent.

However, if they do not gain approval from their peers they begin to doubt themselves and feel that society is too demanding, leaving them to feel inferior. Participants in this study described feeling that society's pressure on them to have long hair felt too demanding and left them feeling inferior at this phase of their life: "*I thought how everyone thought that I was ugly*" (Tina). Nat reflected how when she was a child she never felt she was good enough because of her hair "*but I always feel a little bit inadequate*" (Nat).

During their adolescent years (stage 5) Erikson claims that adolescence begin to establish ideas of the roles they may occupy in adult life. If they are not able to establish a role or clear identity for themselves then this leads to role confusion and they become disorganised about their identity and role within society. A key issue participants discussed was how they thought they were unable to occupy the role they wanted to hold in society because of their hair. They wanted to feel feminine and attractive. They felt unable to adhere to this role because of their hair: "*Yeah, well, I look like a boy*" (Alison). Lucy describing being mistaken for a boy when she was a child: "*Everything about me felt like a girl, my hair being short doesn't make me not a girl*". This led to Lucy feeling personally confused by her identity due to her hair. "*I became a tomboy because of the hair; I don't know whether that was because of the short hair or whether the short hair dictated that*" (Lucy). Thus they did not feel they were able to fit in with society's expectations due to their hair.

Participants reflected on how they did not feel attractive or able to establish an intimate partnership when they were in their young adulthood because of their hair (stage 6). Erikson identifies this phase as were people begin to focus more on developing intimate relationships. Some participants described feeling fearful their hair would impact on their ability to form relationships at this phase in their life. Some participants described being concerned that they were unlovable because of their hair. "*No one would want me with my horrible hair*" (Tina).

They feared becoming isolated as others would not feel able to connect with them as a result of their hair.

When participants had their own children or grandchildren they reflected on how their priorities were more focused on their children's happiness and they were less interested in their appearance. This describes Erikson's seventh stage where the main focus is on nurturing and giving back to society and less on their own needs. Lucy reflects this: "*I am no longer worried about me, it's them [her children] that I care about now*".

Interestingly, the older participants in the study describe different earlier experiences when comparing their accounts with the younger participant's accounts. They described thinking there had been less of a focus on appearance when they were younger than there is today. The older participants reflected that younger people with the condition appear to have a harder time with their hair because of this. This cohort effect may explain some of the variation in the accounts of this study.

Erikson's model is not without its critiques. There are a number of critiques to Erikson model; it has been suggested that Erikson ignores emotional and cognitive development, it is uncomprehensive in its descriptions, it is not scientific, it is vague in the causes of development, it is European centric and based on Erikson's own life experiences and the theory is based solely on males (Rosenthal, Gurney and Moore, 1981; Côté and Levine, 1987). Exploring these criticisms is beyond the scope of this thesis but it is important to address the most relevant critique of the model in relation to this study. Erikson's model is based on stereotypical male stages of development and this study only had female participants. Gilligan (1982) highlights there are likely to be a different pattern of development for females, with a more prominent focus on intimacy and social relationships. Josselson (1982) supports Gilligan in her critique of Erikson; she believes that women's

identity status is more related to social and emotional connections and less on occupation and political contexts than Erikson's model outlines. The results of this study would support Gilligan (1982) and Josselson (1982) as all participants placed a high emphasis on their social relationships and intimacy with others, with no one mentioning occupational or political implications within the interview. It may have been that the interview did not facilitate these discussions, but it may be likely to assume they were less prominent features in the participants mind.

Critical Evaluation of the study

This section will evaluate the merits and weakness of the study.

Overall Strengths

It is important to highlight this is the first qualitative study completed on the area of AS. All other studies in connection with AS, to my knowledge, have been focused on diagnosis and treatment modalities. As this condition has been neglected previously within the academic research, the study's main strength is giving those that have experienced AS a voice, which has not been represented within the literature previously. This, therefore, is the first study to highlight the psychological needs and experiences of those with AS and demonstrate how the condition impacts on their wellbeing.

Recruitment

All of my participants were recruited through Facebook. This was the only source of being able to access people with AS. It could be argued that those who use such a site may be more active members of the AS community. However, those who have AS but do not use the Facebook support group could not have been recruited for the study. As the condition is rare and not well known this was the most viable option to recruit for the study at this time point.

Additionally, there is no known health professionals connected with the condition who I could have recruited participants from. This restricted my recruitment for the study to the Facebook support group. It may be possible that people recruited through social media may reflect on different issues than if they had been recruited through other means, although this could not be substantiated.

Due to the methodological approach this study used it was important to recruit a homogenous sample. Smith, Flowers and Larkin (2009) outline that a homogenous sample is important in IPA but the extent of this homogeneity will be dependent on the study. As AS is such a rare condition having a sample of seven White female who all have English as their first language, is adequate for a homogenous sample. Despite this, the study also included participants who lived in a wide geographical location with participants living as far away as USA and Australia. However, whilst there was no noticeable difference in the participant's experiences of having AS based on their geographical location in this study, the study's homogeneity could have been strengthened by only using participants in one specific country.

The Sample

I had initially set out to recruit eight participants but only managed to recruit seven for the study. As highlighted in chapter two, the literature supports the use of small sample sizes in IPA studies and seven participants was deemed adequate. This sample size allowed for rich and detailed accounts to be collated and analysed. The final sample of participants all had a number of attributes in common; they were all female and White. They had all reported to have been negatively impacted by the condition; they were also all motivated to support the research and to promote knowledge of the condition. I recognise there may be other cohorts of people with AS who do not match these characteristics. I would therefore be cautious in generalising these results outside of this cohort. Conversely, Pringle, Drummond,

McLafferty, and Hendry (2011) argue that results of any study, no matter the sample size, are difficult to generalise to other cohorts as there are inevitably wide variations within samples that cannot be controlled for. However, Carradice, Shankland and Beil (2002) argue that research's value should be evaluated by generalising the findings to other studies and situations and not based only on the sample size of the study. This has been discussed above in the comparing results to the wider literature section. Smith, Flowers and Larkin (2009) stipulate that whilst qualitative research results cannot be applied to others outside of the direct sample, there can be aspects of the results which provide useful insights which can have wider implications.

It is important to highlight that all participants were White and so applying the results to people from other ethnicities should be done with caution. It was not the study's intention to only recruit people of White ethnic origin, however the Facebook support group is predominantly people of white ethnicity and so the recruitment process inadvertently may have encouraged this. As little is known about the prevalence rates about the condition it is not known how many people of different ethnicities have the condition. Whilst it is predominantly people of White backgrounds that are prevalent in the literature and on the Facebook support group there are people from non-White backgrounds that are reported to have the condition (Vivek, 2013; Avahia, Woolery-Lloyd, Tosti and Romanelli, 2010). Despite this, the study recruited people from a wide geographical location with participants from the United Kingdom, Australia and the United States of America all being part of the study. These three countries are the countries that are most predominantly represented on the Facebook support site.

The participants were all different ages. This age range was set to aid recruitment. Whilst they all voiced similar experiences of having the condition those of an older age range reflected on how they had felt society had changed to overvalue appearance now and they

envisaged that the condition would have been more challenging to live with now as a younger person than when they were younger. This was not something that I had anticipated when I set the age parameters of the study. Future research may focus on more specific age restrictions to look at the affect this condition has on people of different ages.

As AS is known to be an autosomal dominant form of inheritance, males also experience this condition (Baden, Kvedar and Magro, 1992). However, due to males' hairstyles predominantly being shorter in length it is reported less commonly. This sample only included female participants and a number of the themes they discussed had a large focus on femininity and the role society plays on their gender identity. The results of this study could therefore not be confidently applied to males with the condition.

It is important to stress that only one of my participants had a formal diagnosis of AS. As already highlighted, very few adults with the condition have a formal diagnosis and so it was expected the sample would not have any formal diagnosis. This raises the question of how confident can we be that the whole of this sample has AS? This led me to consider if any other conditions could explain the participants symptomology. A comprehensive search of the literature was completed to investigate any potential conditions which my sample could have instead of AS. Two genetic conditions; Noonan Syndrome and Trichorhinophalangeal Syndrome both cause hair difficulties similar to AS. However, these conditions have a number of significant health and body deformation such as heart and limb abnormalities and height and weight difficulties. These symptoms were not present with the current studies sample and they all described themselves as having no other health difficulties. I was unable to find evidence of any other conditions that could explain why their hair would not grow. Additionally, I considered if there could be environmental factors which could explain my population's hair presentation. Hair growth is known to be affected by a number of factors; chemical over processing, over cutting, damaging hair manipulation, traction alopecia

(prolonged wearing of too tight hairstyle that cause damage to the hair shaft), lack of moisture or protein, and poor diet. Participants denied any of these factors and reported being very careful and protective of their hair in fear of damaging it. As the participants without a diagnosis have had their hair difficulties since birth it could also exclude these environmental factors. Thus, I can be somewhat confident that my sample all have AS. Participants reported they were not motivated to seek a diagnosis as they have only recently found out about the condition, after living with it throughout their lives and there being no current 'treatment option'. Despite this, all participants strongly identified with having AS and gave detailed accounts of how having the condition had impacted on them throughout their lives.

Hayley, the only participant with the diagnosis received her diagnosis from a trichologist when she was in her forties. When attending this appointment Hayley had not intended to gain a diagnosis, she was aiming to gain support to help her hair to grow again. It is important to highlight that Hayley had still suffered with the condition for over twenty years, which is still a long time period for her to have experienced the condition for. Therefore it can be confidently assured that all participants have longitudinal experience of having AS.

The Interview

Whilst ideally the interviews would have all been completed face-to-face for consistency, this was not possible. Four of the seven interviews took place over the telephone, due to geographical restrictions. Novick (2008) advocate that interviews completed over the telephone can yield just as effective data as face-to-face interviews. This approach can be particularly effective when approaching sensitive topics as it can aid reducing embarrassment. Turner, Barlow and Ibery (2002) supports this and gained effective results completing their IPA study over the telephone. I noticed no difference between the two different types of interviews. However, some participants may have felt more comfortable

using a face to face approach which may have aided the development of the relationship. Phone based interviews also prevented me from observing non-verbal communication cues, such as hand expressions and body posture, which I was able to detect from those where the interview was completed face to face.

I was conscious that my experience of having the condition may have impacted upon the interviews. All participants were aware of me having the condition and we discussed this prior to the interview taking place. It is important to highlight this may have affected the way that I asked the questions, I may have appeared confident in my understanding and I may have had a less curious stance than someone who did not have AS. However, my clinical training and experience has taught me the value of always having a curious stance which I can rely on during the interview. Additionally, I have a real passion and interest in this condition so I was genuinely excited to hear about peoples varying experiences of having the condition. As participants knew I had AS they may have made assumptions about my experiences based on their own experiences, which may have limited what they told me. To rectify this I prompted them to expand on their answers as much as possible, particularly when I felt that an assumption had been made in regards to my knowledge. Prior to the interview I was quickly able to establish a strong rapport with each of the participants with each saying it was nice to talk to someone else with the condition, many of them having never met anyone else with the condition. As I had AS it appeared to enable me to establish a commonality and a bond with the participants quickly. Participants may have felt comfortable opening up to me easily, as they may have thought that I would have understood in comparison to an interviewer without the condition.

I felt that as the study progressed and I gained more experience in completing interviews that my confidence developed. As such, I was more confident in my approach on my last interview in comparison to my first interview. I recognised that this had an impact in my

approach to the interview as I did not feel the need to ask as many direct questions when a prolonged silence occurred which gave participants more space to reflect and consider their responses. I used a semi-structured interview as it created a clear structure and focus for me to follow, it also allowed for a degree of consistency across the interviews. However, the use of a semi-structured interview has been criticised for providing a potential framework for subsequent analysis (Swift, Aschcroft, Tadd, Campbell and Dieppe, 2002). Whilst this is acknowledged, I had made it clear to all my participants that I was interested to hear about their experiences and they do not need to be restricted to the questions that I had asked. I actively encouraged them to discuss anything they felt was relevant to the study. Thus, granting them permission to break away from the parameters of the interview schedule and give more open answers.

I had expected participants to compare AS to other conditions and feel more positive about having AS over other potential conditions which limit and alter people's lives and ability to function day to day. This expectation had come from how I thought about the condition and how I had seen others discuss it on the Facebook support group site. However, this was not mentioned by any of the participants within their interviews. I recognise that it is not possible to comprehensively cover all participants' views and experiences of having AS within one interview. It may have been that the interview did not facilitate such comparisons to arise.

The final question asked participants to consider the positive aspects of having the condition and some participants did struggle to answer this. I was aware that participants had spent the majority of the interview discussing the negative aspects of having the condition and to then be asked about the positive aspects of the condition without any warm up could indicate a weakness with the interview schedule. However, a number of participants after taking their time to consider the question were able to provide answers to the question.

Finally, as I was interested in how participants had experienced the condition throughout their lives I was conscious that memory may impact upon the study. I had requested participants to bring photographs in a hope that this would aid their memories. All but one participant used their photographs to aid their memories in the interview, with all of them referring to their photographs in their interviews. I recognised that photographs would not eliminate the impact of memory but this was the best available option of aiding this process. Memory inevitably did impact on some participants ability to recall and this was demonstrated by the language they used such as “I think ” and “I can’t recall exactly but maybe... ”

The Analysis

IPA main strength is its ability to give space for participant’s stories. It has been praised particularly for its utility in attempting to understand health conditions (Leventhal, Nerenz, Steele, Baum, and Singer, 1984). Smith et al. (2009) also highlight how IPA is particularly accommodating when engaging with new areas with limited theoretical background, which aligns well with this study. Brocki and Wearden (2006) criticise the approach for its mysteriousness nature and how ambiguous some studies are with regards to the analysis process. To rectify this, this study has systematically explained how the analysis has been undertaken in chapter two, the methods chapter, in a bid to be transparent about this process. Whilst I am confident of my analysis process and I attempted to be as objective as I could I recognise that the data has been analysed using my lens. As already highlighted I had a number of people look over my transcripts and analysis including my supervisors, my peers in my cohorts IPA support group, and IPA analysis support day at the University of Derby to ensure that others could follow what I had done and recognise my results from the data. Despite this, I acknowledge that I could have asked others to analyse complete interviews to gain a different angle or approach away from my own. This did not take place due to time restrictions. However, a number of sections of my interviews were analysed by others and

their responses included in my analysis to ensure for accuracy and to include others lens than my own.

Credibility and Reliability

As highlighted in the method chapter I had employed a thorough quality control procedure to ensure the integrity of my results. This was particularly pertinent as I am a novice researcher using IPA, as well as being a person who has the condition. This stringent quality check procedure was based on the guidelines set out by Yardley (2000) and Elliott et al. (1999). Table 4 depicts the quality checks set out by Elliott et al (1999) that I undertook on this study and Table 5 sets out the checks highlighted by Yardley (2000)

Table 4

Elliott et al (1999) Quality Checks

Area Reviewed	Evidence
Owning one's perspective	I have attempted to be transparent about my perspective throughout. I have identified that I have AS and my experience of the condition. I have also identified that I am a trainee clinical psychologist with experience of conducting clinical interviews but I am a novice at completing IPA research. I documented my initial beliefs about AS and continued to document how my beliefs developed as the project continued. I engaged in a number of additional interviews (with my parents and my peers) to highlight any potential bias and perspectives that I held that were not apparent to me, as well as having detailed discussions with my supervisors. I also kept a detailed reflective diary throughout this project to identify and highlight my changing beliefs.
Situating the sample	I have included a table of demographics (Table 2) that provides demographic information on each of the participants. I have also provided detailed pen portraits to provide additional social and cultural experiences to provide the reader with additional information to understand the participants.
Grounding in examples	I have provided examples of quotes for each theme throughout the study. This aids the reader to see evidence of the theme and demonstrates that the data has these themes present. It also allows the reader to determine possible alternative meanings and understandings of my data. I have also included a 'who said what table' (Table 3) to show the reader how often these themes were represented in the data.
Providing credibility checks	I completed a number of credibility checks of my themes. My clinical supervisors, with extensive experience in IPA, looked over my analysis and results chapter. They made suggestions and corrections throughout this process. I also asked my IPA support group members to read extracts of my transcripts and my themes to see if they could identify my understandings. They also provided suggestions and things to consider which did result in some changes to my analysis.
Coherence	I have provided both a thematic map of understanding of AS as well as provided a detailed explanation of this understanding. I have grouped them in a way that depicts the relationship between them so as to provide a coherent structure of the data for the reader.
Accomplishing general	This study has highlighted that seven interviews have been conducted with White women with AS and the results cannot be applied to people outside of these parameters. As the sample size is small I would caution any generalisation of these findings. Whilst the findings of other similar conditions have been applied to my results to

versus specific research tasks	provide further understandings of the research it is important to highlight these results should only be cautiously applied to other conditions with similar presentations.
Resonance with readers	I have attempted to bring the participants experiences of having AS to the fore front with this study. I have attempted to document what it is like for people with the condition and put their experiences into a coherent story.

Table 5

Yardley (2000) Quality Checks

Area Reviewed	Evidence
Sensitivity to context	Using the demographics table (Table 2) and pen portraits, demonstrates the awareness I have for my participants' perspective and cultural experiences. I have taken steps to ensure my analysis (documented steps taken in Table 1) generated carefully considered data and did not impose my own assumptions onto the data generated.
Commitment and rigour	I have held myself to the highest standard of rigour when completing the interview and analysis (as highlighted in the Methodology section). This was to demonstrate to the reader they can be confident that my results have been generated using appropriate methodology and analysis.
Transparency and coherence	It is hoped that the reader will be able to see clearly how each of these interpretations has been taken from the data.
Impact and Importance	This research is the first of its kind on the impact of AS so demonstrates the utility of the research.

I have demonstrated the in depth ‘credibility checks’ I have completed in the tables above. It is hoped this will demonstrate to the reader the process I have engaged in so they can be assured of the results provided.

Implications

The findings of this study have a number of implications which will now be discussed for people with the condition, the participants of this study and parents of children with AS, other researchers, health professionals, other professionals and wider society.

People with AS,

This study validates the experience of those with AS and demonstrates the challenges that living with the condition can bring for people. It is likely to help to normalise people’s experiences and may provide those in the early phases of the condition with hope for the future. This is because it demonstrated that others who have gone through the condition do develop different relationships with their hair as they grow older. The study highlighted how challenging it was for people to find out about AS, with most only finding out about it through the internet. This demonstrates the need for more information to be circulated about the condition. Information about AS and the results of this study should be presented on Department of Health websites to inform people about the condition and its expected trajectory. A user friendly report documenting the results of this study will be produce and sent to all the participants as well as it being posted on the Facebook support site.

Health Professionals

There are a number of health professionals that would benefit from gaining knowledge about AS and the results of this study; including General Practitioners, nurses, psychologists,

counsellors, and psychotherapists. The results of this study demonstrate how currently a number of health professionals are not aware of AS and the emotional implications of having the condition. This study highlighted how some participants had difficult and emotional interactions with professionals because of their lack of knowledge surrounding the condition. It is therefore imperative that health professionals are provided with the basic information in relation to the condition and how their clinical practice can be used to help those with AS. This is particularly pertinent for General Practitioners who require more knowledge of the condition to support them to diagnose the condition and refer sufferers to appropriate teams or departments, such as dermatological specialists, to aid them with living with the condition.

As Welsh and Guy (2009) already highlighted health services for patients with hair difficulties, such as alopecia, are frequently bio-medically focused but often it is the psychological challenges that patients normally suffer with the most. It is therefore important for psychological provisions to be provided to support individuals who experience hair loss or disruptions to their hair growth like AS. Psychotherapists therefore need to be aware that people with AS frequently experience feeling distress from not being able to grow their hair long. This has important therapeutic implications as this study has highlighted how people with AS frequently think the condition is minimised by others, particularly health professionals. Psychotherapists need to be aware of this to normalise their experience of distress in having AS. There have been a number of successfully documented psychotherapy interventions for people with hair loss with particular benefits in relation to anxiety, depression and adjustment to alopecia (Reinhold, 1960; Sandok, 1964, Teshima, Sogawa, Mizobe, Kuroki, and Nakagawa, 1991). This may suggest that such psychotherapeutic interventions could lend themselves well to people with distress in connection with AS.

To support health professionals to gain this knowledge AS should be highlighted in professional training programs and continuous professional development training platforms. As already stipulated above, the study will be written up for publication to widen knowledge of the condition and its implications within the academic arena. This will also help health professionals to access this knowledge.

Other professionals

The results of this study also highlighted a number of other professionals who would benefit from knowing about AS namely; teachers and hairdressers. Participants had highlighted they had been bullied when they were in school for their hair and participants with children and grandchildren emphasized this bullying is still taking place. Therefore teachers need to be made more aware of AS to enable them to support their pupils who have AS and educate the children who are victimizing them. All participants in this study described a number of incidents of being distressed by hairdressers. This highlights the need for hairdressers to have knowledge about AS and its symptomology. A number of participants also described first going to hairdressers to enquire about why their hair would not grow. Hairdressers are clearly not in a position to diagnose AS but if they had more knowledge of the condition it would provide more support for those with the condition during their hair salon appointments. This study demonstrates the importance of hairdresser's sensitivity with people who have AS. For people with AS going to the hairdressers can be traumatic and so hairdressers having an awareness of this is important. For both teachers and hairdressers this knowledge is best cascaded through initial training and continuing professional development training.

Wider Social Support Networks

As so many participants had reported feeling isolated by having AS it would be helpful for local based support networks to be established. This would provide people with AS the option of being able to meet others with the condition face to face as well as through the online support group. This may alleviate the feeling of isolation prominent with the condition that this study highlighted. This study highlighted that most of the participants with the condition were motivated to support others with the condition, especially those who were younger. This support system could be led by people with the condition who want to support others.

Future research

The current study demonstrated the need for more research on AS. Whilst the results of this study were valuable given the lack of knowledge in the area, it was a small scale study with just seven participants. It would be beneficial to explore whether these findings are replicated with a larger population, as well as people from a more diverse demographic. Future research in this area would benefit from identifying if these results can be replicated within different groups of demographics such as; males, non-Whites, people from different geographical locations and people whose first language is not English. As this study attempted to investigate the long term effects of AS it was inevitably impacted upon participant's memory recall.

A number of participants, when they were recalling historical events, indicated that memory was impacting on their ability to give detail responses about how exactly they felt at the time. It would be helpful for future research to address this limitation by asking participants to record their experiences longitudinally using diary entries to reduce the effects of memory. As children are now beginning to acquire diagnosis of the condition at a more frequent rate, as documented anecdotally on the Facebook Support group. It potentially may provide any

potential researchers with an equipped population to facilitate future research of children and adults with this condition. Additionally, the Facebook support group for this study is well used and has numerous posts daily on it. This would allow for researchers to complete an in depth content analysis of the support page to identify the major themes that are posted on the site. This would again remove the reliance on human memory. Additionally, it would be interesting for research to be completed outside of the Facebook support group, in case this method of data collection attracts different demographics of people. People may have the condition but not feel the need to access support for the condition on such a platform or do not use such platforms.

This study used interpretative phenomenological analysis methodology. Future research could focus on using different qualitative methodology. The participants in this study used interesting language throughout their interviews to explain their experiences of having AS. Discourse analysis, would be an interesting approach to complete on a sample of participants with AS. To investigate how language and how language is used by people to construct their reality of having the condition and the meaning they attribute to it, discourse analysis could be used.

This qualitative study provided rich, detailed and in depth understanding of what it is like to have AS. Future research could focus on establishing how accurate these results are for a wide range of people with the condition. A quantitative survey based study that investigates how people with the condition experience distress, anxiety or resilience could enable this. It would also enable results to be generalised more widely to a wider range of people with AS.

Finally a key theme this study identified was that participants felt that nobody understands or knows about this condition as each of them had been isolated with the condition prior to finding the support group. They all felt finding others with the condition had been a positive

experience for them. As more children with the condition are now aware that others have the condition, through the support group, this may alleviate the feeling of isolation. It would be interesting to see the effects of this online support over the long term. Parents of those with the condition are highly motivated towards this research with many making requests to include their children in the current study which demonstrates the demand for more research in this area.

Conclusion

This study explored the lived experiences of those with Anagen Syndrome. It is the first account that documents how people with AS experience the condition. The results demonstrate the longitudinal challenges that AS can bring for sufferers. It has highlighted how relationships with their hair changed over time, with most participants transitioning from having a turbulent and distressing relationship with their hair, to a more accepting, tolerant relationship with effective coping strategies. Participants described initially feeling imperfect as a result of not being able to live up to society's standards because their hair would not grow but, with time they began to recognise they are more than their hair and they can live a good life despite having AS. Throughout their time with the condition they thought that nobody understood and they are left feeling insecure, isolated, and misunderstood. The findings highlight the relational impact of having a condition that impacts on physical appearance. It also demonstrates the need for more knowledge and awareness surrounding AS in wider society to support people with the condition.

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Appendixes

Appendix 1

Interview Topic Guide

What follows is a guide to the topics that are likely to be covered in the interviews with participants in order to explore their experiences of having AS (Short AS and Loose AS). Some topics may emerge spontaneously and so the order of the questions and the exact content may vary as the interview develops. Participants will be asked to bring along photographs that bring the condition to life for them and can be used throughout the interview to aid their reflections. Some questions will specifically ask the participant to look at their photographs in order to aid reflection. (Unless the interview is being conducted over the phone in line with plan B).

1. What does SAS/LAS mean to you?

Probe for: Symptoms (What do you experience? What is it like for you to live with these symptoms?)

2. Using the photos you have brought along to help you in what ways 'if at all' has the condition featured in your life?

Probe for: Impact on life domains e.g. mood, emotional well-being, self-concept

3. Can you tell me how you experienced the condition as a child?

4. Has your experience of the condition changed at all over time? What factors 'if any' influenced this change? How do you see the condition influencing you in the future?

5. What are the most challenging factors 'if any' about having the condition? Why? How do you get through a bad day with the condition?

6. What advice would you give to someone with the condition? And why do you consider this important?

7. Have there been any occasions which the condition has brought positive experiences to your life? (Can you tell me about these and the impacts they have on you and your thoughts on the condition?).

8. Is there anything that you expected me to ask you to talk about today which we have not covered that you would like to talk about?

Depth prompts

How do you feel about that?

Ethical Approval



Proof of Ethical Approval

The Secretariat
University of Leeds
Leeds, LS2 9JT
Tel: 0113 343 4873
Email: FMHUniEthics@leeds.ac.uk
Website: <http://ris.leeds.ac.uk/MHFREC>

Danielle Osler
Clinical Psychology
School of Medicine
Faculty of Medicine and Health
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Leeds, LS2 9JT

School of Medicine Research Ethics Committee (SoMREC) University of Leeds

17 June 2019

Dear Danielle

Title of study: What are the experiences of people with Short AS and Loose AS?
Ethics reference: MREC17-084

I am pleased to inform you that the above research application has been reviewed by the School of Medicine Research Ethics Committee and following receipt of your response to the Committee's initial comments, I can confirm a favourable ethical opinion as 24th July 2018. The following documentation was considered:

Document	Version	Date
MREC17-084 Full document set		
Reviewer comments response TC comments.docx	1	12/06/18
MREC17-084 Reviewers Comments (1)_TC signature.docx	1	12/06/18
MREC17-084 Full Ethics submission.docx	1	13/04/18

Please notify the committee if you intend to make any amendments to the information in your ethics application as submitted at date of this approval as all changes must receive ethical approval prior to implementation. The amendment form is available at <http://ris.leeds.ac.uk/EthicsAmendment>.

Please note: You are expected to keep a record of all your approved documentation and other documents relating to the study, including any risk assessments. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited. There is a checklist listing examples of documents to be kept which is available at <http://ris.leeds.ac.uk/EthicsAudits>.

Yours sincerely

Jennifer Blaikie
Senior Research Ethics Administrator, the Secretariat
On behalf of Dr Anthony Howard and Dr Naomi Quinton,
School of Medicine Research Ethics Committee Co-Chairs

Participant Information Sheet



UNIVERSITY OF LEEDS

Participant Information Sheet

Version 3: 10/06/2018

What it is like for people living with short AS or loose AS?

My name is Danielle and I am the main researcher working on this project, which is part of my training to become a Clinical Psychologist at the University of Leeds.

You are being invited to take part in this project as you have expressed an interest in taking part through the online Facebook support group. Before you decide to take part I would like to highlight why the project is being completed and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

What is the project's purpose?

I am interested in exploring the experience of adults who short AS or loose AS. Not a lot of research has been conducted on people's experience of the condition and I am interested in gaining more knowledge about this. Presently the disorder is not widely known about, particularly within healthcare settings, and it is hoped the research may help to make it more recognised and establish if more support is needed for people with the condition. The project has been granted ethical approval from the School of Medicine Research Ethics Committee (SoMREC/SHREC project number MREC17-084).

Why have I been chosen?

You have expressed an interest in the research through signing up on the online Facebook support group forum for the condition.

Do I have to participate?

No, participating in the research is voluntary. If you choose to take part you will be sent an electronic consent form to establish that you have consented to take part in the study and meet the eligibility criteria. You will be able to withdraw from the project at any point up to a week after being interviewed and you do not need to give a reason for this.

What would participating involve?

Participation will involve completing a 60-90 minute interview at your convenience. It will involve asking you about your experiences of having the condition. I will be asking you to discuss your experiences of having the condition, which will include challenges you have faced, how your experience of the condition has changed through time and what the condition means for you. I will arrange a date, time and place (either in person or on the phone depending on location) that works best for you and I will record the interview as part of the research process. I am asking you to bring a range of photographs that you have of yourself that represent your experience of having the condition throughout your life. This is not compulsory but would be used to help you to think about your experience with your hair throughout the different time periods in your life. After the interview the recording will be typed up and anonymised (so that you will not be identifiable from the data). This will help me to analyse and generate themes and the interview recording will then be destroyed. There are a number of interviews that are going to be taking place. Once these have been completed and analysis is finished, a report will be produced which can be made available to you if you wish.

What are the possible benefits to taking part in the study?

You will actively be part of helping to expand the extremely limited research into this area. It is also anticipated that this research will propel more research into the condition. It is hoped to expand the understanding of the disorder and benefit those who have the condition. It is also expected that it will help those who are involved in healthcare to support those with the condition.

What are the disadvantages of taking part in the study?

The interview does not aim to be distressing or uncomfortable but reflecting on your experiences may bring about these emotions. If this does arise then we can take a break or stop the interview. I will be available to talk with you about this if you require such support. If you require more support after the interview then you can access the online forum, your GP or The Samaritans from any UK phone on 116 123.

Would my taking part in this project be kept confidential?

The information we collect about you will be kept strictly confidential. Your name will not be associated with the research and you will not be identified in the report on the research. Any quotes that may be used from your interview will be fully anonymised, with any identifying information removed. All information collected by you will be kept on a password protected M-drive server of the University of Leeds, United Kingdom. The only people who will have access to the anonymised data will be myself (Danielle) and members of my supervising team whose information is listed below.

What will happen to the results of the research project?

The results of this research will be written up as part of my training in Clinical Psychology. This will be available to read in the University of Leeds Library and on their online White Rose e-thesis system in 2019. The research may also be published in an academic journal in the future but you will not be identifiable if this is to be published.

What happens to the data?

The data will be uploaded to the university's M drive after the interview, which is a secure password-protected university server. It is expected that the results of this project will be written up and published, possibly in a peer reviewed journal. Additionally, the findings will be presented at the trainee research conference and possibly at other conferences. Please note that all verbatim extracts will be anonymous and not identifiable.

What will happen next?

I will contact you and give you the opportunity to ask any questions you may have. If you agree to take part in the study then I will ask you a few simple questions to ensure that you meet the requirements of the study and to establish if you feel able to take part. Then a time and place will be arranged, at your convenience, for the interview. Prior to the interview I will ask you to sign a consent form to ensure that you are happy to take part in the research and interview process.

Danielle Osler (Principal Researcher)

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Appendix 4

Example Transcription Contract

DATA PROCESSING AGREEMENT

THE UNIVERSITY OF LEEDS

and

Julie Clark

Researcher name: Danielle Osler

Project title: The lived experience of adults with anagen syndrome: an interpretative phenomenological analysis

Ethics reference number: MREC17-084

AGREEMENT DATED 10th February 2019

BETWEEN:

- (1) **THE UNIVERSITY OF LEEDS** of Leeds LS2 9JT ("Leeds"); and
- (2) Julie Clark, having its registered office at Leeds University, Department of Psychology.

BACKGROUND

- (A) This Agreement is to ensure there is in place proper arrangements relating to personal data passed from Leeds to the Processor.
- (B) This Agreement is compliant with the requirements of Article 28 of the General Data Protection Regulation.
- (C) The parties wish to record their commitments under this Agreement.

IT IS AGREED AS FOLLOWS:

1. **DEFINITIONS AND INTERPRETATION**

In this Agreement:

"Data Protection Laws" means the Data Protection Act 1998, together with successor legislation incorporating GDPR;

"Data" means personal data passed under this Agreement, being in particular digital audio recordings of research interviews;

"GDPR" means the General Data Protection Regulation;

"Services" means transcription of research interviews.

2. **DATA PROCESSING**

Leeds is the data controller for the Data and the Processor is the data processor for the Data. The Data Processor agrees to process the Data only in accordance with Data Protection Laws and in particular on the following conditions:

- a. the Processor shall only process the Data (i) on the written instructions from Leeds (ii) only process the Data for completing the Services and (iii) only process the Data in the UK with no transfer of the Data outside of the UK (Article 28, para 3(a) GDPR);
- b. ensure that all employees and other representatives accessing the Data are (i) aware of the terms of this Agreement and (ii) have received comprehensive training on Data Protection Laws and related good practice, and (iii) are bound by a commitment of confidentiality (Article 28, para 3(b) GDPR);
- c. Leeds and the Processor have agreed to implement appropriate technical and organisational measures to ensure a level of security appropriate to the risk, complying with Article 32 of GDPR, details of those measures are set out under Part A of the Annex to this Agreement (Article 28, para 3(c) GDPR);

- d. the Processor shall not involve any third party in the processing of the Data without the consent of Leeds. Such consent may be withheld without reason. If consent is given a further processing agreement will be required (Article 28, para 3(d) GDPR);
- e. taking into account the nature of the processing, assist Leeds by appropriate technical and organisational measures, in so far as this is possible, for the fulfilment of Leeds' obligation to respond to requests from individuals exercising their rights laid down in Chapter III of GDPR – rights to erasure, rectification, access, restriction, portability, object and right not to be subject to automated decision making etc (Article 28, para 3(e) GDPR);
- f. assist Leeds in ensuring compliance with the obligations pursuant to Articles 32 to 36 of GDPR – security, notification of data breaches, communication of data breaches to individuals, data protection impact assessments and when necessary consultation with the ICO etc, taking into account the nature of processing and the information available to the Processor (Article 28, para 3(f) GDPR);
- g. at Leeds' choice safely delete or return the Data at any time. [It has been agreed that the Processor will in any event securely delete the Data at the end of the Services]. Where the Processor is to delete the Data, deletion shall include destruction of all existing copies unless otherwise a legal requirement to retain the Data. Where there is a legal requirement the Processor will prior to entering into this Agreement confirm such an obligation in writing to Leeds. Upon request by Leeds the Processor shall provide certification of destruction of all Data (Article 28, para 3(g) GDPR);
- h. make immediately available to Leeds all information necessary to demonstrate compliance with the obligations laid down under this Agreement and allow for and contribute to any audits, inspections or other verification exercises required by Leeds from time to time (Article 28, para 3(h) GDPR);
- i. arrangements relating to the secure transfer of the Data from Leeds to the Processor and the safe keeping of the Data by the Processor are detailed under Part A of the Annex.
- j. maintain the integrity of the Data, without alteration, ensuring that the Data can be separated from any other information created; and
- k. immediately contact Leeds if there is any personal data breach or incident where the Data may have been compromised.

3. Termination

Leeds may immediately terminate this Agreement on written notice to the Processor. The Processor may not terminate this Agreement without the written consent of Leeds.

4. General

- a. This Agreement may only be varied with the written consent of both parties.
- b. For the purposes of this Agreement the representatives of each party are detailed under Part B of the Annex.
- c. This Agreement represents the entire understanding of the parties relating to necessary legal protections arising out of their data controller/processor relationship under Data Protection Laws.

- d. This Agreement is subject to English law and the exclusive jurisdiction of the English Courts.

For and on behalf of The University of Leeds

Insert signature of head of department (Allan House)

.....

For and on behalf of Julie Clark]

Insert signature of person signing for the transcription company

.....

ANNEX

Part A

Compliance with Article 32, para 1 of GDPR

1. Consideration of anonymisation, pseudonymisation and encryption.
Is the above possible? If not, please explain why. If possible please insert details.
The audio files have been encrypted and assigned a pseudonymised.
2. The ability to ensure the ongoing confidentiality, integrity, availability and resilience of processing systems and related services.
Please explain how the above will be delivered.
Encrypted USB stick
3. The ability to restore the availability and access to personal data in a timely manner in the event of a physical or technical incident.
Please confirm the above is possible and description of process in place to deliver the above.
It is stored on a secure encrypted USB so can work securely off any computer
4. A process for regularly testing, assessing and evaluating the effectiveness of the technical and organisational measures for ensuring the security of the processing.
Please confirm the above process is in place and broadly what that process is.
Kept in a secure locked office with an encrypted USB

Compliance with Article 32, para 2 of GDPR

5. In assessing the appropriate level of security account shall be taken in particular of the risks that are presented by processing, in particular from accidental or unlawful destruction, loss, alteration, unauthorised disclosure of or access to data transmitted, stored or otherwise processed.
Please describe secure transfer process from Leeds to the Processor and levels of security to be applied by the Processor when the Data is in their possession.
Will be given via an encrypted USB and stored in a secure locked office.

Compliance with Article 32, para 3 of GDPR

6. Adherence to an approved code of conduct referred to in Article 40 (GDPR) or an approved certification mechanism as referred to in Article 42 (GDPR) may be used as an element by which to demonstrate compliance with the requirements set out in para 1 of GDPR – see above.
Please describe any relevant code of practice relied upon.
n/a

Compliance with Article 32, para 4 of GDPR

7. The Processor to ensure that anyone acting on their behalf does not process any of the Data unless following instructions from Leeds unless they are required to do so under English law.

ANNEX

Part B

Leeds Representative shall be Danielle Osler or such other person as shall be notified by Leeds [].

The Processor Representative shall be Julie Clark or such other person as shall be notified by the Processor [].

Appendix 6

Example of initial noting analysis

184

185 I: do you mind me asking about that?

186

187 P: noooo erm it's [pause] I mean obviously it's the physical damage

188 to the damage to my hair which effectively makes it worse in the

189 long run anyway. So that wasn't helping it. That, that effect you

190 know was making it worse. Erm and again you still feel like you're

191 trying to live to an expectation when you have had that

192 reinforcement like I said previously with someone saying "oh your

193 hair looks lovely". Well it's like you know actually that is damaging

194 as well. So yeah I don't feel as much like that anymore but cos I /pair may still be there)

195 think I have learnt to accept it.

196 feeling I needed / surprise + don't consider it anymore - trying to convince herself
of being "lovely" but language we is present tense.

197 I: can we talk a little bit about that, that path to acceptance.

198

199 P: I think it is just age. (laugh) to be honest. It got to a point when I

200 thought you know what if people don't like it then I don't care. But I

201 care a lot about what other people think of me rather than

202 necessarily how I look I care about what others what particularly

203 more so when I was younger thought about people's opinions then

204 it got to a point where I thought I don't care about other people's

205 opinions anymore. I will just do what I want. [pause] Erm I wouldn't

206 say there was a transition as much it kinda was just [pause] I think

207 just purely down to age. It just it was almost like sorta waking up

what is it about age + what does she mean by this? years or maturity.
waking up - start + immediate not transitional.
or enlightened self?

what I wasn't doing to my hair which it wore in the long run as it damaged it

I knew I had to make it look the way that was expected + so that also damaged me eventually

I was making it worse I was in control / charge of damage but others set standards

that is - not was (so damage / pair may still be there)

this has been time limited now - I have evolved + don't consider it anymore - trying to convince herself but language we is present tense.

defiance / feeling control

age made me not care as much what others think anymore

But I do really care what people think of me less about what I look like but then I don't agree - disjuncted / not coherent? indicator of uncertainty with voicing feelings or not believe it to be true

Not evolving? instant

what was behind this?

instant / not clear / confident

9

I contributed to damaging / ruining my hair or not being the way I wanted it to be.

trying to meet impossible standards

Others set the standards I needed to meet

Convincing self the pain is in the past

Fighting back - defiance

Relinquishing control

attempting to not care about what others think

waking up - p to the reality I'm affected by others

Example of initial noting analysis

Challenging her own rules + Concepts for herself

Freedom to express herself as she gets older

Challenging to be self as battle between self + others.

Want to accept myself to be a good role model for my kids

Not confident in self for wedding

Realisation that boyfriend accepts her as she is

416 more bad ass older woman who wears whatever, you know
 417 you see those older women who are sorta like no I am not
 418 dressing for my age who wears whatever, I am going to have
 419 a Mohawk or like a punk and wear loads of colour like that is
 420 like my hope for as I get older (laughter) but I think it is really
 421 hard anything that makes you feel different is really hard. It
 422 is hard to live with em. I do worry about like if my kids have
 423 it like if I have kids and they have it. I think I defiantly want to
 424 ... I know this is thinking really far into the future but I
 425 defiantly want to feel more confident in myself so that I can
 426 model that to kids if I did have them. Or like I am getting
 427 married next year as that is a bit of a worry as well cos like
 428 wedding hair cos erm I have not seen any ... when you look at
 429 wedding hair you don't see anyone with hair like this online.
 430 So I thought about maybe getting extensions or something
 431 but then I think that's stupid as my boyfriend doesn't care
 432 what my hair looks like we have been together for 5 and a

But as I go older who does I wear
 (Cos she's)

moving away from hair? she can wear whatever does this mean she
 can challenge society + not conform? will this old 50-something + have to
 feel better about her hair + not be in 'normal
 group' why does it matter her older-women-
 can she possibly challenge society? shouldn't the
 younger women just get on - she wants to be the one
 demonstrates her views on what she feels about
 as a way of punishing ~~it~~ it for punishing her
 for so long?

defiantly plan said with confidence but laughs
 indicates she might be nervous? get reassured? -
 whether she will never reach 'maturity' to
 actually with to be accepted? + in a state she
 is not yet ready to challenge. The question of
 individuality she implies a form of courage
 against this + structure and protest to stand
 on one side she feels she couldn't do (different relation
 I wouldn't want it anyway) kids are also
 in her challenge society impacts men?
 expression of individuality? how really it?
 Self-imposed rules prior to having kids? why is this
 important? usability of the.

rate of self-confidence for kids but moves on
 to wedding + indicates about being only one
 with short hair... the pull of societal norms does
 he back.
 Control strategy? how time control + the
 need to understand (ambiguity)
 self-criticizing herself for being this person
 dressing for someone else? - the man she
 describes about? indicating power of this.