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# “I wouldn’t wish alopecia on my worst enemy”

Adolescents’ and Parents’ Experiences of Alopecia

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**Amrit Bhatti**

April 2019



A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Doctor of Philosophy

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## Abstract

Alopecia is a dermatological disorder where individuals lose some or all of their hair. The condition can occur at any age, but the onset is most prevalent for young people who develop a patch before the age of 20. However, there is limited research on adolescents (aged 10-19) with alopecia generally and very little focused on the perspectives of close relatives. The current study aims to explore alopecia related experiences from the perspectives of parents who have an adolescent child with alopecia and adolescents who are experiencing (or have experienced) alopecia.

Interpretive phenomenology informed the research design and methods of data collection and analysis. Participants were recruited through an advertisement placed on the Alopecia UK website which was also distributed through their newsletters and social media sites. Thirty individuals (15 parents and 15 adolescents) were included and participated in semi-structured email interviews. Each participant was emailed one interview question a week over a six-week period. The sequencing of the interviews and the time delay of questions allowed participants to reflect on their experiences and perceptions in-depth. The interview emails were analysed drawing on interpretive phenomenological concepts, acknowledging life-world existentials and the interpretive nature of the hermeneutic circle. Thematic Analysis was used to highlight key themes across participants’ narratives, pertinent to the lived experience of alopecia in adolescence.

The semi-structured email interviews were successful in eliciting in-depth participant responses. The analysis developed three superordinate themes from the parental interviews: “the hair is coming out’: living the emotional turmoil of hair loss”; “it’s JUST alopecia’: health professionals trivialising the condition”; “Needing to protect the altered appearance”. Two superordinate themes were developed from the adolescent interviews: “Experiencing exclusion and acceptance in peer relationships” and “covering up and coping with an altered appearance”. Some experiences were similarly conveyed across both parental and adolescent accounts, including how alopecia was a gendered experience, shaped by cultural context and the meanings participants attached to hair. Furthermore, the narratives demonstrated that participants experienced great emotional distress, however, health care professionals did not seem to appreciate or acknowledge the impact of this for parents and adolescents. The analysis particularly highlighted how peers were a key contributor to adolescents’ experiences as a facilitator and barrier to well-being.

To my knowledge, this is the first study within the UK to explore the lived experiences of alopecia from both parental and adolescent perspectives within one study using an interpretive phenomenological approach and email interviews. The research findings inform a number of recommendations for practice and future research. Principally, health care professionals need to be better aware of, and responsive to, the psychological/emotional impact of the condition for both parents and adolescents. Parents and adolescents, at the point of diagnosis should be made aware of supportive services that they can access, be reassured that their emotional concerns are valid and where appropriate, be referred to specialist services for psycho-social intervention. Future research that further explores the gendered experiences of alopecia across cultural contexts would develop the evidence base and acknowledge diverse experiences and needs. In addition, research is warranted which evaluates the

psycho-social support available for adolescents with alopecia, their parents and other family members. It is possible that the development of tailored psycho-social interventions is warranted, acknowledging the critical stages of adolescent development and the communicative needs, barriers and facilitators between parents, children and peers.

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## List of abbreviations

- CIA: Chemotherapy induced alopecia
- TA: Thematic Analysis
- OoL: Quality of Life

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### **I Am Not My Hair by India Arie**

See I can kinda recall little ways back  
Small tryin' to bawl always been black  
And my hair I tried it all, I even went flat  
Had a gumdee curly top and all the crap now

Just tryin' to be appreciated  
Nappy headed brothers never had no latest  
Then I hit the barber shop real quick  
Had 'em gimme little twist and it drove them crazy

And then I couldn't get no job  
This corporate wouldn't hire no dreadlocks  
Then I thought about my dogs on the block  
Kinda understand why they chose a stealin' rock

Was it the hair that got me this far?  
All these girls, these cribs, these cars  
I hate to say it but it seem so flaw  
'Cause success didn't come 'til I cut it all off

Little girl with the press and curl  
Age eight I got a Jheri curl  
Thirteen and I got a relaxer  
I was a source of so much laughter

And fifteen when it all broke off  
Eighteen and I went all natural  
February two thousand and two  
I Went on and did what I had to do

Because it was time to change my life  
To become the woman that I am inside  
Ninety-seven dreadlocks all gone  
I looked in the mirror for the first time and saw that, hey

Hey, I am not my hair, I am not this skin  
I am not your expectations, no, no  
I am not my hair, I am not this skin  
I am a soul that lives within

Good hair means curls and waves  
Bad hair means you look like a slave  
At the turn of the century  
It's time for us to redefine who we be

You be shaving it off like a South African beauty  
Get in on lock like Bob Marley  
You can rock it straight like Oprah Winfrey  
If its not what's on your head, it's what's underneath and say, hey

Hey, I am not my hair, I am not this skin  
I am not your expectation, no  
I am not my hair, I am not this skin  
I am a soul that lives within

Who cares if you don't like that  
With nothin' to lose post it with a wave cap  
When the cops wanna harass 'cause I got waves  
Ain't seen nothin' like that, not in my days

Man, you gotta change all feelings  
Steady judging one another by their appearance  
Yes, India, I feel ya girl  
Now go 'head talk the rest of the world

Does the way I wear my hair Make me a better person?  
Does the way I wear my hair Make me a better friend?  
Does the way I wear my hair Determine my integrity?  
I am expressing my creativity

Breast cancer and chemotherapy  
Took away her crown and glory  
She promised God if she was to survive  
She would enjoy every day of her life

On national television  
Her diamond eyes are sparkling  
Bald headed like a full moon shining  
Singing out to the whole wide world like, hey

Hey, I am not my hair, I am not this skin  
I am not your expectations, no

I am not my hair, I am not this skin  
I am a soul that lives within

I am not my hair, I am not this skin  
I am not your expectations, no, no  
I am not my hair, I am not this skin  
I am a soul that lives within

(Arie, 2006)

## Chapter One: Introduction

### 1.1. Setting the Scene

This thesis aims to explore the lived experiences of adolescents who have alopecia, and the lived experiences of parents. The main concern is the impact of hair loss amongst adolescents, their families, and the support they receive. Exploring these experiences can help identify the needs of individuals who experience alopecia, which can then in turn, be utilised within health and social care. In this chapter, I will provide the reader with an overall understanding of the condition. I will begin with alopecia and the significance of hair, followed by the development of the research. I will then define “alopecia” and its pathology, current epidemiology, health care guidance and support available for adolescents and their families. The structure of the thesis will then be provided.

These lyrics of the song by India Arie set the scene for the thesis. They capture how hair can be a signifier for culture, class and the negative positioning of hair loss in illness, and suggest hair is key to acceptable appearance and to personal identity.

Appearance is important in how people view themselves (Daly, King, & Yeadon-Lee, 2018). It is key to one’s sense of self and enables people to influence how others perceive them (Goffman, 1959). Like facial features, hair is important in recognition and allows people to be categorised by gender and age (Li, Lian, & Lu, 2012). This process of categorisation then influences how people behave in social contexts and how others interact with them (Dua et al., 2017). Hair is therefore more than just a part of the human body but instead, creates stereotypes and self-fashioning. The human body can be dressed to adhere to social, sexual, and religious norms, and hair can also be manipulated to reflect one’s identity and outward affiliations (Trusson & Pilnick, 2017). For example, within Sikhism hair is important, with the turban being a signifier of this religion (Singh, 2010).

The cultural meaning of hair is not uniform. For example, within black culture, there are deep tribal and sacred reasons why African people wear braids and the “Afro” (Johnson, 2016). But with the waning of slavery during the 19th Century, many black people felt pressured to fit in with the norms of the white society, including straight, tamed, smooth hair. Many used a method of relaxing the hair using chemicals to make the hair become smoother and straight (Garrin & Marcketti, 2018). This is a painful process that can burn the scalp. The Afro became a symbol of rebellion against this, showing

pride and empowerment during the civil rights movement (Garrin & Marcketti, 2018) and demonstrates the radical political potential of hair.

However, the persistence of such pressures today is evident. It is not unusual for women of colour to use wigs, weaves, and braids in presenting their hair (Garrin & Marcketti, 2018; Gill, 2015) and it is estimated that expenditures on wigs and weaves by black people is around \$2.5 billion annually in the US (Thompson, 2008). In the documentary “Good Hair” (2009), featuring the comedian Chris Rock, he strives to understand why his daughter, who has the natural curly hair of those of African descent, asks: “Daddy, how come I don't have good hair?”. The challenges faced by black women are also illustrated by the film “Nappily Ever After” . The film portrays the experiences of a young black girl, Violet. Violet’s mother suggests that her natural hair needs to be “fixed” in a manner where she is “ladylike” and feminine. When Violet jumps into a pool with other children she is ridiculed when her relaxed hair transforms back to its natural state.

The significance of hair can be traced back across centuries (Ricciardelli, 2011; Smolak & Murnen, 2011). For example, Jesus has been depicted with a beard to show that he is man, as opposed to a spirit (Gatrall, 2009). Within the Book of Judges (in the Hebrew Bible and Christian Old Testament) there is a tale about Samson and Delilah, and how the source of strength was rooted within hair that lends back centuries. However, the gendered significance of hair is also ancient. St. Paul’s letter to the Corinthians asks: “Doth not nature itself teach you that if a man have long hair it is a shame unto him? But if a woman have long hair, it is a glory to her.” (1 Cor. 11, pp. 14-15), indicating that, although this stereotype is not universal, contemporary gendered meanings of hair are not a modern development.

Hair can have a powerful impact because stereotypes regarding hair do exist. These stereotypes stem from superstition, religious beliefs, and folk tales. The most common association made between “hair” and “fairy tales” often leads to The Brothers Grimm (1987) fairy tale "Rapunzel". The story is about the most beautiful girl who lives in a tower with luscious long blonde hair. Being trapped by an evil witch, her long hair serves as a ladder, first for the witch to climb up, and then later for the prince to climb and fall in love with her. The tale ends with the witch cutting off Rapunzel's hair and banishing her, only to be reconnected with the prince. Following this, Disney's “Tangled” is based on the Rapunzel fairy tale, where the hair holds magical powers for the witch to use to retain her own youth (Stephens, 2017). Both versions capture this symbolic meaning of hair, one being that it represents beauty, youth and ultimately, power (which is lost once it has been cut). Amongst fairy tales, long hair

has often been depicted to princesses such as Cinderella, Ariel, and Belle (Das, 2005). Not only does hair confirm gender-related stereotypes but it also stereotypes hair colour. Throughout these tales we can see that good and bad are associated with blonde and dark retrospectively. This is perhaps why Lester (2000) implied that young people’s literature can interrupt cultural and societal messages that can lead to the formation of harmful concepts about race, gender and in essence, the overall concept of hair.

Some contemporary real-world examples that demonstrate the significance and symbolic notion of hair, includes joining the forces. Within the British Army and Royal Navy, there are strict rules regarding hair for men and women, in which men are required to have short hair (unless for religious purposes) and have a “tapered appearance” with no facial hair (Navy, 2017). Women, on the other hand, have no limit to their hair length, however it should be neatly groomed, and when tying in a bun, must not exceed 2 inches (Navy, 2017). This alone demonstrates that rules are necessary to maintain uniformity within a specific population to ensure individuals are affiliated with a larger group, for example the police and general uniformed services. Such strict rules have also been applied within armed forces across the world, and even Airlines have reported to have set guidelines regarding the appearance of hair. Some cultures appear to be more conformist than others, in which Japanese and American Airlines cabin crew members have to have their hair (including body hair) in certain styles and buns measured (Bristow, 2015).

Baldness and shaving rituals throughout history have also been associated with slavery and shame. This practice finds its roots amongst the ancient Greeks, where slaves and those who had been conquered, had to have their hair shaved (Leitao, 2013). Furthermore, hair shaving practices have also occurred for women who committed adultery within ancient India and Europe (Faruqee, 2018; Montier, 2015). Similarly, head shaving was a symbol of incarceration during the Holocaust (Kim, 2011). The heads and bodies of all concentration camp inmates were shaved as a way to dehumanise and humiliate them, a common method amongst other forms of slavery (Banwell, 2016; Jacobs, 2014; Marillier, 2014). Prisoners who had to work were forced to shave all their body hair when they entered the camps. Extracts from survivor testimonials refer to how shaving was degrading, dehumanising and devastating (Ephgrave, 2016). From these examples we can see that hair shaving, and in turn baldness, became a way to mark deviant behaviour and to publicly shame those whose heads had been shaven. Contrasting this, a documentary “Grayson Perry: Rites of Passage” highlighted a shocking, yet significant tradition for the coming of age of Ticuna Indians girls within the modern day world (Perry,



2018). A girl is said to become a woman after starting menstruation. She is isolated from men once she begins her menstruation and learns from other women about her roles and responsibilities as a woman. After a large celebration, she takes part in a ceremony known as “Pelazon” or “môça nova” translating to “new girl” (Pantone, 2012, para. 2). The father typically pulls out each strand of hair from her head. The ritual is believed to represent her becoming a “woman” and signifies starting a new life, putting aside the “purity” of childhood. This demonstrates that hair is symbolic, complex and has a paradoxical web of meanings. However, such concepts skim the complexity of hair removal practices on body hair, or even more so, hair loss when such traditions do not apply.

Firstly, there is a societal belief that a “hairy woman” is not appealing. Mainstream media and consumer culture have helped contribute to this notion of women with hairless bodies (Terry & Braun, 2013). Connell (2008) suggests that our bodies reflect gendered meaning-making and performance (Terry & Braun, 2013). We live in a society where advertisements that are selling products such as razors, creams and waxing materials make men and women feel as though it is absolutely necessary to buy their items (Fahs, 2011). In turn, media and society are implying that individuals are flawed until they alter a part of themselves, such as their hair. For women, it is shaving their bodies, for men, it is grooming their beard. Hair ultimately contributes towards a massive global economy. It is therefore important to note that current fashion for beards is transitory (Dowd, 2010) and that there will continue to be some form of normative expectation for men’s hair, especially as having a beard was until recently, considered unacceptable (e.g. within the workplace; Krahnke, Hoffman, & Management, 2016).

Whilst on women a hairless body shows femininity, on men hair signifies masculinity (Ricciardelli, 2011). Ultimately, hair is known to be a significant component of the physical appearance (Hirschman, 2002). For women, hair represents health, femininity and attractiveness (Hirschman, 2002). The current literature suggests that women, more so than men, lose the connection with their gender identity when they experience hair loss (Coles, 2013). Hair does play a role for men, being that baldness becomes a representation of social incompetency, age and fragility (Coles, 2013), however the extent to which hair holds a personal significance for males differs somewhat in relation to that of women. Cash (2001) found men with hair loss were perceived to be around 4 years older than their actual age, indicating how hair is important to youth. Not only were men judged to be older, but studies found, when compared to non-balding males, balding men were seen as less physically attractive, less socially attractive and unlikely to be successful within both their personal and

professional lives (Cash & Pruzinsk, 1990). This is interesting considering that with age, (or a perceived older age) older men are thought to hold higher status in terms of resources (Buss, 2016). Thus, whilst the study demonstrated less attractiveness for those without hair, evolutionary ideas about attractiveness for men rate status as more important than looks. Such concepts may again tie in with what was considered “fashionable” amongst social media and advertising.

Researchers such as Oldmeadow and Dixson (2016) have identified that a beard for males allows them to heighten their perception of maturity and social status. Overall, the discussion highlights that certain types of hair and body hair, correspond to gendered difference. Interestingly, whilst body hair has often been regarded as masculine, Terry and Braun (2016) found that men’s hair removal practices are now popular. Rather than keeping the body naturally “hairy” there appears to be increased desire for hairlessness, challenging this masculine norm. This may reflect contemporary cultural differences, and the increased media-driven expectation towards “manscaping” within these advertisements (Frank, 2014). This removal, however, is viewed as a choice for men. Terry and Braun (2013) argue, unlike women, men can be more flexible about their hair removal choices, as well as how much (or how little) needs to be removed. This may help to decode the narrative by Schmidt et al. (2001) that suggests that baldness can make conforming to the norms of physical appearance in Western society difficult: “Hair constitutes an integral part of our self and identity, which is why hair loss may cause a broad range of psychological problems related to identity” (2001, p. 1038).

Despite this, the experience of hair loss has not been extensively constructed from a psychological perspective regardless of the “importance of the body to social interaction” (Trusson & Pilnick, 2017, p. 2) and the notion that other people respond to an individual differently because of their physical appearance (Toseeb, Keeble, & Bryant, 2012). The loss of hair is just as powerful as its presence. The following discussion will describe how having noticeable changes such as alopecia heightens an individual’s awareness of their bodies during a social interaction as described by Dua et al (2017) and Trusson & Pilnick (2017). Furthermore, my literature review (see 2.1) will demonstrate how hair can play an integral role in identity formation, especially for adolescents. I will also explore the ways in which gender and culture may play a role on the experience of alopecia. This will be especially relevant within contemporary Western society where digital, social media and advertising is at its peak and millennials are using the internet more so than ever (O’Keeffe & Clarke-Pearson, 2011).

In regard to my own personal experiences and the significance of hair, I would consider myself a “modern Sikh”. Whilst I follow and identify with the faith, I also cut my hair. As highlighted, in Sikhism, hair is a significant symbol and an important aspect of the identity make-up of the Sikh religion. This is because Sikhs perceive hair to be a gift from God and to keep their hair untouched is a symbol of respect (Mandair, 2017). Gaskell (1960) states, “Hair of the head is a symbol of faith, intuition of truth, or the highest qualities of the mind” (1960, p. 109). The process of allowing the hair to be uncut and grow naturally is called “the Kesh” and is an important component of the Five Kakaars: five items which Sikhs were commanded by their Guru to wear at all times (Mandair, 2017). These items are not only symbols of the religion, but collectively form the identity of a Sikh follower and their devotion to the religion. The five K’s include, uncut hair (Kesh), a steel bangle (Kara), big knife (Kirpan), shorts (Kachera) and a comb (Khangha). It was common for me to be told in my gurdwara (temple), that if I did not grow my hair the other four K’s were of no significance. This implied that I could only be a true “Sikh” follower if I grew my hair.

I was the only Sikh girl in my Catholic primary school and amongst a few in my entire high school. This perhaps is why I was so adamant to “fit in” and cut my hair. My parents never enforced their religion on me, and they themselves, along with my extended family, also cut their hair. There was a Sikh girl in my high school who came into class one day wearing a turban, despite years of cutting her hair. I saw how other girls in my class would openly talk about how “weird” she was because she did not shave her legs, had “hairy arms” and wore a turban. I empathised with her a lot because I understood the reasons behind her choices, but it was never something I would ever remotely consider doing, despite being “religious” as such.

Also, in having an auntie with alopecia, I have witnessed more closely, how much the loss of hair can affect confidence and how her distress impacted the whole family. My auntie would often tell me that ever since she lost most of her hair, she stopped putting effort into how she looked. Years later, she still worries about what people think about her hair and she constantly tries to cover the patches as best as she can. Even after all these years, I still do not think she has fully adjusted to the hair loss.

Throughout this thesis journey, I have become further aware of the impact of my own hair. I, myself, was influenced by British culture growing up. Despite being Sikh, I was first and foremost raised as a British girl, heavily influenced by social norms established by the white Western dominant culture. Social media, pop culture and the growing online presence, have all contributed to these norms and

the ways in which I have altered my appearance over the years, especially throughout the period of adolescence. Thus, for me, cutting my hair enabled me to feel part of the wider British culture and through the period of adolescence, it has enabled me to assimilate to my peers.

### 1.1.2. Development of the Research

Throughout this study, I was primarily concerned with the impact of hair loss amongst young people under the age of 19. Again, this stemmed from my own experiences of the importance of hair culturally and noticing how hair had an impact on those within my life growing up. My first exploration of alopecia-related studies began with an honours level undergraduate essay; the brief was to write critically around a topic within health psychology. I steered towards chemotherapy-induced alopecia (CIA) and body image as this was something which interested me. When I looked at the literature surrounding CIA independently, I realised there was little research amongst young people. I was aware that during this age, there is a degree of pressure to fit in with friends and to follow the current style trends. Furthermore, throughout my psychology degree, I have been mindful of developmental theorists such as Erikson, Piaget, Bronfenbrenner and Kohlberg who all emphasise childhood and adolescence as an important developmental transition that influences how an individual copes within adulthood (Bronfenbrenner, 1992; Erikson, 1968; Kohlberg & Hersh, 1977; Piaget, 1976). Thus, given that this particular developmental period is critical, I wanted to consider what it would be like to have a visible change in appearance during childhood and particularly through adolescence.

My initial PhD study was to expand upon this undergraduate work and to explore the lived experience of CIA amongst young people with cancer. Although there appeared to be little research surrounding CIA, there were numerous studies (see 2.1) which explored the general body image concerns of young people with cancer. I visited the Leeds General Infirmary Hair Loss Support Unit and spoke to the staff about the general day-to-day experience of working with people who lose their hair through chemotherapy. I was told that wigs were heavily relied upon, and that the impact of hair loss was especially devastating for young people with cancer. The visit reinforced my view that this type of study was needed. However, I experienced a number of barriers related to the access to participants. I found health care professionals were often guarded and wanted to limit my access to patients as they were concerned that discussing the impact of CIA may cause additional stress.

In facing potential recruitment difficulties, I was recommended to contact Alopecia UK by one of my PhD supervisors in the hope of accessing potential participants with CIA who benefited from their support. When I spoke to Alopecia UK, I explained the aims of my research (to explore the experiences of CIA amongst young people with cancer). We discussed why I wanted to explore CIA, given that there are considerably fewer studies which have explored the impact of alopecia as a dermatological condition. Alopecia UK appeared to be extremely passionate about researching alopecia, given that those who run the charity have alopecia themselves. They suggested to focus my study on those with all forms of alopecia and were supportive with helping me recruit potential participants. After the discussion with Alopecia UK I began to explore the literature surrounding alopecia generally and found that this area was severely under researched, especially for young people. As I unpicked this further, I also discovered that there was a high likelihood of young people developing patches under the age of 20 (Mulinari-Brenner, 2018) yet the majority of alopecia studies that had been undertaken were focused on adults. As I reviewed the literature surrounding CIA, I also noted how such experiences could differ to those with non-CIA alopecia given the high likelihood of hair regrowth for CIA. As a result, although I have included CIA studies within my literature review to explore the wider phenomenon of alopecia, I decided to not recruit adolescents with CIA within my study. A further rationale for this will be presented in Chapter Two: Literature Review (see 2.2).

I originally put out an advertisement to recruit adolescents (aged 13-19) experiencing alopecia and family members. I intended to capture the experiences of a range of relatives, to explore the impact of alopecia on the wider family unit (see 2.1.5). These included, siblings, grandparents, parents and partners. However, when I distributed my advertisement for relatives, only parents responded. As a result, the focus of my study shifted towards parental experiences of alopecia. It is because of this, I will refer to parental experiences of adolescent alopecia, rather than family members’ experiences.

The World Health Organisation (2016) states that adolescents are individuals aged 10-19 years. As discussed previously, 50-60% of individuals with alopecia develop their first patch of hair loss before the age of 20 (Harding, 2015; Mulinari-Brenner, 2018) in comparison to adults outside this age bracket. I was particularly interested in this age group of 10-19 years, because of the transitional phase that occurs during this developmental period such as changing schools, forming friendships, relationships and identities. This is a pivotal life stage where adolescents experience education, exams and hormonal changes amongst other events (Bell & Dittmar, 2011; Fardouly, Diedrichs, Vartanian, & Halliwell, 2015). Throughout this thesis I will use the term “young people” to reference adolescents.

This is because “young people” covers the age range up to 24 years, whereas “adolescents” refers to the 10-19 year age group (World Health Organisation, 2016). Most of the research whilst referring to “adolescents” often include young people outside of this bracket range. It is for this reason, I have used the term “young people” to cover all research that explores the experiences of alopecia under the age of 24, unless those which solely focus on children (under the age of 10) or adolescents (aged 10-19) independently.

### 1.1.3. Defining Alopecia

On average, we lose around 50 to 100 hairs every day (Sinclair, 2015). As long as this hair shedding is balanced by new hair growth evenly around the scalp, it is a part of the “normal” hair cycle (Sinclair, 2015). This thesis, however, is concerned with the experiences of individuals whose hair loss does not fit this pattern and for whom it comes to signify evidence of physical pathology. Alopecia is a dermatological disorder and occurs when an individual loses some or all their hair (Bhatti, 2018; Fricke & Miteva, 2015; Hunt & McHale, 2005). Although this begins with losing hair on the scalp, alopecia can also progress to other parts of the body where hair would usually grow (Hunt & McHale, 2005). Alopecia is a chronic inflammatory condition with many pathophysiology and forms, which can occur at any age, however, the onset is more prevalent in the younger age groups (Fricke & Miteva, 2015). Alopecia areata (AA) is adopted as a definition for a range of autoimmune alopecia conditions (McKenna et al., 2005). This term has been used throughout the medical literature (Alkhalifah, Alsantali, Wang, McElwee, & Shapiro, 2010a), and has been described as a chronic, autoimmune, dermatological condition which leads to a loss of hair (Rodgers, 2018). However, the term also refers to alopecia totalis and alopecia universalis (to be discussed further below).

The NHS states that alopecia affects 15 out of 10,000 people in the UK (Delamere, Sladden, Dobbins, & Leonardi-Bee, 2008). This figure, however, may underestimate the actual prevalence of AA. This is because some cases may go unreported such as the short-lived, less extensive kinds of alopecia, as well as those which form in inconspicuous body sites, and those which resolve spontaneously. Alopecia is not unique to any gender, age or ethnic group, however as highlighted, around half of individuals develop the condition before the age of 20 (Mulinari-Brenner, 2018). Nevertheless, the figures highlight the sheer volume of adolescents who go through a condition that visibly changes them.

#### 1.1.4. Alopecia Types

The word “areata” is derived from the Latin term “occurring in patches”, which signifies patches of hair loss from the scalp (Bharathi, Venkata Ramana, Sridevi, & Usha, 2015). Despite the clinical evidence demonstrating that alopecia is an autoimmune attack against the hair follicles, we do not know the exact pathomechanism (Dainichi & Kabashima, 2017). It is believed that the usual hair cycle becomes damaged when a person develops alopecia areata (Pratt, King Jr, Messenger, Christiano, & Sundberg, 2017). The hair enters a stage of degeneration in one section of the head that leads to the appearance of bald patches (McKenna et al., 2005). These follicles, although dormant, can become activated at any given time, hence the notion of the condition being described as “unpredictable” (Rodgers, 2018, pg. 51). Alopecia areata, alopecia totalis, and alopecia universalis are the most common types of alopecia which are clinically categorised based on the extent of the condition and loss (Islam, Leung, Huntley, & Gershwin, 2015). In Table 1.1 below, I present the different types of alopecia, beginning with the common types of the condition, along with a brief description.

Table 1.1. The different types of alopecia and their descriptions.

Type of alopecia	Description
Alopecia areata	The condition usually begins with the appearance of round patches of hair loss that occurs on the head. The size of these patches can range from 1cm (which can usually be hidden), to a larger patch of baldness which is more distinctive and harder to hide.
Alopecia totalis	This condition occurs when alopecia areata progresses to the entire scalp (Alopecia UK, 2018).
Alopecia universalis	Hair loss across the entire body, including eyebrows, is known as alopecia universalis (Alopecia UK, 2018).
Cicatricial alopecia	This type of alopecia is also known as “scarring alopecia”. With this condition, hair follicles are severely damaged and scar tissue forms. An individual can have two forms of cicatricial

Type of alopecia	Description
	alopecia. Primary cicatricial alopecia occurs when hair follicles become inflamed (Alopecia UK, 2018). Secondary cicatricial alopecia, however, does not involve the follicles, but occurs with an event such as infection or burn (Alopecia UK, 2018).
Androgenic alopecia	This condition affects 50% of men over the age of 50, and 50% of women over the age of 65 (Blume-Peytavi et al., 2011). It is also known for males as male-pattern baldness. Typically for women, the condition does not lead to total baldness, but the hair becomes thinner all over the head (Alopecia UK, 2018).
Traction alopecia	This condition occurs as a result of repeated stress on the scalp (Alopecia UK, 2018). For example, braiding the hair tightly or tight ponytails can cause traction alopecia.
Chemotherapy induced alopecia (CIA)	This is a form of alopecia which occurs during chemotherapy, a treatment for cancer. CIA can typically occur within 2-3 weeks of initial treatment. It is usually reversible, meaning that for most patients, the hair usually grows back, with regrowth usually occurring between months and up to a year later (Kluger et al., 2012).

The impact of CIA in adult populations is well-documented in published research (Choi et al., 2014; Dua, Heiland, Kracen, & Deshields, 2017). Studies have found that although chemotherapy causes many side-effects including vomiting, tiredness and nausea, alopecia can be one of the most unpleasant side effects, experienced by around half (46%) of participants undergoing treatment (Trusson & Pilnick, 2017). Lemieux et al. (2008) for example, found women refused chemotherapy because they did not want to lose their hair. Such a finding demonstrates the emotional impact of hair



loss when it is known that the hair is most likely to return, unlike those with alopecia as a dermatological condition. Different to typical alopecia, permanent alopecia following chemotherapy is uncommon, even with high-dose chemotherapy (Kang et al., 2018). Whilst in some cases of alopecia the hair can grow back, it is often common for individuals to lose their re-grown hair (Adams, 2015). The condition is viewed as cyclical and unpredictable based on the experiences of regrowth and relapse (Harries, Sun, Paus, & King Jr, 2010).

### 1.1.5. Management and Treatment Guidelines

Alopecia is known to be resistant to treatment in most cases, and as a result, the focus is on managing the condition. According to the National Institute for Health and Care Excellence (NICE) guidelines (NICE, 2018), a health care professional’s support, prognosis and treatment to a suspected alopecia should firstly begin within primary care where they should provide the patient with information about the condition. NICE recommends explaining to patients with mild alopecia that they may experience hair regrowth within a year. However, as stated, this can be unpredictable. Furthermore, treatments may encourage hair growth; however, they cannot fully cure the underlying condition. This means that it is highly likely for future episodes of hair loss to reoccur.

Health care professionals should then provide information on sources of advice and support. These include patient leaflets by the British Association of Dermatologists, the NHS and Alopecia UK. For young people and parents or carers, there is also a factsheet provided by Alopecia UK. After support advice has been given, those with alopecia should be offered advice about treatment options in primary care. The guidelines by NICE (2018) suggest that if there is evidence for hair regrowth, then patients do not need treatment. If there is no evidence of growth, but less than 50% of hair loss, patients are also advised to keep a watchful eye on the condition, again with no treatment needed. For those with more than 50% hair loss, health care professionals should explore medical treatment. These include: a potent topical corticosteroid for adults, a shampoo or lotion which is not to be used on the facial areas. Therefore, the first point of call for those with alopecia involves visiting a primary care setting. Those with the condition would usually be provided with information about the condition, advice, support, and treatment options. It is interesting to see that these guidelines advocate providing a separate fact sheet and leaflet for parents and young people with alopecia (including adolescents). However, the link to this factsheet is expired and no longer exists on the website for users to access. This was noted from 2017 and was revisited up until 2019. Nevertheless,

this indicates that parents and adolescents with alopecia are deemed to require additional support by health care professionals, although it is unclear what support this could be. Furthermore, it is also noteworthy that patients are usually advised to monitor their alopecia instead of being offered treatments, unless their hair loss is more than 50%. This may mean that for up to a year, those with alopecia are left untreated, with no guarantee that their hair will grow back. Thus, from this observation, it is unclear how it feels for individuals within this period, and how they self-manage their condition when monitoring. Furthermore, for those who are offered treatment, it is unclear whether being unable to apply these treatments to facial hair may be significant and why.

For those with longstanding extensive alopecia (i.e. more than 50% hair loss), the prognosis is relatively poor and as such, wigs were viewed as an alternative management strategy (Messenger, McKillop, Farrant, McDonagh, & Sladden, 2012). Advice regarding cosmetic options to camouflage hair loss such as hair extensions eyelashes, hats and scarfs should be provided within the primary care setting. These may not be prescribed on the NHS, unless patients are referred to a dermatologist and therefore patients may have to explore the private route to buy a wig. This leads to the question surrounding wig use and cosmetic options. It is unclear how individuals manage their alopecia whilst waiting for a wig and whether a wig has an impact on the management and emotional consequence of the condition.

Outside of primary care, there are specialist dermatological treatments. Such treatments are based on the duration of the condition, activity, location of the patches, the individual’s age and personal preference (Trüeb & Dias, 2018). Within the British Association of Dermatologists guidelines for managing alopecia, the revised treatments and management (from the 2003 paper) include: counselling, topical steroids, steroid injections, topical immunotherapies, steroid pulse therapies, narrowband UVB, phototherapy, Immunosuppressants and cryotherapies (Messenger et al., 2012). These types of treatments range from aggressive treatments which apply chemicals to the scalp, forming an allergic reaction and modifying the immune response (topical immunotherapy), to milder treatments that involve injections of corticosteroids onto the skin with a small needle (steroid injections).

In these guidelines, the authors note that we need to consider the management of alopecia first and foremost, given that the condition does not have a direct impact on the individual’s physical health. Thus, health is being construed as such by the medical model. Using hazardous treatments such as

contact immunotherapy which has unproven efficacy, may not be justifiable. Taking this into consideration, the guidelines state that one must be mindful of the management of alopecia. As such, the guidelines state that counselling should be offered or signposted, especially given that some may struggle to find the answers to their medical and practical questions throughout the treatment. Furthermore, the authors (NICE, 2018) also state that alopecia for young people is especially difficult, and that treatment options for these should be considered carefully because they are uncomfortable, have significant adverse effects and can be time consuming. Therefore, patients should be referred to experts and patient support groups in the hope of finding a new level of self-acceptance (Messenger et al., 2012). It is important to note however that the guidance does not state how support groups can help with self-acceptance.

In regard to support services available for those who have alopecia in the UK, Alopecia UK is the biggest charity group which provides support groups, annual meetings, online discussions, and social media outlets. They also provide information about external support and links with service directories. Strazzulla et al. (2018) also suggest that patients should be referred to the National Alopecia Areata Foundation in the USA. This foundation provides advice, support, and information about hairpieces, scarves, and how to participate in clinical trials.

Regarding other types of hair loss such as alopecia totalis and alopecia universalis, the guidance surrounding treatments and management is less extensive. For androgenic alopecia there are separate guidelines for men and women (NICE, 2018). This suggests that the experiences or pathology of the condition differ in terms of gender. Upon review of the guidelines by NICE (2018) it is only the treatment options which differ slightly. Males are able to take oral finasteride to reduce a particular hormone (dihydrotestosterone) found in men that is linked with hair loss. In terms of management for women with androgenetic alopecia, health care professionals are advised to “address the fear of going bald which may be unspoken” (NICE, 2016 para. 1). It appears that the guidance aimed towards women differs because of the extra time taken to give advice about the natural course of the condition. This may suggest there are gendered aspects of the condition, however it is unclear if this applies to adolescents with alopecia areata, totalis and universalis.

As stated, none of these treatments have been found to be curative or preventive, with a low success rate (Alkhalifah, Alsantali, Wang, McElwee, & Shapiro, 2010b). A Cochrane database review results found only one trial (amongst 17 randomized controlled trials) gave evidence of short-term benefit of

treatments (Delamere et al., 2008). Alkhalifah et al. (2010b) have found that those who stop treatment have also lost their re-grown hair. It has also been reported that particular treatments for alopecia are not approved by the Food and Drug Administration (Gordon & Tosti, 2011). Many clinicians are reluctant to use aggressive treatments such as contact immunotherapy in young people (Messenger et al., 2012) and studies which explore the effectiveness of these drugs are often uncontrolled (Royer et al., 2011). Some of these treatments are not available to young people given the severity and safety of these types of treatments. Alkhalifah et al. (2010b) therefore concluded that “because of higher psychiatric morbidity in patients with alopecia, psychosocial support is a valuable tool in any management plan” (2010, p. 199).

Overall, the treatment and management options alone suggest a basis for exploration surrounding how those with alopecia cope with the condition, especially adolescents and their families. There are questions which arise when accessing support services and health care professionals. Whilst there appears to be separate information for parents and young people, it is unclear what this information is. Secondly, as discussed, no treatments are more likely than others to be offered by health care professionals, especially for young people with alopecia. Thus, another basis for exploration is how adolescents and families cope with having access to limited or no treatment. We can also see that disguising the alopecia with wigs has often been offered as a way of management. However, accessing these wigs may be difficult given that in order to receive a wig, these patients must be referred to a dermatologist and some may have to seek expensive private health care. Thus, the waiting time to receive a wig may be problematic for adolescents and their families, along with the financial burden. Finally, the guidelines suggest that alopecia-related experiences may be different for males and females given the advice for those with androgenic alopecia differ.

## 1.2. Summary and Structure of Thesis

To summarise, in this chapter I have outlined my impetus for my study, by reflecting upon the significance of hair, familial, peer and personal influences. An overview of alopecia has been provided, explaining the term “alopecia” and the different types of this dermatological condition. There needs to be further exploration of the management and coping potential for the condition especially because of the low evidence-based treatments in alopecia for adolescents. Furthermore, the initial prevalence of alopecia in young people was reported as higher than older adults, demonstrating that this current

study is pertinent to discussions surrounding how adolescents and their families cope with their condition, with consideration of the challenges faced by this age group.

It is also important to note that keeping in line with the previous literature, throughout the thesis, “alopecia” will refer to all forms of the condition as a collective term (Wiggins, Moore-Millar, & Thomson, 2014). This includes the use of alopecia totalis and alopecia universalis under the umbrella term alopecia. Alopecia will be used throughout the thesis unless stated otherwise.

The thesis will be presented in the following sequence:

In Chapter Two: Literature Review, the current study focus is located within the existing literature on alopecia, and it will demonstrate why research exploring adolescent and family experiences is essential. The literature review highlights how the current study will contribute to our understanding of hair loss from a psychological perspective. This chapter will be presented in themes surrounding the particular topic of adolescent alopecia. These are the psychological difficulties of alopecia, issues with identity, coping and adjustment, stigma, gender issues, and decreased quality of life (QoL). Following this, I will present the rationale for the study, along with the research aims.

In Chapter Three: Methodology, the chosen methodology will be presented, detailing a brief overview of phenomenology as a philosophy, as well as, an investigative methodology, and advocating an interpretive phenomenological approach to study. The procedural method is also detailed in this chapter. Here, the recruitment process for participants, ethical considerations, data collection methods, the analytic procedure relevant to thematic analysis and issues of research trustworthiness will be outlined.

Chapter Four: Parents’ Experiences of Having an Adolescent Child with Alopecia, thematically presents the parent participants’ experiences of having an adolescent child with alopecia. That being, “the hair is coming out’: living the emotional turmoil of hair loss”, “it’s JUST alopecia’: health care professionals trivialising alopecia”, and “needing to protect the altered appearance”.

Chapter Five: Adolescents’ Experiences of Having Alopecia, thematically presents the adolescent participants’ experiences of alopecia. Two themes will be explored: “experiencing exclusion and acceptance in peer relationships” and “covering up and coping with an altered appearance”. Following

a similar structure to Chapter Four, this theme will also include a detailed overview of the sub-ordinate themes and sub-themes related. The chapter will then conclude with the key findings which synthesise parents’ and adolescents’ accounts.

Chapter Six: Discussion, highlights the research findings in reference to previous studies and theories. I begin by restating the research aims and how this relates to the key findings. After this, the chapter presents three main issues which emerged across parental and adolescents’ accounts. I will highlight the significance of the study and implications for practice, before providing a reflective exploration.

Chapter Seven: Conclusion and Recommendations, is concerned with an overview of the thesis and a note on the contribution to knowledge the current study achieves. The chapter concludes with suggestions for future research and final thoughts.

## Chapter Two: Literature Review

This chapter details the literature search process and provides a narrative review of the key areas of the literature that are deemed relevant to the experiences of alopecia amongst young people and their families. The chapter concludes with an overview of the empirical and theoretical literature and provides an argument for a qualitative study focused on the lived experiences of alopecia in adolescents and their parents.

### 2.1. The Literature Search Process

The search was conducted initially in 2016 and then subsequently updated in 2019 to explore the current literature surrounding the psychological impact of alopecia on young people. A number of electronic databases were accessed, including Wiley Online Library, PubMed, MEDLINE, and Web of Science, to identify studies relevant to alopecia in adolescents. A combination of search terms were used, including: “alopecia areata”, “quality of life”, “coping”, “impact”, “alopecia universalis”, and “alopecia totalis”. Searching with these terms collectively yielded results above 11,000 for all publication types. Therefore, separating these terms in different databases made the search more manageable. For example, “(alopecia) AND (adolescents)” within the database Summon (an online university search tool), displayed 197 results when filtered by “Journal Article” within “Psychology” and “Nursing” from 01/01/2006.

The returns were limited to English-language articles and I did not include conference abstracts, books or patents. Moreover, whilst androgenic alopecia is a form of alopecia, I decided to exclude androgenic alopecia studies from my search process. This is because the onset of the condition occurs when individuals are older than (above 50 years old) my anticipated demographic.

The journal articles were all online electronic sources and were published within the last 10-13 years (from 2006 onwards). After screening the titles of the returned studies, the abstracts of those retained were then screened for relevance to the lived experience of alopecia in adolescents. The reference lists within the identified studies were also explored to establish further useful sources.

The results of my search suggest that there is a lack of research focused on young people (particularly adolescents) with alopecia, and much of the research is oncology focused, specifically, on chemotherapy induced alopecia (CIA) and its impact. This suggests research has overlooked young people and those with other forms of alopecia related conditions. However, CIA research will still be considered within the review as there may be commonalities of experience and issues of theoretical and practical relevance for this age group. The current review is presented around common themes highlighted within the wider literature as a consequence of living with hair loss. This review of the literature is presented under the following topic headings: psychological difficulties, decreased quality of life (QoL), issues with identity, gender differences, coping and adjustment, stigma, and finally, peer relationships. Each of these themes are discussed in line with the broad aim of the current research in exploring the lived experience of alopecia in adolescence. Where appropriate, I draw on wider literature to explore relevant and related concepts and theories.

### 2.1.1. Psychological Difficulties

Research that investigates the psychological impact of alopecia tends to focus on CIA (particularly in women and adults). These studies have found that CIA causes low body image perception (Choi et al., 2014), low psychosocial well-being (Karambetsos et al., 2013), shame (Power & Condon, 2008) and depression (Lemieux, Maunsell, & Provencher, 2008) amongst women with breast cancer. This particular theme however, is concerned with the psychological difficulties of alopecia amongst the populated CIA studies.

A Taiwanese study for example, explored all comorbid psychiatric disorders found within their longitudinal health insurance database (Chu et al., 2012). In total, 5117 people who were diagnosed with alopecia by their dermatologist had high prevalence of anxiety. Amongst the sample, adolescents who were under the age of 20 were more likely to develop major depressive disorders (Chu et al., 2012). This is alarming given the dearth of research within this age group. Other studies also highlighted high risk of anxiety and depressive symptoms amongst alopecia patients (Sellami et al., 2014). Within these quantitative studies, patients were either recruited through hospitals or registry-based data. This may underestimate the prevalence of those that have not been diagnosed, or those who are on the waiting list to be seen by a dermatologist. Nevertheless, the results are indicative that adolescents may be at a higher risk than adults and that research is needed to investigate this further. Furthermore, the wider literature surrounding alopecia has also found similar results. Body image,



anxiety, low self-esteem and confidence concerns are thus apparent in individuals who have alopecia (Al-Mutairi & Eldin, 2011; Hilton, Hunt, Emslie, Salinas, & Ziebland, 2008; McKillop, 2010).

A study by Karambetsos et al. (2013) is one of the few which explored mental health problems amongst young people within this domain. They looked at the impact of atopic dermatitis (eczema) and alopecia in a comparison study. Their study found that within their Child Behaviour Checklist (a parent-report which measures a child’s emotional and behavioural problems), young people had significantly higher depression, withdrawal and social problems compared to those with atopic dermatitis. Parents of 51 paediatric outpatients answered these questionnaires in this cross-sectional study. It is therefore suggested that young people with alopecia between the ages of 6-14 years have more psychological difficulties compared to young people with atopic dermatitis. It is unknown the extent of this impact considering the study focuses on comparing the two disorders rather than exploring alopecia-related problems independently, and the study also relies on parental reports. However, this study confirms findings which are common amongst other adult studies: that young people may experience psychological distress.

For many with the condition, alopecia is viewed as a traumatic experience, which can often leave individuals feeling stigmatised (to be discussed further below), angry, shameful and helpless (Can, Demir, Erol, & Aydiner, 2013; Kim et al., 2012). Some patients also with cancer may experience negative thoughts and feelings surrounding their alopecia which can last longer than their initial loss of hair, even after the hair has grown back (Brunet, Sabiston, & Burke, 2013; Frith, Harcourt, & Fussell, 2007), demonstrating how traumatic the experience of alopecia can be. As research has shown, trauma is a long-lasting issue and there needs to be an assessment on how best to support individuals experiencing negative thoughts.

Overall, the research within this area tends to focus on adults, especially those with CIA (Choi et al., 2014; Ghanizadeh & Ayoobzadehshirazi, 2014; Sellami et al., 2014). We can see however, that young people, including adolescents, reportedly experience higher psychological difficulties than adults with alopecia. This theme highlights the importance of exploring experiences and emotions that are involved with living with alopecia and that mental health issues needs to be addressed.

### 2.1.2. Quality of Life

The studies highlighted within “psychological difficulties” (see 2.1.1) show the presence of psychological comorbidities amongst those with alopecia such as depression and anxiety. Some studies have aimed to quantify these by using quality of life (QoL) scores. Two systematic reviews by Rencz et al. (2016) and Liu, King, and Craiglow (2016) highlighted low health-related QoL scores from a wide range of ages experiencing alopecia. It was common for mental health, emotion, and social functioning to be significantly low in those with alopecia (de Hollanda, Sodr , Brasil, & Ramos-e-Silva, 2014; Liu, King, & Craiglow, 2016; Masmoudi et al., 2013). They stated it was important to provide an insight into this “otherwise ‘cosmetic’ disorder” by exploring the impact of the condition (Liu, King, and Craiglow, 2016, p. 806). Understanding health-related QoL can demonstrate the need for further patient care and validates the notion to prioritize studies regarding alopecia treatment and support (Liu et al., 2016).

Within the literature, few studies measure QoL amongst adolescents with alopecia, despite some studies demonstrating that low health-related QoL of alopecia correlates with young age (Bilgi  et al., 2014; Choi et al., 2014). Bilgi  et al. (2014) explored the psychiatric symptomatology and QoL amongst 74 young people with alopecia aged 8–18 years. All participants were given questionnaires, including a control group to exclude puberty as being a probable cause. The results found that patients with alopecia had significantly higher anxiety levels than the general adolescent control. This indicates that young people with alopecia may exhibit additional stressors and higher psychiatric symptomatology than those without. However, it is unclear what these additional stressors may be. This study is particularly interesting because it does show that despite other psychological changes that occur during adolescence such as puberty, young people with alopecia have higher anxiety levels than peers without. Exploring this further qualitatively would help understand why adolescents display higher symptomatology.

Supporting this, other studies which explore QoL for adolescents found low QoL amongst those with chronic skin conditions (Beattie & Lewis - Jones, 2006; D az-Atienza & Gurpegui, 2011; Weber, Lorenzini, Reinehr, & Lovato, 2012). The studies highlighted how feelings, personal relations, schools, sleep and leisure had affected the QoL domains within the Children's Dermatology Life Quality Index amongst young people with skin conditions (Weber, Lorenzini, Reinehr, & Lovato, 2012). In particular, school was often reported as being the most difficult for adolescents with alopecia. Beattie and Lewis-

Jones (2006), who measured impairment of QoL in 379 young people with skin conditions using Children's Dermatology Life Quality Index, found teasing and bullying to be the highest domain amongst six young people (out of 11 with alopecia) and nine parents. However, it is unclear why anxiety levels were found to be high, especially as some skin conditions such as atopic dermatitis have other side effects like itching, which could impact sleep. Although these studies may demonstrate low QoL amongst those with skin conditions, the causes of these are not fully explored. Looking at alopecia independently from other dermatological conditions could help to understand the experience of alopecia in more detail, especially considering that, as highlighted within my introduction (see 1.1), the significance of hair is central to appearance.

Although there are adolescent health-related QoL studies which explore a range of dermatological conditions (Karia, De Sousa, Shah, Sonavane, & Bharati, 2015), combining all of these conditions does not allow the scope for a thorough exploration of alopecia. We cannot extrapolate from existing research what the impact of alopecia on adolescents is. Exploring this independently will ensure the experiences of adolescents who have the condition have not been overlooked.

### 2.1.3. Identity

Appearance has found to be a meaningful aspect of identity, especially within a societal context (Trusson and Pilnick, 2017). The social significance of hair presented in 1.1 demonstrated how hair goes beyond the human characteristic which conveys aspects of identity, but instead signifies identity within particular cultures that can be influenced by societal norms (Gonul et al., 2018). Studies have found that appearance change can influence how individuals are perceived, especially when they have an illness-related appearance change such as CIA (Trusson & Pilnick, 2017). CIA is a visual symbol of cancer and plays a significant role of the “cancer identity” for those receiving treatment (Harcourt & Frith, 2008; Shaw et al., 2016).

Many found that the perception of alopecia revealed negative images such as being a “sick” person, or a “cancer patient” (Kozalinski & Williams, 2012; Trusson & Pilnick, 2017). This highlights that alopecia can cause dramatic appearance changes which may lead to a reconceptualization of identity and difficulties related to accepting their altered appearance for those who experience alopecia during chemotherapy (Frith, Harcourt and Fussell, 2007). Other studies have also found that those who do not lose their hair through chemotherapy, experience difficulty because they do not look like the

stereotypical appearance of the bald cancer patient (Trusson and Pilnick, 2017). In turn, they experience less support and sympathy (Trusson and Pilnick, 2017). This demonstrates how baldness is often associated with the identity of cancer. The loss of hair has a profound impact on identity for individuals, and as shown, also comes with expectations amongst cancer patients. Again, within the theme of identity, there appears to be extensive reviews on the impact of identity amongst cancer patients, with the most prevalent being sexual identity amongst breast cancer patients and survivor identity.

Studies which explore women’s experience of CIA highlighted a loss of femininity, sexuality, selfhood and attractiveness (Hansen, 2007; Harcourt & Frith, 2008). Erol, Can, and Aydiner (2012) found that women held concerns about their attractiveness as they lost their hair. Younger women often felt less physically and sexually attractive because of their alopecia compared to those who did not. Hansen (2007) found women associated an absence of hair with the loss of “womanhood” (2007, p. 24) which demonstrates that losing their hair is enough to significantly alter their perceptions of themselves as women. Interestingly, whilst there appears to be huge pressure for body hair to be removed as discussed within my introduction, another phenomenological study which explored CIA amongst women found that pubic hair loss created a significant threat to their sexuality and femininity (Power & Condon, 2008). Whilst the norm appears to be that women should be “hairless” including their private areas (Rowen et al., 2016) there still appears to be a longing for hair even when it is not wanted. This suggests that although hair is not particularly needed, there is a great meaning and significance placed on hair and the choice to have hair (or not have hair).

There appear to be many studies which look at the impact of identity amongst adult women with cancer (Koszalinski & Williams, 2012; Male, Fergus, & Cullen, 2016; Trusson & Pilnick, 2017). Fewer studies explore identity related experiences amongst young people. Eiser (2004) states that within childhood cancer, “loss of hair is perhaps the most often discussed” (2004, p. 72) within the exploration of the physical changes associated with treatment. This is because hair appears to be the most significant and salient physical manifestation of cancer, especially because of the social difficulties they experience from others (Arslan, Basbakkal, & Kantar, 2013). Adolescents’ body image is therefore a complex and intricate feature of identity formation and needs to be explored further (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

The studies which briefly explore identity amongst young people, relate to those with CIA. Williamson et al. (2010) found CIA to be highly distressing for parents whose adolescent child had cancer. Parents often described how their child’s hair was often associated with aspects of their identity such as youth, gender and health. Again this ties with the notion that hair is central to one’s appearance, in which the significance of hair has a long history. Williamson et al. (2010) used template analysis to explore the change of appearance amongst 22 adolescents undergoing cancer treatment. One mother within the study stated: “With no hair she looks androgynous, ageless; she’s joined this anonymous crowd of cancer sufferers” (Williamson et al., 2010, p. 2010). Along with parents, young people within the study, also stated that they would only feel themselves once their hair had grown back, demonstrating the importance placed on hair and the significance to a young person’s identity.

Supporting this, Carlsson, Kihlgren, and Sørлие (2008) looked at the experiences of fear in adolescent girls with cancer and embodied suffering. They found an impact on identity when one girl was mistaken as a boy. This perhaps indicates the lack of awareness and youth amongst this age group. The authors concluded that alopecia could be a manifestation of concerns of self-identity typical to this age group (Carlsson, Kihlgren, and Sørлие, 2008). Alopecia could be especially more difficult for younger people who are not fully aware of their own identity, sexuality and personal growth. Young people are inculcated into this “perfect” world where there are certain expectations of girls and boys. Then, as they grow older, adolescents are later subjected to social media which presents stereotypes concerning the way a body should look, and thus adding to this confusing period (Perloff, 2014).

In this life stage of adolescence, alopecia could have a large influence on identity. Developmental theorists such as Erikson (1968) and Marcia (1980) emphasise the importance of forming a stable identity role between the ages of 12-18. Developing a strong and stable perception of identity has been regarded as a fundamental task of adolescence (Sokol, 2009). These “tasks” are related to the resources and challenges which occur within the social context. Thus, it is suggested that the challenges of having alopecia for adolescents, such as school difficulties and relationships could significantly affect identity. As Erikson (1963) suggests, within the stages of psycho-social development, adolescents face a major identity crisis. If an individual can successfully resolve this stage, they establish a secure identity. Failure within this stage, however, creates confusion and a perceived weak sense of self. Studies have found that this is important within school experiences as friendships, relationships, and religious or political beliefs develop (Sokol, 2009). According to Sokol (2009) whilst identity development occurs continuously throughout an individual’s life, it is within

adolescence that a person becomes aware of how their own identity could be impacted. Thus, adolescents are more self-conscious about their changing identities than at any other life stage (Kornienko, Santos, Martin, & Granger, 2016).

There are numerous studies which highlight how media messages can impart an unrealistic ideal of beauty standards. Within social media, there is also an increase in body image dissatisfaction (Klein, 2013). More adolescents are following popular media figures such as celebrities and social media influencers. Having a significant change in appearance during this life stage could potentially cause a great impact on identity for those with alopecia. Studies have found that non-alopecia adolescents engage in social comparison when using social media (Chan & Prendergast, 2007; Chua & Chang, 2016; Halliwell, Easun, & Harcourt, 2011). Furthermore, exposure to such sites can impact an adolescents’ identity formation (Adams & Stevenson Jr, 2012; Davis, 2013; Dittmar, 2009). However, there are little to no research which fully explores alopecia related experiences for adolescents going through this paradox, despite CIA studies highlighting the importance of alopecia on identity. Most of the research within this area is saturated within CIA and comparatively fewer studies focused on adolescents. This is interesting given this current review highlights that adolescent alopecia needs to be explored further.

#### 2.1.4. Gender Differences

Gender differences has been found in relation to illness and diseases, including perceptions, the meanings attached to disease, and the delivery of health care (August & Sorkin, 2010; Cherepanov, Palta, Fryback, & Robert, 2010; Elliott et al., 2012; Leventhal & Crouch, 2013). This could be particularly interesting within the topic of hair because hair has been an important marker of gender across cultures for centuries (Trusson & Pilnick, 2017). Depending on culture, up until the 1970s men appeared to stereotypically have short hair and women have long (Miller, Lurye, Zosuls, & Ruble, 2009). Furthermore, media and societal norms emphasise the image of women with hairless bodies and depict men with distinct facial and body hair (Smolak & Murnen, 2011). However, as discussed, women appear to experience the loss of hair more severely, despite the empirical evidence for this being inconclusive (Hilton et al., 2008).

Gender differences have also been found in the few studies which explore alopecia experiences. For example, some QoL studies found women who had alopecia scored lower, (Masmoudi et al., 2013; Shi

et al., 2013), whereas other studies found no gender differences, (Dubois et al., 2010; Janković et al., 2016), and some found men had worse self-perceptions (Alfonso, Richter-Appelt, Tosti, Viera, & García, 2005). Despite this, other authors concluded that alopecia is “substantially more distressing for women” (Lee & Lee., 2012, p. 250). This assumption may reflect the widespread cultural aspect that the significant loss of hair is more frightening for women because according to Coles (2013) hair represents femininity, attractiveness and health, whereas for men, hair on the head is merely an identifier for age. According to Fahs (2013), men have greater significance placed on their body hair and beards to signify their masculinity. However, there appears to be a discrepancy between the findings of gender differences amongst those with CIA and alopecia. It can be argued that these quantitative studies may have focused on the wrong measurements to explore the experience of alopecia. Qualitative studies have found that both genders experience significant impact following alopecia, however each gender responds to their alopecia differently (Hilton et al., 2008).

Hilton et al. (2008) found both men and women cancer patients experienced various similar negative reactions following their alopecia, however the issues differed. Within their interviews, men stated that they found the loss of hair all over their body distressing, something which was not mentioned by the female participants. This again strengthens the notion of the significance of hair and bodily hair representing masculinity. Women instead focused solely on the head and face, such as eyelashes and brows. Similarly, Earle and Eiser (2007) found that young people responded differently to their cancer diagnosis, in which boys were concerned whether they will be able to play football and girls were worried about losing their hair. This provides interesting findings that coincide with current gender ideology which marks women’s self-worth based on their appearance.

These findings could perhaps be explained by Coles (2013) who found that books which represent and explain hair loss to young people, appear to be different based on the gender they are targeting. For girls, alopecia is stated to be “difficult”, “scary” and “traumatic” highlighting a severe social disadvantage amid books such as “Kathy’s Hats: A Story of Hope” (Krisher, 1992) and “In The Long and the Short of It: A Tale about Hair” (Mays & Meyers, 2011). Whereas books such as “Taking Cancer to School” (Cynthia and Gosselin, 2001) which were aimed at boys, portrayed CIA as a positive concept (Dua et al., 2017). These books allowed boys to challenge norms related to appearance and body image and encouraged them to be proud of what made them unique (e.g. that they had alopecia, compared to others who have hair).

Overall, studies have found gender discrepancies surrounding the alopecia experiences. A majority of research appears to conclude that women’s experiences are more severe than men’s (Kyriakis et al., 2009; Tan, Tay, Goh, & Chin Giam, 2002; Welsh & Guy, 2009). However, research which has explored the impact qualitatively found that the experiences differ in terms of what hair was lost (Hilton et al., 2008). The limited research appears to focus on the experiences of women more so than men (de Boer, 2017; Skalnaya & Tkachev, 2011; Thompson, Park, Qureshi, & Cho, 2018). This is interesting given the prevalence of alopecia is not dependent on gender (Pratt et al., 2017). Conducting a study that is inclusive of both girls and boys can allow the experience of adolescent alopecia to be explored more thoroughly and be more representative of what it is like to be an adolescent with alopecia, irrespective of gender.

#### 2.1.5. Coping and Adjustment

Numerous studies have found that cancer patients use many self-management techniques to deal with their CIA. This includes social avoidance, concealing the alopecia, and also seeking support and information (Marie Borsellino & Young, 2011; Shaw et al., 2016). More recent studies that explore alopecia-related experiences have found similar forms of coping and adjustment.

Those with alopecia are often encouraged to cover their hair loss, especially women (Davey, Clarke, & Jenkinson, 2018; Montgomery, White, & Thompson, 2017; Nozawa et al., 2013). According to Dua et al., (2017) such encouragement may reflect ideologies that illness and disabilities should remain hidden. Furthermore, this encouragement again may be underpinned by the social significance of hair and the overall portrayal of body image within the media. Studies have found that wearing wigs had a positive impact on those with alopecia because this reduced the likelihood of comments regarding their hair (Montgomery, White, and Thompson, 2017). Within their study, the researchers used open-ended questions to explore wig users’ experiences of alopecia. Those who wanted to wear their wig in public, and worried if they did not, displayed greater levels of depression. Thus, the study overall captures the dependency placed upon wigs and how this can transcend into avoidance. This has been supported by studies which found that some people who had alopecia used social avoidance, or limited their social life because of the worry of how others would react to their hair loss (Brunet et al., 2013; Choi et al., 2014; Rasmussen, Hansen, & Elverdam, 2009). Holding such worries and concerns not only means adolescents would feel “different” to others, they may also choose to not socialise



with others because of this. These aspects could potentially develop into conditions that could influence how an individual perceives themselves, their self-concept and their body image.

Sposito et al. (2015) looked at the coping strategies of young people with CIA in hospitals between the ages of 7 and 12. Young people often described how they found it difficult to cope with their hair loss at the beginning of treatment because of the impact it had on their self-image. However, the study interestingly found that young people began to realise that their hair loss was temporary and came to accept the loss. Thus, coping appeared to get easier when cancer patients came to terms with the probability that their hair would eventually grow back. Given the characteristics of alopecia, coping amongst young people with alopecia could be different, especially as the hair is unlikely to grow back and the regrowth of hair is often short term. It could be argued that the coping and adjustment of alopecia would be significantly more difficult than those with CIA, and yet most studies are saturated amongst CIA despite its temporality. Whilst alopecia areata may occur at any age, it is the third-most-common dermatosis in young people (Wohlmuth-Wieser et al., 2018). The lack of research on adolescence and experiences of alopecia is alarming considering the prevalence of alopecia in adolescents is high. Yet there is a dearth of studies that are focused on adolescents themselves and what it is like for this age group to experience alopecia.

The study by Rafique and Hunt (2015) is amongst the few which explore alopecia amongst adolescents using a qualitative approach. Rafique and Hunt (2015) explored the coping behaviours of adolescents (aged 15-19) with AA in Pakistan. Eight adolescents who were diagnosed with alopecia, were interviewed and data analysed using interpretative phenomenological analysis (IPA). The study found participants expressed a loss of self, held concerns for the future, and expressed negative emotions and thoughts. The coping used within this sample included practical coping such as wearing headscarfs, adaptive coping such as use of herbal homeopathic medicine, self-distraction such as studying more often, religious coping such as reading the Holy Quran, future practical coping such as saving for a hair transplant, support seeking from friends, acceptance of God’s will, and humorous coping such as making jokes. This is the only study to date that looks at the effects of alopecia specifically on adolescents independently. The study, however, can be seen as limited to apply to my particular demographic because the types of support available may be different in the UK. It would be interesting to evaluate the types of support available within the NHS especially because the guidelines appear to be limited. The acceptance of the hair loss being “God’s will” could potentially reflect the cultural differences, as coping was heavily focused around reciting the Holy Quaran and praying up to

five times a day. Chapter One: Introduction (see 1.1) demonstrated that hair has cultural significance. This means the experience of those within the UK may differ than those within Pakistan considering the media and social influence will not be the same. Nevertheless Rafique and Hunt (2015) concluded that interventions following alopecia should focus on supporting individuals with hair loss, especially in terms of coping with alopecia.

Chronic and long-term illnesses have been conceptualised as a “crises”. Other research domains have developed theoretical models of stress and coping to such diseases. For example, Moos and Schaefer (1984) formulated a model to demonstrate how individuals adapt to a life crisis such as chronic illness. They conceptualised that there are multi-facet variables which impacts an individual’s evaluation and how they cope with a crisis event (Senol-Durak, 2014). The model overall helps understand how personal and social environmental influences can impact the characteristic of the event within the crises and transition periods (Senol-Durak, 2014). Such models have then in turn, been utilised within practice. Similarly, health behaviour models such as Leventhal, Nerenz, and Steele (1984) self-regulation model indicates that having a supportive network could allow those to adapt to an illness. Such models provide a basis for the multi-facet variables which could impact the coping responses and how this could progress to more severe difficulties, for example, depression (Senol-Durak, 2014). Alopecia can certainly be regarded as a “crisis” for adolescents because of the impact of identity and appearance issues influencing whether they are successful and unsuccessful with their coping. This suggests that research needs to explore how wider influences may impact the adolescents’ adaptation to, or coping with, alopecia.

### *Family and Coping*

According to Rees, O’Boyle, and MacDonagh (2001) the wellbeing of an individual is influenced by the wellbeing of those around them. Diseases cannot only impact the individual, but the life of the family unit and other close relatives too. The burden of skin disease has been found to affect the individual, their family and friends however; it is frequently underestimated or unidentified. A review by Golics et al. (2013) found that most chronic diseases have a significant impact on family members such as their psychological and emotional functioning, being unable to socialise with others, effects on interpersonal relationships, and an impact on financial strain. This is perhaps why Basra and Finlay (2007) conceptualised the “Greater Patient”. The “Greater Patient” involves those closest to the patient and whose life could also be impacted from such conditions.

Recently, Sampogna et al. (2017) explored the impact of dermatological conditions amongst patients and family members by reviewing the dermatology instruments amongst the current literature. Research within skin conditions and family was found to be predominately focused on young people with atopic dermatitis. Four of the instruments were specifically designed for measuring atopic dermatitis within this review (Chamlin et al., 2007; Kondo-Endo et al., 2009; Meads, McKenna, & Kahler, 2005). The authors concluded that the onset of atopic dermatitis generally affects young children who are dependent on their parents and thus, the burden that this has on family members may help us understand this choice of focus.

Such results have been supported by other studies (Balkrishnan, Housman, Carroll, Feldman, & Fleischer, 2003; Gelmetti et al., 2012; McKenna et al., 2005). For example, Goh, Lane, and Bruckner (2007) found support groups and activities not only enhanced coping strategies, belonging, and QoL for those with dermatological conditions such as alopecia, but also supported their family members’ coping behaviours. However, there appears to be (or are) variable results within empirical studies which explore family influences within the treatment of chronic conditions and illness (Richards, Fortune, & Griffiths, 2008). Some studies such as H.L. Richards, Fortune, and Griffiths (2008) found family intervention had no improvement on QoL within the family unit. Whereas other studies have found more intensive 9-week cognitive behavioral programs had demonstrated significant improvements of psychological functioning for families (Cohen & Kuten, 2006). It could be argued that given the lack of research, these interventions may not be exploring issues which are important to families. Speaking to family members and exploring their experiences could form a basis for intervention tailored to dealing with these conditions such as alopecia.

Support groups specifically for those who have alopecia have also reportedly been used by families. Goh et al. (2007) arranged support groups for young people with alopecia and their families. Within their report, they stated that support groups were successful in allowing parents to share their experiences and frustrations amongst others, including medical advisors. Similarly, Aschenbeck, McFarland, Hordinsky, Lindgren & Farah (2017) highlighted the significance of group support for relatives of people who have alopecia. A number of participants (46.2%) who attended a group support for those with alopecia were family members or friends. Lui, King and Craiglow (2018) within their QoL study, explored family related QoL amongst 229 family members who had a relative with alopecia. They found emotional distress was the most frequently reported and the most affected. It

was also interesting that families who had a young person with alopecia had worse Family Dermatology Life Quality Index (FDLQI) scores than families who had an adult member with alopecia. Aschenbeck et al. (2017) state that the psychological burden of alopecia may transcend the expected reactions and cause additional stress to the larger family structure who take on this burden.

Having additional support from family members may help young people cope with their condition. This has been supported by Rumsey, Clarke, White, Wyn-Williams, and Garlick (2004) who found that gaining support from friends and family helped cope with a visible disfigurement. Adolescent studies such as Williamson et al. (2010), who explored cancer patients’ experiences of managing alopecia found receiving compliments and acceptance from their family and friends helped them cope with their condition. Family and friends used supportive methods such as comparing them to positive role models, physically shielding them from staring and protecting them from negative encounters (Dua et al., 2017). Such forms of social support have also been found in adult studies which demonstrate less distress when patients received emotional support from their families (Kim et al., 2012). This finding suggests that coping with alopecia could be a family affair, thus the whole family unit should be explored when investigating the impact of alopecia.

More recently Putterman et al. (2019) explored QoL in parents of young people with alopecia aged between 1-22. Within this study, parents attending clinic visits completed a Quality of Life in a Child’s Chronic Disease Questionnaire (QLCCDQ) and the Family Dermatology Life Quality Index (FDLQI). These included domains such as emotional, occupational and social roles. The results found low emotional domain scores coincided with the scores of parents of young people with chronic medical diseases (Putterman et al., 2019). To my knowledge this research is the only study which explores parents’ experiences of alopecia independently. However, as criticised previously, using these scales does not explore the parents’ experiences fully nor tell us why these parents had such low emotional domains. Thus, using qualitative methods such as interviews will create an in-depth exploration of what it is like to be a parent of an adolescent child who has alopecia. Furthermore, given these parents were attending clinical visits, it could be argued that they and their child may have received some form of intervention, treatment or support. Parents who are waiting to for their child to be seen by a dermatologist may be experiencing higher distress, however this is not captured within this study. Using platforms such as social media sites, or services which have access to alopecia patients may be a more suitable recruitment method, given that parents may be accessing these sites before visiting the hospitals.

In summary, research suggests alopecia can have a large impact on the wider family unit, particularly parents. A proportion of studies focus on atopic dermatitis, however caregiver-oriented research is limited. Given that families are actively seeking support by attending such groups, and because there appears to be dermatology research that indicates an impact on emotional well-being, burden of care, and day-to-day life, it may be indicative that family members who have an adolescent child with alopecia may reveal experiences which are not yet fully represented.

#### 2.1.8. Stigma

Many studies have acknowledged the role stigma plays within an illness experience. Amongst the understanding of disease-related stigma, sociologist Goffman (2009) has been widely influential. He defined stigma as an attribute which associates an individual to an undesirable stereotype (Fujisawa & Hagiwara, 2015; Wilton, 2017). He believed that when a person becomes stigmatised, they are reduced from a person who was once whole and ordinary, to (in people’s minds) someone who is disgraced or discounted (Goffman, 2009).

Stigma is a very broad subject and within this umbrella term there are features of stigma which relate to the topic of alopecia. Perceived health-related stigma in particular refers to a personal experience (or social process) which captures the perception of exclusion, rejection or blame from others, often driven by past experience or anticipation of an adverse social judgment (Scambler, 2009). Often, judgement can be based on an enduring characteristic of identity which is usually associated with a health problem or condition. Perceived health-related stigma has been widely studied in conditions and illnesses which have not been fully understood, lacked effective treatment, or invoked fear within a population such as HIV and mental illness (Gilbert & Walker, 2010). This has been extensively explored in many systematic reviews such as Gronholm, Thornicroft, Laurens, and Evans-Lacko (2017).

Recently, there has also been an increasing number of studies regarding cancer-related stigmas (Knapp, Marziliano, & Moyer, 2014). This may be led by negative perceptions of cancer in which individuals have a fear of the illness or associate it with death more than other serious conditions (Wang, Bai, Lu, & Zhang, 2017). Cancer is a crisis in our society, or that is certainly how it is portrayed by the media (Clarke, Everest, & medicine, 2006; McGannon, Berry, Rodgers, & Spence, 2016). The significant number of news stories about products which professionals believe cause cancer, children

with cancer, or celebrities dying from cancer is phenomenal (Myrick, 2017). Therefore, in terms of stigma, people are certainly scared of cancer and those with the illness because they are unsure of what to say and feel helpless. Rosman (2004) for example, found that many women spoke about their feelings of stigmatisation. Having alopecia made it clear that they had cancer because in Western society most women do not choose to be purposefully hairless, and the privacy they previously had about the condition had been taken away. Participants in their study discussed in great lengths feeling isolated because of this and how this impacted their interaction with others. In Harcourt and Frith’s (2008) thematic analysis, they found that amongst 19 women experiencing chemotherapy, a majority of them felt two types of stigmatizations. Firstly, they felt stigmatized because they had cancer and secondly, because they looked different from their loss of hair.

Similarly, studies have found that facial disfigurement presents a serious social challenge and often creates stigma. Often, the response of facial disfigurements within the public realm ranges from stares to pity, anger and disgust (Bradbury, 2012). Interestingly, young people with hidden disabilities do not experience a backlash based upon appearance but are often subjected to “there’s nothing wrong with you” (Blum & Society, 2007, p. 211). This demonstrates that there needs to be a visible sign of a condition. The study by Masnari et al. (2012) found that those with facial differences experience more negative encounters from their peers than those without, particularly, confusion and stares. This is alarming given that some of the facial differences were small and young people aged 9 months to 16 years experienced high levels of stigmatisation. This suggests that even a slight visible difference can cause extreme problems for young people. Young children often spend a lot of time at home supervised by parents, therefore, are less exposed to the reactions of others within the public realm. As young people grow older however, they have more encounters with non-familiar people (Masnari et al., 2012). Stigmatisation therefore may increase at school when appearance-related teasing is a common phenomenon (Masnari et al., 2012). This could therefore lead to the avoidance of social situations and ultimately, isolation (Harcourt & Frith, 2008).

Goffman’s theory of stigma (1993) explains “the situation of the individual who is disqualified from full social acceptance” (Goffman, 1963, p. 9). In this case, individuals with alopecia do not conform to the relevant stereotype of having hair. As a result, an individual is mentally classified as an undesirable, rejected stereotype, as opposed to an accepted, normal one. This is indicative that adolescents with alopecia may be socially rejected by their peers however, few studies explore this notion further. Stigmatization from peers may reduce adolescents’ self-esteem and their social support systems,

leading to isolation. This may be why McKillop’s (2010) study exploring the management of alopecia (of all ages), found that young people felt uncomfortable disclosing their alopecia to their peers and why Bradbury (2012) states that having a visible difference, and walking past a group of teenagers can be considerably traumatic.

This has been supported by Hankinson, McMillan, and Miller (2013). Young children within the study were shown images of young people with alopecia and said they felt uncomfortable and stated that they were less likely to interact with them because of the fear that they could catch the condition themselves. This could mean adolescents with alopecia could be severely isolated from their peers as a result of their peers’ lack of understanding. Whilst this focuses on young children, the findings provide a good understanding of how adolescents at school could face difficulty because of their alopecia, something which has not yet been illuminated in past research. Previous studies have shown that there is a greater emphasis placed upon appearance within non-alopecia adolescents which could lead to social isolation, especially for girls (Vannatta, Gartstein, Zeller, & Noll, 2009). Thus, a visible change in appearance such as alopecia could have a similar impact and there is a need for further research to be done.

#### 2.1.9. Peer Relationships

Peer relationships also become more prominent in adolescence. This is because the transition from childhood to adolescence alters adolescents’ social context and social norms which heightens the significance of peers (Carrizales, 2018). Bronfenbrenner (1979) suggested different systems that effect development, one being the impact of school and social circles. With his socio-ecological theory, Bronfenbrenner developed four ecological systems nested around the individual which represent who the individual interacts with (Neal & Neal, 2013). Firstly the “microsystem” involves immediate relationships and interactions such as the relationships between an adolescent and their peers, or between a parent and child. Secondly, the “mesosystem” involves everything which encompasses the microsystem and relates to the interactions between the direct individuals within the microsystem such as, the relationship between parents and the school teachers (Neal & Neal, 2013). Thirdly, the “exosystem” involves aspects which may not impact the individual directly, but changes or influences the individual indirectly, for example if a parent had financial burden this would reflect upon the development of the adolescent (Neal & Neal, 2013). The final nested system involves the “macrosystem” and represents the all-encompassing nature of the model, capturing the cultural and

societal norms which can impact an adolescent’s development (Neal & Neal, 2013). Bronfenbrenner (1979) noted the usefulness of exploring within the context of multiple environments to understand the development of an individual, in this manner, an adolescent. By doing so, the researcher can explore the wider related influences such as stressors, awareness and support of the condition which can influence their experiences.

Eccles and Roeser (2011) demonstrate school is central to adolescent development, nested within the ecological systems, and peers being an important component of this. Adolescents are more likely to spend more time with friends who are a similar age, with lower adult supervision, and they value their peers’ opinions (Teunissen et al., 2012; Weerman, Bernasco, Bruinsma, & Pauwels, 2015). New types of relationships can also emerge within the adolescent period, especially romantic relationships (Smith, Welsh, & Fite, 2010). Within this transition, relationships with others become more complex, especially when selecting friends, partners or friendship groups. Adolescents become more aware of how these relationships could influence their reputation within the broader peer system (Boulton, 2013). There are a wide number of affiliations within the field of peer relationships. Consequently, this section will focus on the four important components within this field including, romantic relationships, friendships, interests and activities.

Several reviews have demonstrated that non-alopecia adolescents who have been rejected by their peers, experience increased levels of aggression, lying, and depressive symptoms compared to those who have not (Gooren, van Lier, Stegge, Terwogt, & Koot, 2011; Rubin, Wojslawowicz, Rose-Krasnor, Booth-LaForce, & Burgess, 2006; Timmermans, van Lier, & Koot, 2010). Such findings are highly important in demonstrating how peer relationships can influence adolescents’ sense of wellbeing. If adolescents look different, they may be more vulnerable to negative comments from their peers and develop low self-esteem (Dua, Heiland, Kracen, Deshields, 2017). Adolescents could also be less willing to go to school because they might be singled out and bullied (Breen, Coombes, & Bradbourne, 2009). This has been shown by Earle and Eiser (2007) and Gunawan et al. (2016) who often reported hairlessness as being a cause of bullying-related experiences.

Most studies explore the general body image concerns of adolescents who have cancer and highlight the importance of peer relationships and the implication this has on identity. The wider literature has established that social anxiety impacts the construction and quality of romantic relationships for young people (Hebert, Fales, Nangle, Papadakis, & Grover, 2013). Larouche and Chin-Peuckert (2006)



looked at adolescents (aged 12-18) and the effect of physical changes. Many adolescents reported that the loss of hair was their greatest challenge. Participants compared themselves to their peers and emphasised the physical differences of their appearance, including their alopecia (Larouche & Chin-Peuckert, 2006). This has also been seen within other studies (Carlsson et al., 2008; Williamson et al., 2010). Such comparison according to Williamson et al. (2010) can cause low-self esteem, anxiety, avoidance of social activities and appearance-related concerns, as demonstrated within their study of adolescent girls with cancer (aged 14-19).

The variance in peer relationship could be influenced by the developmental age of their peers. Hankinson et al. (2013) study which explored perceptions of alopecia amongst young children (see 2.1.8) demonstrated that young people were less likely to interact with other young people with alopecia. This could mean peer relationships for adolescents could be severely affected as a result of the condition. Adolescents may feel isolated at school because they look visibly different to their peers. Previous studies have shown that there is a great emphasis placed upon appearance within non-alopecia school-aged individuals which could lead to social isolation, especially for girls (Vannatta et al., 2009). Thus, a visible change in appearance such as alopecia could also have a similar impact.

Group socialization theory could shed light on such phenomena. Along with comparing themselves to models, adolescents also compare themselves to same-sex peers (Tatangelo & Ricciardelli, 2017). Social comparisons are used to collect information about highly valued attributes, social expectations, and norms (Masters & Smith, 1987). Thus, we can argue that hair can be a great object of social comparison considering the Western norms of hair, the importance placed on hair, and the social expectations of hair (see 1.1). The broader literature has found that social comparison contributes to body image dissatisfaction. Social comparison heightens the pressure for people to conform to those who they compare themselves to (Mueller, Pearson, Muller, Frank, & Turner, 2010). This means that adolescents tend to follow a similar look to their friends (Mueller et al., 2010). Young people are bullied for reasons such as not wearing the right brand of trainers or not wearing the right shade of foundation (Thornberg & Society, 2015) and this is regardless of not having hair. Fashion is so important to teenagers (Thornberg & Society, 2015), and for a young person to have to enter that environment and not be able to conform and/or express their identity through their hair style is a major issue. Having a visual difference such as alopecia may mean that adolescents may not follow the similar look to their peers and may also compare their appearance to their friends. These comparisons are crucial to self-evaluations, with less emphasis on objective circumstances and more

on how an adolescent perceives the self in relation to others on a particular attribute, such as hair styles. This demonstrates that looking like their peers is an important element to how an adolescent may view themselves. Despite such findings, there is little research which explores the experiences of school, support and impact on adolescents who have alopecia. Thus, asking participants themselves about what it was like to attend school when they lost their hair may be particularly interesting.

## 2.2. Literature Overview and Rationale for Study

To unpick the experience of adolescent alopecia, other experiences amongst similar phenomena were explored to build upon the literature and to gain an understanding of this condition. This includes CIA studies, adult alopecia, facial disfigurement studies, non-alopecia adolescent studies, and other dermatology conditions, all of which feature predominately amongst the literature. Studies have found that hair loss, or CIA, can sometimes complicate identity construction and occasionally make it difficult for an individual to connect to a social group to which they formerly felt like they belonged to. Despite numerous studies demonstrating that mouth sores, fatigue and nausea are many side-effects of chemotherapy, the social significance and meanings of hair transform CIA into a psychological issue which is troubling and emotionally devastating. Adolescents focus on their appearance as a primary regulator of self-esteem. Numerous authors have suggested that adolescents begin developing sexual relationships and become more socially dependent on their peers (Bradbury, 2012). Studies which focus on various other dermatological conditions and facial disfigurement amongst adolescents have particularly highlighted stigma, low QoL and psychological differences amongst this period.

Within the current literature, there are some overall limitations which demonstrate why adolescent alopecia needs to be explored further. Firstly, as previously mentioned, the cause of alopecia is unknown, therefore research appears to focus on finding successful treatments. Martinez-Mir, Zlotogorski, Ott, Gordon, and Christiano (2003) stated “there are few diseases as prevalent as alopecia in which a complete lack of understanding precludes prediction of disease course or even development of a widely effective treatment” (Martinez-Mir, Zlotogorski, Ott, Gordon, & Christiano, 2003 pg. 199). As this suggests, medical literature has not fully illuminated the aetiological understanding of alopecia and further research is certainly needed. Hordinsky (2018) discussed the experience of medical clinical treatments. The author concluded that support groups continue to be an important resource within this area because of the emotional support they provide. Hordinsky

(2018) also stated that individuals with alopecia should also be assessed for their psychological well-being including their self-confidence, anxiety, and guilt (especially with the younger patients). Thus, whilst treatment and clinical studies are vital, there also needs to be a focus on the psychological impact of alopecia. Having a study which explores alopecia-related experiences qualitatively could build upon the current research which exists amongst the medical domains, especially considering the treatment of the condition may not be effective or suitable for this age group.

Secondly, the studies which explore the psychological impact of alopecia predominately focus on those with CIA (Kang et al., 2018; Rossi et al., 2017; Shin, Jo, Kim, Kwon, & Myung, 2015). CIA is typically a temporary side effect of treatment (Harries et al., 2010). However, for those with alopecia, the chance of regrowth is relatively low (Kluger et al., 2012). As highlighted, studies found patients coped better with their CIA when they realised that their hair will grow back (Sposito et al., 2015). Adolescents diagnosed with alopecia are often advised that the possibility of regrowth is low and that even if the hair does grow, there is a high chance that the hair may fall out again (Harries et al., 2010). The impact on adolescents with alopecia, their well-being and mental health could arguably be higher, especially as those with alopecia could experience the loss of hair on more than one occasion (Smith, Trüeb, Theiler, Hauser, & Weibel, 2015). Despite this however, much of the research is guided towards those with CIA. Again, by looking at alopecia independently, away from CIA studies, it is hoped to reveal phenomena which have not been fully explored or seen in CIA studies. Looking at the experiences of alopecia from adolescent perspectives could provide a rich exploration in an otherwise under-researched area. Unlike those with CIA who have prior support to help them cope with their hair loss, the experience of those with alopecia will differ given that the condition occurs suddenly without any warning. Therefore, the coping may not be the same as for adolescents with CIA.

Thirdly, it is also important to be mindful of the measurement tools that explore such experiences. The measures of Body Apperception (van den Hurk, Mols, Vingerhoets, & Breed, 2010) and The Importance of Hair Questionnaire (McGarvey et al., 2010) were developed to explore CIA amongst an adult population. These questionnaires have added a couple of items to their scales such as hair desirability and the importance of hair. It could be argued however, that studies which use these measurements could reflect general appearance-related concerns rather than specific alopecia related appearances. A more precise tool should independently investigate alopecia rather than a broader measurement of body image. Furthermore, there are studies which explore health-related QoL and alopecia (see 2.1.2). Again, such studies are not mindful of separate QoL issues regarding the

experience of alopecia as a whole. This is because QoL captures a wide range of psychological issues, for example physical functioning and pain. It could be argued that some of these scales may not be necessary or specific when exploring alopecia. As such, Health Psychology and the wider literature does not fully know the complexity of issues and concerns regarding alopecia because the psychometrics are impaired. As a result, exploring this phenomenon qualitatively will, in turn, ensure that alopecia-related experiences are discussed. Participants will have the opportunity to talk about issues which are considered important to them, and not so restricted by specific questions surrounding QoL. The advantage of doing a semi-structured interview is that the interview can be guided by the participants themselves and they can discuss what they want to, in their own words (King, Horrocks, & Brooks, 2018).

Fourthly, as highlighted throughout this chapter, these studies which explore CIA tend to look at the impact of alopecia from a woman’s perspective. Hilton et al. (2008) concluded that males had been overlooked in studies which focussed on women’s experiences. The section that focuses on gender issues, (see 2.1.4) demonstrate that both men and women experience a significant loss following their alopecia. Various studies suggest that the impact of hair loss for women is significantly higher, despite discrepancies between results. Studies which only focus on women’s experiences can be critically flawed for not considering the impact on men. Men are more likely to develop a more severe form of alopecia which could mean the impact of alopecia could also be more damaging (Wohlmuth-Wieser et al., 2018). Studies that measure QoL using quantitative measures demonstrate that men could also account for the majority of the sample. In a study by Al-Mutairi and Eldin (2011), 65% of new patients with alopecia (2963) were men. Such research shows that there is a great need for a gender-sensitive approach and the potential to illuminate these complex issues. There is a need to be mindful of the differing experiences between women and men. This could be addressed using qualitative research to unravel such gender experiences that focus on both genders equally and not excluding one over the other within the recruitment process. Thus, by having boys and girls within the current study, the overall phenomena of alopecia can be explored more retrospectively.

Whilst there appears to be a significant number of studies which explore CIA amongst patients with cancer, there are considerably fewer studies which explore other forms of alopecia. Those that do explore alopecia tend to use samples which are recruited through dermatological hospitals (e.g. Sellami et al., 2014). These studies are not representative as many patients with alopecia have criticised the long waiting time of referral to dermatology hospitals, and the time taken to receive an

appointment (Davey et al., 2018). This means that there is a potential sample of individuals with alopecia that are still unknown and have been overlooked in these studies. This is not accounting for those who may not have a high awareness of alopecia and therefore did not participate in the registry, something which has been suggested by Wohlmuth-Wieser et al. (2018) when they evaluated their own sample in their study of childhood alopecia. In a similar way to a study conducted by Montgomery et al. (2017), using support services such as Alopecia UK could help to access participants who are waiting to be seen by their GP, dermatologist or are just seeking support. Furthermore, it is hoped by using such a gateway, I will be able to explore the experiences of a range of parents and adolescents across the UK with different forms of alopecia.

A proportion of these studies which explore alopecia samples tend to be analysed quantitatively. It has been argued that clinical and quantitative evaluation alone is not enough to describe the feelings experienced by those with alopecia. Until recent years, there appeared to be varied results between quantitative and qualitative measures. However, given that there are limited studies within the phenomena of adolescent alopecia, it could be argued that quantitative studies may be difficult to understand context of the phenomenon. Whilst these studies highlight higher levels of anxiety, they do not highlight *why* alopecia causes distress. It could be the items used in these self-reports were not inclusive enough for participants and they were unable to present their thoughts in a complete manner. Qualitative approaches may be more suitable given that it would come from the perspective of the adolescents themselves in their own words, rather than confining themselves to restrictive answers which perhaps do not truly capture their whole experience. Interviews with adolescents can highlight issues which are not captured in questionnaires and in much further depth, thus, it would be a suitable method to use.

Another critique regarding the overall literature as highlighted, is the focus on adults with CIA or alopecia. Studies which include an adolescent sample tend to overlook how significant their roles are within the data set, especially given the first onset of hair loss presents itself at a young age (Alkhalifah et al., 2010). This is alarming considering the lack of research in this area. Little research has examined adolescents as a distinctive group, being mindful of possible effects of social changes, puberty, and development on psychiatric status (Bilgiç et al., 2014). Adolescents may experience a higher distress about how different they look because at this age, they are more aware of their bodies (Dua et al., 2017). Studies have found alopecia to be one of the most significant side-effects of cancer because of its impact on body image, and broader studies have found general body image concerns amongst non-

alopecia adolescents (Fardouly et al., 2015; Zucchetti et al., 2017). More studies have noted the influence of social media and cultural elements which can further impact the perception of body image. As highlighted, adolescents are progressively using more social networking sites and are exposed to the current ideology of appearance that is pushed by social media influencers and celebrities (Fardouly et al., 2015; Jones, 2001; Perloff, 2014; Tiggemann & Slater, 2017). Alopecia is devastating for adolescents. They are unable to look like their friends and idols and become confined to the “cancer and sick people” group based on their hairlessness, rather than the group in which they want to belong. Body image, therefore, is considerably heightened within this age. Those who look visibly different may be more susceptible to comments from their peers and could present negative views about themselves (Dua et al., 2017), being mindful of the importance of body image and appearance during this stage, it would be rational to explore adolescent alopecia to build upon the saturated adult alopecia studies, especially considering Yang et al. (2004) found that if an individual develops the condition when they are young, they are more likely to have extensive alopecia throughout their lifetime.

As discussed, there are very few studies which explore adolescent-related alopecia experiences. Those that do, are heavily dependent on parental reports. Parents of children with CIA often describe their children’s behaviours following alopecia, rather than the young people themselves. Whilst this highlights potential changes, there may be thoughts or difficulties that adolescents may not discuss with their parents or may even hide. Firstly, family members are often asked to rate the level of QoL on behalf of their child, or secondly, family members’ QoLs are explored in the hope that this would also be similar to their child’s. However, studies such as McCaffrey (2006) which looked at major stressors amongst young people with cancer, found hair was often reported as a concern for young people but was not discussed by health care professionals or parents. Similarly, the Eiser and Morse (2001) study showed parental scores of the health-related QoL of young people did not match the experiences of the child themselves. Supporting this, Beattie and Lewis-Jones (2006) measured the impairment of QoL in young people with skin disease using a questionnaire on both parents and young people. The study found that for those young people who had alopecia, parents had reported bullying or name calling more severely than the young people themselves. Moreover, whilst young people scored low for being embarrassed or upset, the parents had reported their child’s mood as high. This demonstrates that family members experience the condition differently to the individual with alopecia. It is important therefore to go back to the people who are experiencing the phenomena themselves. Instead, it would be sensible to measure the impact of both family members and young

people experiencing alopecia separately but allow them to discuss their own experiences. This is especially important as these studies have highlighted that there are some difficulties which have not yet been fully explored. Like Rafique and Hunt (2015), my study will explore the experience of adolescent alopecia qualitatively, however my study will be specifically amongst adolescents within the UK, given that they will have access to NHS services and different types of support.

Family members could offer insights and thoughts which may not be mentioned by adolescents with alopecia. Studies which explore the impact of disease amongst family members tend to focus on chronic or life-threatening conditions (Årestedt, Benzein, & Persson, 2015; Cipolletta et al., 2015). Few studies explore the impact of skin disease on family, especially those with alopecia. These studies have focused on a large range of skin diseases including atopic dermatitis, psoriasis and acne. However, little is known about the impact of alopecia on families of adolescents. Basra and Finlay (2007) concluded that the concept of the “Greater Patient” should be brought to light and similarly, Sampogna et al. (2017) suggests that the individual is at the centre of the “web” (2017, p. 1429). The authors concluded that family members should be considered when planning interventions, especially when the patient is a young person. This should be recognized by health care professionals to understand and address the needs of this unit and, in turn, there will be better patient outcomes. Parents will be interviewed within the current study to capture the wider family experience and will explore issues which may not have been discussed, or overlooked by the adolescent, but is significantly important to the relative.

Like Montgomery et al. (2017), the current study will use Alopecia UK as a gateway for recruiting participants and will use online methods to collect my data. However, my study will differ as I intend to focus on adolescents as opposed to adults. Furthermore, my focus will be less on the role of wigs, but the overall experience itself, given we have still much to learn about what it is like to be an adolescent with alopecia, or a parent of an adolescent who has alopecia. My study will also differ to that of Montgomery et al. (2017) as I have chosen a qualitative approach for my method of inquiry as opposed to a mixed method. Similar to Rafique and Hunt (2015), I will qualitatively explore the experiences of adolescents with alopecia. However, my participants will be based in the UK, accounting for the support services and treatment accessible through the NHS and privately, which will differ to those who are based in Pakistan. Given that the significance of hair can differ across cultures, I will also be mindful of the role of norms and culture when exploring experiences, especially considering Rafique and Hunt (2015) found religious coping behaviours of adolescents with alopecia

which may not occur within this sample. Research by Putterman et al (2019) also formed a basis for my rationale given the study includes QoL amongst parents of adolescent alopecia. Given my participants will be recruited through Alopecia UK, I will not be limited to those who have a dermatologist, and whose experiences may differ to those who are on the waiting list or have not yet been seen by their GP. To my knowledge, the current study will be the first which will explore alopecia-related studies amongst parents and adolescents in the UK within one project.

Thus, in light of all these considerations, the aim of this study is to explore alopecia-related experiences from the perspectives of parents (with an adolescent child aged 10-19) and of adolescents (aged 13-19). This will be done by using semi-structured online email interviews to:

1. Explore the lived experience of alopecia amongst adolescents and parents.
2. Explore the lived experience of support available for adolescents and parents of adolescents with alopecia.
3. Identify the needs of adolescents with alopecia and their parents.

### 2.3. Summary

Our current knowledge of adolescent alopecia is insufficient. The current study is concerned with the experience of adolescents diagnosed with alopecia. This is because there are many distinct features of alopecia that influence the experience of those who are diagnosed with the condition, which maybe also unique to this age group. Such issues could be related to identity development and general bodily changes, making it an interesting topic of investigation from a psychological health care and support perspective.

The impact of alopecia may be very extensive and deserves a wider study and understanding, therefore parental experiences of having an adolescent child with alopecia will also be explored. An holistic approach will be used to interview people living with alopecia (Welsh and Guy, 2009). The current study will therefore explore alopecia from the perspective of parents and adolescents to capture their experiences. By using a qualitative approach, I aim to recognize and “give voice” (Larkin, Watts, & Clifton, 2006; p. 102) to parents who have an adolescent child with alopecia and to the adolescents themselves.



Chapter Three: Methodology, discusses the methodology and design of the current study, detailing the research process. I will firstly present the theoretical underpinnings of the current study and build upon my rationale to explore appropriate interpretive methods. Ultimately, a thematic analysis within an interpretive phenomenological approach was used to analyse the data. I will discuss research design influences and the interview guide, providing a rationale for my choices. I will then present a discussion of the recruitment process and outline my sample with detailed information related to data collection and analysis. After, I will discuss ethical considerations appropriate to the current study and how I established research trustworthiness before presenting the findings within Chapter Four: Parents' Experiences of Having an Adolescent Child with Alopecia.

## Chapter Three: Methodology and Method

Within this chapter, I will begin with an account of the journey which led to my chosen methodology, initially exploring the reason for undertaking a qualitative study and moving on to discuss phenomenology and the work of Husserl (1859-1938) and Heidegger (1889- 1976). I will then argue my position in following a broadly interpretive phenomenological approach to the study. In doing so, I will pay specific attention to the arguments of van Manen (1997) and J. Smith (1996, 2009). Thematic analysis (TA) will then be outlined to both organise the data and convey the lived experiences of participants.

The procedural method, including the data collection process and the stages of analysis will then be detailed. I will discuss my sampling strategy, including the inclusion criteria for my participants, the recruitment process, and the overall demographics of my participants. I will then discuss my method of data collection (email interviews) and how I formulated my interview guide for each data set. Following the method of data collection, I will present the procedure and how I analysed my data using an approach broadly driven by interpretive phenomenology. Finally, I will discuss the ethical considerations and issues of research trustworthiness.

### 3.1. Theoretical Underpinnings

There has been long debate surrounding the use of qualitative and quantitative methodologies (McCusker & Gunaydin, 2015). Within this debate, however, the differences between them concern their underlying philosophies and epistemologies as opposed to just their methodological techniques (Leung & care, 2015). The quantitative paradigm features a positivist epistemology, and it assumes that knowledge is gained most effectively through objectivity and experimental methods because we can find a causal relationship between variables (Leung & care, 2015). Ultimately, this approach investigates questions surrounding “what”, “where” and “when”, mainly to explain what has been observe by forming statistical models (Garner, Wagner, & Kawulich, 2016). Until recently, mainstream social sciences have favoured this approach as it was held to be more rigorous and robust compared to qualitative methods, especially with regard to the generalisability of quantitate approaches.

As highlighted in Chapter Two: Literature Review, the limited research surrounding alopecia has been mostly quantitative and adult-focused. This makes it difficult to gain an in-depth understanding of the

experience of alopecia for adolescents and their parents. Adopting a qualitative methodology allows an exploration of the experience itself and how alopecia has impacted those living with the condition. By choosing a qualitative methodology, there is scope to gain new insights into the experience that have perhaps been previously overlooked. There is also value in learning about a phenomenon directly from those experiencing it, or with experience of it, and for researchers to be directed by the dialogue of their participants (Alase, 2017). According to van Manen, a rigorous human science needs to be more reflective in its effort to explore the meanings of life's phenomena (van Manen, 1997). Qualitative methodologies, therefore, have taken an alternative approach by acknowledging the influence of history and culture, and becoming mindful of how knowledge is formed inter-subjectively (Hammarberg, Kirkman, & De Lacey, 2016).

### 3.1.1. Phenomenology

Numerous methodologies fall under the broad umbrella of qualitative research. One distinct methodology is inspired by, and underpinned by a philosophical approach known as phenomenology. Phenomenology is a dynamic philosophy that consists of many constructs that overlap (Henry, Rivera, & Faithful, 2015). These constructs are all rooted within, and agree on, the critical concept of phenomenology, which is that we only know “phenomena”, meaning how the world *appears* to us (subjectivity), as opposed to trying to get the world to reveal its objective nature to us. Over time phenomenology has developed in different directions and along with this, it has integrated postmodern ideas.

Phenomenology as a research methodology is interested in the study of consciousness (Langdrige, 2007). It aims to combine philosophy, science and the life-world (Kozoll & Osborne, 2004). All phenomenological approaches, in essence, aim to explore the life-world of individual human beings and the meanings of their experiences (Blank, 2011). The life-world is, therefore, a key concept and is the main focus within phenomenological research methodologies (Brooks, 2015). It involves everything concrete and of significance to an individual as they experience it (Brooks, 2015; Morrow, Rodriguez, & King, 2015). Thus, the life-world includes the self, body and relationships and how we experience and understand these (Morrow et al., 2015). By exploring social, perceptual and practical experiences, phenomenology allows us to describe the thoughts and meanings which individuals use to guide their everyday actions and interactions (Langdrige, 2007).

Overall, phenomenology emphasises the importance of rich contextualised descriptions that are formed by experiences; it is concerned with experiences and meanings (Langdridge, 2007). This is achieved by capturing how a phenomenon is experienced, within the context in which it occurs (Langdridge, 2007). The focus of my research was to disclose the experience of alopecia as a phenomenon amongst adolescents and parents. I felt that the nature of phenomenology being dialogical, emergent and deeply reflective was a suitable approach especially given the epistemological position aims to bring visibility to that which is invisible (Perri, 2013). I felt that by taking a phenomenological approach, the related methods of data collection would allow the closest and most responsive ways of perceiving, experiencing, and expressing the lived experience of alopecia.

Different branches of phenomenology explore phenomena through in-depth descriptions or narratives. This in turn can highlight the lived experiences and life-worlds of individuals (Langdridge, 2007). There are two main strands of phenomenology; descriptive approaches based on the works of Husserl, and interpretive (sometimes termed hermeneutic) approaches based on the work of Heidegger.

### Husserl

As noted, descriptive phenomenological approaches are underpinned by the work of Husserl, deemed to be the founding father of phenomenology (Hopkins, 2015). Husserl's (1913, 1970a) original work was purely epistemological and descriptive. In particular, his work was concerned with experiences which had the distinctive nature of being conscious *of* something, something which enables an object-directedness (Zahavi, 2003). This meant that the world could only be seen for the experiencer, and how it is seen (the appearance), goes beyond the world in itself, but instead towards the subject and their consciousness (Zahavi, 2003). Husserl aimed to explore consciousness and how phenomena in the world were formed by human consciousness (Davidsen, 2013). That being, how a particular phenomenon appears to the individual, and how the experience is constructed. Ultimately, he believed it was impossible to separate objects from the individual who was experiencing them (Langdridge, 2007).

Many have adopted Husserl's (1970a) methodology to explore human experience. Husserl does not provide prescriptive methods, but instead, he notes what is needed for a phenomenological

clarification or investigation regarding the core concepts of psychology (Davidsen, 2013). The works of Husserl (1970) are utilised within phenomenological qualitative methods. Adopting the concept of *intentionality* from Brentano (1874), he did not differentiate between the intentional and the real object (Reiners, 2012). Husserl believed that human consciousness can be regarded as intentional because consciousness is always directed towards something (Moran, 2005). An individual is unable to “think or feel, without thinking or feeling something” (Davidsen, 2013, p. 321). Thus, when an individual is conscious, they are conscious of something of the world which is outside of the phenomenon of interest (Moran, 2005). The understanding of intentionality here is how consciousness is projected out on the world, and the relationship between an individual's consciousness and the world, including relationships amongst others (Davidsen, 2013). Intentionality involves any form of behaviour that identifies an object but also interprets something in a manner that the full object is presented in their consciousness (Davidsen, 2013).

Husserl (1970) also believed researchers should not overlook the natural attitude (Davidsen, 2013). “Natural attitude” refers to our own attitudes and meanings pertaining to the phenomenon of interest (Moran, 2013). Therefore, Husserl conceptualised “phenomenological reduction” and the concept of “epoché”. The idea of reduction is to put aside pre-conceived ideas, thoughts and beliefs (our natural attitude) related to the phenomenon and to prepare for a critical attitude (Butler, 2016; Davidsen, 2013). It is essential to block our susceptibility to the natural attitude and bracket its validity. Through this method of epoché we are able to see an essence in its purest form, just as Husserl suggested, and develop a more fundamental understanding of the phenomena (Butler, 2016).

While Husserl (1970) believed it was possible to achieve this transcendental reduction, some argue that this cannot truly be done. These included Heidegger (1962), Sartre (1969), and Merleau-Ponty (1962), who were all situated within existentialism (Langer, 1989). They argued that “we could never truly bracket off all our presuppositions” (Davidsen, 2013, p. 321). Others, however, such as Giorgi (1992) who adopted Husserl's descriptive method, maintain the argument that it is possible to understand and explore the essence of a phenomenon by providing a detailed description, without needing any form of interpretation.

### Descriptive Phenomenological Methodology

The descriptive phenomenological methodology was based upon Husserl's ideas (1859, 1938). As highlighted, Husserlian phenomenology (and later adopted by Giorgi, 2012) aimed to describe an experiential object, anything which the human consciousness can experience (Amedeo Giorgi, 2012). The researcher is required to put aside any pre-conceived ideas related to the phenomenon under investigation, using the process of epoché and bracketing (Amedeo Giorgi, 2012).

Another stage of this approach is to capture “universal essences” (Natanson, 1973). Universal essences are features which are common to those who share a specific real-life experience (Dahlberg, 2006). If a researcher can uncover an “essence”, they are then able to generalise and provide a “true” description. The “truth” is separate from the history or content of the phenomena and individual. Through the process of bracketing and uncovering of essence, an individual could identify the pure character of raw consciousness (Amedeo Giorgi, 1997). Therefore, the method is concerned with describing the essence. However, for Husserl (and Giorgi), the description is not an interpretation or an explanation, but instead, language is used to articulate and describe the object of experience (Amedeo Giorgi, 1997).

The process of any descriptive phenomenological method first begins with forming descriptions about structures from others which are usually taken from interviews or written narratives (Amedeo Giorgi, 2012). The researcher then adopts the reductive phenomenological attitude (as highlighted) and attempts to be sensitive and mindful to the concept that they are exploring such as the experience of having alopecia (or the experience of having an adolescent child with alopecia). Analysis begins with having a close engagement to narratives and transforming data into “meaning units” (Blank, 2011; Amedeo Giorgi, 2012). These meaning units are developed into descriptive expressions, rather than interpretation (Amedeo Giorgi, 2012). In doing so, the researcher aims to understand the essence of the phenomena being explored, and as such, the knowledge about the essence of alopecia for example, can be achieved. Interactionists amongst others argue that this process could be regarded as purely essentialist (Langdridge, 2007). This type of phenomenological approach could lead to a rich description of the essential structures shared by both adolescents and parents with a lived experience of alopecia which has not yet been conceptualised.

However, in consideration of all phenomenological approaches available and relevant to the aims of the study, I felt more comfortable following a more interpretive approach. By adopting the notion of

bracketing, I felt as though I may overlook features which remain hidden within purely descriptive approach. By using elements of interpretation, I would be able to capture how adolescents and parents make *sense of* the condition. I am aware of how my own experiences, and relevant literature searching, may influence how I see the data. Thus, I felt exploring approaches which acknowledge the role of the researcher within the data interpretation would be more suitable.

### Heidegger

Hermeneutics (or interpretive phenomenology) shares similar qualities with descriptive phenomenology. These being that the concept of intentionality is essential, they both utilise the analysis of text for data, and use a small number of participants in studies (Langdridge, 2007). However, the two approaches differ predominantly in terms of the role of the researcher. Within hermeneutic phenomenology, the researcher plays an essential role within the process using their presumptions and previous knowledge in data gathering and making sense of the data (Langdridge, 2007).

Heidegger (1962) developed the concept of intentionality (where an individual is always conscious of phenomena) to a theory of Being. “Hermeneutics” stems from the Greek word “hermeneuein”, which in general terms means “to interpret” (Agrey, 2014). Therefore, hermeneutics is concerned with interpretation (Langdridge, 2007). The focus of such is to interpret while also being mindful of the context. Unlike the views of empiricists who believed that their results were definite and true, hermeneutics argues that results are open to interpretation of reality and that there can be many interpretations influenced by the historical and cultural context of that time (Kafle, 2011). Thus, Hermeneutic phenomenology explores the meanings or interpretations within an individual's experience that may not have been uncovered by the participant themselves.

Heidegger (in contrast to Husserl) believed that there were more complex issues involved within the process of “bracketing” than previously described. Heidegger (1962) argued that we could not overlook the background of the individual, or their situatedness in the world, and considered how this could influence their understanding. As a result, prior history is a way in which an individual can understand, and through such understanding, an individual determines what there is to know.

Thus, Heidegger (1962) moved towards unravelling the existential components within phenomenology, aiming to seek out and understand existence. Heidegger was concerned with "Dasein," the situated meaning of the human world (Langdrige, 2007). The exact translation of Dasein is "being there" or "there being". However, this does not mean that Dasein only refers to human existence (Svenaesus, 2011). Instead, it is an ontological term that captures how humans are, and how they understand themselves, as opposed to what they are (Langdrige, 2007). Therefore to achieve an understanding of a phenomenon, it is crucial that we also explore other ways of uncovering our Being and this can only be done by an interpretation of our understandings (Kafle, 2011). While phenomenology requires description, such descriptions are arguably only formed by interpretation.

Heidegger's (1962) emphasis on interpretation adds to the development of understanding by focusing on the ontological foundations of experiencing. Understanding always emerges within time and space (Kafle, 2011) and an individual is always situated within a pre-existing world which consists of people and language and culture norms, all of which contribute to their experience or existence (Davidsen, 2013). An individual's understanding derives from their situated position in the world, also known as "thrownness", which is intertwined in a historical world that is shared with others (Davidsen, 2013; Guignon, 2012). We understand things from a specific position that as individuals, we are unable to describe or objectify completely (Kafle, 2011). An individual sees a concept in its appearing, and so a phenomenon cannot be observed clearly, but makes itself known (Kafle, 2011). This means that finding meaning involves some elements of interpretation.

By emphasising the value of interpretation, and providing insight into fore-understanding, Heidegger (1962) has developed the notion of bracketing (Kafle, 2011). Our pre-reflective ways of Being-in-the-world forms the foundation from which the world is understood (Blank, 2011). As a result, an individual is unable to separate themselves from the world, and view the objects from the outside in, like the concept of bracketing suggests (Kafle, 2011). This means that they are unable to truly see an essence in its purest form just as Husserl proposed, through the method of epoché. Heidegger concluded, that an individual instead should undertake a process in which a researcher notes their preconceptions and fore-structures that they are aware of and make this transparent in their working (Kafle, 2011).



Gadamer

As researchers, we establish a horizon of meanings because the world gives different meanings to us (Vessey, 2009). This means that within the process of exploring a phenomenon, there is always a person who is trying to understand and a person who interprets (Vessey, 2009). Essentially there is always an active role of the researcher (Langdridge, 2007). Many writers such as Gadamer (2004), have adopted the metaphorical circle to demonstrate this ongoing process of engagement, also known as the hermeneutic circle (Blank, 2011; Warnke, 2011). The circle represents no beginning and no end to the process of understanding and highlights the continuing movement between the researcher's own subjectivity, their engagement with participants, and their engagement with the data during analysis (Blank, 2011; Regan, 2012).

This accentuation on interpretive activity highlights the hermeneutic component to the circle (Blank, 2011). The hermeneutic circle is firstly involved with an individual's Being-in-the-world, their backgrounds and fore-understandings. Through engaging with the other and the world of the other, new meanings or understandings can be formed (Shalin, 2010). This is demonstrated in figure 1.

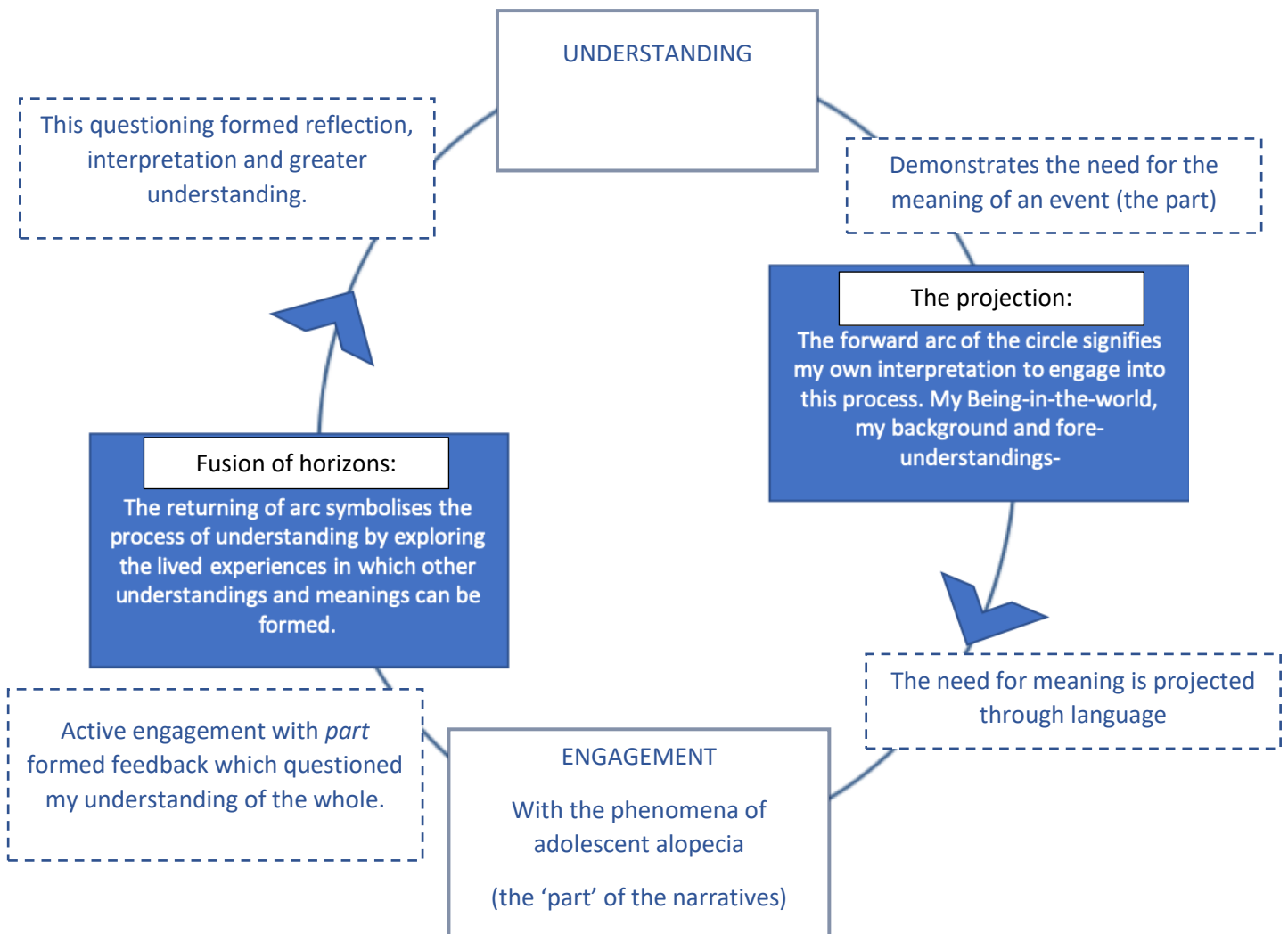


Figure 1. The hermeneutic circle in the current study.

The current study incorporated this metaphor of the hermeneutic circle into its analytical process, furthering my rationale for choosing an interpretive strand of phenomenology. I also wanted to acknowledge my position as a Sikh girl growing up with Western norms and my own personal connection to alopecia. As such, the analysis and interpretation was evolved by inserting my own position, perspectives and understanding of the phenomena. In turn, the interpretation and views of parents and adolescents then enabled me to develop new understandings of the lived experiences of alopecia.

Following on from Heidegger’s emphasis of interpretation, Gadamer (2004) believed that the concept of eliminating preconceptions through interpretation was impossible. Instead, by utilising their prejudices within interpretation, an individual can understand something which appears different or new (Langdrige, 2007). Gadamer was concerned with how language uncovers Being. This was underpinned by the philosophical concept that all understanding is phenomenological and can only be brought to the surface through language (Langdrige, 2007). For Gadamer, language, understanding and interpretation were all intertwined. Similar to Heidegger, he focused on the notion of Being, rather than the epistemological stance of knowing, as adopted by descriptive phenomenology and philosophy (Langdrige, 2007).

Gadamer formed the notion of a “horizon” as a way to conceptualise understanding of when an individual employs hermeneutics to the interpretative process (Clark, 2008; Langdrige, 2007). An individual’s horizon is how far they can see or understand. An example of this would be when a patient and doctor enter an appointment with a horizon and through this “encounter”, they both establish their own new horizon (Clark, 2008). Our understanding occurs when the present understanding (or horizon) is shifted towards a new understanding or horizon because of an “encounter” (Clark, 2008). Thus, “understanding” (see figure 1), is the fusion of the past and present also known as “fusion of horizons,” where the old and the new horizons combine to form something which is considered valuable (Clark, 2008). Certainly, the present cannot be produced without the past, and the two are unable to exist without the other (Clark, 2008).

Understanding the “whole” helped and developed my understanding of the “parts” of experience and subsequently, understanding the “parts” maintained and expanded my understanding of the “whole” (see figure 1). This movement of understanding is a continuous circle from the “whole to the part, and then back to the whole” again (Clark, 2008, p. 59). We break down our understanding and make a comparison against a different view or new experience. When we piece these different views together, we develop a new understanding or horizon (Clark, 2008). The metaphor of the hermeneutic circle is portrayed as a circular movement because according to Clark (2008), a phenomenon which requires interpretation, cannot be fully understood just once.

I understand that the method of displaying my horizon can never be fully realised or be fully comprehensive for others, but I have undertaken this direction as far as I can. I have lived with the data and recognise how my interpretations and Being towards the phenomenon has evolved over

time. This was through interviewing my participants at different times and looking at my data sets at different intervals. Over time, there has also been changes in social, political and personal contexts. For example, I had my own experience of body shaming. The event made me reflect upon how my perception of body image was influenced by the comment made by this person and the impact this had on how I felt about myself and my body. I became more aware of social media that presented what I did not have, and this only deepened my upset further. This situation allowed me to connect with the data and see perspectives in another horizon. As such, I felt there were times in which I brought my pre-understanding or prejudices into developing new understandings. These new understandings signify the interpretive account of my analysis. The methodology adopted within my study provided a guide to build my interpretation and further my awareness that the analytical process needs to go beyond description, but not beyond the data itself.

#### The Human Science Approach: van Manen

While I drew on the ideas of other phenomenological researchers such as Husserl (1859-1938) and Heidegger (1889- 1976), I am also interested in the concepts described by van Manen (1990; 2014) and his human science approach. Following on from the philosophies of Heidegger and Gadamer, van Manen's methodology similarly examines what it is to be human, Being-in-the-world, and meanings an individual places on the world through exploring human expression (Magrini, 2012).

The approach acknowledges the importance of the linguistic quality of human existence while also paying attention to the poetic dimension of existence (Magrini, 2012). I believe that this is important when exploring an emotionally difficult phenomenon such as adolescent alopecia. It was also argued by van Manen (1990, p. 29) that there are no "fixed procedures, techniques and concepts" when it comes to undertaking phenomenological research. This can be beneficial to studies such as mine as I aimed to draw on phenomenology without necessarily being fixed to certain concepts and procedures. Instead, I wanted to draw on interpretive concepts such as those proposed by van Manen and also using TA as an analytical technique to do so. Furthermore, van Manen supports having a "creative engagement with method" (Langdrige, 2007, p. 122) and being exploratory in nature.

While I am mindful that research needs to have both rigour and resonance, I am also open to whatever approach is relevant to my aims and can provide the most impact. Finlay (2012, p. 19) states that the "broader political, instrumental, or strategic interests cannot be ignored", and it means that

researchers need to be reflexively aware of such concepts when they are analysing and exhibiting their research (Finlay, 2012). In principle, a phenomenological piece of work can be regarded as the “most successful when readers feel addressed by it” (Finlay, 2012, p. 15). Similarly, I value how these concepts can resonate within our everyday experience of life.

As referenced by van Manen (1997), the four life-world existentials provide an interpretive lens and guidance to uncover the essence of lived experience (Rich, Graham, Taket, & Shelley, 2013). The four life-world existentials include the lived body, lived time, lived space, and lived human relations. Lived body is concerned with our physical body or our bodily state including our feelings, how we reveal, conceal and share through our lived body (Rich et al., 2013). Our body, in essence, is a vessel that enables us to be present in the world and because of this, we are able to communicate, feel, interact, and experience the world through our bodies (Rich et al., 2013). Exploring the experience of alopecia further and looking at bodily concepts presents interesting findings, especially given alopecia is a bodily experience, and hair can be displayed (or concealed) in numerous ways. Secondly, the concept of lived time is concerned with the time in which it is experienced. This does not mean literal time, but instead, how we experience it as a temporal meaning. That being said, it is also how we experience moments and demands set by time that influences how we feel (Rich et al., 2013). Thirdly, lived space can be how we experience an area; the environment of our Being can impact the way we feel and experience phenomena. Finally, the existential of lived human relations is concerned with the relationships that we develop, form, or maintain with “others” in our life-world.

All four of these life-world existentials enable us to explore dialogue from different positions. With each life-world pertaining an existential focus, we are perceiving through a different lens the phenomenological nature of the data and thus, the experience. These concepts, however, often intertwine and influence one another. I was mindful of these concepts when interrogating my data and this has helped me to uncover experiences and achieve some level of adequate description and interpretation of what it is like to be a parent of an adolescent experiencing alopecia, or an adolescent living with alopecia.

Both descriptive and interpretive phenomenology approaches have sought to uncover the life-world or the human experience as lived. However, interpretive phenomenology addresses further the complexity of experiences by introducing concepts such as temporality and Being-in-the-world. I agree with such thoughts and recognise especially that time, or temporality, is a crucial experiential

component. Furthermore, I believe that individual’s relationships with others can contribute to their experience and how they make sense of their experience. Additionally, phenomenologists whose work can be deemed as interpretative, such as van Manen, do not restrict themselves to one analytical method. Instead, the context of the phenomena influences how data is explored (Langdridge, 2007). I agree with the position of van Manen in that there is a poetic dimension of existence which impacts our everyday experience of life. Rather than following set analytical procedures bounded by an approach, I wanted to explore suitable interpretive methods which could help me understand the lived experience of adolescent alopecia in a manner that captures a wide range of experiences from both adolescents and parents.

### 3.2. Exploring Appropriate Interpretive Methods

I have discussed key influencers in driving the chosen interpretive phenomenological approach to complexity of the lived experiences of adolescents with alopecia and their parents. I also thought that I would be unable to bracket out my own experiences and perceptions. As a result, I draw on the work of Husserl, Heidegger, Gadamer and Van Manen predominantly, in adopting an interpretive phenomenological approach to study. In doing so, it is also essential to highlight why I have not followed many other health psychologists and health-focused studies and used Interpretative Phenomenological Analysis (IPA), especially given its tenets are close to my phenomenological preferences for study. It is therefore appropriate to further disclose my reasons for taking forward a less prescriptive approach to study, and how utilising TA has helped me to both organise and convey the study findings.

#### 3.3.1. Smith - Interpretative Phenomenological Analysis (IPA)

According to Langdridge (2007), IPA has become one of the most adopted and leading approaches of phenomenology and has been used frequently within qualitative research (Al Omari, Wynaden, Al-Omari, & Khatatbeh, 2017; Rafique & Hunt, 2015). Along with combining the exploration of discourse, and recognising the relationship between discourse and cognition, IPA also identifies the body and explores the relationship between it and cognition. The way people perceive their bodies is dependent on the context, society and time. Smith, Flowers and Larkin (2009) formed a series of steps to undertake an IPA study. However, these have been emphasised as guidelines and not a rigid process

that needs to have strict adherence. This nonetheless makes it appealing to researchers because it provides a set of steps to follow and detailed examples of how to conduct the analysis.

As highlighted, the theoretical underpinnings of IPA are situated within phenomenology and interpretive; however, the method also has an idiographic perspective (Shinebourne, 2011). The observer can identify the issues which are raised are those of the participant and thus grounded in the text. IPA is concerned with the particular, exploring the experience of each participant involved independently and revealing something in detail about the participant group (e.g. those who have an adolescent child with alopecia or those with those with alopecia). By doing so, IPA does not generalise about larger populations but makes more general claims of individual cases after in-depth analysis. This has been demonstrated by Smith et al. (2009) who highlighted the importance of the particular:

"IPA is committed to understanding how particular experiential phenomena (an event, process or relationship) have been understood from the perspective of particular people, in a particular context." (Smith et al., 2009, p. 29)

As highlighted, phenomenology considers that knowledge (or experience) is always to a degree, constructed and interpreted, although the individual believes that this is "real" (Davidsen, 2013). As a researcher, I am trying to make sense and interpret the meaning of experiences presented using an interpretive phenomenological approach. My interest is to access parents' and adolescents' voices and their experiences of alopecia. IPA, therefore, was an attractive method to enable access to these experiences, particularly as this lacked within the current literature.

However, while this was an immediate consideration, given the richness of uncovering individuals' everyday subjective experiences, IPA explores in-depth individual characteristics of participants, necessitating small sample sizes (Finlay, 2012). By studying ideographic processes, meanings are examined at the individual level before the collective, to offer general insights, but it is highly concerned with the analytical process. As such, contributors to IPA such as Smith (2006) and Eatough and Smith (2008) advocate research with a strong idiographic and narrative element. Smith et al. (2009, p. 3) concludes that "IPA studies are conducted on relatively small sample sizes, and the aim is to find a reasonably homogeneous sample, so that, within the sample, we can examine convergence and divergence in some detail". As such, IPA studies only accommodate a small number of samples (Kennedy, 2014).

Given the dearth of research focused on adolescent alopecia, I decided to interview a larger sample than advocated by IPA scholars, and concentrate mainly on the experiential similarities or patterns across participants, while also providing an in-depth, rich analysis. Finlay (2012) has stated that if a researcher wants to explore generality across a field, then they should use a broader sample to capture the different aspects of an experience. I tried to talk to more people than advocated by IPA and wanted to obtain a range of lived experiences because the research in this area is sparse.

During my first year of postgraduate study, I attended the Alopecia UK conference to discuss my research proposal. I was shocked by the number of people who wanted to participate and voice their experience of living with the condition. Therefore, I deemed it appropriate to talk to a collective sample of people (Finlay, 2012; Mason, 2010), rather than be mindful of engaging with a minimal number of participants to be cognisant of an in-depth analytic procedure (Smith & Osborn, 2004). In doing this, I could still appreciate individual experiences but more so, explore the commonalities of experience, to arguably highlight in greater depth what it is like to be an adolescent with alopecia or to parent an adolescent with alopecia. Therefore, I had to put aside the stronger ideographic focus which IPA is commonly known for. This did not mean I had to disregard phenomenological concepts. Instead, I used a broadly interpretive phenomenological approach to study alongside TA which has aided my organisation and presentation of findings.

### 3.2.2. Thematic Analysis

TA is a highly popular methodology which has been used as a concept, tool, process, method or approach for analysing qualitative data (Braun & Clarke, 2006). Although TA can be utilised as a process within the analysis for IPA, it is also a method which stands on its own (Braun & Clarke, 2006). The flexibility of TA means it that is not guided by a specific theoretical framework or epistemological position (Braun, Clarke, Hayfield, & Terry, 2019). As a result, it can be applied to many theoretical approaches such as phenomenology.

There are three leading schools of TA these are, coding reliability TA, codebook TA and reflective TA (Guest, MacQueen, & Namey, 2011). However, to accurately define TA, I wanted to first establish the term “theme”. A domain summary is where a researcher identifies an area or domain of the data, often reflective of the research question that is usually surface level of meaning (Braun et al., 2019). A theme, however, is more interpretive and creative. This tells a story about the data and reflects the



interpreter's reflective lens (Braun et al., 2019). The theme is a patterning of shared meaning, underpinned by a central concept or idea (Braun et al., 2019). A theme is often abstract and has precise meaning behind the context, often revealing data which at first sight may not be clear. These are usually formed from smaller meaning units and built from codes (Braun et al., 2019). Braun et al. (2019) states that a theme captures the essence of the data, the central idea, and the patterning of shared meaning that ties all the researcher's analytical observations into a story they are trying to convey. With the theme described, a strong TA can be formed.

As highlighted, there are three schools of TA, the first being coding reliability TA. Coding is regarded as structured because a coding book guides the process (Braun et al., 2019). In summary, themes are developed at the very start of the process and codes are categorised into these themes accordingly (Braun et al., 2019). Overall, this method was not chosen because it can be too structured, constrained and does not allow for reflexivity (a key concept which is encouraged within interpretive phenomenology). The second is codebook TA, in which similar to coding, a codebook is used (Braun et al., 2019). Often, themes are conceptualised as domain summaries; however, this approach is more flexible and more fluid because themes can be developed and changed (Ando, Cousins, & Young, 2014). Furthermore, this approach tends to be established in the applied context such as in framework (Braun et al., 2019).

Reflexive TA, however, is an organic and iterative process (Braun et al., 2019). The approach represents both qualitative techniques and qualitative philosophy. The coding is fluid and flexible, and not fixed in any way, meaning that codes can evolve and change throughout the coding process (Braun et al., 2019). Reflexive TA aims to reflect how the researcher is conceptualising the data and how that conceptualisation is shifting and developing (Braun et al., 2019). The concept of reflexive TA is not accuracy, but an interpretive and in-depth engagement that ensures the coding process reflects the data (Braun et al., 2019). The process involves the researcher actively engaging and storytelling the data “through the lens of their own cultural membership and social positionings, their theoretical assumptions and ideological commitments, as well as their scholarly knowledge” (Braun et al., 2019, p. 6).

When using TA, the researcher has to first choose the theory or approach that informs the work they are doing (Braun et al., 2019). Once this has been established, the position of TA shifts (Braun et al., 2019). This means I can begin my analysis using TA by adopting an interpretive phenomenological

approach. The theme cannot explicitly explore language use, but instead, it can investigate the lived experience, people's views and the factors that underpin or conceptualise a particular phenomenon.

### 3.2.3. A Rationale for Using Thematic Analysis alongside an Interpretive Phenomenological Approach

To summarise, both interpretive phenomenology and reflexive TA are suitable to use within my study, they are complementary and both coincide with my research aims and overarching question. It is for this reason I have presented a table (see Table 3.1) to demonstrate the main differences and similarities between interpretive phenomenology and TA and to highlight how they can both be used.

Interpretive phenomenology involves studying a phenomenon, the way we experience things and how phenomena has meaning in an individual's experience (Smith, Trüeb, Theiler, Hauser, & Weibel, 2015). TA has the capability to utilise interpretive phenomenology within its analysis process and can explore matters and meanings across the data set. Furthermore, Braun & Clarke (2006) state that doing a rich thematic description across the entire data set can be useful when exploring an under-researched area. Given the dearth of adolescent alopecia literature, especially those which utilise family members’ experiences, using TA with interpretive phenomenology appears to be complimentary.

Table 3.1. Summary of Interpretive Phenomenology and TA

	Interpretative Phenomenology	Thematic Analysis
Defining features	<ul style="list-style-type: none"> <li>• Explores human experience</li> <li>• Explores meaning and sense-making in a particular context</li> <li>• Can use TA within its analysis</li> </ul>	<ul style="list-style-type: none"> <li>• It can be used to address a wide range of research questions such as exploring people’s experiences and perspectives.</li> <li>• Understands coding as an active and reflexive process (Braun et al., 2019).</li> </ul>
Epistemological Learning	<ul style="list-style-type: none"> <li>• Interpretative</li> <li>• Subject meaning is interpreted from discourse</li> </ul>	<ul style="list-style-type: none"> <li>• Can be used across the epistemological and ontological spectrum (Braun et al., 2019).</li> </ul>

	Interpretative Phenomenology	Thematic Analysis
		<ul style="list-style-type: none"> <li>• Can be underpinned by phenomenology</li> </ul>
Strengths	<ul style="list-style-type: none"> <li>• Has latitude to explore data more profoundly and extrapolate beyond the text</li> </ul>	<ul style="list-style-type: none"> <li>• Can demonstrate both similarities and differences across data sets.</li> <li>• Allows for social and psychological interpretations of the data</li> <li>• Theoretically flexible</li> <li>• Can formulate unanticipated themes</li> </ul>
Sampling Strategy	<ul style="list-style-type: none"> <li>• Homogenous</li> <li>• Small</li> </ul>	<ul style="list-style-type: none"> <li>• No specific requirements for sampling in TA</li> </ul>
Key sources	<ul style="list-style-type: none"> <li>• Van Manen, Gadamer, Heidegger</li> </ul>	<ul style="list-style-type: none"> <li>• Braun and Clarke (2006, 2012, 2013)</li> </ul>

I set out to use a TA method informed by interpretive phenomenology, to explore the experiences of the two groups and then aimed to consider key issues across both parental and adolescent data. Rather than adopting a smaller, demographically homogenous group commonly used within IPA, TA can be used on a larger sample. Using an interpretive phenomenological inquiry, I am able to pick out existential, idiographic elements of individuals' meaning-making processes. However, I am also able to see patterns across the data more clearly because I have a larger sample. By using TA underpinned by interpretive phenomenology, I argue that I have created a multidimensional understanding of the phenomenon.

### 3.3. Design

The current study adopted an interpretive phenomenological design, using TA to assist in the organisation and presentation of the study findings. All phenomenological methods are rooted within some phenomenological philosophical foundation that aims to reveal the lived world of the participant. In the same manner, it also uncovers the world of the researcher, and others who shared or will share similar experiences (Langdrige, 2007). Therefore, the chosen design is deemed appropriate for exploring alopecia related experiences and the meaning associated with these experiences.

#### 3.3.1. Sampling

The sampling strategy to recruit participants was opportunistic. I deemed it appropriate to allow for sample diversity and wanted to recruit until I reached an appropriate quantity of participants (Guest, Bunce, & Johnson, 2006).

#### Inclusion Criteria

To begin my study, I had to formulate a set of inclusion criteria, being mindful of recruiting across the types of alopecia, and across the UK. The original criteria referred to family members who had a relative (aged between 10-19) with alopecia. Participants had to be over the age of 16 and be a parent of an adolescent who is experiencing, or has experienced alopecia, a legal guardian, a grandparent or sibling. This age range of the adolescent age within this study was compliant with the World Health Organization (2019) definition of adolescence and more extensive global studies relevant to adolescent health (Patton et al., 2012; Patton et al., 2009; Sawyer et al., 2012). However, it was decided that adolescents who were being interviewed, should be over 13 years old. This is because recruitment advertisements were to be placed on additional social media sites such as Facebook and Twitter, compliant with Alopecia UK's marketing platforms and policy. The minimum age for most social media sites in accordance with the Children's Online Privacy Protection Act (1998) is 13 years old. This prohibits websites from collecting information on young people under 13 years old. Thus, the inclusion criterion for adolescents’ experiences was the age of participants to be between 13-19 years old who currently or previously had alopecia. Experience of at least one of the three types of alopecia was needed to participate in the study (alopecia areata, totalis and universalis). Participants also had to be living in the UK and be English speaking.

### Recruitment Process

Alopecia UK has several support groups nationwide and an online presence. Participants were recruited through an advertisement (see appendices 1 & 2) placed on the Alopecia UK website and additionally distributed through their newsletters and social media sites. Participants who were interested in taking part in the study contacted me through the email address provided in the advertisement.

The participants were sent further information about the research, including the information sheet (see appendices 3-6) that included information about providing consent. If a participant was under the age of 16, I also required parental consent in a separate email from their parents. The consent of the participants had to be emailed back to me in the form of a statement. The statement went as follows "I confirm that I have read and understood all the relevant study information and that I consent to taking part in this study" (see appendix 7-10). Within this email trail, the participants also had the opportunity to ask any questions before agreeing to take part in the study. Once the consent had been received, I emailed the participant a description about myself, in the hope of building a level of rapport before proceeding to the interview and asked participants to complete their demographic information (see appendix 11).

Although Alopecia UK provides the scope to reach participants nationally, recruitment through a single web site (Alopecia UK) has some limitations. Firstly, it is important to note that participants who were recruited through Alopecia UK were computer literate and had access to the internet. As such, there may be others who were unable to take part in the study, such as those from a poorer economic background. Secondly, the sample of my study may be of those who are experiencing a higher level of distress than the general population as they are actively seeking support and solutions online. There may be others who may be unaware of the charity or have a less intensive form of alopecia, who have not taken part. However, it is hoped that by using different platforms such as Alopecia UK's Twitter and Facebook, and encouraging shares through these outlets, I was able to have further opportunities for recruiting potential participants.

Whilst formulating a strategy for recruitment, the impact of recruiting parent-child dyads was carefully considered. Researchers have suggested that richer quality data can be collected from individual members, whereas others suggest dyadic sampling and analysis also holds benefits such as, trustworthiness and broadening the context of the topic (Eisikovits & Koren 2010). However, given

the age of the participants interviewed and the sensitivity of the topic, I decided against recruiting dyads. I believed that adolescents may be unwilling to disclose personal experiences such as relationships or sexuality because I would be interviewing their parents. This has been highlighted in previous research such as Keijsers et al. (2010) who found adolescents often do not disclose their intimate experiences with their parents. Whilst it could be made clear that no information will be relayed, this could have been a barrier to recruitment and furthermore, participants may also feel as though they may not be able to voice criticism of the other.

### Participants

Table 3.2 below shows the demographics for the parent participants who were interviewed before any interviews were undertaken with my adolescent sample.

Table 3.2. Summary of the participants' characteristics using pseudonyms

Participant	Name of participant	Age of participant	Name of adolescent	Adolescent age at the time of the interview	Age of onset	Alopecia Type: Areata/ Totalis/ Universalis	Presence of alopecia at the time of interview?	Experience of regrowth?
1	Gemma	43	Sam	12	10	Universalis	Yes	No
2	Rachel	35	Adam	10	8	Totalis	Yes	No
3	Anna	50	Danny	17	15	Areata	Yes	Yes
4	Sandy	45	Nathan & James	16 & 18	16 & 15	Totalis	Yes	No
5	Joanna	48	Alex	17	6	Areata	Yes	No
6	Susan	49	Jack	12	4	Areata	Yes	No
7	Jessica	54	Josie	11	7	Universalis	Yes	No
8	Amanda	36	Hannah	11	5	Universalis	Yes	No
9	Stacey	45	Stuart	15	12	Areata	Yes	Yes
10	Savannah	42	Alesha	14	13	Totalis	No	Yes
11	Monica	48	Joey	10	6	Universalis	Yes	No
12	Emma	55	Andrew	17	15	Areata	Yes	No
13	Lucas	42	Isabelle	14	12	Totalis	No	Yes
14	Jenny	43	Danielle	17	10	Areata	Yes	Yes
15	Alison	46	Sarah	17	9	Areata	Yes	No

Table 3.3 below shows the demographics for the adolescent participants who were interviewed after the parental interviews had taken place.

Table 3.3. Summary of the adolescent participants' characteristics using pseudonyms

Participant	Name of participant	Age of participant at the time of interviews	Age of onset	Alopecia Type: Areata/ Totalis/ Universalis	Experience of regrowth?
1	Emily	14	7	Areata	Yes
2	Harry	15	6	Totalis	No
3	Liam	17	15	Areata	Yes
4	Anna	16	5	Areata	Yes
5	Priya	17	11	Universalis	No
6	Jason	17	4	Areata	No
7	Sarah	18	8	Areata	No
8	Hannah	16	7	Areata	No
9	Georgina	18	1	Universalis	No
10	Adam	15	10	Totalis	No
11	Laura	18	3	Totalis	No
12	Louise	18	12	Universalis	Yes
13	Chris	17	10	Areata	Yes
14	Amanda	16	12	Totalis	Yes
15	Danielle	17	9	Areata	No

Overall, thirty participants in total were included in the current study, with the aim of capturing how participants made sense of their experiences and the differences in their meaning-making. Within the parents' perspectives, fourteen of the participants were female, and one was male. Within the adolescent sample, five of the participants were male, and ten were female.



### 3.3.2. Method of Data Collection

Semi-structured interviews were used to collect the data. As opposed to structured interviews, semi-structured interviews can be altered in line with the research question. I also chose this method as it is flexible and allows the development of rich data concerning participants' experiences (Kelly, Bourgeault, & Dingwall, 2010). Given that this is an exploratory study, I also felt semi-structured interviews were appropriate because it allows the interviewer to ask follow-up questions based on participant’s responses (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). Furthermore, semi-structured interviews also enables the researcher to explore people’s perceptions and experiences (Kallio et al., 2016), especially within emotionally sensitive issues such as the experience of a condition or illness (Nies, Ali, Abdullah, Islahudin, & Shah, 2018). I wanted to focus on matters that were considered significant to my participants and not particularly restricted to the questions which were formulated by the guide. This ensures that diverse perceptions are expressed by participants, which hold meaning, rather than being guided by the research questions, thus, capturing a more true representation of experiences (Cridland, Phillipson, Brennan-Horley, & Swaffer, 2016).

As computers are becoming increasingly used worldwide, so are the number of internet-based studies (Morison, Gibson, Wigginton, & Crabb, 2015). Keeping in line with more contemporary qualitative studies which use online methods such as Davey et al. (2018), I chose to adopt email interviews as a method of data collection. Ultimately, email interviews provide the researchers with “a unique set of tools and advantages” compared to traditional face-to-face interview techniques (Bowden & Galindo-Gonzalez, 2015, p. 79). The rationale of this will be discussed further.

#### Online Interviews

Online interviews can refer to forums, focus groups, discussion boards, web-based surveys, Skype interviewing, instant messaging and email interviews (Meho, 2006). Although there is an extensive body of literature surrounding the traditional face-to-face interviews, there is also a growing body of literature around the use of email interviews (Bowden & Galindo-Gonzalez, 2015; Burns, 2010; James, 2007).

Online methods have been increasingly used to explore phenomena perceived to be difficult to talk about face-to-face (Bouchard, 2016). Participants may be more willing to talk through an online platform when discussing sensitive topics such as having alopecia, because of the anonymity that

comes with online interviewing. The absence of the individual being physically in front of the researcher may mean participants can be more open and honest with their responses (Atkinson & DePalma, 2008). This is especially relevant in health studies as online research methods makes the research appear more “user-friendly” (Lathlean, 2008). A study by Suzuki and Calzo (2004) Suzuki (2004) for example, found that adolescents were more willing to use the internet in comparison to face-to-face when seeking advice on health and sexuality, and this has been supported by more contemporary studies relating to health (Ali, Farrer, Gulliver, & Griffiths, 2015; Rickwood, Mazzer, & Telford, 2015), Furthermore, due to the sensitive nature of the topic, this medium offered a degree of anonymity.

Previous research studies which have used online interviews have highlighted the benefits of using this method of data collection (Davey et al., 2018). Cook (2012) for example, looked at women’s experiences of sexually transmitted infections (STI) using email interviews and analysed their data using TA. They found that the retention of the study was high, and the participants reported the use of emails as a great platform to discuss sensitive topics. The researcher found that even though participants had not taken part in a qualitative study before, they regularly used the internet as access to information regarding STI information. Thus, participants who were recruited through Alopecia UK would be familiar with the form of communication as they use the sites and social media to access forms of support. Furthermore, because my demographic was recruited through Alopecia UK, I was also confident that they would be computer literate.

Another study by Pattison, O’Gara, and Rattray (2015) explored patient support after critical care. Although there was a variation in what was discussed (ranging from a few lines, to pages of typed text), the narratives were in-depth and presented deep emotional disclosure. I anticipated that the amount of data gathered could be low due to the age of the participants within my adolescent sample. However, I felt as though the depth of data would be considered rich and emotive, especially because it is regarded as a sensitive topic.

Furthermore, some studies have found that adolescents feel more comfortable discussing topics online in comparison to face-to-face methods (Shapka, Domene, Khan, & Yang, 2016), suggesting that online email interviews may be a better choice, especially as adolescents in comparison to other life stages have preferred online communication (Best, Manktelow, & Taylor, 2014). Adolescents have more willingness to speak online due to their higher sense of control over their self-presentation

(Shapka et al., 2016), therefore, online interviews may increase adolescents’ susceptibility to taking part in the current study. It could also be considered that I would be exploring adolescents’ experiences in their “natural communication environment” (Mason & Ide, 2014, p. 41). This is because, according to the Pew Research Centre (2018), 95% of adolescents are now online, and around half (45%) use the internet several times a day. Therefore, I felt email interviews would be appropriate.

Previous literature suggests that online interviews are less time consuming, more cost-effective and can be used when the geographical distance is problematic and participants are spatially dispersed like those within my study (Sedgwick & Spiers, 2009). As this is a sensitive topic, online interviews provide a safe space for participants to talk openly about their experiences. Research has shown that those with alopecia display social isolation and often limit their interactions with others (Rafique and Hunt, 2015) thus, participants may be less likely to take part in face-to-face interviewing. Given the sensitivity of the research, text-based interviews (such as emails), provides a greater degree of anonymity compared to other forms of remote methods (i.e. Skype interviewing). Therefore, text-based interviews were deemed more appropriate.

#### Types of text-based interviews

Text-based interviews can be divided into two categories: synchronous and asynchronous. The most common form of synchronous interviewing is instant messaging (IM), which is usually facilitated using platforms such as Facebook messenger, Whatsapp and Windows Live Messenger. Synchronous interviews are undertaken in real time and allows the exchange of text-based messages instantaneously (Oseni, Dingley and Hart, 2018). This means the researcher is required to schedule the interview with the participant so that they are online at the same time (King et al., 2018). Synchronous interviews are similar to traditional face-to-face interviews and offer spontaneity as interviewees are able to answer the researcher straight away (Oseni, Dingley and Hart, 2018).

Asynchronous text-based interviews refer to methods which are conducted in non-real time and are mainly facilitated via emails. This is a method in which emails are sent online between the researcher and participant within a specified timeframe (King et al., 2018). The interviewees are able to decide when they would like to respond to the emails in their own time and at their own pace (Bowden & Galindo-Gonzalez, 2015). Moreover, it allows the researcher to hold multiple interviews within the

time period rather than focusing on one at a time, unlike synchronous methods (Bowden & Galindo-Gonzalez, 2015; King et al., 2018). This type of method can be useful for studies such as mine, as participants could work in different patterns such as shift work or school.

Whilst synchronous text-based interviewing has many advantages, the fast-paced nature of synchronous interviews means participants could fall behind. This, as well as the unclear distinction between responding and sending, may create some overlapping conversations whereby the participant may send brief responses. As such, there could also be fewer opportunities for the interviewee to probe further or clarify responses. Given the age of my participants would be as young as 13 years old, I felt as though they would benefit from more time to type their replies and make the interaction as transparent as possible.

Furthermore, as highlighted by King et al. (2018) there is also the possibility that the interviewee may not be able to give their full attention during synchronous interviews. There may be distractions which occur during the time of the interview which the researcher may not be aware of. This can be prevented within traditional face-to-face methods as the researcher is able to respond to these such as pausing the interview or moving to a quieter room. However, it is more difficult when the researcher is unaware or unable to see using synchronous text-based methods. As a result of this, the participants may formulate less quality data. If an interview was conducted via email, the respondent has the opportunity to reply at any time that is convenient and less distracting.

Asynchronous emails were chosen given that it allows participants to formulate more thoughtful and detailed responses (Bowden & Galindo-Gonzalez, 2015). This absence of fast-paced instant responses allows the participants to take their time considering the questions and their responses and allows them to re-read and reflect upon what they have previously stated (James & Busher, 2006). Furthering this, the researcher has more time to formulate a more concise and thought out follow-up question based on the interviewee's response, which according to Meho (2006) allows rich data to be formed. As I considered myself a novice researcher when I began my PhD, I felt this was appropriate as I could reflect upon what was stated by participants and I could focus on the key issues which may have been missed if I had interviewed them face-to-face or using synchronous methods.

Having the interview over a longer period of time allows the data gathered to be more in-depth and richer. This is especially given that the repeated interactions within email interviews allows a greater

degree of rapport to be developed in comparison to synchronous interviewing. Alopecia is a highly sensitive and emotional topic. I felt this would be more appropriate because it allows me to build a relationship with the participants were they would feel comfortable disclosing their experiences.

#### Embodiment within text-based Interviews

Unlike face-to-face methods or remote skyping, non-verbal cues (such as body language) and paralinguistic cues (such as the tone of voice) cannot be captured using a text-based format (Hewson, 2007). Ratislavová and Ratislav (2014) however, state that the richness of data in comparison to face-to-face interviews has been similar and, in some cases, greater because participants are more focused when involved in email interviews. Participants can give a more structured response because they have more time to gather and reflect on their thoughts and elicit a denser reply, which then, in turn, makes the participants more attentive (Harricharan & Bhopal, 2014; Ratislavová & Ratislav, 2014).

Researchers within phenomenology, however, have argued that it is important to not overlook the interview as an embodied relationship (King et al., 2018). Phenomenology has often drawn researchers to the awareness and importance of exploring our bodily relation to the world (King et al., 2018). It could be argued that email interviews and other forms of methods that prevent seeing the participants are considered a “disembodied method”, given that the body is an important part of experience and expression. Although within the traditional face to face interviews, researchers and participants are able to interpret the social characteristics of one another through verbal and non-verbal cues (such as tone of voice and facial expressions), within email interviews this can be limited. Non-verbal cues are seen as intrinsic to the “presentation of self” in which, expression and posture are important components of how an individual views themselves and how they are perceived by others (Busher and James, 2012).

However, cues such as expression or exaggeration could be presented in a manner that allows the participant to convey their meanings and for the interviewer to interpret their experience accordingly. For example, emphasis could be made by the elongation of words or the capitalisation of text. There are also methods suggested by (King et al., 2018) which can allow the researcher to be more sensitive to embodiment within the interview process. King et al. (2018) suggests that the researcher can pay more attention to what the participant says about the bodily aspects of their experience and probe further based on their responses. Moreover, the researcher can make note of their own bodily

reactions during the interview process. As such, whilst some argue that embodiment could be neglected within email interviews, there are other forms of communication and sensitivity which allows the embodied nature of the interview to be present (King et al., 2018).

### Formulating the topic guide

According to Kelly et al. (2010), semi-structured Interviews need to have a degree of previous research within the topic area because interview questions are based on previous knowledge. This has been supported by Rabionet (2011) and Kallio et al. (2016) who stated that the researcher needs to understand the key areas within the phenomenon prior to the interview. Questions were planned before the interview using a topic guide (Adams, 2015), which explored the main themes of the study. While this guide forms a structure for the interview, it does not mean that the guide needs to be followed strictly (Adams, 2015). The method means that similar information can be collected from each participant around the topic area, but in their own words and in their own way, and therefore, is viewed as a guidance to which participants discuss specific topics (Adams, 2015).

A topic guide is a set of open-ended questions that enables the discussion to be steered towards the research topic (King et al., 2018). Thus, the quality of an interview guide could impact the application of the interview and the overall analysis (Kallio et al., 2016). As highlighted, semi-structured interviews are flexible, and the topic guide needs to reflect this flexibility that can be undertaken during the interview. This means that the questions need to be open and can allow the researcher to change the order of the questions based on the participants' responses (King et al., 2018).

Creating an interview guide can be done by implementing a comprehensive literature review which explores the key areas of study (Kallio et al., 2016). However, if there is fragmented knowledge within in the literature (such as adolescent alopecia), it could also be possible to consult experts within the field to seek understanding of the study phenomenon (Rabionet, 2011). When formulating the topic guide, I decided to explore the Alopecia UK discussion board and conduct a broad TA of the questions which were asked from parents or adolescents who had alopecia. People within the discussion board are indeed “experts” of the topic, especially as they were the ones experiencing the condition first hand. This was done by searching terms such as “teenage” or “child” to limit the searches based upon the topic of adolescent alopecia. In particular, the search found issues within the discussion board surrounding school, self-confidence, the initial loss of hair, types of support available and the impact

of the condition. I therefore decided to split my topic guides around these particular areas to truly capture the experience of adolescent alopecia. The topic guide was therefore developed from these key issues raised by the Alopecia UK discussion board and where appropriate, previous research.

The way I constructed the topic guide meant that I could easily flow from one question to another (King et al., 2018). This can be seen in figure 2, for the parents’ interview guide.

1. Going back to the very first time X lost their hair - could you tell me what happened?
2. What has been the impact of X’s alopecia on you? Can you describe a recent occasion where this has occurred?
3. What has been the impact of X’s alopecia on other people close to you?
4. I'd like you to think about when X attended school during a period in which the alopecia was most prominent. Could you describe how you felt during this time?
5. What support have you received?
6. Has anyone spoken to you about your own needs of having a family member with alopecia? What would you consider your needs to be?

Figure 2. Parents’ interview guide

Interviews that are used with adults can also be used for children over the age of 12 according to guidance by the National Children's Bureau (2011). The interview guide for the adolescent sample was therefore, adapted from the parents’ guide in order to be considerate of the age group’s literacy, cognitive ability and capacity to understand abstract concepts (National Children’s Bureau, 2011). This can be seen in figure 3.

1. Going back to the very first time you lost your hair - could you tell me what happened?  
Prompts: I’m interested in knowing about things like the first things you noticed, what you did, how you felt and who you went to see?
2. What was it like for you at school? I'd like you to think about a time you attended school during a time in which the alopecia was most visible. Could you describe how you felt during this time? How did you feel?
3. What support have you received from your family and friends?
4. What support would you have liked?
5. What do you find the most challenging about your alopecia?
6. If you were to meet someone with alopecia who is the same age as you, what kind of tips would you give them?

Figure 3. Adolescents’ interview guide

The questions contained within each guide were formulated to produce the richest possible data. According to King et al. (2018), a good topic guide needs to be participant-oriented, open-ended, clearly worded, and not leading. The aim of formulating these two topic guides was to gain responses from participants which were in-depth and spontaneous (Kallio et al., 2016). As such, answers captured the individuals’ personal feeling and stories, in their own words, while also enabling new concepts to emerge which may have not directly been accessed within the guide (Kallio et al., 2016). As suggested by Chenail (2011), I used questions which started with terms such as “what”, “who”, “when” or “how”.

Given the nature of online interviews, I wanted to pay particular attention to first establishing a rapport with my participants. This meant creating a relaxed environment and creating a narrative to break the ice. To do this, I began the interviews with a brief description of myself (see appendix 11 for example). After this had been done, I asked participants to describe the first time they had lost their hair. This was a topic which participants knew they were going to discuss, thus was familiar and central to this study (Whiting, 2008). After this, the questions or related topic areas could be re-ordered based on their response, for example, if a participant discussed issues surrounding school; I would then follow-up with questions based on the school experience and explore how they felt in more detail. The first question, which could be viewed as an opening discussion, meant that I was able to move



into more in-depth questions such as the support they had received during this time, and then more emotionally focused questions (Whiting, 2008).

Follow-up questions were also implemented to make these themes easier to understand (Kallio et al., 2016), such as “Can you describe a recent occasion where this has occurred?”, or “could you explain to me a little further about XX”. Having these follow-up questions meant that I was able to obtain accurate and optimal information while staying as close to the experience of the participants and keeping the flow of the interview (Whiting 2008). These follow-up interviews can be pre-formulated such as “Can you describe a recent occasion where this has occurred?” or based from the participants' response to a question where further clarification is needed (Chenail, 2011). By doing so, I was able to formulate questions to ask other participants in my study that would further my topic. For example, a few participants within my study described their choice to conceal their alopecia (see 5.2.1), I, therefore, was mindful of asking participants how they managed their alopecia and their reasons for such choices.

When developing the interview guide for adolescents in particular, I wanted to end on a somewhat positive note and a lighter theme. As such, I decided to asked adolescents with alopecia the open-ended question of “if you were to meet someone with alopecia who is the same age as you, what kind of tips would you give them?”

Meho (2006) and King et al. (2018) suggests that participants should be given a time period to respond when conducting online email interviews. This was something which I adopted, and I placed a one-week period for participants to respond. Participants were therefore clear of what was expected of them, and it also prevented the interview lasting longer than intended. It was also recommended that if the participant did not respond, they would only receive a maximum of two follow-up emails to prevent them feeling pressured to reply. This was advocated by King et al. (2018).

### 3.3.3. Procedure

The interview process began with sending the participant a brief description of the current study along with the attached consent and information sheet (see appendix 3-10). This brief description involved explaining to the participant that they will be sent one question a week over a total period of 6 weeks. The email also informed the participants that they could begin the study on a date convenient to them

and taking part in the study was entirely their decision. I also explained that the interviews would follow a guide; however, their responses would help shape the questions which were asked. The email interview also explained given the nature of the process; I would expect a reply within the week, in order to receive the next question. However, if a participant needed longer to reply to an email, they could inform me via email. Participants were also told that if they forgot to reply or did not receive an email, I would send another email to check they were still happy to take part.

Once participants had agreed to take part in the study and sent their consent, I asked the participants to fill out their demographic variables. This included their occupation, age and location. Within this email, I also included a brief paragraph about myself as a researcher and provided the opportunity for the participants to tell a little about themselves. I explained that I was a 22-year-old student at the University of Huddersfield, who also works part-time as a tutor for children who have autism. I also discussed my hobbies briefly, and then described my interest within the topic area. I also explained that I had a personal connection to alopecia because I have an aunt with the condition. After introducing myself I asked the participants “if you do not have any objections, would you be able to tell me a little about yourself?” My introduction differed slightly when I interviewed adolescents (see appendix 11), by being more casual and explaining my hobbies in more detail, although the email followed a similar format.

After this had been done, participants were sent one question a week over the course of six weeks (after the information sheet had been sent, and consent has been obtained). I then remained in contact with the participant and asked (when appropriate to elicit further detail and reflection) personal “probe” questions based on their initial response. Thus, the email interviews usually included additional questions, such as:

Could you tell me a little more about the different styles that you wore? I find this really interesting! Was there one style you liked in particular? How did trying these styles make you feel?

During the discussions, participants were given the opportunity to talk, at length, about what they wanted to disclose. Notes were taken alongside the interviews in the form of a brief reflexive journal, often leading the researcher to ask more questions for further clarification, and noting any interesting points made by the participants. For example:

Jessica has discussed in great length how she received no support at school and had to fight for Josie's bandanna because of the policies set by the school. Are these policies regarding hats and scarves similar across the UK? Are schools unwilling to make exceptions for children with alopecia if it would make their experience easier? There appears to be some form of disconnection between head teachers and parents, are these experiences shared with all participants?

The use of my journal notes making meant that points for further discussion were followed-up and ensured that all aspects of the experience were discussed. Although the interview schedule was used as a guide, the participants in the study were typically open about their experiences and often discussed their issues without the questions being asked.

### 3.4. Analysis

In order to describe how I analysed my data, I will begin by presenting the six stages of Braun and Clarke’s (2006) thematic analysis. Along with this, I will also provide a brief overview discussing how I undertook these steps. It is also important to note that parents’ and adolescents’ data were analysed as two separate data sets as they are individual samples in their own right.

1. Familiarising with the data: This includes transcribing data, reading and re-reading and recording any provisional thoughts and notes.

As highlighted, my research took place online via email. Throughout the process, I read each participants response several times, before emailing my reply with additional questions and probed responses. All of these email data were copied into a word document as it emerged, meaning that I did not have to transcribe the data. Whilst I believe that this was a great way of capturing data, as the language used by the participants was legitimate, in precisely their own words, and with minimal researcher intervention, others such as Sutton and Austin (2015) have suggested that transcribing data allows an immersion which can be lost when others pay those to transcribe their data. I, however, believe that throughout the email interview process, I had sustained engagement with my participants and by doing so, I was able to be immersed in the data.

After one full interview had taken place, I read and then re-read the narratives. Through this process, I highlighted key phrases which stood out in particular and fundamental data which was beginning to emerge at this stage. Alongside these key phrases, I also made a note of any provisional thoughts. An example of this can be seen below in an extract taken from Gemma's narrative in the parental findings:

Table 3.4. Example of explanatory coding taken from Gemma's narrative.

Transcript	Provisional thoughts and notes
<p>The first time we noticed that Sam's hair was falling out was December 2013 (aged 10). It was at breakfast, and the light over the table was shining on a small patch at the front of his head. I took a look and could see three small patches that were the size of about a penny. I initially thought that he had rubbed the three holes in his hair from when he sat with his hands in his hair while studying because the three patches matched finger marks and so my husband and I said that he needed to try to stop doing it and he agreed. We thought nothing more of it until a few days later when he brought up that they were still there and it became obvious that the patches had got bigger. He said that he had not been rubbing so we decided to keep an eye on it.</p>	<p><u>Remembers the exact date of his hair falling out. Perhaps holds significance to her?</u></p> <p><i>Use of light to describe the hair loss. Use of we- Sociality of others- who does she mean by we?</i></p> <p>How her views on what it was has changed. The meaning of time has changed what she thought it was.</p> <p>3 patches of loss</p> <p><u>days passing by how the holes became more apparent. Days making the alopecia worse.</u></p> <p>Keep an eye on it- Now it is something which is been brought into attention by both parents First was not thought of- now it has changed to something of importance.</p> <p><u>At what point did they make the decision to go to the doctors?</u></p> <p><i>Long perhaps suggests a few days have gone by?</i></p> <p>Temporality- days going by before they got an appointment- and the hair loss getting worse.</p> <p>Making sense of the alopecia through describing the visual sight of the patches and how it was becoming on bigger patch of hair loss. <i>Not at any great speed- slowly becoming worse.</i></p> <p><i>Use of duty – was the GPs reaction not helpful</i></p> <p><i>Use of wait- how the answers were still unknown</i></p>

2. Formulating initial codes: Noting any features of the data which are interesting and collating data relevant to each code in a systematic format.

Whilst I first began by transcribing the whole first interview, as participants replied at different times, and with questions not necessarily in the same order, I began coding different sections of data to manage these multiple conversations. I coded the interviews as they came separately and then went back to each participant. I believed by doing so, I was able to break down the interview into more manageable pieces. Once I did this, I was able to look at each participant as a whole. Although it may have taken a little more time to do it this way, I believed that this meant I was able to keep on top of the multiple conversations. I felt this was the right decision given the depth of my coding.

As highlighted above, I began by coding the data, and then I looked at the analysis for each participant. After this, I explored the entire data set as a whole and began to establish commonality across each parents’ (and later adolescents’) transcripts. During this phase, I took notes about the commonality of codes, as well as the ones which particularly stood out that did not necessarily align with what others had discussed, but provided insight into the condition and participants’ experience of it. Through this process, I was able to see potential themes which may have arisen within my findings. I was mindful not to jump to the next phase as I was aware that the primary aim within this particular process was to form a list of codes and to have the data relevant to each code that was collated (see left of Table 3.5).

In order to demonstrate stage two, I provided an example of my coding process (see left of Table 3.5). This was done in an attempt to capture the essence of what was said and included comments and questions that were grounded in the text and transparent.

Table 3.5. Example of initial codes taken from Gemma’s narrative:

Initial Codes	Transcript	Provisional thoughts and notes
Time period as alopecia starts to get worse Concealing the alopecia	As the weeks passed more hair fell out, it was as if it was moving around his head in a circle, the hair on his crown was a good length, so we were able to cover it (until the wind blew!) We informed his	Progressive loss- at a fast pace Empathy for child- putting herself in his shoes- knows he is upset Hiding the patches of hair- from who?

Initial Codes	Transcript	Provisional thoughts and notes
Shock of others reaction Upset Excessive checking of the alopecia Worry Worry of the reaction of others  Hiding the alopecia Concealing the loss of hair	teacher and I remember <b>being upset with her response which was that she had not noticed!</b> (although I did not express to her that I was upset) I am sure you will think that it was strange for me to be upset, but I knew how he felt about it. <b>The constant checking of his hair to make sure that the patches were not showing, He was really rather worried about it.</b> It was almost as if it was a <b>secret that he was trying to hide from everyone at school</b> and he was <b>scared that it would become exposed.</b> I felt that as she spent more than 6 hours a day with him, for all lessons including PE	watching her child go through this distress- sense of helplessness Constant- thing which is always at the forefront of the mind. Trying to hide the alopecia- worried that it will show ( <u>worried about showing to who?</u> ) Secret- trying to hide (hide from peers) <u>worry or embarrassment?</u> Again use of time trying to show the importance of how spending time a long period she would have noticed the alopecia. Mention of P.E is this a lesson where the alopecia would become more apparent?

3. Developing themes: Systematising the codes into potential themes and collecting all the relevant data.

Within this stage I searched and formed themes which captured important elements of what it was like to experience adolescent alopecia. I was also mindful of only gathering the highest frequency of a particular theme as this does not necessarily mean that it was crucial to my participants. Braun and Clarke (2006) states that themes which are not as prevalent across accounts should not be overlooked. Explanatory codes that were linked with the emergent themes were brought into the next stage, leaving behind the data which was not significant (Braun et al., 2019). This is an essential process of implementing a systematic structure and managing the data. From this process, a list of emergent themes was generated that enabled the formation of recurrent themes for each participant. These were presented on a diagram of cut-out cards. This was easier for me to group the themes and see the relationship between and within the themes. Moreover, by using this visual demonstration, it was

more accessible to see connections which were not apparent when it was presented on the computer. An example of this can be viewed in the appendices (see appendix 12).

After this had been done, I explored the coded data and reviewed them against the potential themes. It was during this process that I highlighted the most salient themes that captured the experiences of alopecia, and that gave my data and participants justice. This process took a few attempts as when I looked at my themes, I found that there were gaps and need for elaboration and exploration in some particular areas. As a result, I went back to my coding and themes to see if there was anything which I had missed in the second stage of analysis that aligned with my current themes. An example of this can be seen below in figure 4 during my preliminary findings for the parental themes:

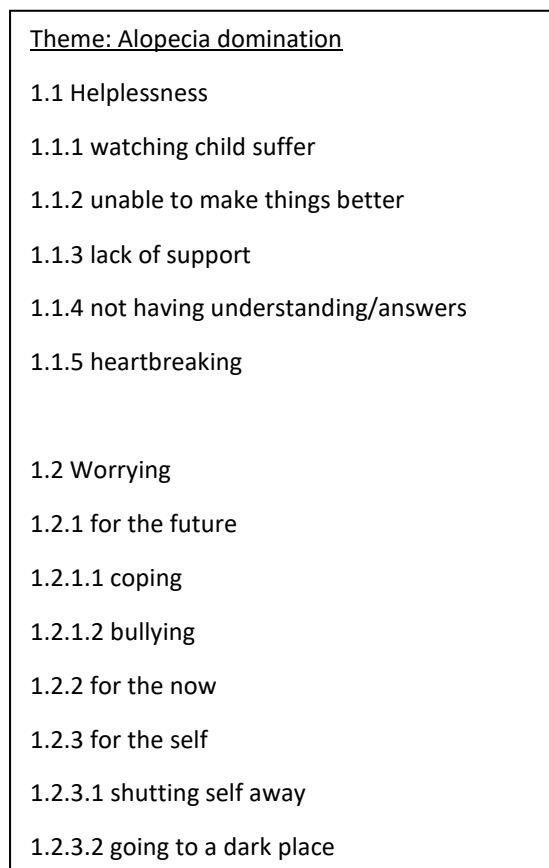


Figure 4. Preliminary findings of themes

- 4) Reviewing the potential themes: Cross referencing the themes and the coded narratives amongst the entire data.

This phase of analysis involved looking at the quotes which were linked to the themes across all 15 participants for each stage and copying these onto a separate word document. By doing so the themes and sub-themes were defined more clearly and provided a form of transparency to see that the analysis had evolved from the text. The process of reviewing the data began by revising each theme individually, before going back to the entire data set to determine whether the chosen themes had aligned with the overarching essence of the narratives.

Although the emergent themes were of those who were recurrent throughout most of the narratives, there was some that were mentioned by only a few participants, however, held a strong significant meaning to the phenomena as highlighted. In particular, “experiencing the merry-go-round”, and the “cycle of emotions” were discussed by a minority of participants because only a few experienced the regrowth of hair. However, excluding this would have diminished the experience of alopecia as a whole, for those who had experienced the loss of re-grown hair.

4. Naming the themes: Refining the details of each theme and whether this captures the overall story of the analysis. Formulating a succinct definition and name.

I firstly began by doing an in-depth review of each of my themes (three parents' and two adolescents' themes), which was done by explaining the concept to my supervisors. By doing this, I made sure that each theme was distinct from one another, told a meaningful story and was also cohesive. The names of these themes had been reviewed several times. This was because I wanted to ensure that the name of these themes captured the complexity of the experiences. I found including direct quotes from participants’ narratives enabled me to do so. I also wanted to ensure that these quotes were clear enough for the reader to understand what the theme consisted of. An example of this can be seen in appendix 13. The reader will be able to see that this was an ongoing process and themes have since evolved or disregarded.

5. Producing the account: The final analysis phase that captures the most captivating and clear narratives that relate to the research aims, question and the broader literature.



The final themes were evaluated, and the most potent and transparent themes were included in my final thesis. These themes revealed a great story and uncovered the essence of what it is like to have an adolescent child with alopecia or be an adolescent with alopecia. I also cross-referenced this to the research aims before picking the final themes and names.

### 3.5. Ethical Considerations

The University of Huddersfield’s School Research Ethics Panel approved the current study before I contacted Alopecia UK to advertise my study and any recruitment communication with participants. The nature of the study (undertaking online data collection and focusing on an emotionally sensitive topic) meant many ethical issues required consideration. As such, I followed the ethical guidelines proposed by The British Psychological Society (2018).

1. The ethics of undertaking an investigation that could be emotionally sensitive and with “vulnerable” participants

The first ethical consideration was consent, especially given that my study involved interviewing adolescents aged between 13-19. I wanted to explore what age it was deemed appropriate to receive consent from both the parents and adolescents themselves. Some research ethic guidelines state that consent should be obtained from both parents and the young person up to the their 18th birthday (Royal College of Paediatrics and Child Health, 2002). As a researcher however, I believe consent for adolescents over the age of 16 and independent of their parents can have many beneficial implications. For example, it can increase a sense of control, capacity to make informed decisions and provide the opportunity to assert their independence in contexts that have meaning to them (Graham, Powell, & Taylor, 2015). The Medical Research Council (2004) ethics guide, General Medical Council (2016) and Department of Health (2001) all state that adolescents between the age of 16-18 are presumed to be competent to give their own consent, therefore I was confident in my decision that parental consent was not necessary for this age group.

I also ensured that the appropriate readability age of language was used throughout the interview process. Following the guidelines, I wanted to adequately inform prospective participants in a manner which was readable and comprehensive to their age (Foe & Larson, 2016). By having the documents cross-referenced, those who would be partaking in informed consent and interview process should be

clearly educated about the nature of the study. The consent and information sheet for adolescents (see appendix 4-6) were a significant element of the research process. Therefore, the language used within these forms had to be concise, clear and accurate to ensure that potential participants were well informed about what the process involves and what they will be discussing. Given that alopecia is a highly sensitive topic I had to ensure that this had been done sufficiently. When developing all my documents (e.g. information sheet, consent and interview guide), I cross-referenced them against an online readability consensus calculator (Readability Formulas, 2019). The online tool analysed the reading level and grade level of the documents to ensure that those between the ages of 13-19 were able to understand the text (Foe & Larson, 2016).

## 2. Remote data collection, with parents and adolescents.

Given that the participants in my study are “vulnerable” and the nature of the condition is sensitive. I had to be aware I did not detail too many of the condition’s characteristics to protect confidentiality and anonymity. An online interview offers the advantage of increasing the sense of anonymity and as such, social desirability was not a concern because individuals could disclose honest opinions and values in more confidence (Davey et al., 2018). However, it could be that the high level of detail provided about the nature of the condition may mean that those could be identified. Therefore, I had to comply with the Data Protection Act 1998 to ensure this was prevented (The British Psychological Society, 2009).

Firstly, all interviews were conducted on a secure university email. During data collection, all data was anonymised. This was done by copying the emails to a separate word document and any names and locations were changed. These documents were password protected and access to the system also required a password. Once this had been done, subsequent emails were then erased. Throughout the process, there was appropriate storage and restricted access.

In the written thesis, anonymity was also ensured through the use of pseudonyms for names and locations. No information released could enable the reader to identify participants. All participants were aware that their dialogue might be used to disseminate the findings; however, their identity would be protected. All my transcripts will be deleted after completion and following publications.

### 3. Participant safety and withdrawal

The nature of qualitative interviews means that feelings and thoughts can be explored in-depth. Perhaps the most thought through choice surrounding the issue of the age of my participants and the sensitivity of the topic area was the potential anticipatory harm. I am aware of the significant impact of the condition because I have a family member with alopecia and have witnessed how distressing the condition can be. Within health care research, beneficence is one of the fundamental ethics (Oberbaum & Gropp, 2015) and the safety and the welfare of my participants was important. I felt that the literature review and my own experiences led me to the decision to have some procedure in place.

My main concern was participants being overwhelmed with the process because of the sensitivity of the topic. I wanted participants to be aware that they have a choice and control over how the interview process was led and if they wish to, end the interview. An example of this would be if a participant felt upset during the interview. I had to be aware of the needs of the participants and offer the choice to terminate the interview. This would be done by stating at the end of the email upon discussing sensitive issues:

Hope these questions are ok to answer, if you do not want to answer any questions you do not have to. It is entirely your choice, and you can talk about whatever you feel comfortable.  
I understand it can be difficult

I was also mindful of referring the participant to supportive services should they require it; however, no participants stated their need for such support.

Alopecia is a highly sensitive and raw emotional topic to discuss. Because of this, there may be an occasion in which participants could have discussed potential harm. The information sheets (see appendix 3-5) noted how confidentiality was not absolutely guaranteed as they may be occasions (such as potential harm) where I had a professional duty to report the information to the appropriate authorities. However, when exploring this issue, it was also suggested by my ethics panel, that there may be occasions in which information from the interview with adolescents had to be relayed back to parents. There could be times in which this was possible, for example, if an adolescent was to disclose that they were being abused inadvertently. The welfare and safety of my participants was the main

priority, and therefore I contacted the NSPCC with concerns about relaying information to parents. An email correspondence with the NSPCC stated:

We would advise you speak to a Safeguarding Officer or to ourselves; do not discuss it with the parents. If the child is making a disclosure it should be discussed with a child protection professional FIRST as it may not be safe to speak to the parents as they might be the abuser. You can call our 24 hour helpline on 0808 800 5000.

Should the adolescent have disclosed information that they themselves or others may be in potential danger, I decided against contacting parents prior to contacting the NSPCC first. There was, however, no time in which this was needed.

#### 4. Researcher safety

Due to the sensitive nature of alopecia, there was also a potential research risk. As the interview process was conducted online, no lone working policies had to be put in place in terms of home visits. While I felt I was able to cope with the topic of alopecia and the interviews, I also wanted to ensure that I had access to the relevant support. After the interviews had been conducted, I met with my supervisors to discuss any complications that I felt had occurred. I was also aware of the counselling services provided by the University of Huddersfield if I needed it.

### 3.6 Establishing Research Trustworthiness

As described, there are no set ways of undertaking a TA research underpinned by interpretive phenomenology. Qualitative research is regarded as a respected paradigm of inquiry (Nowell, Norris, White, & Moules, 2017). Given the complexities of such methods, it requires a rigorous approach. Therefore, I will describe how this study can be accepted as trustworthy and credible.

Nowell et al. (2017) demonstrates how research trustworthiness can be established in TA. With a particular focus on Lincoln and Guba (1985), they refined the concept of trustworthiness and applied this to their study. They showed how dependability, transferability, credibility and confirmability all contribute to establishing research trustworthiness within TA. Rodriguez (2009) argues that good phenomenological studies can accomplish quality if they demonstrate the complexity, ambiguity and

ambivalence of participants’ experiences. Studies which adopt a phenomenological underpinning when exploring the life-world should be able to highlight inconsistencies and integrate opposites, as by doing so, they establish holism (Rodriguez, 2009). This is particularly relevant to my study given the nature of TA means I can look across participants’ accounts and explore such convergences.

As a researcher undertaking an interpretive exploration, I need to be mindful of my pre-understandings or prejudices and how this could influence my data collection and interpretation. Nowell et al. (2017) suggests that developing audit trails and being reflexive in this process helps the reader see the choices and decisions made in terms of the theoretical, analytical and methodological process of undertaking the study. Having this process achieves dependability because researchers can demonstrate how the research process was logical, traceable, and well documented (Nowell et al., 2017). By being aware of reflexivity, the researcher can gain transparency. This can be achieved by developing a broad reflexive journal (Nowell et al., 2017). The journal helped me remain self-aware, by noting my thoughts, feelings and activities throughout the study. This journal prevented me from overlooking data and going back to my own pre-conceived thoughts and ideas. Importantly, this journal formed an audit trail documenting the analytical process and demonstrating how the interpretation was developed (King & Horrocks, 2010).

Secondly, Nowell et al. (2017) highlight how transferability can contribute toward the trustworthiness criteria. This is concerned with the generalizability of inquiry and case-to-case transfer. Through providing thick descriptions like phenomenological approaches and rich TA qualitative data, researchers who want to generalise the findings to their own samples can do so on their own decree. Thirdly, Nowell et al. (2017) explored how the credibility of the study can be understood by how readers are able to recognise experience when it is presented to them. As such, credibility refers to how accurately the data “fits” amongst the interviewee’s experiences and the researcher’s representation and interpretation of them (Nowell et al. 2017).

To assess credibility, Lincoln and Guba (1985) provided many techniques including prolonged engagement, peer debriefing, and checking the data with the participants (member checking). I felt as though the four-year PhD journey was sufficient enough to have prolonged engagement with the data analysis and collection. Furthermore, having discussions with my supervisors helped me establish an external check on the research process and provided me with the opportunity to discuss how my findings and interpretations matched that of the raw data.

Additionally, member checking was not adopted in the current study. Although sending feedback regarding the findings to participants is regarded as a useful way to ensure credibility within the interpretation process (D. R. Thomas, 2017), researchers such as Goldblatt, Karnieli-Miller, and Neumann (2011) have highlighted that there could be some potential limitations when doing this. Given that the interviews had taken place over two years previously, the experiences since the interviews could make it difficult for participants to reconnect and go back to their previously reported experiences (Goldblatt et al., 2011). Furthermore, there could also be a possibility that participants could misunderstand the analysis and findings because of the jargon and language used. I felt that member checking was a burdensome task and an extra commitment to add to the six-week period and therefore I decided not to approach. I am confident that the discussions with my supervisors and prolonged engagement ensured the credibility of my study. I intend to forward an executive summary of the thesis to Alopecia UK for them to disseminate on their website. I also plan to disseminate findings in peer reviewed journals which is deemed appropriate given the time invested by participants. My current dissemination involvements have been highlighted in Chapter Six: Discussion.

The final check of trustworthiness involves confirmability (Nowell et al. 2017). This is the process which demonstrates that the interpretations stem directly from the data, meaning that the researcher has to demonstrate how they have reached their conclusions. This can be done once credibility, transferability, and dependability have been reached. According to Nowell et al. (2017), researchers are recommended to provide a rationale and clearly highlight their choices for theoretical, methodological, and analytical underpinnings throughout their study so that readers can recognise the context in which these decisions were made. I hope that throughout this process, I was able to demonstrate confirmability.

Finally, Gadamer (1997) provided clarity that the reader may incorporate their own prejudice(s) to the experience of understanding the data. It is important to recognise that each reader or researcher may exhibit different interpretations of how they make sense of the narratives and the meanings this hold for them. To end this, I will state that the findings of my thesis have been formed by my own interpretation and understanding of alopecia related experiences. Such understandings and interpretations could differ to another researcher who wants to explore this phenomenon. However, it is hoped by taking account of the concepts highlighted, I have established research trustworthiness.

### 3.7. Summary

This chapter has provided the reader with my rationale for using thematic analysis underpinned by interpretive phenomenology. I presented the reader with an introduction to phenomenology, interpretive phenomenology and TA, before discussing the design of my study, including my analytical process.

The research design and methods based on key interpretive phenomenologists such as van Madsen and Smith were chosen to describe the day to day experience of living with adolescent alopecia. Phenomenology acknowledges, and relies on, the researcher's use of self to form interpretations. By demonstrating my considerations of working with participants and broader health care professionals, developing and conducting the interviews, providing a rationale for my sample, and providing demonstrations of rigour and adequacy, the manner has allowed me to be both reflective and mindful of the process and how I interpreted my findings.

The next two chapters will provide the reader with my findings which were developed through undertaking a TA, driven by my research aims and theoretical assumptions. That is, to explore the lived experience of alopecia, detailing how parents who have an adolescent child with alopecia, and adolescents with alopecia, make sense of such experience.

Although data were collected simultaneously, the parent findings will be presented before the adolescents. Where qualitative research has been conducted within health domains exploring adolescents’ experiences, often what is conveyed is the by-proxy perspective. Professional or parental views are accessed in an attempt to convey the experiences of the children. This study is unique in that it has also obtained the experiences and perceptions of the adolescents themselves. It is for this reason, that I will firstly convey the parent perspectives and then highlight the adolescents’ voices. Showing further that by attending to the experience of adolescents themselves and in their voices, our understanding of health-related phenomena relevant to youth experience is both deepened and enlightened.

## Chapter Four: Parents' Experiences of Having an Adolescent Child with Alopecia

This chapter will present the three main themes developed from the analysis of the parent interviews; "the hair is coming out": living the emotional turmoil of hair loss", "it's JUST alopecia": health care professionals trivialising alopecia", and "needing to protect the altered appearance". A striking feature of the data was how complex their meaning-making process was, as parents tried to make sense of their experiences, while at the same time trying to make sense of their child's condition. Many parents described the powerful emotive impact the condition had on them which was often relentless and intrusive. For those whose child experienced the regrowth of hair, the further loss of hair was even more devastating. Such emotions became reinforced when the health care professionals did not offer the support which was desperately needed. Often parents felt let down by the health care professionals and were left to manage the condition on their own. Parents also described how their child looked visibly different because of the alopecia. Often it created feelings of confusion and heightened their need to protect the adolescent and manage the condition.

Table 4.1 shows an overview of the super-ordinate themes, sub-ordinate themes, and sub-themes that captured the lived experience of parents who have an child with alopecia. These will be discussed further, and the key findings will be demonstrated.



Table 4.1. Parents' super-ordinate themes, sub-ordinate themes, and sub-themes overview

Super-ordinate theme	Sub-ordinate themes	Sub-themes
4.1. "the hair is coming out": Living the emotional turmoil of hair loss	4.1.1. Feeling shocked 4.1.2. The dominating worry 4.1.3. The experience of heartbreak 4.1.4. Re-living the cycle of emotions	4.1.1.1. Experiencing a lack of control over the hair coming out 4.1.1.2. Feeling powerless 4.1.1.3. Feeling confused 4.1.1.4. "It happened so quickly" 4.1.2.1. The worry for the self 4.1.2.2. the worry for their child 4.1.3.1. Feeling emotionally "hurt" 4.1.3.2. Feeling "broken" 4.1.4.1 "Alopecia is uncontrollable" 4.1.4.2. "Not again" 4.1.4.3. I feel "hopeless"
4.2. "It's JUST alopecia" Health care professionals trivialising alopecia	4.2.1. Who is the expert? 4.2.2 Needing support for me and my child	4.2.1.1 Being "Let down" by health care professionals 4.2.1.2 Feeling helpless 4.2.1.3 Lack of professional responsibility 4.2.1.4. Experiencing a long wait for appointments 4.2.1.5. Becoming an expert on the condition 4.2.2.1. Feeling unsupported by health care professionals 4.2.2.2. The need to "remain strong" 4.2.2.3. It is just "cosmetic" 4.2.2.4. Receiving emotional and practical support from family

Super-ordinate theme	Sub-ordinate themes	Sub-themes
4.3. Needing to protect the altered appearance	4.3.1. Wanting to protect the child from “others” 4.3.2. The struggle to comprehend the change 4.3.3. It is not just the head!	4.3.1.1. Experiencing the impact of bullying 4.3.1.2. Wanting to shield the child from others 4.3.1.3. Alopecia can only be shown at home 4.3.1.4. Wanting to protect the child at all times 4.3.2.1. Feeling shame 4.3.2.2. Feeling confused about how different my child looks 4.3.3.3. Experiencing bereavement 4.3.3.1. The experience of masculinity/femininity 4.3.3.2. The worry for the child’s relationships with peers

#### 4.1. Theme One: "the hair is coming out": Living the Emotional Turmoil of Hair Loss

The super-ordinate theme "the hair is coming out: living the emotional turmoil of hair loss" was captured by the sub-ordinate themes "feeling shocked", "the dominating worry", "the experience of heartbreak" and "re-living the cycle of emotions". The theme of "the hair is coming out" captured the emotional experience and turmoil felt by parents as they saw their child's hair physically fall out. Often parents felt a loss of control, powerless and confusion. Adding to this, it was apparent that there was a temporal element to this state because of the unpredictable nature of the condition. As well as feeling shocked, their sense of worry was a key aspect of parents' experience. This worry was concerned for the self and their child. The experience of heartbreak captured the intense embodied experienced felt by participants. Often parents felt broken and were emotionally "hurting". These emotions were further intensified when they described the loss of hair that had grown back, capturing the cycle of emotions parents experienced when their child with alopecia lost their re-grown hair. This will be discussed further.

##### 4.1.1. Feeling Shocked

Seeing the hair fall out from their child's head created an intense feeling of shock, with some parents even describing the experience in ways that could be interpreted as traumatic. With this, there was a sense of confusion and difficulty for parents as they tried to comprehend what was happening to their child. This emotional experience showed that the "hair is coming out" was always unanticipated for parents. Furthering the temporal nature to this experience, participants discussed how the rapid nature of hair loss occurred within a short period of time. For most parents, the initial shock of the alopecia was also attributed to their lack of knowledge of the condition at that particular time. During this immediate phase of the condition, parents reported intense emotions, including being "stunned" and feeling "powerless".

Although I asked parents to talk about the first time their child lost their hair, all participants went beyond this and described the events leading up to their child's diagnosis. Some participants detailed the first signs of alopecia that they, with hindsight, felt they had missed, often describing signs when their child was younger. Others described the day in detail following the moments of "the hair is coming out".

Sandy discussed how her son had described some signs of alopecia before she noticed the bald patches during a game of football.

Two weeks before his sixteenth birthday he told me quite out of the blue that he had brushed his hair that day and lots of hair came out in the brush. I'm afraid to say that at that moment we were rushing out to go to his football match and I didn't even look at his hair I just told him not to worry and that all of us lose more hair some days than others. It was just like any other normal day but as he played football that morning from the sidelines I saw a clear bald patch on the top of his head and I was, of course concerned. At the end of the match I had a look at his head and just touching the hair left it in my hands. Over the next few days his hair fell out in large clumps and within a week there was none left. His body hair soon followed. Initially we saw our GP who referred him to a dermatologist. We were given an appointment for approximately two weeks time but I phoned the hospital and asked to be seen urgently since I could see there would be no hair left in two weeks. I was just in utter shock (Sandy).

It was clear that the incident became significant to Sandy following the diagnosis of alopecia. She stated, "lots of hair came out in the brush", and at that particular moment Sandy felt this amount of hair loss stood out from the ordinary and had now become the point of realisation that this may have been the beginning of alopecia. Sandy finished the narrative and stated she was in "utter shock" to summarise her strong emotional experience. The rapidity of the hair loss also captured the temporal elements of the experience that heightened her sense of shock. Sandy began to describe the journey of her child's alopecia and discussed the severity of the loss from hours, followed by days, up until the week it took for the total loss. The concept of time here was also linked to the panic, the seemingly rapid nature of the hair loss, and their desperate urgency for an intervention. This was highlighted by her need to call the hospital earlier than she was advised and she had anticipated.

Jenny similarly highlighted her shock at seeing the bald patches appear on her daughter's head, but her sense of shock was portrayed as more significant as she used the discourse “horror” to describe her emotional turmoil:

Danielle's hair was fine, so it was evident straight away she had them [head lice]. I began to comb through and to my horror that's when I discovered a huge bald patch on the right side of her head behind her right ear and extending down to her neck and across the centre

towards the left of her head. Almost the whole of my hand covered the bald patch. The skin was smooth. There was just a line of hair at the base towards the neck. I was treating Danielle's hair with the Hair nit treatment so was combing through before applying it. I was in complete shock and upset. I knew exactly what it was because at that time both of my brothers were in the second and third year of alopecia areata (Jenny).

Jenny's recognition of her daughter's alopecia was guided by her previous experience of both her brothers, who shared the same condition. Despite this, Jenny still experienced shock and distress. This particular experience captured the horror of the moment of realisation (combing through and discovering the bald patch). Her account is very much in the style of horror stories in which it leads the reader in suspense to a scene that is unimaginably awful. For example, like a character going to a door and turning the handle, and the reader (or viewer) being aware that there is something terrible behind it. Once the hair began to fall out, Jenny began to feel as though nothing could be done. Parents struggled to come to terms with the hair falling out, and at an accelerated rate. I interpreted this as parents feeling as though a patch of baldness could be managed, however, full hair loss (or the thought of total hair loss) seemed much more difficult to cope with, and even more so, unable to control. This has been captured by Jenny's narrative:

Over the summer the patches got worse. I had begun to realize once the hair loss started there was no way of stopping it. I describe it as a ball rolling downhill it continues to roll to the end (Jenny).

Jenny tried to make sense of her feelings and the experience of the alopecia by comparing it to a ball rolling downhill. The concept of “downhill” suggests that the alopecia became worse, and the situation deteriorated whilst also building a momentum. The condition then continued to deteriorate with no way of stopping it. Although this description could describe the severity and speed of the alopecia, it could also be interpreted as a holistic description of herself, as she stated further on in the interview, “it's a very emotional time and can drag you down”, as though she herself was carried away by the ball. This metaphor also highlighted the sense of being unable to stop the hair from falling out, as the ball continued to roll to the end, the figurative speed increased, thus becoming increasingly difficult to stop. “The end” therefore, could also represent total hair loss, or the full realisation that nothing can be done, as a ball rolling downhill can often be out of reach and at a speed that an individual may not be able to cope with.

This sub-theme is especially insightful because as highlighted, CIA is often anticipated. It is common knowledge that chemotherapy often results in hair loss. Hence why the identity of baldness is often associated with having a cancer illness (see 2.1.3). This experience of shock discussed by parents differs to those with CIA because the nature of the condition means it comes without warning (unlike CIA); there are no symptoms prior, nor any sign that hair loss is about to occur. The narrative by Jenny, in particular, captured the characteristics of alopecia, but also the horror that most parents experienced; the full realisation that nothing can be done and inevitably, and at a rapid rate, all the hair will fall out.

#### 4.1.2. The Dominating Worry

Parents' experience of worry also appeared to be linked to their anticipation of how their child would cope with the condition. All, but one parent discussed the perceived coping of their child as being a cause for their worry, something which was apprehensive and intrusive. This sense of worry was described as "dominating" due to the concern being uncontrollable and appearing in their thoughts regularly, even in the present day. This theme captured how such worry has been placed directly into their lived world, as they discussed the worry for themselves, their future, and their child.

For some parents, the dominating worry also prevented them from carrying out their everyday activities:

No words can describe how frightened, worried and sad I was when Nathan lost his hair. To see my son crying, afraid, bewildered and devastated when he could see all his hair was falling out was just horrendous. I, like all mums, want only for my children to be happy and healthy. But I constantly worried about him all the time, how he is coping and if others will be kind. His unhappiness was mine and worst of all I could do nothing to change things. It was continuous thought that I had, and these worries really dragged me down some days, I didn't want to leave the house... walk the dog... see my friends (Sandy).

From the narrative, we can see that the intense emotional pain experienced by Nathan was mirrored by Sandy. Sandy's worry was heightened through her sense of helplessness, as she was unable to prevent her son from being upset or stop his hair loss. This mirror image has been further shown by

her statement, "his unhappiness was mine" to capture the shared experience between mother and son. The statement led me to question whether this experience went beyond emphasising but is experienced simultaneously due to the maternal bond that she shared with her son. Moreover, her experience of worry demonstrated how her "continuous thoughts" can be both intrusive and dominating. Adding to this, the narrative "these worries really dragged me down some days" captured how the worry could in metaphorical terms, physically "drag" Sandy down, because the weight and burden stopped her from carrying out her everyday routine.

Alison described a similar emotional burden as she explained her concern as taking over her thoughts and dominating her feelings:

I had no sense of wellbeing for so many years. I would wake in the night and it was the first thing I'd think about and then once I'd got to sleep I'd be rudely awoken by the alarm clock only to remember how sad I felt and worried for Sarah. I still feel like this every morning (Alison).

It appears that sleep may have provided a brief respite from Alison's worries; however, as soon as she was awake, she became aware of her worries and sadness again. She was temporarily freed of her worries during sleep, but when she woke up, these thoughts flooded back. The narrative highlights the prolonged lack of feeling and wellbeing, through the pervasiveness of worry throughout the day and night. The persistence of the same worrisome thoughts can be demonstrated in Alison's description. The "years" it has taken her to come to terms with her turmoil highlights how her worry was not necessarily a temporary emotion, but is still present every morning when Alison wakes up.

#### 4.1.3. The Experience of Heartbreak

The terms "heart-breaking" or "heartbroken" were commonly used to describe parents' overwhelming distress or intense emotional pain. This meant parents felt emotionally "hurt" and "broken". Although it is a metaphor, I visualised heartbreak as being a literal heart, which was once together and whole, is now broken and fragmented. Along with this, participants expressed a feeling of frustration and helplessness through their heart-breaking experience, as they state their desires to take away the pain from their child but are unable to do so.

To be honest its heartbreaking! I'm in bits. It makes me feel very down and I wish I could take his pain. I hate to think how he feels and we try to talk about it in a positive way as I said before (Susan).

Susan's notion of being "in bits" emphasised the embodied nature of her experience, which I interpreted as low mood. Following Susan's breakdown, she also wished to "take his pain", which highlighted how her son's experience of the condition led Susan to worry, and in turn emphasised the "heartbreak" she experienced. Susan wished she had the emotional pain of the condition instead of Jack, especially because witnessing her child's pain was unbearable ("I hate to think how he feels"). She was unable to remain collected or composed, and instead, she experienced emotional feelings which were scattered. The term "in bits", can often be used colloquially to express how she was unable to function as a coherent and whole person. It could also mean "broken", the opposite of "collected and composed", to demonstrate how she felt incomplete, fragmented and unable to remain "composed" emotionally.

For some parents, the experience of alopecia was a heartbreak that felt unreal, like being in a dream world:

The worst day in those first months were when we went to the hairdressers, Andrew had very patchy hair and took to wearing a lot of hats, he felt the time had come to shave his head and we took him to a hairdresser to do this. This was the first time we had seen the full extent of the hair loss and it was heart-breaking to see. It felt like I was in a dream but I couldn't wake up. Seeing him like that broke my heart and I felt awful (Emma).

Emma's dream was experienced as a reality; however, the comprehension of this reality was not something which came easily ("I felt awful"). Her experience of heartbreak was further heightened by her state of mind as being something which she could not escape from. Emma stated "I couldn't wake up" to emphasise her sense of feeling trapped. Her narrative "I couldn't wake up" also suggested that she struggled to come to terms with her new reality. Emma recalled that this was "the worst day in those first months". Emma may have had other days that could be described as "the worst" in the coming months and years, meaning the experience was not over and was long term. Again, this demonstrated the longevity of the experience. For Emma, her heartbreak was a result of seeing the



full extent of her son's alopecia for the first time, as the hair was "coming out". However, the experience also establishes that parents do not realise the severity of the hair loss because adolescents with the condition try to conceal their alopecia as much as possible. Perhaps this experience may have differed if Andrew had not hidden his alopecia. It was only when Andrew had decided to shave his hair and no longer hide his patches of hair loss, that Emma experienced this heart-breaking process.

#### 4.1.4. Re-living the Cycle of Emotions

The idea of hair regrowth for some parents seemed difficult to deal with because they could not bear the prospect of further upset if the treatment did not work as hoped. This was shown by Rachel:

We decided not to pursue any medication i.e. steroids, creams etc. My husband & I felt that as it couldn't guarantee hair growth that it would be too upsetting to give false hope (Rachel).

Some parents did experience hair regrowth, and this significantly improved their quality of life for both themselves and their child. Unfortunately, six adolescents lost their regrown hair. Parents were not only concerned about the uncertainty of hair loss, but whether they would have to go through the traumatic experience of losing the hair again once there has been a degree of regrowth (for those where that has happened).

It seemed that despite their longing for regrowth, the loss of the newly formed hair could be even more difficult for parents to deal with. This has been captured in Susan's narrative as she describes living the cycle of regrowth as "draining":

It wasn't until we changed schools that the children started to make fun of him and would run around the playground and take his hat off him. This left him feeling very upset and we had several conversations about 'why me?' and 'I wish I wasn't here' and 'no-one will ever want to love me' It was a very distressing time. But with Jack his hair grows back so he becomes more confident. The only problem is it then falls out again and we have to deal with it all over again. I just feel as though I am going through the exact same process over again and it's draining (Susan)

The sub-theme has therefore been described as a "cycle" as Susan believed she was going through the same experience again and was reliving the same emotions. Susan's description also highlighted that her son's hair repeatedly grows back and falls out. For Rachel, there was a sense of unrealistic hope, or even the worry that the regrowth may be short lived. This has, in some ways, been mirrored by Susan’s narrative, in which she was recounting Jack having this hope, only for it to be taken away again. What was particularly striking about this narrative, was that Jack’s confidence was dependent on his hair regrowth. It also highlighted the bond shared between Susan and Jack, given that he was able to release his emotion and discuss issues such as relationships. However, given the sensitivity of this conversation, there was no doubt that Susan does not want to be in this continuous distressing loop. Susan, therefore, experienced the alopecia as problematic through a “Groundhog Day” perspective. I used this comparison as a metaphor because the character within this film experienced the same day repeatedly, whilst retaining the memory of each iteration he had lived before. Each time, however, he changed his behaviour and learned from his previous mistakes. The film conveyed the message within a single day of someone's life, and how much learning can be made. However, despite reliving the same experience, her narrative suggests that she was unable to alter her experience or learn how to prevent it from occurring again. Instead, she retained the memories of how distressing this experience was from the previous occasions Jack lost his hair, and Susan was unable to do anything about it.

#### 4.2. Theme Two: "It's JUST alopecia": Health care Professionals Trivialising the Condition

Dissatisfaction with the services provided by health care professionals was not the focus of the research. However, parents emphasised the role of health care professionals as being centred on the care of their child and therefore was a crucial part of their experience. Parents contacted their GP, on behalf of their child, with the hope of receiving a diagnosis, treatment and support. The narratives, however, revealed a high degree of disappointment with the service they experienced. Parents felt as though their child's condition was often trivialised. While parents were experiencing an emotional turmoil, they were told by health care professionals "It's JUST alopecia". As I began to unpick this theme, I could see how it was underpinned by the perceived roles and expected roles of health care professionals. Parents expected health care professionals to be more empathetic, provide emotional support, and be efficient with their referral appointments, not least because they thought the medically experienced would understand their stress and urgency. There appeared to be a shift of

roles and responsibilities from the health care professionals to the parents, who in turn, became "the experts". Many were told by health care professionals, that the condition was "JUST" hair, and "cosmetic", leaving them feeling unsupported. Because of this, parents discussed how they received practical and emotional support from their families.

#### 4.2.1. Who is the Expert?

Parents described the health care professional experience unfavourably, with a recurring issue of the time pressures to be seen by the health care professionals as quickly as possible, lack of support regarding management and treatment, and the service they received. Within their appointments, parents felt as though health care professionals simply provided them with a potential diagnosis, with no form of support offered. Instead, they experienced dismissive or insensitive encounters with health care professionals. Parents' sense of feeling "let down" was therefore shaped by the lack of empathy, urgency and information they expected, given their experience of the condition was highly distressing and parents were worried for their child. In turn, parents' experiences with health care professionals further contributed to their feelings of distress and hopelessness.

Difficulties obtaining an appointment with a dermatologist was a common theme in the parent's narratives. As I asked Lucas to tell me about the first time his daughter Isabelle lost her hair, he stated:

At this point, the facts were, within one week Isabelle's hair was falling out rapidly but there was nothing could be done until we had seen a dermatologist who had a twelve week waiting list. We all felt very helpless and very much let down by the NHS (Lucas).

Lucas' summary highlighted how "let down" he felt by the NHS and also what was perceived to be the long wait. He stated that there was "nothing can be done until we had seen a dermatologist" to demonstrate his lack of control over the condition, and his feelings of helplessness captured in the themes. It also showed his dependency and expectations of the dermatologist to help with the condition before all the hair was lost. Perhaps Lucas had thought that the dermatologist could help slow down the process of hair loss, or at least provide some form of management during this time. Time for Lucas, in this particular experience, was valued as important and urgent; however, the 12-week waiting meant that the urgency was heightened, as he felt he was unable to manage the condition during this period. The long waiting period indicates health care professionals may not share

this same sense of urgency, thus exacerbating Lucas’ feeling of hopelessness and panic. Hair was falling out, and at a rapid rate, which also adds to this perceived loss of control.

Similar to Lucas, Rachel's sense of urgency was not shared by her dermatologist:

We were waiting and waiting for an appointment for the dermatologist. I was constantly chasing them up and passed on to the next person. It just felt to me that nobody cared that this was happening to my child and everyone was making it so difficult (Rachel).

Although Rachel tried to speed up the process, she was left feeling let down, and felt that her child was uncared for. It appeared as though her sense of time has been highlighted through her repetition of "waiting and waiting" which demonstrates her disappointment of how long this process felt. By being "passed on to the next person", it appeared as though no sense of responsibility had been shown by the health care professionals. Similar to Lucas, there appeared to be no sense of urgency; it was Rachel who took responsibility to chase up appointments. We expect health care professionals to provide care and ease our experience by offering support and help. In Rachel's case she said, “everyone was making it so difficult”, which suggested that instead of improving the situation, health care professionals were making it difficult and added to the stressful and emotional experience. However, before Rachel had even gone to her appointment, it appeared as though she already experienced barriers with no sense of responsibility. Parents expected health care professionals to be empathetic towards their child and their situation, yet instead, parents felt no responsibility was taken.

We didn't know what was happening and was it a more serious illness, though we had no idea or thoughts on what and as we couldn't get a hospital appointment for so long and nobody could re-assure us that it was in the Doctor's words "JUST alopecia". Various Doctors referring to JUST alopecia and a suggestion that I had pigeon holed Joey as he was a boy for refusing an NHS wig (Monica).

It was not just dermatologists who were perceived to be dragging their feet, but parents also experienced some difficulties with their GPs. Monica's frustration can be seen by her capitalisation and emphasis on "JUST". This highlights that she believed the impact on both her and Joey was underestimated. Monica felt as though the doctor trivialised the condition and was dismissive with

his statement. It is clear that the condition held more meaning to Monica, and this empathy was not reciprocated by the doctors like she had anticipated. This was problematic as before the appointment, Monica experienced panic and urgency. Monica's sense of feeling let down is further captured by her statement "and a suggestion that I had pigeonholed Joey as he was a boy for refusing an NHS wig". The narrative highlighted the divide between parents and health care professionals, especially regarding how the needs of the child should be met. "Pigeon-holed" refers to someone being given a label, entered into a classificatory system, rather than being treated as an individual. However, I also interpreted this as stating that she had ultimately restricted Joey into this category because she refused the wig. The notion that various doctors had trivialised the condition demonstrates that this dismissal was not a one-off occurrence. It appeared that throughout the parents' narratives and from Monica's statement, health care professionals did not recognise the impact the condition had on both the parent and the child, often being dismissive or insensitive. This may be because, unlike a life-limiting condition such as cancer, alopecia is "JUST" a condition of losing hair. Yet we can see from these narratives that there were great complexities and emotions that derives from a condition which is "JUST" the loss of hair.

Monica was the only parent who stated that a health care professional offered her a wig for her adolescent boy. Whilst I cannot speculate that no other parent with an adolescent boy received this advice, it is interesting to see how the idea of a wig was refused by Monica. There appears to be blame put on Monica, for pigeonholing Joey and restricting him, suggesting that she ultimately may have come to the decision of refusing the wig, perhaps more so than Joey himself. Therefore, I wanted to explore why Monica dismissed the wig, as this was something which had been missed within the follow-up interview. "As he was a boy" implies that the gender of her child may have influenced this decision. There could be a stigma, or a negative connotation attached to boys wearing wigs, and this may be something that was shared by Monica. Nevertheless, the statement which was said by medical health care professions were out of the expected norms. Monica did not have support for her decision of managing her child's alopecia, nor did she experience "non-judgemental behaviour", something which is articulated within the medical and ethical guidelines (General Medical Council, 2014). This further added to the experience of feeling "let down" and demonstrates why this particular experience stood out to Monica, because it did not necessarily fit in with the "role" of a health care professional and therefore, was profoundly upsetting.

“Becoming an expert on the condition” was a phenomenon that the majority of parents experienced upon leaving their appointments with health care professionals. As parents felt dissatisfied with health care professionals and their medical experience, parents had to become "experts" in order to manage their child's alopecia. This was done by researching the condition, looking for treatments, reading the research, and searching for support. For most parents, they refused to believe that "nothing can be done", and so became dominant in professional parent exchanges, whilst also becoming the information gatherer and sharer.

Parents went on to research the information themselves after their appointment:

Our GP was really nice about it & spoke to Adam to explain what Alopecia was, what was happening but said she wasn't an expert & referred us to the hospital to see a dermatologist. I went straight onto google to try & research cures.....if only!! We waited 6 weeks for hospital appointment and in between I was researching as much about alopecia as I could. By the time I came to the appointment I felt as though I knew as much about his alopecia than the consultant because I researched it that much. He was rubbish (Rachel).

It is common that most GPs are not particular experts in alopecia and deal more in general medicine and healthcare. Thus, they were unable to give as much information as parents hoped. Although it would be unrealistic for health care professionals to be "experts" in every condition they encounter, there was a level of expectation that all questions and concerns would be dealt with within their appointment. This was highlighted in Rachel's narrative as she began to research cures as soon as she left the GP appointment. It appeared as though the diagnosis and explanation of alopecia alone, was not enough. The wait for the appointment was seen as a learning and research experience that allowed Rachel to become an "expert". By doing so, Rachel experienced a dominant parent exchange, as she felt as though she was more knowledgeable about the condition compared to the health care professional. She was the one with the “lived” experience of alopecia, rather than a consultant who may have only read about the condition. This again falls out of the expected roles of health care professionals who were perceived to be "experts" of alopecia. Dermatologists have vast experience and years of study to understand the complexities of the condition, however, within a few weeks, Rachel had become an "expert".

#### 4.2.2. Needing Support for Me and my Child

As highlighted, parents felt a lack of support and empathy was offered. Least of which, they also felt their emotions were unjustified because of the encounters they experienced with health care professionals. This meant there were emotions and feelings which were left unresolved. The following sub-theme highlighted how needing support led the family to come together.

Along with feeling let down by health care professionals, parents also felt unsupported throughout their journey. Parents expected health care professionals to be empathetic towards their child and their situation; however, they stated their disappointment and shock when this had not been reciprocated. Many parents stated how they were left to manage the condition, and support their child, without the aid of professionals. Parents felt as though health care professionals undervalued the condition and therefore overlooked the amount of support that was needed, and what was hoped for. This level of support was needed by not only the child with alopecia, but also the parents themselves when they were experiencing a range of strong emotions. Parents felt they had to remain strong but discussed how help was needed.

Some parents stated how they only saw their GP once throughout their whole experience. When asked, parents frequently stated they would ask for help from their GP, but usually described this in the context of their child's needs, rather than their own. Parents felt as though the GP could have done more in terms of the support that was offered. This was shown by Sandy:

Other than our initial GP appointment when he was referred to a dermatologist we have never seen the GP again. Looking back I am quite shocked that our doctor did nothing to follow up that appointment. It was clear to him when he saw Nathan that here was a sixteen year old boy who was going through such a dramatically life changing event yet there was no concern as to how he dealt with it (Sandy).

Sandy felt shocked as she expected her doctor to follow-up and show concern. The expectation placed by Sandy could perhaps be viewed as unrealistic because she wanted highly personalised care from her doctor. Although all parents did not hold this specific expectation, parents did expect some form of personalised care from their doctor, for example, physically examining the hair or following up appointments. Sandy felt as though the doctor trivialised how much impact the condition had on her

son Nathan. Sandy’s disappointment had been further heightened by the notion that he was a “sixteen year old boy who was going through such a dramatically life changing event”. According to Sandy, the condition was more important and complex because her child was an adolescent. This perhaps shows that parents expected more empathy and have higher expectations from the doctors due to the age of their child. This is not the first-time parents expected a higher degree of empathy for their child because of their age. Lucas stated further within his narrative:

The speed of Isabelle's hair loss seemed to be at the extreme end of the scale and I am aware that this may not be the norm for most people but she was at that time 14 years old, and at an age when image is so important and for her there was no help available (Lucas).

Adolescence is a critical time because of hormones, reaching puberty, sitting exams at school, GCSE's and going to college. Furthermore, adolescents have the added pressure of social media and needing to maintain an “image” (Simmons, 2017). Lucas was aware that there were more complex issues occurring in his daughter's life and the loss of hair could only impact this further. Overall, the narrative demonstrated how some parents felt as though health care professionals perhaps underestimated how difficult the adolescent period was. Parents often realised that they had unmet needs, mainly as the little information regarding support was for their child, and not for themselves. For this reason, some parents went to seek support on their own.

I've not had any information about talking about me or any details for support for parents. As I mentioned previously we've only been to see a GP once and not had any other appointments or heard from anyone else. He has received great help online which is the main thing, but is it selfish to say I might need someone to talk to too? (Joanna).

The narrative highlights that health care professionals have underestimated the support needed for parents, such as Joanna, as no information about support services were offered. This is something common across all participants' accounts. Joanna struggled to make sense of her needs, because she questioned whether her need for support was considered selfish. Although Alex's needs were important to Joanna, she also questioned the guilt she experienced from this emotional paradox. As highlighted, when asked, parents frequently said they would ask for help but usually described this in the context of their child's needs, rather than their own. When I tried to understand this experience, I envisaged the saying "putting the kids first".



Moreover, as most parents discussed and focused on their child within these appointments rather than themselves, it could be that parents may not have disclosed that they too need support. The fact that Joanna feels guilty about putting her needs forward may suggest that she has not actively sought support from health care professionals within the appointment. Perhaps this again ties in with the expectations placed on health care professionals. Joanna may have felt as though the health care professionals should follow-up and ask about her needs, and recognise that parents also need support, rather than Joanna asking for help herself. Furthermore, it also ties in with the unrealistic expected personalised care, in which follow-ups and appointments should be made by health care professionals to "check in" on patients. Thus, there was also a fluidity regarding responsibility in this narrative, in terms of, who was responsible for checking the needs of both the child with alopecia and the parents themselves.

This notion that parents may not have disclosed their distress has been supported by the perception that they "need to remain strong". Releasing their emotions was done privately, away from the child. Stacey for example, showed the conflict parents experience, as they discussed their desire for their child to be open about their true emotions but concealed their own true feelings. It was clear that parents needed help; however, they were unable to release their true emotions in front of their child:

I get a knot of emotion inside that I try not to show as it would just make him feel worse. We have those occasional nights where he cries because he doesn't want to go to school (because of the other children who pick on him). It's hard to hear all these things and I just have to sit there and listen to him because I know it is hard for him to tell me his feelings. Inside I am torn up but if I let him see it, he wouldn't have felt comfortable talking about. That's the type of boy that he is, would have made sure I am ok because he is such a sweetheart. It is him that has alopecia, it is him who has to go through all this, it seems silly for me to make it about me (Stacey).

The need to remain strong was to prevent burdening their child with their own emotional state. Stacey's metaphor of the "knot of emotion" could be taken literally and demonstrates how she felt her emotions through her embodied experience. Despite the physical discomfort the emotion has given Stacey, she does not want to show this pain in front of Stuart. The "knot" was an emotional representation of how Stacey found it difficult to withdraw her emotions in order to protect her son.

The difficulty of staying strong was showed by Stacey stating the word "try", which indicates that hiding her true emotions was not always successful. Stacey's role was to support her son. She had to remain strong as a parent and it was not the right moment in time for *her* to release her emotions. Instead, it was Stuart who had to be supported, whilst Stacey was controlling her own emotional response. It was only when she was in a private setting that Stacey was able to cry. Revealing her emotions at that particular moment of time (when Stuart was crying) would have hindered their communication and may have made Stuart's emotions "worse".

Stacey's awareness of time is demonstrated, as she chose to support Stuart at that particular moment and separated her time to release her emotions away from Stuart. There was also an added sense of guilt as she stated, "it is him that has alopecia, it is him who has to go through all this, it seems silly for me to make it about me". Stacey perhaps felt her emotions were not justified as it is her son that has the alopecia and living that experience. Showing her true emotional distress "makes it about" her and takes the attention away from Stuart. It appeared that remaining strong as a parent seemed to present the focus onto the child with alopecia rather than themselves. For some parents, the need to remain strong was something that had to be done in order to keep an open communication between parent and child. Parents were able to provide their child with the space to release their emotions, express their inner thoughts and keep the focus on their child. Being there for their child and only providing their presence is challenging for parents, especially as they are also experiencing such strong emotions. Parents appeared to create an internal conflict between their need to release emotions and their role to protect their child from seeing them in an altered emotional state. However, parents had to release their emotions.

What was interesting about Stacey's narrative was how she later discussed how she felt unsupported by health care professionals for not recognising the impact the condition had on her and her family:

Nothing was offered for us, yet it was clear how we were upset about it. All that was said was we may have to wait a while [for the dermatologist appointment] because it was deemed cosmetic and not urgent. It was obviously devastating for us to hear and like I said no form of support was offered (Stacey).

The pronouns "we" and "us" implied that support was needed for both Stacey and her son, and this was something which she felt the doctor overlooked. However, Stacey states how "obvious" it was

that she was emotionally devastated, yet the previous extract highlighted how she felt she was unable to disclose her emotions in front of Stuart. Thus, she expected health care professionals to recognise how distraught she was but tried her best to keep this hidden from Stuart who was also present within the appointment. The narrative also highlighted a sense of trivialisation given how the condition was deemed "cosmetic", yet throughout these narratives, the reader can see that the condition is far more "urgent" than that seen by health care professionals.

Whilst they experienced a lack of perceived interest and support from health care professionals, parents discussed how their family came together to provide support and make decisions. An example of the family coming together and receiving emotional and practical support was shown by Lucas:

I know it affects her but we are trying to stay strong as a family and not let this get us down. We have to because we know it won't make Isabelle's condition better if we collapse under the strain. We try and have a very matter of fact attitude and continue life as normal as possible (Lucas).

The sense of togetherness is captured by his use of "we" and "us" to highlight that this particular experience was shared by his whole family. The desire to continue as normal as possible as a family unit shows that staying strong was the best thing to do. This was further shown by his narrative: "if we collapse under the strain", which indicates the dependency placed on each family member. If one member "collapsed", it would make it difficult for Isabelle to cope with the condition, which in turn would make it difficult for Lucas to cope. The narrative by Lucas highlighted how support from family can ease the parent's experience of having a child with alopecia.

Similarly, Anna stated how her mother provided emotional support that allowed her to make sense of how she was coping with the condition.

I think I became aware of how much I was carrying on my shoulders I was doing too much, I was looking after the kids, looking after Danny looking, looking for support for Danny, looking for new treatments, going to work, coming home and supporting his sister. I spoke to my mum and she just told me to really break it all down, really take time away for myself. It was just really nice to talk to her and it helped me see things differently. (Anna).

For Anna, breaking down her experience into smaller manageable pieces made her aware of the different aspects she was taking on. At this moment, Anna focused on the alopecia and how this impacted her social world. It may be that parents who can "*break*" down the experience would help them make sense of the condition. Anna supported her whole family and her role as a mother was to provide emotional support for her son. There appeared to be a linear movement in which Danny confided in his mother Anna, and Anna confided in her mother for emotional support (the mother provided the emotional support in each case). Speaking to her mother enabled Anna to reflect upon her experience and make sense of it by seeing things from another perspective.

Overall, the theme "'it's JUST alopecia': health care professionals trivialising the condition" demonstrates how parents experienced dismissive or insensitive encounters with health care professionals that further exacerbated their unpleasant emotions. As a result, parents were left feeling unsupported and let down. This is surprising given how the previous theme demonstrated how powerful these emotions were experienced (see 4.1). The findings highlight that health care professionals need to be aware of, and recognise the importance of hair, and how having an child with alopecia can be emotionally devastating. Another critical finding within this theme demonstrated how wigs, although offered, may not be suitable for adolescent boys with alopecia. This suggests that there were gendered aspects regarding wig management.

#### 4.3. Theme Three: Needing to Protect the Altered Appearance

The final super-ordinate theme explored how the adolescent looking different could be particularly challenging for parents, often leading to a change of identity of their child or a significant altered appearance. The parents shared their child's distress, especially because the impact of "others" in their social world was so direct. Parents stated how the bullying, staring, and comments left them feeling helpless. This, in turn, made them want to protect their child at all times. Along with this, parents also had to comprehend the change of their child looking different, which intensified their feelings of worry and guilt. "Needing to protect the altered appearance" therefore captured parents desire to be as "normal" as possible, not only for the adolescent but the participants themselves, a concept highly rooted within these experiences. For some, the change of losing hair was difficult to comprehend. Furthermore, some parents described how losing the hair on other parts of the body was equally devastating. As I began to unravel the experience, I could see how social constructs and

pressures from the parents’ social realm underpinned, and steered parents towards how they perceived and experienced the condition.

#### 4.3.1. Wanting to Protect the Child from Their Peers

This theme encompassed the need for parents to protect their child who looked visibly different compared to their peers situated in their social world. This need to protect went beyond the broad spectrum of parental protection, but instead specifically stemmed from the social pressures when both parent and adolescent left their private realm at home. Experiences such as parenting have a different impact, depending on the broader social context. In this case, the staring, bullying and comments alluded to the greater need to protect their child. Parents felt that they should shield them (by acting as a physical barrier) or cover the alopecia (by using wigs and hats).

Many parents described their need to protect their child at all times, even when this may have been unrealistic:

When I used to drop Hannah off at school it was so hard every time because I wanted to protect her at all times and I felt helpless because she wasn't with me. One time I dropped her off and a teacher happened to say to me "Morning Amanda are you OK" and I broke down in tears. You want to just make sure your children are ok at all times, that no one will say anything to hurt or upset them (Amanda).

Hannah being physically present with Amanda’s care allowed her to fulfil her protective role as a mother. The narrative also demonstrated how Amanda’s sense of helplessness was dependent on Hannah’s presence. The perceived failure to protect her child and the sense of helplessness resulted in Amanda breaking “down in tears”. The term "break down" implied a disintegration of something which crumbled into smaller pieces. This could have perhaps captured Amanda's perceived emotional coping, something which was whole and together before, was now scattered through her tearful release. The release of emotions further captured Amanda's coping through her response to a question which does not usually result in crying. Such a response could have highlighted that Amanda was not in control of her emotional breakdown. Amanda described her need to protect her child in first person narrative "I", which then changed to second person narrative "you". The use of second person included myself as an interviewer, as though she was appealing to me by attaching her own

opinion to "you", as if asking for confirmation of her actions and suggesting that wanting to protect her child is a universal response of motherhood. A number of parents stated how their social worlds contributed to their meaning-making process. In Amanda's case, it was the anticipation and worry of the school environment that formed her sense of protectiveness.

This sense of protectiveness highlighted by parents, further adds to the "role" these mothers experience. Mothers traditionally serve as the primary caregiver who establishes a parent-child bond, safety and comfort for their child (Mallers, Charles, Neupert, & Almeida, 2010). When this was compromised, parents resorted to wishful thinking, often with extreme measures. Gemma, for example, felt highly cautious about the reaction of others and so avoided stepping into her social realm:

Everyday life changes because you can't go anywhere because of the staring. This makes me more protective and quite often on guard. I want to wrap him up and run away from the unkindness of the world and just be us as a loving family (Gemma).

Gemma's role as a mother was to protect her child; however, she stated that pressures from her social world made her "more protective". I envisaged her need to "wrap him up" as a mother wrapping up a new-born baby in a blanket to provide comfort and warmth. This perhaps reflected how Gemma views Sam, as a baby who needs his mother to support him. Her need to wrap up Sam could also be interpreted metaphorically, as the wrap could represent a shield from the "unkindness of the world". Gemma also stated how she wants to "run away", as it appeared as though unkindness from others and the need to protect her child were encouraged by her desires to escape. This need was reflective of Gemma's wishful thinking, as she wanted her family to be isolated from the rest of her social world. Gemma's state of Being-in-the-world was dependent on her family being together, away from the social pressures that provided her with a sense of relief about Sam's alopecia. Gemma doesn't exist as a single entity since becoming a mother, she is part of a symbiotic family unit. Wishful thinking was a shared experience amongst parents. This is the combination of forming beliefs and decisions according to what might be pleasing to imagine, however, it is not something which is evidenced or a reality (Siegel, 2017). For Gemma, to take away her child from the rest of the world cannot rationally be regarded as justifiable, so she experienced wishful thinking as a way of coping.

Parents felt the school was beyond their control and a distressing issue. Although parents wanted to protect their child from their peers, they were unable to do so when their child was at school. This, in turn, left them feeling emotional and helpless. Participants discussed how bullying had become one of the main struggles of their experience, as they try to support their child whilst also dealing with the emotional and psychological impact it had on them.

Stacey stated:

School has certainly been the main difficulty that Stuart has with his alopecia. More specifically, the cruel bullying from kids at school has been the most upsetting and troubling aspect of it all. It upsets me greatly and I worry constantly about what sort of day he is having at school. I just don't think they understand how much it takes for him to build up the strength to go into school, all they see is a child who has no hair so isn't normal to them. He gets called Voldemort, Dr. Evil it's honestly devastating -Stacey.

Parents discussed the emotional struggles of the adolescent which was experienced privately at home: "I just don't think they understand how much it takes for him to build up the strength to go into school". This perhaps indicated why parents experienced emotional distress, because they witnessed their child being upset as a result of the bullying. Parents saw their child build up their strength, only to see it shattered again once they went back into school. There also appeared to be some form of sense-making process, where Stacey tried to understand the other children's behaviour by looking through their lenses, as highlighted by the narrative, "all they see is a child who has no hair so isn't normal to them". However, the comments made by peers was also interesting, especially given my literature review highlighted that we situate within an appearance-obsessed culture and there are also symbolic and cultural meanings attached to the hair. Being called "Voldemort" or an "egg head" added to this concept that hair loss is described amongst our culture as negative. Popular books and fairy tales such as Harry Potter, with 500 million copies been sold worldwide, were presented to adolescents at times when they were ready to remember and understand them. Growing up with the stories that bald characters resembled aliens and bad people, could make adolescents feel as though those who did not have hair were bad characters, and therefore excluded adolescents with alopecia amongst these "evil" characters. The whole experience was called "devastating" to capture how highly destructive and damaging it was for her.

Similarly, Gemma described how the impact of bullying impacted all areas of her lived world:

"He stopped sleeping properly, was in a state of sheer terror going in to school every day, and was utterly depressed. I would stay up with him talking until 3/4am in the morning and we would both be shattered the next day. Every time he told me about someone saying something to him at school my mind went into overdrive and it actually made my blood boil. I just didn't understand how they could be so cruel over someone having no hair. I wanted to go in with him and sort the kids out myself, really kick off about it and just make them stop."  
-Gemma.

It appeared that in both narratives, parents observed the emotional struggles of their child away from the school environment. The impact of bullying was experienced by both parents and adolescents as Gemma highlighted how her everyday routine became affected by her son's emotional state: "I would stay up with him talking until 3/4am in the morning and we would both be shattered the next day". This demonstrated that having an child with alopecia could be physically and emotionally exhausting. Gemma's anger was intense in this narrative as she described how she experienced an internal bodily turmoil ("it actually made my blood boil"). This embodied experience signified an uncomfortable intense heat, and the uncontrollable nature of her anger as she stated how her "mind went into overdrive". Both metaphors captured how Gemma experienced the process of understanding and explaining through her description. The concept of a mind going into overdrive often involves a state of intense activity, where information and thoughts come to the forefront at a rapid pace. It can be uncontrollable and difficult to focus when in this state of overdrive, as thoughts can be cluttered and cloudy. This, tied in with sleep exhaustion, could make it difficult for Gemma to cope, and could perhaps hinder her sensemaking process of how to deal with the bullying rationally, as shown by the narrative: "I wanted to go in with him and sort the kids out myself, really kick off about it and just make them stop." Moreover, the statement highlighted Gemma's desires to protect her child from bullying, by stepping in herself. As well as the need to protect, Gemma also felt the need to defend her son from others, almost as though she wanted to shield her son from the outside world, even when this may not be realistic.

Parents tried to manage an ideological dilemma produced by their cultural norms of hair, which in turn, heightened their need to conceal the alopecia. Thus, individuals may have to try and make sense of, and manage, how hair has been presented within their cultures. For example, the hair loss being a



signifier for a cancer illness, or body hair on men and hairlessness bodies on women. As highlighted within my literature review, (see 2.1) and as my themes have demonstrated, the data often depicted hair as a "normal" phenomenon, something which everyone should have. Having a child with alopecia meant that parents often experienced stares, comments and bullying from their peers, because of this perceived "abnormality". References to evil bald-headed characters in the media demonstrated the symbolic and cultural meanings attached to the hair, with representations of Voldemort and Dr Evil as being bald. This shows the reader how this creates negative imagery for adolescents who lose their hair and how this can impact their parents.

For some parents, seeing the alopecia was preferred to stay within their private realm. This has been shown by Jenny, as although the alopecia was visible at home, she "made sure" Danielle left the house with the alopecia hidden.

It didn't stop us going out but I made sure Danielle went out shopping for example with a head band on. I found myself looking at people and noticing people's reactions more once they'd noticed Danielle's hair. The first 18 months or so were the hardest learning to deal with something like this (Jenny).

Jenny felt uncomfortable leaving the house without covering the alopecia. She began to notice "others" within her social realm, almost as though their reaction was already anticipated before they saw Danielle's hair. Due to her anticipation, Jenny "made sure" the alopecia was covered, something which must be done to act as a form of protection, not only for the adolescent but for her own sense of relief.

Other parents described the difficulty of managing the wigs:

When she gets a new wig ( as she did this week) I always want to cry because she looks pretty much normal for a while ( if the colour is right!) Coming out of school her friends have all got lovely hair, ( all but one, very long hair) and she just looks not right. The wigs dry out and look unkempt..and just not like her own hair (Jessica).

Crying appeared to facilitate a feeling of relief as a result of the wig. This desire to cry was out of the ordinary because it was happiness, as opposed to worry or anger, like other parents. This, therefore,

showed that the wig held a significant meaning, and that covering the alopecia was needed so Jessica could regain a sense of normality for her daughter. However, parents also stated how wigs were difficult to style, expensive and over time did not look real. The relief of wigs, therefore, could be a temporary feeling, as shown by Jessica's later statement, "the wigs dry out and look unkempt..and just not like her own hair". It was difficult trying to comprehend how unusual Jessica's daughter looked compared to her friends. Comparing her child to others, often made the difference in appearance appear even greater, almost as though if Jessica was alone, she might not have noticed. It was apparent that comparing the hair did not comfort or make Jessica feel better, but instead was a reminder of how different she looked. However, the social comparison amongst peers could provide an insight into why Jessica made the choice to hide her daughter's alopecia, given that seeing those of a similar age with hair was "normal" because this was embedded into Jessica's cultural ideal.

The notion of covering the alopecia to stop the pressures of their social realm was common amongst most parents interviewed in the study. Interestingly, there appeared to be a variation in what deemed as an acceptable amount of hair loss as highlighted by Alison:

When it was smaller it was easier for us, but now because it's become so bad we constantly had people looking at us and making comments. We had to get her a custom-made wig to make it look as natural as we can. It's not as if she was a boy and could get away with it!  
(Alison).

More severe forms of alopecia evoked moral judgment from their social realms. It was as though insignificant hair loss was easier to cope with because it was less noticeable, and people didn't see the alopecia or comment on it. What was interesting was that there appeared to be (according to Alison) more flexibility for boys in terms of "getting away with" having alopecia. Unlike for girls, where judgment is high, boys appeared to manage their alopecia easier in Alison's opinion, again perhaps rooted within these norms. We can also see the need for hair to look "natural". Hair has been described as a natural phenomenon (see 4.3.3), thus in order to lower scrutiny from others, there was an increasing pressure to conceal the alopecia. This went beyond receiving a synthetic wig through the NHS, but instead, going through more expensive routes to make the wig look more "natural". Again, this may link in with the social pressures experienced by parents, and the need for the alopecia to remain hidden as much as possible.

Using wigs and covering the condition made the adolescents feel safe and enabled parents to feel as though their child was "normal" again. This pressure to use wigs and hats derived from parents noticing social reactions around them, especially their child's peers. My analysis also demonstrated that cultural ideals might have also driven parents' desire to conceal. The quote by Alison adds to this concept that alopecia could be a gendered and cultural experience. It appeared as though some parents held this view that having a bald head may be easier for boys, because of the perception amongst our culture of baldness being more apparent in men amongst our society (see 2.1.4). This implies that parents with an adolescent boy did not have to go to these lengths to hide their alopecia. Overall, however, the theme demonstrated how parents hold meaning and importance to their child's wigs to regain their sense of normality and help them cope with the condition.

#### 4.3.2. The Struggle to Comprehend the Change

Some parents experienced feelings of shamefulness when they saw their child without a full set of hair, only to feel even more shame when they realised how distraught they were over the visible change of appearance. Although this particular subordinate theme was not universal across participants' accounts, the narratives by both Jessica and Alison both portray a powerful experience of an altered appearance change. This was recognised in Jessica's narrative:

I have thought and thought about this and I dont want to have to admit that I was distraught, but I was distraught. She looked so forlorn, and she looked so unwell/ poorly, I was distraught. (Jessica).

From this extract, it was identified that Jessica had a difficulty in admitting to herself that she was distraught about Josie's appearance change. The repetition of "distraught" emphasised how Jessica's thoughts had taken over and held more meaning than being simply worried or upset. Moreover, the difficulty of admission was also showed by her ruminative thinking "I have thought and thought about this", which highlight a parent's struggle to comprehend the change. When describing her daughter's alopecia, Jessica stated the change in her daughter's appearance as akin to an illness, "she looked so forlorn, and she looked so unwell/ poorly". This perhaps links with the notion that participants associated a loss of hair with cancer or an illness embedded within the cultural significance of hair (see 1.1). Such imagery would be highly emotional for a parent to witness their child with hair loss.

To some participants, the change in appearance became a grieving process for their child who once had hair:

I Did feel terribly upset - rather like my daughter had died and now there was a different child living with us. It gave her a new identity and I felt really confused. She was absolutely Sarah BUT somehow she wasn't. I felt, for many years, as if I had lost something and was looking for it (Alison).

Alison struggled to come to terms with the physical change of her daughter's appearance. To Alison, this was described as the loss of a child, in which she was grieving for her child who had hair. Alison described the conflict in which she acknowledged her daughter's presence, but she struggled to make sense of the physical change because she felt as though her daughter was replaced. This was not only been described as a loss of a child, but also a loss of self as she highlighted how she spent many years searching for something which had become a part of her. This, therefore, could be a physical loss, something which Alison was looking for. It perhaps represented the absence of something which she is not complete without. Thus, hair loss was likened to not only to bereavement of the hair, but of their child themselves.

#### 4.3.3. Not Just the Head

This theme captured how having hair was defined as a “normal” phenomenon that was a biological extension of the human body. Furthermore, hair often was described as an essential quality of both masculinity and femininity. This was shared by Gemma:

It's just hard because it wasn't just the head he lost it from. Having hair is supposed to be a natural part of being a man and this was taken away from him, and I know this will impact him not only now, but when he's older and getting into relationships, things are never going to be normal for him again (Gemma).

Gemma's narrative highlights how the hair was a "natural" phenomenon and how losing hair took away her sense of normality. Amongst the participants (fifteen), the loss of normality was described in some way by over half of the parents. Gemma saw hair as representing masculinity, and that taking away this aspect of masculinity would make things difficult for her adolescent child growing up. Whilst

we were unable to speculate what specifically Gemma was referring to in this narrative when she discussed the "impact", this, alongside "being a man", alluded to the notion that she was referring to relationships. The prospect of future relationships was something mentioned by other participants ("I worry if she would ever find a husband or have kids"- Alison). Such narratives demonstrate how the hair was linked with sexual attraction. These parents recognised the lack of body hair and alopecia as a whole and was a critical factor in making sense of sexual attraction. Normality then goes beyond the loss of hair, but the loss of relationships, masculinity or femininity, and loss of the future. Normality and loss appeared to be intertwined in this narrative by Gemma.

The notion that hair was described as "natural" for boys highlights how having hair is a significant expression of a masculine embodiment.

Yes, we may not have a normal life, but it doesn't make that a bad thing. We try to focus on the other things which make her beautiful... you may not have hair but you are kind hearted and warm and at least you don't have to shave your legs! (Amanda).

Interestingly, while Gemma's narrative described how hair is considered a masculine concept, Amanda demonstrated an awareness of her daughter's need to conform to norms of femininity. This brought light to how both boys' and girls' bodily hair were of a complete contrast within the realm of society. Women as a whole, have less visible body hair than males (Dixson & Rantala, 2016). Boys have a biologically-located embodiment, evolutionary producing more hair than girls, whereas girls have a socially located embodiment, something which they have to work on to create a "hair-free body" (Terry & Braun, 2016). It was also interesting that despite Amanda stating how they tried to focus on other things which make her beautiful and her internal attributes, she brought it back to the alopecia by referring to how she does not have to shave her legs. Whilst other parents negatively described a loss of normality, Amanda tried to put a positive outlook on the loss by highlighting this.

This theme, in particular, was interesting given how parents discussed how the loss of bodily hair also caused worry and upset, often being referred to as a loss of masculinity or femininity for their child. This experience of loss also transcended into experiencing difficulties in relationships and helped me explore how cultural meanings and sexual attraction can understand hair loss. Whilst such experiences regarding hair were discussed by parents, it would be interesting to develop this further and see whether adolescents too share these same thoughts. Nevertheless, the loss of bodily hair has been regarded as a fundamental sense making process for my participants.

#### 4.4. Summary of Parents' Experiences of Having an Adolescent Child with Alopecia

Overall three main themes were detailed following the analysis of 15 parent interviews: "the hair is coming out": living the emotional turmoil of hair loss , "it's JUST alopecia: health care professionals trivialising alopecia", and "Needing to protect the altered appearance".

Parents expected a certain level of care which was not perceived to be fulfilled in reality. Participants own expectations and experiences with health care professionals guided them towards their assumptions about how they and their child, should be treated. This was with care, empathy and no judgement. However, within the sub-theme "who is the expert", the expected roles and behaviour was not what they anticipated. Instead, parents experienced a long wait, lack of responsibility and a lower level of care that was impersonalised. This was shocking for parents given the age of their child, the severity and the rapidness of the loss. Again, expectations of the way health care professionals should behave perhaps stem from parents own experiences which align with the code of conduct given to health care professionals, that is, to provide care, provide information and be empathetic (General Medical Council, 2014) as opposed to trivialising the condition.

There was a great need for parents to be supported, especially considering the complex range of emotions that participants experienced. Parents, as highlighted, expected a high level of personalised care, and when they did not experience this, parents felt unsupported. Within the theme, we can also see that no form of support was offered to parents who had a child with alopecia. However, as I unpacked this, I began to question whether parents had asked for support, or whether it was expected from health care professionals to know themselves that help was needed. This perhaps was why there was great importance placed upon the family in providing support (relationality). In particular, we can see the role of "mum", as being the one to provide support. This was particularly interesting within Anna's narrative (see 4.2.2) as there appears to be a linear pattern. Danny received support from Anna when he was upset, and Anna received support from her own mother. Again, within this theme, we see how mothers provided protection and made their child feel safe. It was also interesting that Lucas' narrative focused on keeping a matter of fact attitude and not collapsing under the strain. Whilst Lucas was the only father in the narrative, it could be that the mothers provided emotional support, including the need to protect their child and make them feel safe, whereas fathers had more of a role in influencing an adolescents' perceived capabilities to manage and adapt to new challenges, such as

coping with the condition. These results could demonstrate a potential gendered experience in how parents cope with the condition.

Concerning the data, to suggest that adolescents should conceal their alopecia to conform to particular aesthetics and norms is socially problematic. However, there appeared to be considerable pressure from parents to do so. The reason for hiding their child's alopecia varies; however, others within their social realm such as their child's peers, created an idealised position surrounding their decision to conceal and strive for normality. Thus, to what extent does hair place upon the perception of "normality"? This can be understood by Schutz (1976, pp. 7-10) who states, "We perceive, experience and understand in accordance with normal and typical structures, models and patterns, which previous experiences have inscribed in our subjective lives" (Overgaard & Zahavi, 2009, p. 13). This could help us try to understand why parents who had a child with alopecia experienced a great loss of normality and experienced pressure to conceal their child's alopecia in an attempt to look "normal". Perhaps within their subjective world, they have only encountered adolescents who have a full set of hair. Thus, alopecia did not necessarily fit in with their "normal" and "typical structure" of what an adolescent should look like. Again, this may be rooted by social and contextual meanings of hair, especially given some often likened the hair loss to an illness, for example, "she looked so unwell/poorly" (see 4.3.2). Such a narrative could have been formed by their previous experiences inscribed by their subjective lives that hair loss is associated with cancer. A particularly powerful experience amongst the parents' narratives was how the loss of hair was interpreted as a grieving process. This again demonstrates the significance of hair, and how identity can be stripped away from a child, causing loss and confusion for parents.

This concept of gendered experiences can also be highlighted with the theme "not just the head", as we can see a clear distinction between masculinity and femininity. This was particularly when it came to the ideology of body hair, in which hairless body was viewed as a feminine concept, and hair on the body was viewed as masculine. The theme "not just the head" (see 4.3.3) demonstrated how this could tie in with the perceived pressures by society to look a certain way (e.g. women to be hairless on their body, and men to remain "hairy"). Another gendered aspect highlighted how the experience of managing the alopecia was also dependent on the gender of the child. Within parents' narratives, some highlighted their thoughts on how it would be "easier" to manage the hair loss if their child was a boy, "it's not as if she is a boy and could get away with it!" (Emma). This suggested that parents may feel more pressure to conceal their child's alopecia because they are a girl. Such thoughts could be

understood by the ideology that baldness in men is more common, (see 1.1) which created the perception amongst parents that it was an "easier experience" for boys. However, whilst girls can conceal their alopecia by wearing wigs, another gender issue highlighted how boys could not. Monica's experience especially demonstrated that although offered by health care professionals, wigs were rejected because of gender (see 4.2.1). Overall, these findings highlighted how alopecia could be a gendered experience.

The following chapter explores the adolescents' experiences of having alopecia. Although this is a separate data set, the chapter conclusion will aim to draw in the key findings across parents' and adolescents' accounts. By doing so, I will highlight a number of issues that were raised by both samples and highlight the key findings in a way that throws more light on the issues.



## Chapter Five: Adolescents' Experiences of Having Alopecia

The 15 interviews resulted in the development of two super-ordinate themes, "experiencing exclusion and acceptance in peer relationships" and "covering up and coping with an altered appearance". Table 5.2 details an overview of the super-ordinate themes, sub-ordinate themes, and sub-themes that captured the lived experience of adolescents with alopecia. Whilst I concentrated on three interpretive themes within the parental data set, the two themes captured by the adolescents provided a rich, deep understanding of what it was like to experience alopecia. These themes will be discussed further, drawing in crucial issues such as the gendered experiences of alopecia to form my conclusion.

Table 5.2. Adolescents' super-ordinate theme, sub-ordinate themes, and sub-themes overview

Super-Ordinate theme	Sub-Ordinate Themes	Themes
5.1. Experiencing exclusion and acceptance in peer relationships	5.1.1 Being unable to conform to expected norms of appearance amongst peers	5.1.1.1. Feeling judged 5.1.1.2. Challenges of wanting to fit in 5.1.1.3. Being "relentlessly bullied" 5.1.1.4. "I didn't look cute anymore"
	5.1.2 Friends being "my rock"	5.1.2.1. Carrying on as normal 5.1.2.2. Offering practical and emotional support 5.1.2.3. The need for peer support
5.2 Covering up and coping with an altered appearance	5.2.1. Trying to hide the alopecia	5.2.1.1. The difficulty of hiding the patches 5.2.1.2. Repairing the altered appearance 5.2.1.3. Beauty is pain
	5.2.2. Managing the emotions	5.2.2.1. Experiencing the merry-go-round 5.2.2.2. Learning to accept the condition 5.2.2.2.1. Using humour to cope 5.2.2.2.2. Understanding the condition 5.2.2.2.3. Seeking help from others with alopecia

### 5.1. Theme One: Experiencing Exclusion and Acceptance in Peer Relationships

A notable feature of the participants' accounts was the experience of peer relationships which all participants discussed in great depth. Peer relations, such as peer acceptance and friendships are meaningful experiences which support adolescents' sense of belonging (Gooren, van Lier, Stegge, Terwogt, & Koot, 2011). However, having alopecia can impact this perception of belonging, especially when they experience negative behaviours from peers.

Participants felt very self-conscious and often worried about being judged. Whilst they felt conscious around others within their social realm, it was amongst their peers that they felt the most aware of how visibly different they looked. Thus, the sub-ordinate theme of "experiencing exclusion and acceptance in peer relationships" is concerned with adolescents' struggle of conforming to expected norms of appearance amongst their peers. In particular, the key issues were: worry of how their peers would react to their hair loss, wanting to fit in with their peers, feeling the odd one out within peer groups, being bullied, and changes in one's sense of self and attractiveness. The adolescents interviewed in the current study were the only ones in their school with alopecia. This meant there was a heightened sense of difference amongst their peers, which furthered their sense of alienation. Another distinct feature of their experience was being bullied. Whilst remaining close to the data, the bullying experience captures how severe and extensive the bullying was for these adolescents. Priya's narrative "I didn't look cute anymore" summarises how adolescents felt a change in both their appearance and perceived attraction. All of these experiences captured the difficulties associated with the inability to live up to normative ideals of appearance amongst peers.

Adolescents also discussed the importance of friendships. In particular, there was a tension between the supportive and unsupportive aspects of relationships with peers. Friends being "my rock" derived from Anna's narrative, "my friends became my rock, I wouldn't have been able to do it if it wasn't for them." This demonstrates the importance placed upon friends and how they coped with their condition. In particular, friends were often praised for "carrying on as normal" when adolescents lost their hair and "offering practical and emotional support" such as providing advice with wigs and hairstyles. Some participants also expressed their "need for peer support", especially from those with the condition, to alleviate the loneliness experienced. These experiences capture the notion of friends being "my rock" and the importance of peer relations within the super-ordinate theme "experiencing exclusion and acceptance in peer relationships".

### 5.1.1. Being Unable to Conform to Expected Norms of Appearance amongst Peers

Many adolescents often experienced concern as to how their peers would react towards them when they saw their hair loss. There appeared to be a process of reshaping identity (highlighted later within 5.2.1) with the participants themselves realising how much of their identity was shaped by their perceptions of their body image and subsequently, how much of that body image perception was dictated by their hair. For some, there were challenges around transitioning into high school and college. For others, there was a worry of comparison from their former appearance. All of which contribute to the experience of "being unable to conform to expected norms of appearance amongst peers." Throughout the chapter, however, it appears that there was an increased preoccupation with managing one's looks because it could impact how they are treated, how they fit in, how they are identified by others, and their overall sense of belonging. In particular, how adolescents perceive others view them, and how they view themselves.

#### *Feeling Judged*

One key finding within the adolescents' narratives was a sense of feeling judged by their peers. For example, Georgina felt she would be compared to her former appearance:

So for me I think the reason why school was the hardest part was because everyone there knew what I looked like before - it's like that sense of real judgement as walking down the street no one would have known I had long blonde hair before looking like my current hairless self, whereas at school everyone saw my hair fall out and the journey I went through whilst it was falling out. I think it was more about my self pride in my appearance- I found it hard that people saw me change and probably compared the two appearances (Georgina).

The school environment could be a particular challenging aspect for adolescents who experience alopecia. This is because other than the home, the school was where adolescents interact with other individuals frequently (Eccles & Roeser, 2011). Peers at this particular age may be more likely to make this comparison because of the importance placed on how they look. Adolescents often experience bodily changes which are not in their control and so physical appearance becomes a primary concern (de Vries, Peter, de Graaf, Nikken, & adolescence, 2016). This was highlighted by Georgina's views of her own appearance, "I think it was more about my self pride in my appearance". The narrative suggests, that she no longer had this sense of self-pride because her hair appeared to be an essential

feature of her appearance and her overall alopecia experience. The impact on identity (discussed further below) and sense of judgment is further heightened as peers are able to see physical representation of the condition through the patches of baldness, "people saw me change and probably compared the two appearances". This may be why the school was seen as the "hardest part" of Georgina's experience. Having individuals know what their former appearance looked like may be difficult for adolescents who go through an appearance change. There was a heightened sense of "judgement" which sometimes resonated into feeling scared.

Another common experience shared by adolescents was their difficulties concerning fitting in and their struggle to find where they belonged within their social circle. Thus, capturing the theme of "feeling judged". This experience was caused by their sense of differentiation from their peers. The challenge of wanting to fit in often resulted in feeling isolated and heightened their desire to be "normal".

Adam, for example, conveyed the sense that his appearance singled him out from his peers. He was scared of going to school because of what his peers would say:

i was scared because i had no idea how to respond to the questions and i also felt different to everyone else and at that age it was not normal for me to not have a full head of hair. Being the only one with alopecia was hard because i stuck out like a sore thumb. it was really hard at first to get used to being the only one with no hair and i really didn't like it, i just wanted to be normal. (Adam).

Adolescents experienced a huge anticipation of going into school when the majority of their hair was lost. This has been captured by Adam's narrative "stuck out like a sore thumb" to emphasise the noticeable difference of appearance, that being, he looked different to his peers because he had no hair. Although a common phrase, it also highlights the uncomfortable nature of being amongst his friends and not being able to blend in. It is also interesting that Adam used the discourse "felt" different, rather than "*looked*" different. This implies that there was also an internal change, capturing the re-shaping sense of identity. Adam may not have had the resources to deal with his condition, as he stated, "i had no idea how to respond to the questions". This also signalled his lack of capacity to cope with the questioning from his peers. The whole narrative was underpinned by the desire to look normal and fit in, which was common amongst all participants. Being the "only one" with alopecia

meant that adolescents felt as though they were separated from their peers in terms of their appearance. It also demonstrated how their experience made them feel as though they were alone. This will be explored further in Hannah's narrative. Adam also states that his experience is out of the ordinary based on his age, as though if he was older, it would have been easier for him to blend in amongst his peers. This led me to explore whether there appeared to be a gendered and aged difference in coping styles. Adam's narrative implied that being an adult with alopecia was more "normal" because he perceived baldness in older men to be typically more common. This is further supported by Liam who stated: "I guess if I was older it wouldn't be as bad because you see a lot of older men without hair and you can just say it's because of age." Society's perception of baldness is that hair loss is associated with age rather than an illness, and the notion that the older you are, the more likely you are to lose hair (Cash, 2001).

Laura discussed how her appearance appeared to be policed by her peers:

So I guess at secondary school everyone has a very similar look, and everyone wants to look that way so they fit in. This meant girls had to have nice long hair, rather than no hair at all. I was the only one in the entire school with alopecia. So I felt different and a little like I didn't fit in with the style guide as such (Laura).

Laura stated that she found it hard to know where she fitted within the existing "style guide". Not being able to fit into this mould heightened her sense of difference as she stated how her peers had a "very similar look", almost suggesting the need for uniformity. An interesting find was the notion of peers mirroring each other's look. The majority of female adolescents within the study suggested they needed affirmation or approval from their peers, as they tried to mimic their friends' appearances and makeup choices. Girls stated how they often used to wear accessories and have similar hairstyles to their friends. This has been shown by Danielle, as she discussed: "all my friends have long hair with full fringes, everyone at school used to say we looked like sisters". This captures how having the same hair style made participants feel part of a group, that in turn, became a part of their identity and sense of belonging. There was a reference to a perceived "normal" image and how this related to "attractiveness". Whilst this was a shared appearance, the "norm" can be very different in sub-cultures such as goth, punk and geek. Thus, there was an emphasis on shared similarities and a community of sameness. Taking away a participant's hair could, in essence, take away a participant's

sense of identity. This is because their perception of uniformity was eradicated, and they lost something which other people previously admired.

### Challenges of Wanting to Fit In

Tying in with the theme "wanting to fit in", adolescents felt as though they were the odd one out because of their difference in appearance from the loss of hair. Hannah illustrates this:

I don't think they understand how hard it is being the odd one out. These people find it so easy to just make friends and be popular, and then there's me who doesn't have the confidence at all. There's an internal battle I have that they don't really see because I look so different than all. I can't just walk up to someone like that, you know? It just holds me back from doing things like that (Hannah).

In the above narrative, Hannah described her non-alopecia peers as "these people" as though she had established her peers as a visible out-group and to emphasise her sense of difference. By referring to them in this way, she also demonstrates the isolation she experienced which was discussed further in her narrative, "sometimes I do feel like I am alone because I am the only one in my school with alopecia". Thus, "feeling the odd one out" may lead some participants to feel as though they were experiencing their condition on their own. Perhaps sharing the experience with someone who has the condition may help because they "understand" how she feels and can demonstrate that she is not alone. This may also allude to why Hannah used the phrase "you know?" when describing her experience of feeling the odd one out. By doing so, it included me in her story and allowed me to coincide with her experience. It created shorthand for her frustration, whilst also implying that unlike her peers at school, there was also a shared understanding between Hannah and myself. This may be because I identified myself as having a relative with alopecia, and therefore she can explain herself to someone who identified as having a relative with the condition and would "know" what she was trying to convey. It may also be because she felt as though peers at this particular age did not understand her, whereas an adult would be more mindful of how she feels.

Hannah implied that a loss of hair was a direct cause of her low confidence and her ability to form new friendships, as though it was her hair which made her popular. The phrase "holds me back" demonstrated Hannah's embodied experience, as though it is a physical force that prevented her from

physically moving forward, whilst her other peers progressed onwards and flourished. This adds to the "internal battle" that Hannah experienced. The metaphor creates vivid imagery of a war where the present version of Hannah is fighting against the old version of herself who has hair and confidence. There was an internal conflict that Hannah experienced where she wanted to develop her confidence, but her condition was stopping her from doing so. It could also represent a battle between approach and avoidance, in which she wanted to approach people and make friends, but she was also avoiding them because of the fear of rejection, something shared amongst other adolescents.

Adolescents experienced some form of disconnection from others in their social realm. This is because most participants felt as though they were the only one who was targeted by their peers because of their hair. Adolescents felt as though they were unable to talk to anyone who was in a similar situation and could share experiences with them. Some stated that no one understood how they felt, further intensifying their loneliness. This has been shown through Hannah's discomfort when she felt alone and the "odd one out" because she chose to no longer participate in gym class or swimming like her peers:

The teacher asked me whether I felt comfortable taking off my wig in front of everyone because they were concerned about them saying something. So I decided not to take part in swimming. I had to do work or other activities instead but sometimes I felt a bit alienated from the rest of the class and a bit lonely, I think that hurt a lot inside. (Hannah).

At a time when being part of a peer group is highly essential, being excluded from activities such as swimming and gym class, only furthered Hannah's sense of being ostracised. However, from this narrative Hannah excluded herself from activities, but she was not excluded by the teacher, demonstrating that this related to her lack of confidence. Being set aside because of her alopecia made Hannah, in her own words, feel "alienated" and "lonely". It is also interesting that teachers noticed the concerns that most adolescents felt about their alopecia (that their peers might negatively react to their hair loss). Raising questions about the safety of Hannah at school reinforced her sense of feeling unsafe, something which was similarly expressed by Louise when she stated, "I didn't feel safe at all" (see 5.1.1) Moreover, repeating the phrase "a bit" to express her sense of isolation appeared to have downplayed, or underestimated, how much emotional impact it truly had on Hannah. This is because she stated how it "hurt a lot inside", something which was not apparent with

the use of "a bit". Furthermore, the use of this phrase showed the struggle Hannah experienced when accepting her isolation from her peers and she was unsure how she felt about this.

Despite feeling the "odd one out", some adolescents felt as though they had to "get used to" the reaction of their peers, often as a form of coping:

it came to a point that I was just so used to them [peers at school] looking at me like I looked SOO different to everyone else, that I just wasn't that upset about it any more (Georgina).

In the above narrative, Georgina explained that she was "just so used to" her peers staring at her. How she described this, almost sounds passive. Using the discourse "just", intensified the occurrence of the stares as it suggests that it happened constantly and becoming "upset" would not make a difference. Georgina was left with no choice but to accept her difference because there was no alternative to stopping the reaction of her peers, or perhaps she became habituated and desensitised to the staring. Moreover, the emphasis on "SOO" which was purposively capitalised and elongated, could have a dual interpretation. Firstly, it could emphasise how the difference in appearance is perceived to be enormous, heightening her sense of "feeling the odd one out". Secondly, it could also be interpreted as sarcasm, perhaps elucidating how the difference in appearance was not justified by the stares, and that her difference in appearance did not make her any more different to her peers. Therefore, peers may have exaggerated their actions by staring constantly. The use of the word "them" also placed Georgina as separate to her peers, which could demonstrate the isolation she felt. However, both interpretations capture the emotional experience of "wanting to fit in".

### *Being "Relentlessly Bullied"*

All participants discussed how some of their peers within school bullied them by physically removing their wigs, name-calling, spreading stories and excluding them. Although some participants did not use the term "bullying", non-physical or indirect comments and aggression caused adolescents great distress. All participants experienced at least one incident of name calling when they were at school. For some participants, the thought of going to school was profoundly upsetting.



A key aspect of Louise’s bullying experience was her sense of insecurity:

I didn't feel safe at all. I was constantly asked where my eyebrows were or where my eyelashes were, I even had a boy grab the top of my wig and yell "pull it off!". It was heartbreaking and I received no help from anyone. From nursery until year 11 I was relentlessly bullied (Louise).

Louise's bullying experience was relentless; especially as it occurred over a long period of time. Whilst some may hold concerns regarding how they would be perceived, Louise's anticipated experience of feeling unsafe and terrified, became fulfilled in reality. Peers had invaded her personal space by pulling her wig, causing a great sense of threat. A vital aspect of the experience was that it was “heart-breaking”. It emphasised the embodied experience which held a strong emotive meaning, given the longevity of her experience. Many adolescents questioned the inadequate amount of help and support received from teachers in terms of bullying. Louise stated she "received no help from anyone" which suggested that schools were not equipped to help with this form of bullying. The negative impact this had on adolescents' willingness to attend school was severe. Many felt as though the bullying carried on, regardless of the school's intervention. This can be seen by the number of years Louise was bullied and the lengthy period of suffering.

The narrative also highlighted the negative impact of wearing wigs. Many girls felt uncomfortable going to school without their wig. Stephanie, for example, stated, "I wouldn’t go anywhere without my wig and made it very difficult when it came to things like P.E, but to me it was like a comfort blanket”. The wig was part of her identity. Wearing wigs at school could potentially aid a participants' sense of security as a source of comfort going into school. The thought of this security "blanket" being taken away by peers could perhaps be another reason why Louise did not feel safe.

As highlighted, adolescents felt anxious about going to school, Chris explained how he felt a sense of dread going into school, even long after he left:

I still remember that feeling of dread knowing that I had a whole week of them saying stuff to me and making my life hell (Chris).

The use of "hell" symbolises how much the behaviour of others influenced Chris' experience, as this word represented the pain and torment he received from his peers at school and could also be a

metaphor for how he portrays his school. The school was an extremely unpleasant place to be when he was losing his hair. The "dread" that was felt by Chris depicts school as something that provoked anxiety every Sunday evening before the "week ahead" had even begun. Time became repetitive as this dread was continuously experienced on a weekly basis. The phrase "whole week" links to his perceived sense of time, as his experience of bullying, became dragging. It is almost as though it was a dreaded, anticipated experience that was fulfilled in reality.

For some participants, being relentlessly bullied was something which remained within this present day:

There was this girl in particular which really scarred me. She told a few people that I was wearing a wig even though I told her in secret and a group of guys asked me in front of everyone in my form. I was so embarrassed, my stomach just sank there and then. Since then I've been called wiggy, baldy, get dirty stares from people. It was my fault for telling her but I don't talk to her now (Amanda).

Many adolescents discussed how they distanced themselves from friends, or ended a friendship, because they felt as though their friends were not supportive. Amanda interpreted the bullying behaviour as being her "fault" despite it appearing to be a purposely public humiliation. There was a sense of disappointment and hurt over confiding in her friend, and a betrayal of telling other people about her condition. For many adolescents, confiding in friends for advice or disclosing their alopecia was common. However, they were only a select few friends during the onset of alopecia that knew about the condition, and for some, it took a very long time to tell their friends about their alopecia. Some participants were still hiding their hair loss from their friends. Therefore, the sense of betrayal and disappointment Amanda experienced was even greater, especially as the opportunity to tell her peers was taken away from her. Amanda uses the discourse "scarred" as a metaphor to illustrate the lasting effects of the bullying. The term "scarred" could represent a mark that was still present in her everyday life, a reminder of how her bullying experience begun, and how she has not come to terms with this experience. She stated, "my stomach just sank there and then", a powerful metaphor to describe the embodied experience of embarrassment. As such, the narrative highlights how the condition could impact friendships amongst peers for adolescents.

"I Didn't Look Cute Anymore"

Another theme within adolescents' experiences was that their condition had impacted on how they presented themselves and maintained an identity as a sexually attractive person. Some girls discussed the future for themselves, their romantic relationships and indeed, the sense that their sexual status had changed. For example, Priya thought that being viewed as the "girl with no hair" meant that others would not find her attractive:

When I got picked on I felt that everyone just looked and saw a girl with no hair and just an easy target. I had a boy who asked me out before say something about my wig as a joke and from that I felt like I didn't look cute anymore. That REALLY knocked me and since then I have struggled talking to any boy in that way (Priya).

Priya acknowledged that she lost her confidence with boys because of her experience. The impact of this was highly emotive, and she described how she views herself differently and finds it difficult to form relationships with any boys. By perceiving herself as "a girl with no hair", Priya has stripped her own sense of identity and demonstrated that her peers did not see herself beyond her lack of hair or name. It appears as though validation of her appearance was determined by her male peers. The emphasis on "REALLY" highlights Priya's struggle and could be taken figuratively. How adolescent girls viewed themselves because of their alopecia could be dependent on perceived perceptions, as it was the comment from a male peer that changed the way Priya felt about herself. As such, the narrative demonstrates that boys (as well as girls) heavily "police" girls' appearance and that some adolescents experienced a loss of identity as a sexually attractive individual.

Anna has shown this:

It was one thing for me to feel ugly, and another for someone else to say it to your face. He made me feel like I was nothing and it took me a really long time to get over the whole thing (Anna).

The male peer reinforced her thoughts of feeling "ugly" which left her feeling worthless and distressed. Participants, male and female alike, generally considered bald patches unattractive, ugly, shameful and disgusting. Most went to great lengths to keep the patches hidden. This further strengthened the notion that the perceptions and behaviours of others influenced how adolescents

viewed themselves, particularly by their peers at school. Moreover, it is apparent that the impact of peers remained with adolescents for an extended period of time. Again, Anna captured how her sense of identity had disappeared by stating that she felt like she was "nothing", almost non-existent because she had lost her hair. Only girls discussed the notion of relationships and how this impacted on how they viewed themselves. This may be because their hair could be viewed as an aspect of their femininity, and the loss of hair meant that their sense of attractiveness had also been lost.

This sub-theme emerged for four of the fifteen participants and was experienced by girls. The potential gendered experience will be explored further within the discussion. In comparison with the other sub-themes of being bullied, and perceptions, the theme did not feature as prevalently as other accounts, however, it did capture the richness and meaning of how peer relationships could be hindered as a result of feeling unattractive and the loss of identity as a sexually attractive individual. As such, it contributes to our understanding of what peer relations mean to adolescents experiencing alopecia.

#### 5.1.2. Friends Being "my rock"

This sub-ordinate theme focused on the roles of friends in making sense of, and the management of, adolescents' alopecia. Although at times, the impact of peer involvement was frustrating as highlighted in the previous sub-ordinate theme "being able to conform to the expected norms of appearance", adolescents expressed the value of the help their friends offered. This was because friends played a key role in helping them cope with their condition, by carrying on as normal, helping them engage in social activities, and providing both emotional and practical support. All participants talked about how these concepts had shaped their experience of support in some way, thus capturing the perceived help within the super-ordinate theme, in which "help" in this context was synonymous with the term "rock". Participants expressed how they felt shame and isolation, both of which heightened the need for peer support. The sub-ordinate theme captured how seeking support from peers could be crucial as adolescents entered their developmental period and illuminated why peer validation was favoured over any adult intervention.

### Carrying on as Normal

As well as providing practical support (to be discussed), some adolescents described the importance of their friends carrying on as normal as they would before they had lost their hair. This sense of "normality" included their friends not treating them differently and not being sympathetic. Knowing that their friends were there for them enabled them to cope with the condition. Some boys described how this was the most helpful support offered:

I just told them that I had alopecia and they made a joke out of it, since that we didn't talk much about it. I liked that they didn't make a big thing out of it, I think that kept me stable the most because we just carried on as normal (Chris).

This narrative highlighted the substantial role friends played in facilitating the adjustment to their condition, especially as carrying on as normal allowed Chris to remain "stable". Carrying on as normal could have helped Chris manage his feelings of difference described earlier in the theme, especially as his peer's response appeared to be viewed as a positive, as opposed to a look of shock as highlighted by many participants such as Jason: "I would usually get the look of shock followed by horror". The narrative also ties in with the concept of wanting to "blend in", like most adolescents within this subordinate theme. This implied that it was something which adolescents wanted the most (to not stand out amongst their peers). There was a great need for adolescents to appear normal, therefore not making a "big thing" about the condition was viewed as comforting. When Chris explained that his friends kept him "stable", I envisaged an image of his friends around him, keeping him secure and sturdy, almost in a structural sense, which is firmly grounded and cannot move or fall. Whilst he may have used this term to describe his perception of psychological state, this imagery also captures how peers can be a vital network of support.

Adolescents' desire to carry on as normal often meant that there was a need to engage in social activities to regain this sense of normality. This was only dominant within male accounts. Male adolescent narratives appeared to be more concerned with social activities, and how engaging with their peers and doing social activities allowed them to remain "normal". Some felt that socialising with their friends emerged as a way of avoiding loneliness:

For a while when I first lost my hair, I would stay at home, and it was easier for me to chat online to my friends on the PS4 than go out anywhere because I wouldn't have to face

everyone. That helped me for a while but as time went on it started to get a bit boring and lonely to stay in the house so eventually I started to go out a bit more with my friends, play football and things like that (Alex).

Alex's narrative demonstrates how some adolescents, during the initial stages of hair loss, had experienced some form of isolation; however, they still had the opportunity to connect with their friends. This was especially useful in helping Alex avoid facing others. This is perhaps why there was a need for online support groups to be made available for these adolescents, because they may have favoured online communication to peers of a similar age, as described later within this chapter. Staying at home and communicating to Alex’s online friends almost served as a protective barrier from the external world. However, as the narrative demonstrated, this was not effective in the long term. Whilst friendships, in a general sense, eases the experience of isolation, it is also important to highlight that engaging in social activities with peers, allowed Alex to go into a world which he avoided for a long time. Adolescents who discussed their peers often spoke about how they had encouraged them to continue life as normal as possible. Having a peer who understands them will ease their experience of engaging in social activities, especially if they anticipate the reaction of others.

This has similarly been demonstrated by Jason,

so at school I felt a bit lost because i did not know what it was and everyone kept asking and i could not say because i didn't know what it was. I just tried not to think about it by keeping myself busy with football / sport and only hanging out with my friends because they were being kinder and more understanding of how i was feeling (Jason)

Jason's narrative again highlighted the feeling of disconnection (“I felt a bit lost”), and how he favoured his friends' company over others. This appeared to be especially important during the initial stages of alopecia, as shown by Jason's unawareness of the condition (“i did not know what it was”) and Alex's avoidance of his other peers when he first lost his hair. Friends appeared to be a form of distraction whilst also providing empathy and a way to connect to their social realm. Feeling as though their peers will be “kinder”, provided an insight into how adolescents within this developmental period felt as though they connected to their peers more than adults, because peers understood their experience. For Jason, the loss of normality was a major threat. His friends reinforced and sustained a level of normality for him. By his peers not influencing or changing their behaviour towards him, he was able

to play football and had the confidence to play the trumpet. He was Jason, not the one who "stuck out like a sore thumb" as he mentioned previously.

#### Offering Practical and Emotional Support

Offering both practical and emotional support was captured by some of the participant's references to sharing advice and providing comfort. It emerged that offering practical support such as helping them choose their wigs was important. The following theme highlighted how social validation provided by peers served to cushion or protect members from stresses in the school environment as shown by Priya:

Sometimes my friends come to my house and we just hang out watch movies and do each other's makeup. That's really nice because we are just in our own world and I feel like how I was before all this happened. We all have a laugh together and each time they come over they all try a new hairstyle on me and experiment with different accessories, some look hilarious, but some are really cool (Priya)

Priya demonstrates how sharing her experience with her friends provided her with a sense of normality. It appears as though her home environment was where she felt safe and comforted. Being at home meant that Priya was able to be in her "own world" with her friends. It highlighted how her experience of disconnectedness was a positive one which she shared with her friends as a form of escape. Doing this allowed her to be "how I was before", demonstrating how her sense of normality was interlinked with her sense of self. Being with her peers allowed her to feel normal and ordinary; she was able to gain some form of validation of different hairstyles and made it a fun experience with her friends. At this moment, in her "own world", she did not feel "scared and awful" about herself (as highlighted in 5.1.2) but instead, happy and back to her old version of self. This process allowed Priya to manage her alopecia by experimenting with different hairstyles and allowing the process to feel fun.

Similarly, Amanda discussed how her best friend provided both practical and emotional support:

My best friend Alice has been there with me from the beginning, she's always been there if I need someone to talk to especially when someone had said something to me at school she's

always stuck up for me. When I went to get my wig as well, she came with me and my mum. She is quite stylish and knows what suits me. My mum would say I looked good in anything, but she gave me her honest opinion (Georgina).

Having peers provide validation is essential, especially as adolescents develop their sense of identity of how they look from external sources. This has been shown by Georgina, as it appeared as though Alice's comments were favoured over her mother because she was "stylish". It may be that Georgina felt as though peers of a similar age were aware of what was the "norm" and even the "style guide" described by Laura (See 5.1.1), thus Alice's opinion may have been viewed as greater. Georgina's narrative also demonstrated how peers can form a protective role for the individual who has alopecia. Bullying was discussed amongst all participants, and having a friend being protective may help. Social validation from Alice may have also served as further protection in helping Georgina resist pressures to conform, emanating from her broader peer group at school.

Within my analysis, the theme "offering practical and emotional support" was only presented within girls' accounts. This represents a potential gender difference between the coping styles adopted by girls and boys, especially given the previous section described the "need to carry on as normal" amongst the boys within the current study. Girls appeared to value their friends in offering practical and emotional support, whereas boys wanted their friends to behave as though they had not lost their hair. A key finding within this theme highlighted how opinions of friends were valued over that of parents. This could be because friends were situated within the adolescents' school realm and thus, were aware of appearance norms amongst their peers. The findings overall highlighted how friends were a valuable emotional and practical support tool.

### *The Need for Peer Support*

Throughout the narratives, there appeared to be a great need for peer support, especially from those who were also experiencing alopecia. Some adolescents felt isolated as a result of being "the only one" and the "odd one out". Therefore, speaking to someone who was in a similar situation, and could share experiences with, may have helped manage the condition.

Louise, for example, discussed how she felt as though no one understood how she felt:



I wouldn't say i've received the best support from anyone really. My family have always accepted me, and my parents have brought me wigs or eyebrow pencils/eyeliners when i needed them. but when my alopecia started really getting to me in year 9-11 there were days when I would cry before school and couldn't bring myself to going in they would shout at me and we would get into arguments. When my parents and I argued I felt alone and felt as if they didn't understand (Louise).

Louise's disconnectedness and sense of feeling alone were highlighted through her narrative as she described how her parents “didn’t understand”. There appeared to be a lot of effort and time needed for Louise to hide her alopecia, both of which she struggled with. Her parents not understanding these difficulties meant that she felt alone. I interpreted this as "family don't understand, so no one understands", as it appeared as though parents understanding placed a direct impact on her sense of isolation from everyone within her social realm. This perhaps further explains why peer support was favoured over any adult form of support, as highlighted previously, which may have been useful for Louise. Peers of a similar age may have been able to understand Louise's frustration, especially because they were aware of the importance of looks and "blending in" within this age group. Having a platform to share her experience with someone who has alopecia, or with her peers, may have reduced Louise's sense of isolation.

Throughout the narratives, it was clear that there was a great need for peer support, especially when some adolescents felt as though health care professionals did not fully understand how much impact the condition had on them:

I never really received any support from doctors. They never mentioned the charity or support groups that I know of now. At the beginning it didn't matter too much to me- but I really do wish I'd have known about them earlier.[...] It was October 2015 when it got really bad and I was really depressed about it all. When the dermatologist simply told me that I had the type of alopecia that would grow back, I thought it was reassuring, but there was a lack of support from them which I really needed. I don't think they realised how upset and down about it I really was (Emily).

Many adolescents felt that more support could be given in terms of managing their alopecia and often stated their disappointment that they were not signposted to other adolescents who were also experiencing the condition:

After the doctors, I was really down about it, my parents were obviously upset about it, but I don't really think they understood how devastated I was. I wish I had someone who was in a similar situation to me to talk to when it did get bad, even at collage my closet friends don't know I wear a wig or anything about the condition, entering collage was when I needed someone the most who knew how I felt, but I had nowhere to turn (Emily).

Although diagnosis provided some form of understanding of the condition, there was a need for further support, especially as their alopecia had got progressively worse and at high speed. There appeared to be a degree of distance between the adolescent and their health care professional. It could be that Emily did not convey her level of upset within the appointment. It should be normative for adolescents to ensure their feelings are brought to light within their appointment, especially if they do not have regular contact with their health care professionals. However, it could also be that adolescents may not have felt comfortable disclosing their issues because of the lack of contact they had with their health care professional, thus hindering the type of support they had access to. There is a need for some form of support to be accessible for adolescents with alopecia in an environment where they have an opportunity to access and feel at ease doing so. This was increasingly important in Emily’s narrative as she highlighted that her ability to cope with the condition had become progressively worse, and support was needed months after her initial appointment with the doctor. Health care professionals should be mindful that support is needed throughout the alopecia experience and more so during the progressive loss of hair. The reason why there was a lack of support was unknown. It could be that health care professionals were not aware of the available types of support, or there was a lack of understanding about what type of support adolescents needed, especially if they did not disclose this.

While parents appeared to mimic Emily’s distress; there appeared to be a deeper meaning for Emily which she felt only those who were experiencing the condition would understand. Talking to adolescents with alopecia was desperately needed, especially because she hid the condition from her new friends when she entered college. Some adolescents felt that they could hide the alopecia when they went to college because unlike high school, their peers did not see the progressive loss of hair,

thus making it easier to conceal the condition. However, this meant that Emily did not receive the peer support that other adolescents within my study valued. Emily may have felt that sharing her experience with someone of a similar age would differ to the type of support given by her parents, or her friends. This was because they would understand how she felt, and they too, were situated within this pressure to look a certain way by their peers.

However, adolescents were rarely signposted to support. This was illustrated by Priya, who demonstrated that accessing support online was difficult for this particular age group:

The doctors were great in trying to figure out what was going on with me and for finding me the wigs that allowed me to feel much more confident, but they didn't give me psychological help, that wasn't the support they gave. At that age I also didn't have much access to the internet and so I didn't get in contact with support groups or other people who had suffered/were suffering from alopecia (Priya).

Receiving a medical diagnosis and a wig appeared to provide some relief for Priya. However, the need for support was again overlooked. Priya hoped for a different kind of support to the one she received, which was considered to be more critical for adolescents, as she further stated, “I wanted to know what I could have done to stop feeling scared and awful about myself”. Health care professionals focused on the physical and external needs of managing the alopecia, which included wigs and treatments, whilst adolescents required a deeper internal form of support in terms of managing their self-esteem and confidence. Eight adolescents in total highlighted that support groups would have been useful. For many participants, communicating with individuals who have shared the experience of having alopecia was regarded as significantly important. Online support communities could have been an avenue in which individuals could identify people who were in a similar situation as themselves. Priya however, highlighted how losing her hair at a young age further hindered her social communication, "at that age I also didn't have much access to the internet". This suggested that peer support during this time may have helped because of the limited access online. Losing her hair at eight years old, meant that there was already some form of disconnection because she was too young to gain any additional online support, or seek further information on the condition. This led me to question how Priya was able to communicate with others who had alopecia at this age.

Overall, experiencing peer relationships, both acceptance and exclusion, was meaningful, and played a vital role in the way in which adolescents experienced their condition. This was demonstrated by how they viewed themselves, through the perceptions of others. It is almost as though there was a two-fold effect within the experience of peer relationships. On the one hand, peers offered support and reassurance of how they looked, on the other, peers appeared to make their experience more difficult by judging each other based on looks. Throughout this sub-ordinate theme, I began to explore what support was needed when adolescents experienced pressure to conform to expected norms of appearance amongst their peers. Furthermore, adolescents who experienced alopecia, often felt as though they "stood out" amongst their peers at a time in which they were trying so hard to blend in and appear "normal" (i.e. someone with hair). All of these experiences could further our understanding of what contributed to adolescents' management and coping behaviours. A key finding within this theme demonstrated that coping behaviours and the support valued by adolescents was often a gendered experience. Girls described how offering practical and emotional support was particularly useful, whereas boys felt that their peers who carried on as normal, helped their experience. However, it is apparent that there was a greater need for support to be more readily available for adolescents. Some were unable to access online support, often because they were not aware of these services or had restricted access online. Adolescents often expressed their need to communicate with others who had alopecia, as though a shared experience with those with alopecia would be especially helpful. Overall, the super-ordinate theme captured the complexity of peer relationships and how peers contributed to adolescents making sense of their experience.

## 5.2. Theme Two: Covering up and Coping with an Altered Appearance

The following section will explore the "experience of managing the alopecia" by discussing the strategies, and styles of adjustment, adopted by participants. This involved the struggle of hiding the patches of hair loss, and wearing wigs, in an attempt to repair the altered appearance. I will also explore how adolescents experienced discomfort, both emotionally and physically, through the process of trying to hide the alopecia. As I unpick this theme further, the reader will begin to see that these decisions to manage social pressures, guided the experience of alopecia. This will be explored within the chapter.

The second subordinate theme will be concerned with "managing the emotions". Whilst the first subordinate theme focused on the outward physical experience of managing the condition; the second

sub-ordinate theme will be concerned with the internal emotional experience of the condition. Two themes have captured this, "experiencing the merry-go-round" which highlighted the unpredictable and emotive experience of the condition, as well as the second theme, "learning to accept the condition". The experience of accepting the condition involved different elements in helping adolescents ease the panic, stress, and helplessness they experienced.

### 5.2.1. Trying to Hide the Alopecia

The first sub-ordinate theme captured the experience of trying to hide the alopecia. A common experience shared by participants was how bald patches were formed, and at an increasing rate ("once it started it just wouldn't stop and within days all the patches came together..." - Jason). The hair loss was experienced as out of control, and participants realised that they had to manage the alopecia quickly. The experience of this, ultimately led the participants feeling stressed and scared. A quick "fix" as such, was to cover the bald patches with their own hair. However, the rapid and uncontrollable loss meant that this was not sufficient enough to completely hide the alopecia. Many adolescents covered their alopecia once it could no longer be hidden by their own hair. As the alopecia became progressively worse, hiding the alopecia also became progressively more difficult. This captured the theme "the difficulty of hiding the patches". A "solution" to this was to shave the hair completely; however, this was a form of management only adopted by the boys within the study. Some participants (boys included) tried to repair their altered appearance by wearing wigs and hats. Whilst this was a form of management, there was always a sense of relief that they looked like their former selves, especially for the girls that were interviewed. Girls, however, described the wigs as being uncomfortable, but continued to wear them. Thus, capturing the theme "beauty is pain". This sub-ordinate theme will explore the experience of hiding the alopecia in more depth.

#### *The Difficulty of Hiding the Patches*

As highlighted, during the initial stages of the condition, the patches of hair loss were often covered by the adolescents' own hair. Participants described how they lost hair within a matter of days, making it difficult to make small adjustments. Soon, it became unbearable and difficult to hide, and the idea of preventing the uncontrollable nature of the condition was raised by many participants as a way of gaining some form of control and managing this problem.

This was shown in Jason's narrative:

We would spend hours hiding each patch a spray before school and I had to wake up earlier and earlier. The more hair lost the worse it got [...] I think it was more stressful having lots of patches because it looked so bad and I was scared it was going to get worse, so we decided to shave the rest of it off (Jason).

The thought of his alopecia getting worse was frightening for Jason, and he tried to manage his alopecia by shaving his hair. However, there also appeared to be a question of whether he was forced to shave his hair because he had no other choice but to do so. Whilst girls could hide their alopecia by wearing wigs, no boys in the interviews discussed this form of management. This, as well as being unable to wear hats in school, may mean that males felt as though they *had* to shave the remaining hair to stop further patches being shown. The thought of having control over their alopecia, however, may help adolescents to manage the condition. This has been supported by Alex who briefly discussed his choice of shaving the "remaining bits". When he described his experience, he said, "we decided that rather than wait for it all to come out to just to get it over and done with and shave the remaining bits off". It is also interesting that within both these narratives, shaving their hair was shown as a shared experience, and the decision was made as a family. Although, within the previous theme, adolescents described the importance of peer support, it appeared as though for boys, managing the alopecia was a decision to be made with family, rather than friends. There is also an interesting difference here between boys’ and girls’ management of hair loss. Jason decided to shave his head because he did not want to spend hours covering his alopecia. It became very time consuming, and it was too difficult to wake up at an unreasonable time and spend hours hiding his alopecia. Having a shaved head is not out of the contemporary western norm for men (see introduction). Thus, coming to this decision, although difficult, may have been influenced by these norms. Girls, however, appeared to do the opposite, by spending even more time styling their hair because it is not the “norm”.

This has been shown by Hannah,

When it first started there were 2 or 3 tiny dots at the back of my hair near my crown. It was my mum who first noticed it and eventually they sort of joined together to form a MASSIVE patch. I would wake up really early every single day spending about an hour or 2 on my hair

just trying to tie it into a high bun so no one could see it. I would be conscious of it all day and would constantly keep touching my hair to see if it is still up right. It was all just really exhausting! (Hannah).

The narrative highlighted (1) the uncontrollable nature of the condition, (2) the difficulties hiding the patches of hair loss and (3) the time taken to cover the alopecia. It was interesting that Hannah described the size of the patches as "tiny", however, when they came together it formed a "MASSIVE patch". This emphasis may perhaps indicate that the alopecia wasn't as big as she had described, but because she was conscious of it, it became larger in her thoughts, creating this sense of uneasiness. The discourse of exhaustion could also be interpreted in two ways. Firstly, it could be used to describe how frustrating it was for the alopecia to be at the forefront of her mind all day. Thus, highlighting her perception of time experienced as a constant drain. Secondly, the exhaustion could also be physical exhaustion, because she had to physically wake up early and spend a lot of time styling her hair. Therefore, the experience of hiding the patches of hair loss was both emotional and physical for Hannah.

Within this theme, boys who covered their alopecia wanted "little" effort to groom their hair, in contrast to the "massive" effort the girls within the study engaged in. The gendered expectations were uneven. This went beyond the choice of wigs and shaving the hair, but tied back to the idea that men are within the socially accepted "norm" to have a shaved head. Again, such narratives suggest there could be a gendered meaning attached to the hair.

#### *Repairing the Altered Appearance*

It appeared that the difficulties of hiding the patches of hair loss were rooted within how uncontrollable and unpredictable the loss of hair became. As a result, adolescents were often left feeling panicked and scared. Repairing the altered appearance was another common experience shared by adolescents with alopecia. Despite becoming more socially acceptable, there also appeared to be a widespread stigma about using them. Wigs are now a popular fashion accessory and are available online and in stores (see 1.1). Although wigs were worn by the girls who were interviewed, most also described how they were hesitant to use one. As we discussed this more within the interview, it was revealed that the thought of wearing a wig created a feeling of hiding something, that it may not look "normal", or that something was "wrong". Although there was initially some form

of hesitation, girls usually resorted to wigs when baldness finally seemed inevitable or had already become a reality. Moreover, many girls described how wearing the wigs allowed them to reclaim their old sense of self and their appearance before they lost their hair.

This has been demonstrated by Emily:

I don't really feel myself unless I have my wig on, like I don't feel fully dressed without it (Emily).

Like many participants, wearing a wig was an extension of the usual activity of dressing. I tried to relate this feeling to my own experiences. When I do not wear makeup, I do not feel "myself". I feel less confident when I don't wear makeup, and I become more aware if someone is looking. I avoid going to popular places because I always want to look my best. It is not so much that I *look* different with makeup on; it is that I *feel* different. Whilst wearing makeup is different from hair loss, there is a shared feeling of femininity and confidence rooted within the ideology of feminine beauty standards. Makeup use is closely linked to adolescence, appearance and self-image improvement (Gentina, Palan, & Fosse - Gomez, 2012; Rudd, 1997). Furthermore, makeup use also relates to how an identity is formed within this period (Gentina et al., 2012). Hair grooming could also arguably be tied into self-image improvement, and identity construction, in which Emily did not feel her best without her wig, nor herself. Wearing a wig, however, was not an optional accessory for Emily, but instead had become a part of who she was. The narrative highlighted how much importance and emphasis was put upon hair. Once the wig has been put on, she transformed herself into *Emily*, demonstrating how wigs enabled participants to reclaim their old self.

This was also shared by Hannah who described how a wig enabled her to reclaim her former appearance:

I would say it [the wig] helped me enormously, when I put it on I was like... “yes, I look like me again (Hannah).

Having the wig transformed Hannah, as though without the wig she was not herself. This has been captured by the use of second person point of view here to illustrate a "dual-self dialogue", that provides her with self-reassurance and self-agency (“yes, I look like me again”). Going beyond this, I



began to think about who Hannah and Emily became when they wore their wigs. Who did they become once the wig was taken off? Even when I do not wear makeup, I am still Amrit; however Hannah's narrative indicates that she is, in fact, a completely different person as she states “before I had the wig I was just sad, ugly and depressed but now I am more confident, happier and I look like me again”. It suggests that she lost a part of herself when she lost her hair, only to have found herself again once she put on the wig. Thus, along with repairing the altered appearance, it also repaired the individual’s sense of identity.

Whilst repairing the altered appearance helped reclaim the old self, Sarah’s narrative highlights the relief that the alopecia is hidden and that "no one could tell":

I didn't really pay much attention to my hair before but now I am very aware it, I was always worried about it showing, and I would refuse to leave the house until it was covered. In the end we got a wig because it just got too much it was a really painful time for me and now I realise I took it [her hair] for granted. I felt so relived because no one could tell. They look like real hair! I like accessorising my hair and trying new styles and looks, like flowers headbands and butterfly clips (Sarah).

Within this chapter, the reader can see that adolescents were very image conscious, and styling the hair was an essential part of this image. We can then argue that adolescents were likely to be hair conscious before hair loss. However, Sarah stated how she “didn’t really pay much attention” to her hair. It was only when Sarah became aware of the alopecia, that she recognised its importance. The contrast between Sarah with, and without her wig was fascinating. Sarah described her experience as a painful embodied experience, "it was a really painful time for me", but she could now accessorise her wigs with flowers and butterflies. Butterflies and flowers are delicate, feminine, innocent and soft, which is a juxtaposition to her painful experience, and could capture how she metaphorically transformed herself into a flower. Flowers are generally described as beautiful, and therefore, in essence, Sarah beautified her wig, perhaps because the hair loss removed some of her beauty. Whilst before she did not pay much attention to her hair, using “flowers headbands and butterfly clips” drew attention to it. The analysis has demonstrated that adolescents want to appear "normal". In this context, "normal" was a person who fits in and has hair. A common experience as highlighted, was the need to blend in amongst their peers and some stated how they became “ugly” (Hannah) when they lost their hair. Thus, whilst Sarah tried hard to conceal the alopecia and make it look natural, she

also made a very loud statement by adding these colourful clips and headbands, spending a lot more time and effort into her hair than she had done so before.

The impact of the wigs was a positive experience for the girls; however, this was very different for boys. None of the boys within this study discussed wearing a wig, nor considered wearing a wig to manage their alopecia. When I asked Jason if he considered any forms of management such as wigs, he replied: "no, maybe if I was a girl I would wear a wig". Whilst there appeared to be some form of stigma related to girls wearing wigs; there was also the expectation that girls need to have hair, but boys did not. There appeared to be an even greater stigma (or negative connotation) attached to boys wearing wigs. Sarah's narrative demonstrated how wigs were considered to be more of a feminine accessory. This has been further supported by the literature surrounding the management of alopecia, where women are often referred to specialist wig manufacturers, and men are encouraged to shave their hair (see 2.4.1). This again ties in with the Western norm that male baldness is more "acceptable" and that females should hide their alopecia. However, the findings do suggest that the psychological impact of alopecia was significant for both boys and girls within this study, as they experienced a range of complex emotions. Boys, however, appeared to repair and manage their alopecia differently to the girls within this study, by wearing hats or shaving their hair.

### *Beauty is Pain*

For most girls, a barrier to managing their condition was how uncomfortable the wigs were. Wigs were described as itchy, uncomfortable and challenging to maintain. Many girls spent hours washing and styling their wigs before leaving their home. Despite this, they still favoured wearing wigs over showing their alopecia. This theme will explore why girls (and not boys) were drawn to use a concealment item even though it was so uncomfortable, both physically and emotionally.

Refusal to take off wigs was common throughout girls' narratives, demonstrating the hierarchy placed upon wig wearing for female adolescents and the importance of having hair:

As soon as my wig came I never took it off. I slept in it and everything. My mum would get so mad at me because it would get so knotty and even when it was hot and itchy I refused to take it off (Emily).

Before wearing a wig, Emily avoided looking at her alopecia "I refused to look at it in the mirror because it upset me every time. I think it made it harder because you don't see girls my age with patchy hair loss, so it made me worry when I saw how it looked". This explained her refusal to take off her wig, even at night when it had been advised not to. Furthermore, the narrative demonstrated the cultural meanings attached to the hair, especially given Emily highlighted she had not seen girls with alopecia before; thus, her appearance was out of the ordinary. This further deepened her need to wear a wig continuously, not only to avoid the concern she experienced, but to also conform to the expectations placed on society that girls *should* have hair. It is also interesting that she also used the discourse "girls" rather than "*people*"; by doing so she created a gendered meaning attached to hair. Although the wig allowed her to cope with the condition, there still appeared to be some form of avoidance. Refusing to take the wig off after a long period of time could lead to further problems in addition to the comfort issues it will cause. Adolescents could be so dependent on their wig, that they could experience a further shock when they remove it, as they have become used to how they look. Thus, further adding to the sub-ordinate theme "beauty is pain". Despite the disapproval by her mother, Emily did not listen to the advice. Many adolescents felt as though adults did not understand the difficulty of the condition and how they felt. This could explain why Emily did not listen to her mum, even though it became difficult to manage, and perhaps why peers' advice could be more valued over adults for some adolescents.

Most girls felt as though the wigs were challenging to manage. However, looking like their previous self with hair, outweighed the bad:

But I wouldn't wish alopecia on my worst enemy. The ugly truth is that the wigs get really itchy and its super uncomfortable. It's just nasty to deal with and I wish I didn't have to deal with it, but it's better than having no hair at all- Hannah

There was a cost of being able to look like their previous image. The uncomfortable nature of the wigs was so painful that she felt as though no one deserved to have the condition "wished" upon them, demonstrating the severity of managing alopecia. "The ugly truth", further adds to the concept "beauty is pain" as the truth (that the wigs are uncomfortable), was something which was "ugly" to Hannah, because it was so difficult to cope with.

Female adolescents believed they were left with two choices when it came to managing their alopecia; to show their hair loss, or to wear wigs. All girls in the narrative, however, opted to wear a wig as they wanted to hide their alopecia. Even though wigs were challenging to manage and uncomfortable, the theme "beauty is pain" captured how they preferred to be in "pain" over the alternative of showing their alopecia. This appeared to be underpinned, and contextualised by, complex cultural meanings that are attached to the hair. That being, girls their age, did not have patchy or total hair loss. Furthermore, given this theme has only been presented by girls, the narratives suggest that wig use could also be a gendered experience which was unique to girls within my study.

### 5.2.2. Managing the Emotions

Similar to parents, the unpredictable nature of the condition was difficult to grasp, and losing re-grown hair created further experiences of distress and confusion. However, few adolescents within my study mentioned positive experiences of the condition. Some highlighted how they developed a new outlook for life and used laughter as a way to accept the condition. The following section will explore the theme “managing the emotions”.

#### *Experiencing the Merry-go-round*

A total of six adolescents (out of fifteen) discussed a period of regrowth through their alopecia experience. For many, however, the growth of hair was short-lived and was eventually lost. Many individuals felt devastated as their hair loss worsened, only to be left disappointed with a condition surrounded by so much uncertainty. Going through the process of losing their re-grown hair was challenging for adolescents, especially as they wished for their hair to grow back throughout their alopecia period. Wishful thinking appeared to be a shared experience amongst adolescents, as highlighted by Hannah's narrative within the beauty is pain theme (see 5.2.1) and Emily's narrative within the need for peer support theme (see 5.2.1). For those experiencing alopecia, given the unpredictable nature of the condition, and the sudden loss of hair, participants left their wishful thinking to fate, because it was perceived to be a circumstance out of their control. Even though participants were told there was "nothing that can be done", participants still hoped that their hair would grow back, despite the evidence and advice suggesting otherwise.

Participants described how losing their hair for a second time left them feeling worried and on-edge:

It was worse this time because I had suffered with it before, and I was so over it happening. I hadn't let it get me down too much before, but it was getting worse, and I struggled to deal with it. I'd recently gone into year 10 at school and wasn't having the best time either, so things stacked up! I remembered how upsetting the alopecia was to have before, and that combined with the thought that it's happening again, was really unpleasant. I was fifteen at the time, and as I'd grown up I'd begun taking more care in my appearance, and so this was a real confidence knock.- Anna

There were further stresses within this particular developmental period which heightened the impact of alopecia, "I'd recently gone into year 10 at school and wasn't having the best time either", highlighting that adolescents could also experience additional distress from the recurring hair loss which is particularly unique for this age group because of their lifestyle and needs. Anna stated that in Year 10 she was not having the best time, so there really was a sense of "stacking up" for her.

Similarly, Liam described the sense of powerlessness he experienced when he reminisced, and ruminated, in the events leading up to the loss of hair:

I was just sat there thinking 'It's happening again... here we go... not again'. I just knew what was coming and I knew I was going to go through it all again. That was the hard thing that there was nothing I could do. That first morning I saw that hair I knew I was going to feel the exact same... if not worse because I don't think I was completely over the first time I lost my hair. (Liam).

Anna and Liam felt as though they were able to "see" what was about to happen. Both participants knew that they were going to lose their hair again, but felt they had no control. This was further heightened as participants felt that the second impact of hair loss would be even harder to experience because they were still "recovering" ("if not worse because I don't think I was completely over the first time I lost my hair"). The worry heightened the expectation and intensified their loss of control even more, adding to their sense of helplessness. Feeling the merry-go-round is a traumatic experience in itself as adolescents need time to heal from, and recover from, the first encounter of their alopecia. After receiving an initial blow of going through a difficult experience, losing their hair for a second time is almost hitting them with a second blow when they are already down. This

emphasises why adolescents felt both anxious about losing their hair and were dragged down emotionally: “hadn’t let it get me down too much before”.

Many participants felt as though losing their hair during their teenage years had impacted their sense of identity and took away some form of their appearance which they prided themselves on. Therefore, losing their hair during this stage impacted participant's confidence and self-esteem.

#### *Learning to Accept the Condition*

Acceptance within these narratives did not suggest that adolescents were able to pursue everyday activities, in spite of their alopecia, but argued for behaving in chosen ways with their alopecia which contributed towards coping with their condition. This level of acceptance may have been integral to their coping and subsequent adjustment.

Whilst this, arguably, could also capture peer support in some narratives, using jokes and humorous exchanges appeared to help deal with the condition. For example, Jason described how he adopted a playful approach to cope with some of the difficulties adolescents face with alopecia:

It's good that me and my brother don't treat each other differently. When he calls me egg head just I just reply and say well at least I am not chubby or I am still the good looking one. We come up with some right one liners I think that's the best way to deal with it by just having a laugh, otherwise you will just end up depressed (Jason).

There appeared to be creativity and in Jason's wording and a witty communication exchange between him and his brother. Whilst others have expressed a negative experience of name-calling and bullying, Jason appeared to have shifted this negative comment towards humour. This could be because he understood that his brother's comments were not meant for ill intent and to hurt (unlike others' experiences within school). Instead, there was a sense of gratefulness and gratitude that his brother had not changed his behaviour towards him, perhaps because his relationships with others within his social realm had changed, or perhaps because he expected there to be a change. It could be that since Jason lost his hair, his friends and family may have been more sensitive around him and may have felt as though they could not joke about the condition. However, we can see from the narrative, that such exchange had allowed Jason to manage his condition in a positive way, in which, the accounts consist

of dialogue that suggests they attempted to normalise the situation. Jason also recognised there could be consequences such as depression, if he did not maintain this humorous approach. Recognising humour as a coping strategy was found to be an essential step towards managing the emotions.

Similarly, Harry also described humour as a form of management:

It's funny but I can go and get drinks, and no one really questions it because I look like I am over 18. My friends joke about it all the time, but you have to make a good situation out of a bad (Harry).

What was particularly interesting about this narrative was the statement "no one really questions it because I look like I am over 18." The previous literature has found that a loss of hair, or thinning of hair, is used as a visual signifier of "old age" for men, especially within media. Contrasting, a full set of hair is used to convey youth (see 1.1). The findings of such study support the associations made by those who served Harry, maintaining this societal belief and assumptions that if someone has lost their hair, they are likely to be of a certain age. This particular experience could also be viewed as a gendered experience. Whilst Harry demonstrated a degree of acceptance; he also demonstrated that he was experiencing a level of dissatisfaction as he is in a "bad situation". Both narratives suggest that they are trying to remain optimistic and focus on the positives because they have no other choice but to do so. Harry's chosen response to his alopecia affected whether he could overcome a bad situation or succumb to it. Rather than dwelling and focusing on a bad situation, he transformed it into something positive. Thus, humour and jokes were viewed as a way of coping, for boys within the current study.

Another way of managing the emotions was by developing an understanding of the condition. Many participants experienced shock, horror and sadness when they saw their hair falling out, often linking this loss to their pre-defined schema of a cancer illness. Whilst this lack of understanding may be because of the age of the participants, many experienced panic upon seeing their hair during this time.

I was really scared and terrified when I saw it. I didn't know what was happening or how to stop it from getting worse. I was more scared than anything because I thought I was dying (Liam).

Thus, a way of managing such emotions was to understand the condition. Once participants were diagnosed, they explained how they (or their parents) researched the condition to develop an understanding. This has been captured in Liam’s interpretation of the condition:

There is kind of like a fight with the body rejecting your hair follicles because they see as being foreign to them, almost like your body attacks your insides when you are seriously ill. I was really nervous about going to the doctors but I couldn't avoid it forever, especially because it was just getting worse and worse and he explained it really well. It was a relief having the diagnosis but confusing at the same time. (Liam)

Whilst the increased loss of hair was why Liam went to the doctors, "worse and worse" could represent his lack of coping, as well as the amount of hair he lost. There were two issues within this narrative; making sense and coping, and undoubtedly, these two were inter-related. The repetition of "worse" demonstrates how the more he tried to avoid the alopecia, the more difficult it had become. From this narrative, Liam drew upon the imagery of a battle which happened within his body. The alopecia was seen as the enemy, which could aggressively attack the body. Later on, within the interview, he stated how the doctor prescribed him with steroids in the hope that it would "shock the immune system". It is almost as though he was in charge of creating a counterattack, in order to regain resistance. The narrative captured the battle of control Liam was trying to achieve in order to manage his condition. Moreover, grasping onto his predefined schema of hair loss, Liam initially thought he had cancer, "it's a strange thing to think now looking back because I felt fine, but when you do have cancer in the end you lose your hair". Although Liam perceived this thought to be "strange" he attempted to make sense of why he came to this conclusion. He compared his hair loss to having a severe illness, and the imagery of battle appeared to be physically exhausting. The common narrative using this metaphor is to fight cancer. Alternatively, it could be that Liam still had some thoughts linked to cancer which he cannot differentiate. There also appeared to be a form of separation of internally feeling "fine", along with the assimilation of illness making him "seriously ill" therefore, the experience to him did not make sense.

Overall, the sub-ordinate theme “managing the emotions” captured the gendered aspects of alopecia in terms of coping and managing the condition. In particular, my themes demonstrated that girls within the narratives felt pressure to hide their alopecia because hair loss amongst girls their age was perceived as uncommon. As a result, girls spent a great amount of effort and time concealing their



alopecia. Contrasting to this, boys within my study shaved their hair to limit the amount of time spent. Thus, whilst boys opted for convenience, girls wore their wigs even though it was uncomfortable and hard to maintain. In relation to managing the alopecia, there appeared to be a contrast amongst boys and girls. The theme also highlighted a perceived stigma (or negative connotation) for boys to wear wigs. Whilst girls appeared to be dependent on their wigs, boys did not consider this form of management. Instead, boys often shaved their hair or wore hats, as opposed to wigs. The adolescents within my study also described how they tried to manage the emotionally devastating impact of the condition. In particular, humour was often a great source of coping that helped normalise the condition. Overall, from this theme, we can demonstrate how living with alopecia can be complicated and deeply personal. Adolescents are forced to navigate through cycles of hair loss and feelings of unpredictably into the unknown. However, this theme highlighted how accounts were shaped by gendered meanings of hair and contextualised by complex cultural meanings.

### 5.3. Summary of Adolescents’ Experiences of Having Alopecia

The data from the adolescent interviews, and my analysis, generated two salient themes related to "experiencing exclusion and acceptance in peer relationships" and "covering up and coping with an altered appearance ". It has been demonstrated within the findings that the perception of body image can be a contextual construct. Overall, the findings of the thematic analysis have explored the impact of the construct in relation to adolescents' bodies, in particular, the ways that alopecia was discussed and made sense of by both boys and girls within my study.

Peer relationships are meaningful experiences which support adolescents’ sense of self. We can see from these findings that peer relationships are more complex than the current literature pertaining to peer relationships suggests, regardless of context. For example, my findings demonstrated the "norms" and expectations placed on adolescents to look a certain way, often creating difficulties for those experiencing alopecia. Feeling “judged” especially, was a key issue within adolescents' experiences. If adolescents did not look a certain way (e.g. if they lost their hair), they were scrutinised by their peers and often experienced bullying. Adolescents also appeared to mirror each other’s looks.

The narratives highlighted the difficulties of peer relationships, and my findings also highlighted the supportive aspects of relationships. The sub-ordinate theme friends "being my rock" highlighted the essential roles peers play in making sense of, and the management of, their condition. "Carrying on as

normal" was the most helpful support offered to adolescent boys within my study. In the sense of chaos, where peers' behaviours towards the adolescents were changing, friends who carried on as normal appeared to help adolescents stay grounded. It reinforced the idea that they are still themselves, not someone to be looked at in overt "horror" as described by Jason. However, it was only boys within my study that appeared to value their friends carrying on as normal. Girls, on the other hand, leaned on their friends for practical and emotional support. Thus, adding to the notion that alopecia was a gendered experience.

A key issue within my findings was the negative connotations related to wig use for boys. No boys within the study discussed wigs as a form of management. The narratives implied that boys rejected the idea of wearing a wig because it is identified with girls. Girls, on the other hand, appeared to place a significant dependency on their wigs. This sense of dependency was also captured by the theme "beauty is pain". Wigs were described as "itchy" and "uncomfortable" but wearing an item which made them feel physically uneasy, was still favoured over having "no hair at all". Thus, my findings demonstrate the pressures for adolescents to look a certain way because of the pressures experienced within their social realm.

Having communication with friends can help adolescents feel less isolated, especially as they would sometimes avoid stepping into their social realm because they were worried about how others would react. A vital aspect of this more positive experience was achieving an online social media presence. For example, online gaming enabled adolescents to remain connected with the outside world and to have an identity that existed aside from that which was characterised by alopecia. There was a need to share experiences with those who were also experiencing alopecia; however, the age when the participants lost their hair may have contributed to the lack of support they may have received.

Overall, the key findings within the lived experiences of adolescents who have alopecia captured the gendered experiences of the condition. This is because girls and boys within my study appeared to manage and cope with their condition differently, and their management of the condition was often underpinned by societal perceptions of hair and perceived pressure from their peers. The second key finding highlighted that friends could be valuable in offering support. However, the experiences also demonstrated that peers could provide risks for a range of adjustment difficulties. This will be discussed further within Chapter Six: Discussion.

#### 5.4. Synthesis of Findings across Both Data Sets

Overall, the findings from both parents' and adolescents' data, demonstrated deep interpretive meanings of experiences which helped me understand what it was like to have an adolescent child with alopecia, or be an adolescent with alopecia.

Both parents and adolescents formed an integral part of the gathering of experience, and some appeared to be similar or mimicked by the other data set. For example, the concerns regarding bullying in school described by parents were discussed in great lengths by adolescents. By exploring this separately, however, I was able to see the direct impact this had on parents, who felt helpless, and adolescents, who felt isolated amongst their peers. What was interesting in both data sets was how alopecia appeared to be a gendered experience. Both parental coping styles, and adolescents coping styles differed. Girls within my study, for example, were highly dependent on their wigs, whereas boys opted to shave their hair and wear hats. Both parents and adolescents also displayed negative connotations about wearing wigs. This could perhaps be understood by the social and cultural meanings which are attached to the hair. What differed amongst the data, however, was that only parents discussed the loss of bodily hair, whereas adolescents focused solely on the head. The gendered experiences of hair will be explored further within the next chapter, pulling in key issues surrounding meanings attached to hair, and the more extensive literature, to understand this phenomenon.

Secondly, social and peer validation underpinned adolescents' choice of managing the condition. The findings demonstrated that adolescents favoured their peers' opinions over their parents. It was as though adolescents were guided by their friends' opinions because they were aware of the social norms and style guides, as opposed to parents. Overall, the findings demonstrated that peers could help girls find wigs that are socially acceptable and can help them "fit in", as well as offer emotional support that parents may be unaware of. At the same time, however, peer groups and norms also negatively shaped the experiences of adolescents and parents. Similar to adolescents, parents often compared their child's appearance to their peers, which in turn, created further distress. All adolescents and parents discussed bullying related experiences. To understand this, I will explore peer related theories within the next chapter, drawing in the "norms" and style guides experienced by adolescents and how this contributed to how they made sense of the condition.

Finally, the narratives demonstrated the deep emotional and personal impact alopecia had on both parents and adolescents. Although parents and adolescents struggled with the condition, both discussed how no form of emotional support was offered by health care professionals. In particular, parents described negative social interactions with health care professionals. Often parents felt as though health care professionals trivialised the condition which further contributed to their distress. This was a key finding across both parental and adolescents accounts, in which, both data sets felt as though more could be offered by health care professionals and that there was a need for them to recognise the impact of having alopecia.

Chapter Six: Discussion, will discuss these critical issues further and draw in current literature and theory to deepen our understanding of adolescent alopecia. This will in turn, help develop implications for practice and future research.

## Chapter Six: Discussion

### 6.1. Research Aims and Key Findings

The current study aimed to explore alopecia-related experiences from the perspectives of parents (with an adolescent child aged 10-19) and of adolescents (aged 13-19). This included to:

1. Explore the lived experience of alopecia amongst adolescents and parents.
2. Explore the lived experience of support available for adolescents and parents of adolescents with alopecia
3. Identify the needs of adolescents with alopecia and their parents.

Data analysis from a total of 30 participants (15 adolescents and 15 parents) aimed to explore two different sets of sense-making processes. Throughout the thesis, experiences and meanings between parents and adolescents appeared to be interlinked or parallel. This chapter will summarise and discuss the key issues in both parents’ and adolescents’ experiences. It will highlight how peer influences and gender issues were central to the parental and adolescents’ experiences within the lived world of alopecia. Furthermore, the chapter will demonstrate how negative social encounters with health care professionals further added to the participants’ experiences.

I will first present a critical overview of my findings and add further explanation as to why peer relations, gender issues and health care professional support were the key issues I wanted to discuss. I will then explore these three important issues, exploring the wider literature on parents’ experiences of having a child with dermatological conditions, adolescents’ experiences of alopecia or CIA, and the broader meaning-making literature. Ultimately, this research contributes to: understanding the ways in which adolescents in particular feel the need to “blend in” with their peers; how health care professionals underestimate the psychological impact of the condition for both parents and adolescents, thus, creating negative encounters which contribute further to negative feelings; and lastly, how alopecia is a gendered experience. As a result of this, I will outline specific recommendations for wider support services to help manage these experiences. Finally, I will provide a reflective exploration of how this research shaped and influenced my overall thesis.

### 6.1.1. Summary of Findings in Relation to Key Issues

A good phenomenological description of gathering experience, according to van Manen (1990), provides some illumination of an aspect of an individual’s life-world. In order to do this, my study needed to capture the essence of what it means to live with alopecia. This could be done by reflecting the main themes derived from rigorous research processes, as this has allowed some form of ontological description about the phenomenon being explored (van Manen, 1990). The findings as a whole showed the life-world of participants was affected in all aspects of van Manen’s existentials (lived body, lived time, lived space, and lived human relations) and the findings illustrate these.

Overall, parents’ and adolescents’ experiences were highly complex and deeply emotional. Emotions and thoughts were intertwined with the unpredictable nature of the condition, as participants navigated through the continuous cycles of hope, helplessness and hopelessness. They experienced a lot of shifts and changes within their life-world created by this condition. Within participants’ narratives, the distress and confusion that were often experienced, were moulded and contextualised by cultural meanings and norms. The themes that captured the way alopecia is experienced from a parents’ perspective included “the hair is coming out’: living the emotional turmoil of hair loss”, “health care professionals trivialising alopecia”, and “needing to protect the altered appearance”. Within the theme “needing to protect the altered appearance”, another important finding was how the loss of bodily hair often created distress and upset. However, the experience was underpinned by gendered issues.

Adolescents’ themes include “experiencing exclusion and acceptance in peer relationships”, and “covering up and coping with an altered appearance”. These encapsulated the deeply complex and personal accounts of adolescents who were trying to make sense of, and manage, this condition of unpredictable hair loss, whilst also navigating a range of complex relationships and experiences with their peers. These narratives captured how support from peers was significant in enabling adolescents to manage their alopecia; on the other hand, peer influences also negatively impacted adolescents’ experiences. Social and peer validation underpinned the way in which adolescents managed their condition (e.g. the choice of wigs and hats). Adding to this, girls often felt “not cute” because of comments made by boys, further lowering their self-esteem.

Highlighting the poetic or arts element of van Manen (1990), references such as “Voldemort” enabled the reader to visualise the experience, imaginatively dwell and relate. The experiences of bullying created a negative impact on adolescents and the presence of peers heightened their sense of wanting to “blend in”. Gendered experiences were also found in the coping behaviour of girls and boys highlighted within the theme “covering up and coping with an altered appearance”. Similar to parents, boys appeared to have negative conceptions about wig wearing. Adding to this gendered aspect of experience, girls often placed great dependence on their wigs, whereas boys opted to shave their hair. Lastly, similar to parents, there appeared to be a need for support and evidence of problematic relations with health care professionals.

The peer theme within the adolescent chapter was perhaps the most discussed by adolescents. Whilst the importance of peers was reported more by adolescents than parents, this key finding was central to my aims. Firstly, because the experience of peers demonstrated how they made sense of the condition, the types of support they experienced from their peers and finally, that adolescents needed peer support, especially from those experiencing the condition themselves. Secondly, it was apparent that alopecia appeared to be a gendered experience, hair seemed to have different meanings depending on whether the adolescent was a boy or girl. This was especially striking considering such phenomena were similar for both adolescents and parents and as such, this finding was a key theme. As I unpicked this further, I could see that these experiences had again been underpinned by the cultural and contextual significance of hair and therefore could help contribute to our understanding of adolescent alopecia. Where prior research has been predominately quantitatively focused it has enabled researchers to demonstrate alopecia causes distress. However, the current study adds to our understanding through these contextual meanings of hair being a signifier of masculinity and femininity.

Finally, the negative encounters from health care professionals cut across participants’ accounts. Parents and adolescents felt as though the condition was often trivialised and more could be done in terms of offering emotional support. Drawing in on the life-world existentials has highlighted how temporality was especially relevant for participants. Participants wanted to be seen urgently and time was critical because the hair was falling out, and at great speed, but health care professionals did not reciprocate this sense of urgency. The temporal elements of these experiences elucidated my findings

given that both data sets highlighted powerful emotions and urgency following the loss of hair and yet, they were often given the message by health care professionals that it is “JUST” hair.

#### 6.1.2. The Experience of Peer Influences

*“Positive peer pressure will lead you to your dreams. Negative peer pressure will lead you to your nightmares”*

**-Dankie SirKwanele**

Overall, the narratives revealed that the majority of those who experience alopecia were influenced by those within their social realm, in particular, their peers. As highlighted, adolescents shift their attention away from their parents and towards their peers. Peers then become a significant influence on their development (Kornienko et al., 2016; Reitz, Zimmermann, Hutteman, Specht, & Neyer, 2014). For example, peers help with adolescents’ development of self-concept, wellbeing and behaviour (Gorrese, Ruggieri, & Differences, 2013), all of which emphasise the importance of what the particular adolescents within the current study were experiencing. My findings suggest that peers are crucial to adolescents’ experience of alopecia, influencing in both negative and positive ways. Adolescents felt the need to conceal the condition in order to “blend in” with their peers and were bullied because of their appearance. The findings highlighted the need for adolescents to access online support with those of a similar age who have the condition. Whilst peer support is valued, adolescents with alopecia may need to share their experiences with someone of a similar age who also has alopecia. By reviewing the current findings in the light of existing theory, I will discuss how peer relationships could influence how adolescents make sense of their condition and provide further understanding of the phenomenon of adolescent alopecia.

My findings suggest that peer relationships were more complex than anticipated for those who have alopecia. This is because adolescents’ often faced difficulties establishing an “in group” and felt isolated amongst their peers. This was an interesting key finding because this heightened their desires to “blend in” with their peers. Furthermore, this peer influence demonstrated why adolescents felt the need to cover their alopecia. In particular, adolescents wanted to look like their peers and follow the “style guide”, almost mirroring the appearance of their friends. Like all adolescents, there appeared to be great pressure to follow this strict policy. Whilst this phenomenon was predominately discussed by the majority of adolescents, interestingly, some parents compared their child’s



appearance to their peers. This suggests that parents too felt the pressure of the “style guide”. This potentially corroborates further findings from this thesis in which parents and adolescents with alopecia adhere to a certain style policy. Previous research has shown that non-alopecia adolescents try to mirror the behaviour and attitudes of their peers (McPherson, Smith-Lovin, & Cook, 2001), posing psycho-social challenges for adolescents with alopecia.

Adolescents appear to steer towards peers who already have similar behavioural proclivities and attitudes, known as selection effects (McPherson, Smith-Lovin, & Cook, 2001). Over time, however, adolescents’ and their peers’ behaviours and attitudes also tend to become more similar (socialisation effects). This is also known as homophily, in which peers attempt to look like each other (McPherson, Smith-Lovin, & Cook, 2001). Such a concept could explain why the adolescents needed to mirror the looks of their peers, and why there was a “style guide” to adhere to. The loss of hair meant that adolescents did not feel as though they could fit in amongst their peers based on their appearance. This is especially given that this process develops over time within their friendship groups and creates an identity and sense of belonging within these groups.

The existing research demonstrates that non-alopecia adolescents have high levels of aggression, depression and low self-esteem when they have been rejected by their peers (Gooren et al., 2011; Rubin et al., 2006; Timmermans et al., 2010), and adolescents who encountered social rejection, displayed depressive symptoms one year later (Masten et al., 2011). Thus, it would be appropriate to assume that those within the current study may also display such negative experiences, if not heightened. We need to be aware of the consequences for adolescents with alopecia following peer rejection and the pressures of not being able to fit in with their peers. My study found that adolescents experiencing rejection from their peers could severely impact how they perceive themselves, as demonstrated by the “not cute anymore” theme. Furthermore, some adolescents with alopecia have been labelled and referred to as aliens, or “Voldemort” by their peers, which could further contribute to how they perceive themselves. Adolescents with alopecia may therefore, experience multiple forms of peer rejection.

My findings revealed that those with alopecia also perceived themselves as different to their peers. The current study also provided an exploration into how they felt rejected from their peers, because they looked significantly different and no longer fit into the “style guide”. This was a time of life when these young people were actively trying to construct who they are, or want to be with (Kerpelman et

al., 2012), and the current study found they often established peer relations that acted as a policing mechanism. Attaining a sense of belonging to a peer group with a “style guide” is a complex task for adolescents. If a visible appearance change is added to this, the impact of this has shown to be potentially severe.

Feelings of social rejection can understandably be painful at any age; adolescents may be particularly sensitive to this compared to younger children. Within this period, adolescents form the capability to think abstractly about themselves and other people (Sebastian, 2015). As such, adolescents develop a better understanding of how peers perceive them, and they gain an understanding of social hierarchy and the concept of reputation (Jamison, Wilson, & Ryan, 2015). My findings have demonstrated that alopecia changed the way adolescents think peers perceive them. It also highlights that having a different visible appearance could threaten their reputation and their position in the social hierarchy, because they are continuously judged by their peers (see 5.1.1). In addition, it also demonstrates why this particular age group need their voices to be heard more so than any other. Adolescents are in a stage where they experience substantial changes within in biological, cognitive, social, and emotional domains, including areas involved in emotion processing (Theurel & Gentaz, 2018). This could help us understand why their emotional experiences are particularly heightened at this period of time. As such, we need to be aware of, and support, this particular group of young people.

Both parents and adolescents within the current study discussed bullying-related experiences. Parents displayed great feelings of worry, distress and helplessness when their child went to school, whereas adolescents discussed their feelings of frustration, loneliness and upset. Masnari et al. (2012) found that children aged nine months to 16 years with small facial differences experienced stigmatisation (see 2.1.8). My study demonstrates that adolescents with alopecia aged 10-19 years also experienced high levels of stigmatisation; however, the bullying experience also demonstrates how such an impact can develop into negative self-perceptions. Adolescent girls appeared to modify their perceptions of themselves and the world because of their experience of being bullied, often describing how they felt “ugly” and “not cute anymore”. This is striking considering parents had concerns that their child may find it difficult to form relationships and the adolescent findings appear to reflect these concerns.

Parental fears about future relationships and adolescents’ fears about “not being cute any more” could further our understanding of developing sexuality amongst this particular group. Although I do not know the sexual orientation of these young people, it could be argued that their experiences with peers regarding their appearance could potentially complicate their feelings about what sexual orientation they can feasibly desire and “perform” in their world. Previous research has demonstrated how CIA can impact intimate relationships. For example, Fobair et al. (2006) found that body image problems (from weight change and hair loss) were correlated with sexual problems for young women with cancer. The current study highlighted how parents also worry about their child forming intimate relations and the impact this could have on their sexuality. Furthermore, by exploring this qualitatively, I was independently able to see the direct impact of hair loss and the particular concerns that parents displayed.

Sexual socialisation is an important part of adolescence, and therefore the findings of this study provide valuable insights into the experience of alopecia within this realm. Namely, sexuality issues for adolescents with alopecia are linked to peer relations. Studies have suggested that having friendships (both same-sex and different-sex) allows adolescents to form skills that later help them form and maintain romantic unions (Kreager, Staff, Gauthier, Lefkowitz, & Feinberg, 2016; Suleiman & Deardorff, 2015). This suggests that both friendships and romantic unions are coherently linked, and this is not surprising given that research has found an association between negative interactions with peers and negative experiences of intimacy and forming romantic relations (Collins, Welsh, & Furman, 2009; Connolly, Furman, & Konarski, 2000). Girls in my study not only experienced social rejection but also feelings of rejection primarily from boys, when they no longer “looked cute”; this could severely impact their future romantic involvements. As such, it is important to recognise the impact of peer influence and how this can transcend into adolescent behaviour and sexual relationships and identities.

Whilst peer impact can be negative for some participants, the key finding also highlighted how friends can act as a vital support for adolescents experiencing alopecia. The sub-ordinate theme, friends “being my rock”, highlights the importance of peers in making sense of, and in the management of, their condition. It was interesting that online gaming enabled adolescents to remain connected to the outside world. Having this communication with friends may help adolescents feel less isolated and

ease the difficulties of their experience. Some argue that internet interaction may hinder relationships (Mikami, Szvedo, Allen, Evans, & Hare, 2010). However, this study confirms how online activity can help adolescents with alopecia remain connected to their friends when they feel isolated as a result of their condition. This is perhaps because these adolescents are able to create identity that exist aside from that which was characterised by alopecia and one that they have control of. Online avatars and personalisation for example, could enable adolescents to be on a “level playing field” amongst their friends when they are using the internet. They are able to tailor how they are perceived online and thus; this may be why some adolescents favoured online communication. Although studies have found that online virtual worlds and avatars are used by those who have low body image (Becerra & Stutts, 2008; Thomas & Johansen, 2012), the current study could provide an insight into how online activity could potentially be useful for those with alopecia. This is because rather than highlighting the physical attractiveness, these particular adolescents could be valued and “judged” on their personality and internal attributes.

Furthering this, girls within my study also reported how they would like to connect to others experiencing the condition. They were unable to do so online or did not know about such services. This demonstrates that girls too value support from their peers, especially in terms of management and coping. However, there was a need to share experiences with those who also had alopecia. This led them to seek out online support groups; however, the age at which the participants lost their hair may be why some adolescents did not receive the support they had hoped for. Younger adolescents may not have access to the internet because they may be too young. Studies within the dermatology domain have found that “online support communities offer both a valuable educational resource and a source of psychological and social support”. Thus, it would be expected that such support would also be beneficial for those experiencing alopecia, however, this may have to be in a controlled environment that is specifically for young people. Alternatively, when adolescents reach an appropriate age to use the internet, they could perhaps be signposted to such support sites.

### 6.1.3. Alopecia as a Gendered Experience

*“The problem with gender is that it prescribes how we should be, rather than how we are.”*

— **Chimamanda Ngozi Adichie**

Alopecia as a gendered experience was the most noticeable theme within the interview narratives. I will provide an outline of the peer impact and the wider social influences shared by both parents and adolescents in relation to this gendered experience, paying particular attention to wigs and negative connotation for boys, gender differences in the experience of bodily hair, and differences in coping between boys and girls. The primary key finding of gendered experience amongst the narratives was evident throughout my themes. For example, baldness is typically seen in older men and hair loss among younger people is usually associated with cancer treatment, irrespective of gender. These cultural and social norms influenced how participants made sense of their condition, and ultimately, how they managed their condition.

Interestingly, the gender issue was mentioned by both parents and adolescents; however, the ways in which this was deliberated sometimes differed. Firstly, both adolescent boys and parents appeared to have some form of negative connotations in relation to males wearing wigs. Whereas girls appeared to believe that it would be easier to have alopecia if they were a boy. Parents who had an adolescent daughter with alopecia often described in detail their experience of wigs. We can see that for these parents, wigs were an important component in how they managed their daughter’s alopecia, and how it held great meaning for them. In contrast to this, parents who had an adolescent boy with alopecia did not discuss wig use or even discuss this form of management as a viable choice.

Wigs were simply not considered an option for boys with alopecia, and this was particularly surprising given how many girls appeared to rely on their wigs. The reasons for this were unclear. One reason could be worries about exposure. Previous studies, such as the research carried out by Davey et al. (2018) and Montgomery, White, and Thompson (2017), found wearing wigs to hide the alopecia, created feelings of inauthenticity. Participants within their studies were worried that people would perceive them as a “fraud” and worried the wig would be exposed. Within parents’ narratives in the current study, some spoke about how those who wore hats and wigs in school had experienced their peers pulling off their wigs. Adding to this, wig-wearing is associated with women and therefore

femininity (see 1.1.), and so boys who wear wigs might be considered effeminate. There is also the possible association with older bald men wearing wigs because of hair being a symbol of youth and virility in men (Cash, 2001). Baldness may suggest impotence and therefore, again, a lack of masculinity. Adolescence is a potent time of developing sexual and gendered identities (Dewinter, De Graaf, & Begeer, 2017), thus adolescents with alopecia face hard challenges in developing credible gendered and sexual selves.

Supporting this, West and Zimmerman (1987; 2009), amongst others, describe how gender is guided by social interaction which helps maintain a sense of reality. Roles and tasks within society appear to be gendered (Carter, 2014). For example, wearing a wig can signify a gendered meaning, not only for the individual who is wearing the wig, but others who are observing them. When an individual fulfils the expected roles for these “gendered” tasks they essentially are “doing gender”(Carter, 2014). Gender, consequently, is constructed and maintained within society. Performing a task that aligns with a specific gender, develops meanings of what it is to be a girl or boy, or masculine or feminine (Carter, 2014). As wig users have been predominately females in the past, this may have created a gendered meaning. Therefore, girls wearing wigs fulfilled these expectations, as it is a behaviour which is associated with women. This may also help understand why boys and their parents were against wearing a wig because it is not a behaviour associated with being a “man”.

Adolescent boys are inevitably caught up in the task of “becoming men”, and this implies that the demands of masculinity could impact boys’ experiences of hair loss. School is an important arena for adolescent boys to engage in gender constructions which allow them to develop and perform masculinity (Connell, 2008). Furthermore, some parents respond differently to their daughters and sons, specifically, that they appear to be more expressive with their daughters (Wong, McElwain, & Halberstadt, 2009). This, then combined with how teachers and peers respond to these adolescents, demonstrate how the nature of gender stereotypes and “doing gender” is produced during this developmental period. Adolescent boys are shaped to behave and act in a particular way, and this may be why the experiences of hair loss differ. However, the pressures and demands of masculinity could create gender role strain and gender role conflict that ultimately impacts mental health in the future (Randell, Jerdén, Öhman, Starrin, & Flacking, 2016). For boys, adherence to certain aspects of traditional masculinity may limit their choices of adjustment and coping strategies. If boys were to

engage in wearing a wig that aligns with the “feminine” norm, they could risk being scrutinised by others as being “wimps” or “sissy” (Chunyan, 2017, p. S52).

Adding to the key finding that alopecia is a gendered experience, the wider literature (see 2.1.1) has demonstrated that hair is an important indicator of gender identity, in which “women with long hair and men with short hair are least likely to have their genders incorrectly assigned” (Manning, 2010, p. 36). My findings demonstrated how the loss of bodily hair can be experienced differently by both boys and girls with alopecia, underpinned by socially constructed Western norms in terms of masculinity and femininity. What was particularly interesting within the overall findings were the perceptions of hair on other parts of the body than just the head. Parents with those who had alopecia universalis, anticipated a loss of masculinity for their adolescent boy, because of the loss of hair on the body. Adolescents with alopecia universalis, on the other hand, did not discuss body hair but reflected solely on their head hair. This in itself is fascinating that parents thought about the whole impact of alopecia, including the future and future relationships, however the adolescents did not highlight this themselves. Perhaps they were concerned, especially during P.E, swimming and other activities where their friends could potentially see their lack of body hair, but did not feel comfortable talking about such experiences.

Overall, the theme, “not just the head” (see 4.3.3), demonstrated how the loss of bodily hair can be experienced differently by both boys and girls with alopecia. It is interesting how parents such as Gemma, felt a loss of masculinity for James because of the lack of hair on his body. The current literature suggests men’s grooming practices are now considered fashionable, including a trend to shave the body hair (Terry and Braun, 2016). Often, these practices are done to keep their youthful appearance, as well as to maintain attractiveness (Terry and Braun, 2016). This suggests that the worries some parents had regarding body hair do not align with the current views of “hairlessness” of men, but instead may be a reflection of generational norms. That being said, body hair loss was viewed by parents as a loss of masculinity for boys with alopecia, which was not mirrored by girls who lost their bodily hair.

Parental views of hairlessness, similarly, aligns with expectations of the wider Western norm for women to remove their body hair and maintain their attractiveness (e.g. Fahs, 2011; Terry & Braun

2013). There is a consistency in the literature surrounding women having hair where it is not “wanted” nor socially accepted (e.g., legs, underarms and pubic areas). Research demonstrates that women across cultures and history remove body hair and as such conform to this “hairless” ideal (Terry & Braun, 2013). Because of this, hair removal practices for women have become relatively mundane and normalised behaviours. This perhaps explains why having unwanted hair on the body could potentially be viewed as positive for their adolescent girl with alopecia, whereas the removal of bodily hair for males was seen as a loss of masculinity. Whilst parents may have felt that the loss of bodily hair can be positive, cancer studies demonstrated a perceived loss of “womanhood” (see 2.1.6) when women lost their bodily hair. This suggests hair is enough to significantly alter perceptions of who they are as women (Hansen, 2007; Power & Condon, 2008). Thus, there appears to be some meaning associated with having control of hairlessness. Previous research has focussed only on the loss of head hair, but my findings suggest that the loss of bodily hair may also have complex, gendered meanings, at least for parents.

Thirdly, adding to the key finding that alopecia is a gendered experience, the management of hair loss was particularly interesting across both data sets. The overall findings highlighted the different coping styles adopted by boys and girls. Whilst the qualitative exploration of gender differences in coping and psychosocial experiences for adolescents has, to my knowledge, only been reported by Rafique and Hunt (2015), the coping styles adopted within my study differed. Within my study, boys shaved their hair because it was a practical issue which required effort and time, girls appeared to do the opposite and spend even more time covering their patches of hair loss. This may reflect the cultural differences given that the Rafique and Hunt’s (2015) study took place in Pakistan, and headscarves and hats are worn as part of religious practices. My findings are therefore relevant to those who are experiencing the condition within the UK. This also further highlights that different coping styles for alopecia may be adopted by different cultures.



#### 6.1.4. Relationships and Support from Health care Professionals

*“Of course it’s happening inside your head, Harry, but why on earth should that mean it is not real?”*

**-Albus Dumbledore (J.K Rowling)**

This section is concerned with the experiences of engaging with health care professionals. The findings showed how parents responded to their child’s alopecia with strong emotional reactions. The emotional reactions that emerged in this study are perhaps unsurprisingly similar to those that have been highlighted previously in studies of parents who have an adolescent child, with both CIA and dermatological conditions (Balkrishnan et al., 2003; Gelmetti et al., 2012; McKenna et al., 2005). Given the high levels of emotions experienced by parents, it was noteworthy that no form of support was offered to parents.

Many with alopecia were told by health care professionals that it is “only hair”. Not only could such experience deepen the distress for participants, but the emotional devastation which they were going through was therefore not acknowledged and even minimalised. Such findings may help understand why parents did not ask health care professionals for support for themselves, despite experiencing powerful emotions. The findings from the current study demonstrate that parents too experience trivialisation from health care professionals, highlighting a need for practices to develop an understanding, and recognise, the significance of hair.

Although in previous studies, doctors had appeared to report an awareness of the psychological needs of their patients, Richards, Fortune, Weidmann, Sweeney, and Griffiths (2004) stated that there appears to be limited evidence to demonstrate that the psychological needs have been identified and addressed. They found little agreement between the views of dermatologists and patients with psoriasis in relation to the presence of clinically significant psychological distress. Interestingly, whilst some dermatologists did identify distress, they found that there appeared to be no form of follow-up or consultation regarding this. The findings from this study could perhaps explain why some parents felt as though their own needs had not been met and demonstrates the difference between views of the patient (or in this case, parent) and health care professionals. Although this is an older study, more contemporary studies have found that guidelines within the dermatological domain are not implemented, the psychological issues are not recognised, and access to psychological services are restricted (Jackson & van Onselen, 2014). Again, my study adds to the current literature that support

is needed for parents who have an adolescent child with alopecia, by identifying the emotional impact and barriers to their coping.

Whilst adolescents within my study wanted to connect to their peers who were experiencing alopecia, they had restricted access to the internet. Some were too young when they first lost their hair or were not signposted to support services within their GP appointment. Parents utilised the internet as a resource to find information, connect to others, and find support. Participants who were interviewed in the study were those who were recruited via Alopecia UK. Thus, this finding is not surprising. However, studies have found that acquiring knowledge about conditions before going to health care professionals made individuals feel more empowered (Fox, Ward, & O’Rourke, 2005; Oh & Lee, 2012) and more involved in the management of their condition. A dermatology study carried out by Orgaz-Molina et al. (2014) found that those with psoriasis and melanoma often used the internet to find sites that offered online support, and such results have been found by studies which found greater patient and physician engagement in health maintenance and care. These findings demonstrate that online information could be a valuable tool and improve the relationship between health care professionals and parents. My study also found that the internet was used as a source of coping. This was interesting as parents did not view the dermatologist as the ultimate health care authority.

Studies have warned both patient and health care professionals about the negative influence of online amongst the patient-physician relationship (Alpert, 2006; Iverson, Howard, & Penney, 2008). This is consistent with previous research which found that some health care professionals regarded the use of the internet to research patients’ conditions as a “lack of trust in their advice and recommendations” (Orgaz-Molina et al., 2014, p. 493). Within my study, we can see that the use of the internet was often as a result of a lack of information or support offered by health care professionals. This resulted in parents needing to use the internet for health care information seeking and support. Given that a majority of the literature emphasises the importance of doctors providing such support, and that parents within the study demonstrated the need for support services to provide better levels of care, it is apparent that there is a need for doctors to be aware of available services. It may be that health care professionals require more training on providing information, which will be discussed further in the next section.

## 6.2. Significance of the Study

In adopting a thematic analysis and drawing on interpretive phenomenology, the current study has drawn attention to features of adolescent alopecia that have not often been discussed by previous theorists. Not only has the current study provided new insights into the phenomenon of adolescent alopecia but in doing so, it encourages reconsideration of the support offered to those with alopecia and their families. Thus, it has been able to contribute to the research literature by offering a broader understanding to what it is like to be a parent of an adolescent child with alopecia and what it is like to be an adolescent with alopecia.

An aspect of the implementation and significance of the current study also lies within the dissemination- both written and oral (Miller, 2007). I presented a talk at the Alopecia UK conference. This provided me with an excellent opportunity to network and advertise my study. Actively engaging with Alopecia UK allowed potential participants to see whom they were speaking to online, visually, and build rapport. I felt this was important given the age of the participants within the current study. Adding to this dissemination, I am also grateful to have received second prize for my poster presentation at the University of Huddersfield Research Festival. This allowed me to adapt and present my poster at the Appearance Matters conference. After surface-level interpretations, I also presented my findings at the Qualitative Methods in Psychology conference. This adds to the significance of this study because I was able to present my findings to experts within the field of qualitative research, communicate perceptively, and reflect on my findings. I have also had the opportunity to disseminate my results within the Evidence-Based Nursing Blog. All of these opportunities have allowed me to reach a wide range of audiences that have different understanding and knowledge of the condition alopecia. It is hoped that through these disseminations, I have provided insight, awareness, education and allowed the audience to reflect upon the findings critically. Furthermore, it has provided scope for future publications (to be submitted) and plans for future postdoctoral study.

The study demonstrates the importance and usefulness of using a qualitative approach to capture the voices of those experiencing the condition and to identify their needs and the support available. This has added to our knowledge and understanding provided by quantitative studies (i.e. Montgomery et al., 2017), as narratives were led by participants in their own words, were in-depth, and highlighted problems which were not previously measured in pre-conceived questionnaires. In particular, the negative encounters with health care professionals was a phenomenon which was perhaps

overlooked by questionnaires that explore general health-related QoL (i.e. Putterman et al., 2019). However, the findings demonstrate how such an impact from these encounters could result in parents and adolescents feeling unsupported, and that this further added to their distress. Furthermore, whilst such measurements from health-related QoL questionnaires enabled researchers to see that alopecia caused anxiety and depression, a more holistic perspective gained from this qualitative research of the lived psychosocial experience of adolescents with alopecia and parents, revealed how, and why, they experienced such powerful emotions, and in which context.

### 6.3. Reflexive Exploration

Braun and Clarke (2013) emphasise the dynamic quality of the researcher in the process of data analysis and encourage a reflexive stance. In this section, I will review how I have been implicated in this research and how co-construction has been developed through illuminating my subjective position, as well as exploring the potential impact of my perspective on the data (Finlay, 2011).

I wanted to present the ways in which this journey has deepened my understanding of alopecia and how my own personal growth shaped the way I engaged with my data analysis. Firstly, given my own experiences of growing up within the Sikh religion and being a girl, I felt as though I had a different understanding of the significance of hair than most in the UK. Being told at a young age by more strict religious followers not to cut my hair, I often felt judged when I went to certain temples. Growing up in a predominately white school, I was amongst only a handful of students who were Asian. When I was interviewing adolescents about their experiences, and they described their experiences of wanting to fit in, I felt as though I could empathise with this. I myself have felt pressure to fit in amongst my peers, cutting my fringe like my friends, wearing bright coloured eyeshadow, and wearing certain fashion brands so I too “fit in” with the “style guide” in my year. Discussing how adolescents wanted to blend in amongst their peers made me reflect upon my experiences at school and explore why I made these appearance choices. Ultimately, it is because I too wanted to fit in. Understanding this experience allowed me to be mindful of the ways in which peers impact upon one’s identity.

Furthermore, being an active user of social media, I also felt the pressure to look a certain way. Beauty influencers and celebrities portray the ideal image of what a woman’s body should look like, with a flawless complexion and hourglass figure. Again, this is historically and culturally specific and remains

fluid throughout the years depending on what is considered “fashionable”. But I felt as though I had experienced pressures in similar ways. For example, seeing my friend bullied for wearing a turban at high school was a confusing time. Other students made comments about her hairy arms, which led me to be conscious of my own. I would shave my arms without telling my parents and roll down my sleeves when the hair grew back. Upon reflection, I understand that body hair grooming is common. However, it was these pressures I felt from peers that led me to these decisions. This is interesting, as it was only when I engaged in discussion that I truly uncovered the significance of external pressures and cultural norms. If I felt such pressures to have an idealised body shape, if I cut my hair to fit in with my peers, I cannot imagine how hard it would be to have alopecia, a very visible condition which makes it difficult to hide or change. As such, it was a challenge to remain open to psychosocial meanings that I did not carry. It could be that my own personal experiences could have prevented me from seeing the “wider picture” and other experiences could have been missed. Yet given the complex, rich data drawn from participants’ narratives regarding peers, I felt as though not discussing the impact of peers would not have done my study justice. Instead, I felt as though a rigorous analysis, and understanding the influence of peers, has allowed me to uncover and explore this phenomenon further. Reflecting on my own personal experiences helped me understand their reasons for concealment. Whilst now I embrace my difference in appearance, when I was younger, I wanted to be like my friends; I wanted to fit in.

The meaning of hair as a young Sikh woman may have affected how I reacted to my participants. Whilst I expected some bullying experiences, perhaps I was a little naïve because the explicit hurtful comments and physical aggression towards adolescents with alopecia shocked me. I did not expect people to say such vulgar comments and hurt those who had lost their hair. Perhaps because in my own experiences it was the “popular” girls who made comments and engaged in gossip, I was not prepared to read how boys and girls alike, were physically assaulted just because they looked different. It was hard to comprehend the actions of others, and at times it made me angry and upset; even more so, when they discussed the impact this had on them. I was grateful that I had formed a level of trust with my participants, especially because I engaged with them online. It felt like a double-edged sword; whilst on some levels, this may have helped them to be confident and open up to me more, the way I could respond to them was limited. I felt that at times, I really wanted to communicate in an empathetic and understanding manner, but on occasions, I felt it was difficult to do so when writing emails. In essence, I experienced a “role conflict” (Dwyer & Buckle, 2009). My “researcher” self was in conflict with the part of being another young woman who had experienced similar things,

and thus felt empathetic towards participants. Forming such relationships, over the course of 6 weeks was a long time and it enabled me to immerse myself into their life-worlds and into the emotion of their lived experience.

In terms of my reflection on methodology, I found the analysis process both long and messy. I considered myself a novice researcher given that I had transitioned from undergraduate level to PhD, without doing a Masters degree to gain research experience. As such, I felt I wanted to report everything that was discussed, heavily relied on the descriptive elements, and struggled to separate myself from only seeing the descriptions. I felt the data was so rich and meaningful that I wanted to present all my findings to the readers and do the experiences justice. Eventually, I steered towards issues and experiences which I felt were the most meaningful parts of the whole. Although I wanted to report as much as possible, I still wanted to relate such findings in an academic manner that allowed the interpretive lived experience to be presented. In order to do this, I returned to my findings and tried to understand what the key issues were. Through the everyday lived experiences that were identified, I had to be reflective. I asked, how were these experiences reflected and related comments framed? What does this tell me about what it is like to be a parent of an adolescent child with alopecia? How do these findings enrich my understanding of what it is like to be an adolescent with alopecia? In what ways did these influence behaviours? Once I understood that I had to be both descriptive, and interpretive, to develop an understanding of these questions, I felt I was able to grasp the methodological process.

I am aware that the process is iterative and as such, themes and titles evolve. Every time I revisited my data, I saw different things which I had not identified before. However, I feel that I have taken my analysis as far as it can go and in effect, reached a saturation point. The themes presented are considered relative to my context of engagement with the text. As such, it can be argued that it is one amongst many interpretations and ways of understanding these experiences, and others may identify other phenomena and present different conclusions than my own.

The interviews demonstrated a broad spectrum of individual experiences, and I hope that this has captured the wider essence of adolescent alopecia. There were a couple of occasions when I felt that the experiences that were discussed by both parents and adolescents were particularly devastating. Seeing the impact of alopecia on a person’s life was deeply upsetting. There were other occasions where adolescents discussed the importance of their peers and the support they have received,

coming out stronger from their experiences. This filled me with optimism and hope that went beyond superficial appearances and expressed the depth of their character and personalities. I am aware that interviews only capture a small snapshot of experiences, and I hope that those whom I have spoken to who were struggling, are now in a happier place. In particular, at the end of one interview, a parent stated, “Interestingly enough, sending my answers has also helped support me on this journey. It has been interesting looking at how I have felt about his alopecia, so thanks for even doing the study.” This confirmed that my study was worthwhile and needed. It also demonstrated that even talking to support services could really help parents make sense of their child’s alopecia and inspired me to continue, even when times were difficult. I hope the insights offered by individuals in this study and my own reflections of my journey, can contribute to others' stories, just as the reflections shared from the participants in the current study, contributed to mine.

## Chapter Seven: Conclusions and Recommendations

In consideration of the findings and discussions, this chapter will provide conclusions, contributions and recommendations for future research. In doing so, it is hoped that the lived experiences of parents and adolescents experiencing alopecia can be improved.

### 7.1. Contribution to knowledge

This study exceeds the individual elements that constitute the findings as it produced an in-depth ontological interpretation, as opposed to describing, underpinned by interpretive phenomenology and mindful of ideas provided by phenomenologists such as Heidegger (1962) and van Manen (1990; 1996).

#### Sample

The nature of the sample has provided the study with a unique data set. Firstly, there are few studies that have undertaken in-depth qualitative research with parents and adolescents which specifically explore alopecia related experiences. Previous research has often been undertaken to explore the experience of cancer related hair loss (Kang et al., 2018; Rossi et al., 2017; Shin, Jo, Kim, Kwon, & Myung, 2015; Sposito et al., 2015). Such studies have highlighted how CIA often caused low QOL and psychological difficulties. However, Sposito et al. (2015), highlighted how cancer patients came to accept the hair loss when they realised that their CIA was short lived. Furthermore, as noted within the literature review, there are effective support services in place to help patients cope with their hair loss prior to treatment. The findings within the current study are unique to those with alopecia because the condition occurs suddenly, without warning. The loss of hair is shocking and devastating, not only for the individual with alopecia but also for their family members. As well as this, the shock of watching the hair unexpectedly fall out was interpreted as traumatic. This has furthered our understanding of the coping and adjustment highlighted within the literature review because arguably, the shock is greater for those who have alopecia as they do not adopt anticipatory coping (see 2.1.5). Furthermore, the coping and adjustment differs for those with alopecia because those with the condition are at risk of losing their hair on more than one occasion which causes further emotional distress and psychological difficulties. The current study helps us to understand what it is like for hair loss unrelated to cancer and for those whose hair may not grow back.



There are limited studies that have explored alopecia related experiences from the perspectives of adolescents, especially within the UK. These individuals were perceived as a vulnerable group by the health care professions who I approached. The current study overall highlights the worth of including young people in research within the UK where they previously had limited voice. Having a charitable organisation provide such access, and shed light on the experiences, perhaps questions this notion of vulnerability from healthcare professionals who were unwilling to provide a recruitment gateway. Rafique and Hunt’s (2015) study within Pakistan has highlighted the benefits of interviewing participants within this age group. The current study has demonstrated that participants are willing to discuss their experiences openly, despite such gateway difficulties and furthermore, highlights the need for young people to be actively involved within research.

Whilst Rafique and Hunt’s (2015) study is valuable, the context to which the interviews took place means that the findings are more difficult to apply to those within the UK. My study has furthered our understanding not only from a methodological/recruitment perspective but equally, demonstrates how the support services and the coping for those within the UK differs. My study has shown that health care professionals trivialise the condition, however, this was not identified within Rafique and Hunt’s (2015) study. This is perhaps reflective of the types of health care services available within Pakistan which differs from the NHS services. As such, my study has contributed to the current understanding of knowledge regarding the provisions and support available within the UK for adolescents and from this, suggested implication for practice (see 7.2). The issues regarding coping within this particular group certainly differs, especially regarding bodily hair and covering the alopecia where scarfs are typically seen as the norm within Pakistan. Rather than scarfs, the girls within my study opted for wigs and boys wore hats. The current study has highlighted that within a societal context, hair is a significant part of identity and culture and these findings demonstrate the importance of the cultural norms and how this can impact the findings.

The challenges around concealing are different within other cultures, and the study has contributed to our knowledge regarding the coping styles adopted by adolescents and the difficulties of losing body hair which could impact the loss of masculinity and femininity. This furthers our understanding of studies which focus on the identity of women with breast cancer and overlook the impact of hair loss on males (Koszalinski & Williams, 2012; Male et al., 2016; Trusson & Pilnick, 2017). The current study has therefore broadened our knowledge of gender differences and the significance of bodily hair during the adolescent period. Furthermore the current study has highlighted how this could

impact their sense of identity, broadening the wider studies of identity related literature (i.e. Adams & Stevenson Jr, 2012; Davis, 2013; Dittmar, 2009).

Furthermore, the current study demonstrates important concepts about how the experience of alopecia is quite different for adolescents and why it is important to recognise this. The parents’ voice does not always echo the experience or concerns of the child and studies evaluating adult hair loss may also not be applicable to the experiences of adolescents. Adolescents due to their stage of development have unique stressors relative to their physical maturation and psycho-social need to identify with their peer groups (Gooren et al., 2011; Kornienko et al., 2016; Williamson et al., 2010). It is a time when they are already developing important understandings of their own identities, bodily changes, sexuality and relationships. Hair loss can, therefore, complicate and indeed heighten stressors that are relative to them navigating their perceived and developing self. As highlighted, alopecia related studies have often focused on older samples (Davey et al., 2018; Montgomery et al., 2017; Nozawa et al., 2013) but there are issues within the current study which demonstrate that adolescents have additional needs. My study has gone beyond these adult studies which have found psychological issues, to highlight unique experiences for adolescents, especially within the school setting. School experiences heighten adolescents need to conceal their alopecia and “blend in” amongst their peers. The experience of bullying is apparent for adolescents with alopecia, however, is not highlighted in adult focused studies. The current study demonstrates how young people within this particular age group experience further stressors to those of an older sample. Adolescents with alopecia have to transition back into school following the loss of hair, whilst at the same time, develop their sense of identity, peer and sexual relationships.

#### *Methodology and methods*

To my knowledge this is the only study that has conducted a qualitative study influenced by interpretive phenomenology and using thematic analysis, to guide the data collection and analysis of data produced by a semi-structured sequential email method. As such, the study can be regarded as distinctive in its methodological focus. Previous studies have used online methods to explore alopecia the current study has demonstrated the advantages of interviewing adolescents within their “natural communication environment” (Mason & Ide, 2014, p. 41). Furthermore, the current study has highlighted how online email interviews has allowed participants to discuss sensitive topics such as relationships, loss of sexuality, bullying related experiences and other issues that may not have been

apparent if I had interviewed them face to face. The time sequencing allowed them the space to reflect and articulate their thoughts and report their experiences at their own pace. This has been reflected in the rich, deeply powerful emotive narratives, highlighting how online methods can be regarded as a suitable tool for qualitatively interviewing participants on health related and sensitive topics, including those of adolescent age using this online method.

My study, however, has furthered the current literature as previous research has typically used face to face interviews with adults (eg., Davey et al., 2018; Sellami et al., 2014; Wohlmuth-Wieser et al., 2018). The research has highlighted that adults with alopecia experience social isolation, as demonstrated by Rafique and Hunt (2015). I have shown how the use of technology, which is now being used in an emerging way, can be used effectively within this topic. This method is a practical approach of communicating with those with alopecia because they do not have to be concerned with self-presentation. Furthermore, email interviews have the potential to reach participants who may not have taken part in face to face interviews because they experience social isolation and do not want to show their alopecia to others.

There are general concerns about online interviewing which relate to the lack of social cues and the difficulties of building rapport prior to the interview process (Bowden & Galindo-Gonzalez, 2015). In the current study, adolescents and parents appeared to be open and comfortable discussing sensitive issues within this arena. Relationships were arguably deepened because of repeated contacts with participants over a six-week period, and this frequent communication has often been viewed as a valuable aspect of this method (King et al., 2018). The current study has demonstrated how rapport can be built with this particular sample using asynchronous emails over a substantial time span.

Email interviews have often been referred to as a “disembodied method” as noted in chapter 3.3.2. This causes difficulties for non-verbal cues (such as body language) and paralinguistic cues (such as the tone of voice) to be captured because the participant is not visible to the researcher. As such, expression needs to be conveyed using a text-based format. However, in more contemporary times, young people have found ways to convey meaning through other expressions (Hu et al., 2017). The email approach recognises how participants can demonstrate social cues through other means such as capitalisation, using emojis and elongation of words, all of which have now become a new way of conducting non-verbal cues (Hu et al., 2017). If there was a certain expression to convey, participants had the resources to do so. As such, the study further contributes to how emojis, capitalisation, and

elongation of words can be effective supplements of non-verbal cues for interviewing adolescents using online text-based methods.

The findings of the current study may have been shaped by participants’ own reflections and their choices in what to include within the narratives. It is possible that the participant’s responses may not have been their immediate, raw response which is typical within a synchronous interview (James, 2016). Allowing participants to have time to respond to my questions may mean that they may have re-written their replies and conveyed themselves in a different manner because they are able to polish their narratives and make it more appealing to the reader (King et al., 2018). However, the ability to go back to their narratives and re-write may also mean they are able to reflect upon their experiences and expand upon their narratives in more depth, rather than formulate short answers to a question. Furthermore, given the nature of this method, there was always a possibility of participant drop off, or a lack of interest as the interview progressed (Bowden & Galindo-Gonzalez, 2015). However, the current study has demonstrated that those experiencing alopecia want their voices to be heard and the retention rate of participants has further added to this. All of these were a strength of the current research and in turn, supports the use of online interviewing as a legitimate first choice for qualitative researchers.

### Findings

I hope the current study has provided the opportunity for readers to reflect upon, and be mindful of, what it is like for relatives and adolescents to experience the condition and allow them to think about the next steps regarding implications to improve the experience of the condition. By doing so, it could potentially encourage further questioning and exploration of this phenomenon. van Manen (1990) states “It should only make people wonder – that’s the point”(Rodriguez, 2009). I am optimistic I have achieved this purpose.

## 7.2. Implications for Practice

In addition to the contribution made to the research literature, the current study also holds real-world importance and application. That is, for health care professionals to be aware of the psychological needs of parents and adolescents experiencing alopecia. Furthermore, health care professionals, family members, and schools need to be mindful that peers could make adolescents’ experiences

difficult. In doing so, we need to be aware of services to help adolescents’ transition back into their everyday routine following the alopecia.

However, it is first important to discuss the issues pertaining to the application of qualitative research to real world settings. Qualitative research often has a typically narrow sample (Pilot & Beck, 2010). This can be problematic from the applied or pragmatic point of view because the transferability of the findings can be limited (Pilot & Beck, 2010). In particular, there is an emphasis on the context in which qualitative research has been undertaken for example, the cultural and demographic features, and to what extent this can be applied to other real-world settings (Pilot & Beck, 2010).

### 7.2.1. Implications for Health Care Professionals

This study shows that distressing feelings experienced by parents, were reinforced by experiences with health care professionals from whom help was sought. Although participant accounts demonstrate how health care professionals trivialising alopecia could create feelings of being let down and helplessness, they also demonstrate important ways in which health care professionals have the potential to not only meet the needs of the parents but the adolescents too. By enabling health care professionals to reflect upon the meanings of hair, such as the links to femininity, or the negative representation of baldness, health care professionals could better recognise the needs and difficulties experienced by parents and adolescents with alopecia. This can be done through online training or allowing them to become familiar with alopecia support websites such as Alopecia UK.

Parents expressed some different needs to the adolescents who were interviewed. For example, parents described how they would have liked more information about the condition, to connect with other parents, and receive information on how to help manage the condition. It is important for health care professionals to distinguish and differentiate between the required level of information and needs for parents and adolescents and act accordingly. However, as reported within the “need to remain strong” theme (see 4.2.2) where parents may not reveal the impact of the condition in front of the child, health care professionals should be vigilant and address the needs of the parents within a separate appointment. Davey et al. (2018) also suggested that counselling and psychological interventions could equally be useful for those with alopecia. However, my study has also found that these interventions could also be useful for parents.

It is important to validate parents’ feelings and acknowledge that they too may be experiencing distress. In particular, it is critical for health care professionals to limit medical discourses and practices that reduce people to patients or cases. The current study has identified particular references to hair which has significantly impacted participants’ experiences of alopecia. As such, an important implication for practice would be for health care professionals to avoid the discourses referring to alopecia being “JUST” the loss of hair, or a “cosmetic” condition.

Furthermore, the long wait between appointments and referrals to the dermatologists could be a reflection of the demands placed on the NHS. Therefore, it is important for support services such as Alopecia UK to help those experiencing the condition whilst they are waiting to be seen by health care professionals. This is especially given that both parents and adolescents demonstrated that online support groups and forums were highly valued, yet the majority were not signposted to such sites. Within the first encounter, GPs should direct patients and their parents to such services. In becoming familiar with these websites, GPs would also have the opportunity to reflect critically on the meanings attached to hair, whilst it is important to avoid particular discourses regarding the condition, it is important for health care professionals to refer patients to these services so they are able to access support, especially as adolescents transition back into school (see 7.2.2).

As pointed out above, caution needs to be applied when referring to a typically narrow sample within qualitative research. Within my study, patients were recruited via Alopecia UK and were seeking online support. It could be possible that all Alopecia UK users had negative encounters with their health care professional and as such, were seeking further support online. My sample may not have been representative of those who have had positive experiences within the healthcare system and did not require further information or support from the charity. Furthermore, the participants within my study had long term alopecia. This means that their experience could differ to those with less extensive forms of hair loss, or hair loss which was short lived. The study has also highlighted that there are cultural features of the condition. For example, wearing a headscarf may be viewed as the norm within Pakistan, however, this was not apparent within my study. Equally, a shaved head within this particular age group was viewed as unusual compared to other cultures where baldness is viewed as the norm (as highlighted in chapter 1.1). As such, the findings of this study could be limited to those within the UK because their experiences and coping may differ from other cultures.

### 7.2.2. Implications for School Services

The findings are consistent with previous research, in which adolescents with hair loss (CIA) experience a number of difficulties within school (Breen, Coombes, & Bradbourne, 2009; Earle and Eiser, 2007; Gunawan et al., 2016). The impact of bullying within the current study was a significant finding. Parents’ and adolescents’ accounts of the bullying was perceived as relentless and intrusive over long periods of time. Despite schools being aware of this, there still appeared to be significant amount of bullying related experiences. It is important to establish a more collaborative approach between support services, schools and parents. There is a need for schools to be more actively involved with adolescents in their transition back into school. Schools can be actively involved with organisations such as Alopecia UK and could have meetings with parents and adolescents to establish the best approach to their transition.

Within the past year, Alopecia UK has developed a “Children and Young People” section within their website. This was not available when I first began my PhD, and some guides for adolescents are still not fully developed. However, the section provides a platform for children and adolescents to receive advice, as it aims to help children and adolescents understand alopecia and answers some questions they could potentially be asked by their peers. For parents, there are tips about how to cope with their child’s condition, tips for interacting with their child’s school or nursery, and advice and quotes from other parents. They also provide tools which aim to support parents with issues they may face at school, such as providing sample school letters. These letters were produced to aid parents with approaching teachers prior to them re-entering school, including information about the condition, how their child has chosen to manage their alopecia (e.g. hats or wigs) and how this should be exempt from the usual school uniform policy. The sample school letters provided by Alopecia UK could help with informing schools about the condition, although these require modification for the high school level. Nevertheless, such letters could assist parents with communicating with schools, especially given the difficulties that adolescents experience within school. This study demonstrates the real-world importance of providing this information to parents and making the transition into school easier for adolescents. Furthermore, it allows schools to have open communication with parents. Action plans could also be developed to help deal with bullying on the basis of appearance, especially given all adolescents and most parents discussed some form of bullying-related experience. The current study has demonstrated that there is a need for schools to be more active in helping adolescents transition back into school following the loss of hair and having such resources could be beneficial.

### 7.3. Recommendations for Future Research

In terms of the sample, there needs to be thought within future studies in how we can reach more diverse participants; it is likely that experiences of alopecia differ in cultural settings where the psycho-social meanings of hair may be quite different from those of my sample. In relation to my own experiences as a Sikh girl, it would be interesting to explore what impact alopecia has amongst the adolescent Sikh population; especially as uncut hair is an important symbol of our identity. Equally, this can be applied to broader religions where hair has other significance, for example, within the Jewish religion, men are required to keep their sideburns (Milligan, 2014). Cultural meanings of hair can be expected to be different, and therefore future studies can explore this further.

Furthermore, studies need to explore how to access more fathers to take part in the study. This is important given that broader literature has found coping behaviours and experiences differ amongst mothers and fathers of those who have mental health issues and chronic illness (Compas et al., 2015; Masa’Deh, Bawadi, Saifan, & Aburuz, 2015; Sharma, Chakrabarti, & Grover, 2016). The advertisement for the current study was disseminated via Alopecia UK, and email responses were primarily from mothers. This may be a reflection of the members within Alopecia UK. Perhaps using other outlets in terms of distribution of the study, such as finding a broader reach through social media, or specifically inviting fathers to take part in the study may encourage a higher take-up. The current study did not aim to be comparative across sexuality, gender or ethnicity, however, having significantly fewer fathers meant that I was unable to truly explore gendered experiences from the perspective of parents. Previous research appears to demonstrate that cultures and genders hold their own specific value of hair (Barber, 2008; Frank, 2014; Rafique & Hunt, 2015; Singh, 2010). The coping styles of parents were demonstrated; however, the makeup of the sample was not sufficient to fully understand the gendered aspect of alopecia and how this could impact experiences amongst parents. Furthermore, returning to my original design, future research should find ways to explore the wider family impact. Alopecia UK may only be accessed by parents and adolescents experiencing alopecia. It could be argued that this may mean they require support because they are actively seeking it. However, given my literature review has demonstrated a wider family impact (see 2.1.5), future research could look at the experiences of adolescent alopecia amongst carers, siblings, grandparents and partners.



Furthermore, building on my theme, “not just the head” (see 4.3.3), it will be interesting to see how adolescents with alopecia universalis experience hair loss on other parts of the body. Within the study, it was parents who discussed the impact of alopecia as a whole-body concept, whereas adolescents with alopecia universalis only described losing their hair on their head. The findings from parents’ narratives indicate that if they had a choice, they would prefer some body hair. Future research could explore this, especially considering bodily hair removal is influenced by current Western norms. However, I need to be aware that adolescents with alopecia universalis may not have felt comfortable discussing these issues with me. It may be that body hair at this age may not be considered particularly important for my participants, or it could be that adolescent boys may not be comfortable discussing the loss of body hair with a female researcher. Further caution and sensitivity are needed when discussing body hair considering it may lead to deeper intimacy issues in terms of sexuality and relationships.

Overall, gender, sexuality and culture continue to be noteworthy domains to explore more extensively and coherently, regarding the meaning of hair and its loss. Research that can explore alopecia within different groups of adolescent girls and boys, and those which investigate generated meanings of hair within diverse cultural backgrounds, can provide further insights into providing support, especially as we are still yet to find effective treatments.

#### 7.4. Conclusion

This study strengthens the value of qualitative research, and how it can be underpinned by interpretive phenomenological concepts to explore in-depth experiences of living with alopecia, particularly using online methods. The findings of the current study have provided insights into the world of adolescent alopecia, and the world of parents situated within it, and both samples formed an integral part of the gathering of experience. In particular, the challenges of peer influence and fitting into the “style guide” compels one to consider different types of management options based on gender, as well as, how the reinforcing nature of health care professionals trivialising this condition, may lead participants to believe their thoughts and feelings are not valued. The current study has highlighted implications for practice within the school setting and healthcare. That is for healthcare professionals to avoid the terminology of “just hair” or “cosmetic” when referring to alopecia. Secondly, to encourage a more collaborative approach between support services and schools to help young people to transition back into school and utilise the resources available.

From these accounts, I hope that wider services are able to recognise and provide interventions to those experiencing the condition, especially as there is a desperate need for such. Furthermore, it is also my hope that the reader (academic and professional alike) can value the interpretations demonstrated in the findings and discussion chapters of the current study. Overall, the current study has helped me understand the lived experience of adolescent alopecia from the perspectives of parents and adolescents. I am optimistic that the study in turn, has helped the audience to make sense of these experiences through my own interpretations. In addition, I believe that my findings fulfil the study’s aim which was to explore how parents, who have an adolescent child with alopecia, and adolescents with alopecia, make sense of the condition.

As I reflect upon my final thoughts, I would like to return to the song by India Arie and note how the current study has added significance to the lyrics presented. In particular, I felt the quote “steady judging one another by their appearance” is deepened by the notion that “judgement” is especially high during the period of adolescence. Furthering this, “judgement” was a substantial contributor towards hiding the alopecia in the current study. It is also interesting to note that India decided to go “natural” at the age of 18 when she became a “woman”. Not only does this reflect the cultural significance of hair being linked to Western culture, it also highlights how hair is a key contributor to youth and the pressures elicited within adolescence. When she was younger, Arie used methods such as curling and relaxing the hair. From the findings in this current study, Arie’s actions could be understood by the pressures to look like her peers and fit into the “style guides” within school. When I now refer back to the lyrics by India Arie following this PhD journey, I feel as though the lyrics have presented new meanings and understandings. Like Arie, I hope my participants find solace and acceptance of their hair and take pride in the "soul that lives within".



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## Appendices

### Appendix 1: Parent Advertisement

**Relatives’ experiences of having an adolescent family member who has alopecia: A PhD student at the University of Huddersfield seeks participants**

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A PhD student at the University of Huddersfield is looking for individuals to take part in her study.

Little is known about what it is like for adolescents (aged 10-19) to experience alopecia. This study wants to understand more about young individual’s experiences of alopecia throughout their teenage life, by interviewing relatives. By looking at family members experiences, we can potentially identify unmet needs and make recommendations for future development for young people with alopecia and their wellbeing.

The study requires relatives (over the age of 16) to talk about their experiences of having a relative with alopecia. You could for example be a parent of an adolescent who is experiencing or has experienced alopecia, a legal guardian, a grandparent or sibling.

This is an online interview so you can take part in the comfort of your own home.

For more information, please contact Amrit Bhatti on [Amrit.bhatti@hud.ac.uk](mailto:Amrit.bhatti@hud.ac.uk)

## Appendix 2: Adolescent Advertisement

PhD Study into teenage experience of alopecia seeks participants

12<sup>th</sup> January 2017

### **Teenagers’ experiences of having alopecia: A PhD student at the University of Huddersfield seeks participants**

A PhD student at the University of Huddersfield, Amrit Bhatti, is looking for individuals to take part in her study.

The study wants to explore how a young person manages their alopecia and the support that they receive. There are not that many studies out there that looks at how a young person experiences alopecia, but we think it is important that young people with alopecia have a voice to talk about what it means to them. From doing this, we can look at how other young people can access the right help and support and improve their wellbeing. The study requires teenagers between the ages of 13-19 who have (or who have had) alopecia, to talk about their experiences.

Should you wish to take part in this study, your identity will remain anonymous. Your name will not be included in the resulting report.

This is an online email interview so you can take part in the comfort of your own home.

These information sheets explain more:

[Information Sheet for Over 16s](#)

[Information Sheet for Under 16s](#)

[Information Sheet for Parents of Under 16s](#)

If you are a parent of a child under the age of 16, you can also contact Amrit directly so you can discuss further what the study involves and what your child wishes to participate in.

For more information, please contact Amrit Bhatti on [Amrit.bhatti@hud.ac.uk](mailto:Amrit.bhatti@hud.ac.uk)

## Appendix 3: Parental Information Sheet



### **An exploration of the lived experiences of the relatives of young people who have alopecia**

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#### **INFORMATION SHEET**

You are being invited to take part in an online interview as a part of my PhD study at the University of Huddersfield. Before making the decision as to whether or not you would like to take part, it is important for you to understand why this study is being done and what it will involve. Please take the time to read the information below and feel free to email me any questions if you are not clear about the study.

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#### **What is the study about?**

Little is known about what it is like for young people to experience alopecia, in terms of what having alopecia means to them and how it may influence their well-being. This study wants to understand more about young individual's experiences of alopecia throughout their teenage life. This information will be gathered through talking to relatives who has a family member with alopecia. From this, we can identify unmet needs and make recommendations for future development for young people with alopecia and their wellbeing.

#### **Why I have been approached?**

You have been asked to participant in this study because I am looking to recruit family members who has a relative (aged between 10-19) with alopecia.

All relatives of individuals who have experienced alopecia are welcome to take part in this study, providing you are over the age of 16. You could for example be a parent of an adolescent who is experiencing or has experienced alopecia, a legal guardian, a grandparent or sibling.

### **Do I have to take part?**

It is entirely your decision if you wish to take part in this study. If you meet the requirements stated above and you are interested in taking part, you can contact me to discuss your participation further. If you chose to continue with the study you will be asked to read and complete an online consent form prior to the online interview. You have the right to withdraw from the study at any time during the interview, and up to one month after the interview has taken place, without giving reason.

### **What will I have to do?**

If you are interested in taking part please contact me directly via the email address provided. If you agree to continue in this research, you will be asked to read and complete an online consent form, and state that you are happy to proceed.

You will be sent one question a week over the course of 6 weeks through the email address you have been provided. This will be arranged at a date which you decide is best for you to start.

You will be asked about your own experiences of having a relative with alopecia. You do not have to answer any questions if you do not wish to do so. There are no right or wrong answers as I am only interested in your opinions and experiences. You can stop the interview at any time or ask me if you need further clarifications on the questions. You can change your mind at any time during the interview, and you can withdraw your data up to one month after your interview has taken place by emailing myself.

### **What will happen to the information?**

Should you wish to take part in this study, your identity will remain anonymous by using a false name in the report. Any personal information given such as your name, phone number and email address will be secured safely and kept up to date of completion. All information disclosed within the interview will be kept confidential, in line with the Data Protection Act 1998, unless you indicate that you or anyone else is at risk of serious harm. Should this occur, I will inform the NSPCC or your local authority.

Your online interview answers will be kept secure in a password protected computer and email address, which only myself and my supervisors will have access too. This will then be

destroyed after 10 years. The information given will be used for my doctoral thesis as well as possible publications such as journals or reports. Your anonymity however, will still remain protected.

If you would like to take place in this study please contact myself directly with the address provided below. If you have any questions further questions please do not hesitate to ask me.

Researcher details:

Amrit Bhatti

[Amrit.Bhatti@hud.ac.uk](mailto:Amrit.Bhatti@hud.ac.uk)

Supervisor details:

Alison Rodriguez

[a.m.rodriquez@hud.ac.uk](mailto:a.m.rodriquez@hud.ac.uk)



## Appendix 4: Information Sheet (adolescents under 16)



### **An exploration of the lived experiences of young individuals who have alopecia**

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#### **INFORMATION SHEET (Under 16's)**

Hello!

My name is Amrit and I am a student at the University of Huddersfield. Thank you very much for taking the time to read this sheet. It tells you all about a study I'm doing so you can decide if you'd like to take part (but you don't have to!).

I'm inviting you to take part in an online interview to help me learn more about what it is like as a teenager to experience alopecia. I'd like to email you some questions over a few weeks, and it would be really useful for me to find out about your experiences.

Before deciding whether you would like to take part though, it is important that you understand why I am doing this and what you will have to do. So please take time to read this information sheet, and talk with your parents/carers or anyone you feel will help.

If you have any questions or need more information, you can email me using the email address below. If you decide you want to take part, I also need your parent/carer to let me know that they are OK with this. They can contact me using the email address or telephone contact details at the end of this sheet.

### What is the study about?

There are not that many studies out there that look at how young peoples’ experiences of alopecia, and in this study, I want to explore how young people like you manage their alopecia and who supports them to do this. I hope that by doing this, we can look at how other young people can access the right help and support and improve their wellbeing.

### Why I have been approached?

I am looking to get in touch with teenagers between the ages of 13-19 who have (or who have had) alopecia so that I can find out from them what it is like from people who know the most about it – people like YOU! You have lots of valuable experience that it would be really useful for me to find out about.

### What will I have to do?

First of all, I will need to make sure that you and your parents/ guardians are happy for you to take part in the study.

Your parent/guardian will first need to give me the go-ahead by emailing me their consent. Then you can email me your consent. To do this, you will have to copy and paste the highlighted text below and email it to me using the email address below.

‘I (insert name here), confirm that I have read and understood the information provided and that I assent to taking part in this study.’

The points you need to understand and consent to are these:

- I have read and understand the information sheet emailed to me by Amrit
- If I had any questions about the study, I was able to email or ring Amrit.
- I know why this study is being done and what I will have to do.
- I know that I do not have to take part if I do not want to and that I can stop taking part at any time without giving Amrit a reason while we are emailing, and one month after.
- I know that my name and name of places will be changed so so no-one will know that any information came from me.
- I understand that anything I say will be kept private unless I tell Amrit about any harm to myself or others, or anything which suggests I am in danger. If this happens Amrit will contact the NSPCC.
- I understand that all the emails will be kept safe.
- I agree to take part in the study

Then I will email you with a question once a week for 6 weeks. It is your choice when you want to start receiving your questions – you can let me know when it is best for you. I will be asking questions about what it is like to have alopecia, such as how you feel, what it is like at school and what it is like at home. Sometimes I might ask you more than one question, but it is only because I am really interested in your reply and I would like to know a little more about it. It is quite important that you do reply to my questions within the week. This is only so that you do not need to stay in the study any longer than needed. It is ok if you are busy or you have lots of school work- if you need more time to answer your questions you can just email me to let me know. If you forget to reply, I will send you a friendly email just to check everything is ok and that you are still happy to take part.

### **What will happen to the information?**

All information from the interview will be kept confidential – this means that no one other than me will ever know that your information came from you. I will be writing a report using your emails, but I will change your name, other people’s names, and the names of places. Instead I will use made up names so no-one will know that this information came from you.

The only exception to this is if you tell me anything about hurting yourself or anyone else, or if something you say makes me think that you are in danger or someone else is hurting you. If this happens, I will have to inform the appropriate authority. For example if I think someone is hurting you, I will talk to the police or NSPCC.

### **Do I have to take part?**

No, you do not have to take part if you do not want to.

It is entirely up to you and your parent/ guardian whether you take part. Even if you do decide to be involved, you can change your mind and stop taking part at any time without giving me a reason while we are emailing. If you decide you have changed your mind after the emails, you can let me know up to one month after that you want to withdraw.

Please get in touch with me if you have any questions or want any more information.

Thank you for taking your time out to read this information sheet, I hope to hear from you soon. If you do want to take part in this study, contact me using the email address below. I really appreciate your help!

**Amrit Bhatti**

Email: Amrit.Bhatti@hud.ac.uk

Telephone: 07578960271

*Supervisors:*

**Dr Joanna Brooks**

Email: J.M.Brooks@hud.ac.uk

and

**Dr Alison Rodriguez**

a.m.rodriquez@leeds.ac.uk

## Appendix 5: Information Sheet (adolescents over 16)



### **An exploration of the lived experiences of young individuals who have alopecia**

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#### **INFORMATION SHEET (Over 16's)**

My name is Amrit and I am a student at the University of Huddersfield. Thank you for being interested in taking part in this study. Please take the time to read the information below and decide if you want to take part (but you don't have to!).

You are being invited to take part in an online email interview to help learn more about what it is like as a teenager to experience alopecia. Before making the decision as to whether or not you would like to take part, it is important for you to understand why this study is being done and what you will have to do. Please take time to read this information and if you have any questions or need more information, you can email me using the email address below.

---

#### **What is the study about?**

We want to know what it is like for a young person to have alopecia. The study wants to explore how a young person manages their alopecia and the support that they receive. There are not that many studies out there that looks at how a young person experiences alopecia, but we think it is important that young people with alopecia have a voice to talk about what it means to them. From doing this, we can look at how other young people can access the right help and support and improve their wellbeing.

### Why I have been approached?

I am looking to get in touch with teenagers between the ages of 13-19 who have (or who have had) alopecia. We think that the best way to try and understand what it is like for a young person to have alopecia, is to email the people who know the most about it... You! You have lots of valuable experience that you can share with us, such as what support you have received and how you deal with your alopecia.

### What will I have to do?

First of all, you will have to send me your consent to tell me you are happy for the email interviews to take place. To do this, you will have to copy and paste the highlighted text below and email it to me using the email address below.

‘I (insert name here), confirm that I have read and understood the information provided and that I consent to taking part in this study.’

The points you need to understand and consent to are these:

- I have read and understand the information sheet emailed to me by Amrit
- I have had the chance to email questions to Amrit about this study
- I understand the reason for this study and how I will be involved.
- I understand that taking part is my choice and that I can withdraw at any time during the interview without giving a reason, and one month after I have finished the interview. .
- I understand that direct quotes may be used in resulting research reports/publications, but that my identity will be protected using a false name and my personal information removed, and that no information could lead to me or anyone else being identified.
- I understand that all information disclosed within the interview will be kept confidential, in line with the Data Protection Act 1998, unless indicated that me or any other individual is at risk of serious harm. I give permission for the researcher to get in touch with an appropriate authority if I tell Amrit about harm to myself or others.
- I understand that the information collected will be kept in secure for 10 years in a password protected email system and that no other person apart from the Amrit will have access to this.
- I agree to take part in the study.

Once you have sent me your consent, I will email you with a question once a week for 6 weeks. It is your choice when you want to start receiving your questions, you can choose a day which you think is best for you to answer. You will be asked questions along the lines of what it is like to have alopecia, such as how you feel, what it is like at school and what it is like at home. Sometimes I might ask you more than one question, but it is only because I am really interested in your reply and I would like to know a little more about it. It is quite important that you do reply to my questions within the week. This is only so that you do not need to stay in the study any longer than needed. It is ok if you are busy or you have lots of school work- if you need more time to answer your questions you can just email me to let me know. If you forget to reply, I will send you a friendly email just to check everything is ok and that you are still happy to take part.

### **What will happen to the information?**

All information from the interview will be kept confidential – this means that no one other than me will ever know that your information came from you. I will be writing a report using your interview, but I will change your name, other people’s names, and the names of places. Instead I will use made up names so no-one will know that this information came from you.

The only exception to this is if you tell me anything about hurting yourself or anyone else, or if something you say makes me think that you are in danger or someone else is hurting you. If this happens, I will have to inform the appropriate authority. For example if I think someone is hurting you, I will talk to the police or NSPCC. After the study has been published, the emails will be put away securely and then destroyed after 10 years.

### **Do I have to take part?**

No, you do not have to take part if you do not want to.

It is entirely up to you whether you take part. Even if you do decide to be involved, you can change your mind and stop taking part at any time without giving me a reason while we are emailing. If you decide you have changed your mind after the emails, you can let me know up to one month after that you want to withdraw.

Please get in touch with me if you have any questions or want any more information.

Thank you for taking your time out to read this information sheet, I hope to hear from you soon. If you do want to take part in this study, contact me using the email address below. We really appreciate your help!

**Amrit Bhatti**

Email: Amrit.Bhatti@hud.ac.uk

Telephone: 07578960271

*Supervisors:*

Dr Joanna Brooks

Email: J.M.Brooks@hud.ac.uk

and

Dr Alison Rodriguez

a.m.rodriquez@leeds.ac.uk



## Appendix 6: Parental Information sheet For Adolescents Under 16



### **An exploration of the lived experiences of young individuals who have alopecia**

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#### **INFORMATION SHEET (Parents/Carers)**

Your child is being invited to take part in an online email interview to help learn more about what it is like as a teenager to experience alopecia. For your child to participate in this research study, it is important that both you and your child understand why this research is being done and what we are asking your child to do. Please read this information sheet carefully and then decide if you are happy for your child to take part if they want to. Your child must have permission from you to take part in this research. If you have any questions or need more information, you can email me using the email address below.

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#### **What is the study about?**

We want to know what it is like for a young person to have alopecia. The study wants to explore how a young person manages their alopecia and the support that they receive. There are not that many studies out there that looks at how a young person experiences alopecia, but we think it is important that young people with alopecia have the opportunity to discuss what it means to them. From doing this, we can look at how other young people can access the right help and support and improve their wellbeing.

### Why I has my child been approached?

Your child is being asked to participate in this study because I am looking to interview teenagers between the ages of 13-16 who had/ have alopecia.

### What will my child have to do?

If your child agrees to take part in the study and you give them your permission to do so, I will need your consent.

To do this, you will have to copy and paste the highlighted text below and email it to me using the email address below. It is important that you email me your consent from a separate email address to your child, to ensure that I have received consent from a parent.

**I (insert name here), confirm that I have read and understood the information provided and that I consent to my child taking part in this study.'**

The points you need to understand and consent to are these:

- I have read and understand the study information (see attached document) and have had the opportunity to email or phone the researcher (Amrit) with any questions I have about the study.
- I understand the purpose of the project and how my child will be involved.
- I understand that I can withdraw my consent at any time during the interview without giving any reason, and up to one month after the interview has taken place.
- I understand that direct quotes may be used in resulting research reports/publications, but that my child’s identity will be protected using a false name and my personal information removed, and that no information could lead to my child or anyone else being identified.
- I understand that all information disclosed within the interview will be kept confidential, in line with the Data Protection Act 1998, unless indicated that an individual is at risk of serious harm. I give permission for the researcher to get in touch with an appropriate authority such as the NSPCC, if my child tells her about harm to his or herself or others.
- I understand that the information collected will be kept in secure conditions for a period of ten years in a password protected email system and that no other person apart from the researcher will have access to this.
- I agree that my child can take part in the study.

After you have sent me your consent, your child will send me their assent, and we can start the study. I will email your child one question once a week for 6 weeks. Your child can choose a day which is best for them to start receiving their questions. They will be asked questions along the lines of what it is like to have alopecia, such as how they feel, what it is like at school, the support they have received and what it is like at home. Although I would usually expect a reply within the week, if your child is busy or has lots of school work, they can just email me to let me know- so there is no

time pressure for your child. I will also send a friendly reminder I do not hear from them within the week.

### **What will happen to the information?**

All information from the interview will be kept confidential, in line with the Data Protection Act 1998, unless indicated that your child or anyone else is at risk of serious harm. In the unlikely event of this, I will contact the NSPCC. All email interviews will be kept safe in a password protected site and will only be available to the research team. Your child’s direct quotes may be used in the publication of results, but a pseudonym will be used to protect their identity. Any information which may lead to them being identified will not be used. Following completion of the study, data will be archived securely at the University of Huddersfield and then destroyed after 10 years.

### **Does my child have to take part?**

No, your child does not have to take part if they do not want to.

It is entirely yours and your child’s decision if you wish to take part in this study. There are no consequences if you do not want your child to take part. If your child does decide to be involved and changes their mind during the interview, that is ok too- they can withdraw from the study at any time without giving a reason (and up to one month finishing the interview).

Please get in touch with me if you have any questions or want any more information.

Thank you for taking your time out to read this information sheet, I hope to hear from you soon. If you are happy for your child to take part in this interview, contact me using the email address below. We really appreciate your help!

#### **Amrit Bhatti**

Email: Amrit.Bhatti@hud.ac.uk

Telephone: 07578960271

#### *Supervisors:*

#### **Dr Joanna Brooks**

Email: J.M.Brooks@hud.ac.uk

and

#### **Dr Alison Rodriguez**

a.m.rodriguez@leeds.ac.uk



## Appendix 7: Parent Participants: Email Consent example

Hello XX,

I am Amrit Bhatti, I’m 22 years old and I am doing my doctoral thesis at the University of Huddersfield. I am also working part time as an applied behaviour analysis for children who have autism. Outside of work I enjoy dancing, rock climbing, keeping active and listening to music. My interest in alopecia started during my undergraduate degree, researching chemotherapy induced alopecia for children with cancer. During this research I discovered that alopecia for young people as a whole had been very under researched. Therefore I intend to look at alopecia from the perspective of both young people with the condition and their family members in order to improve the quality of life and provide findings which may develop appropriate interventions. My personal connection to alopecia is having an aunty (who is like my second mother), loosing patches of hair at a young age.

I really appreciate you taking part in this study, and I’d like to tell you now about what is going to happen. I will email you with a question once a week over a total period of 6 weeks. When we start this process is entirely your decision. The questions I ask will be about your experiences of having a young relative with alopecia. Although there are six questions I will be asking, based on your responses I may get in touch to ask you for a bit more detail or to ask you to expand further on a point that you have made. It is really important that, if at all possible, you do reply to each question I send you within seven days – this means I can send you a new question each week and we will stay within the expected timescale, so that you do not need to stay in the study any longer than needed. If you do need longer to reply to an email, you can just email me and let me know. If you forget to reply or do not receive an email, I will send you another email just to check everything is ok and that you are still happy to take part. Attached to this email is a copy of the information sheet for the study.

As this is a piece of research, it is really important that I know you are aware of some important points before we start and that I have an email from you confirming that you are willing to take part before we start. I’ve listed the points you need to consent to below. Please could you read these and then cut and paste the highlighted text into an email and send it back to me:

**I confirm that I have read and understood all the relevant study information and that I consent to taking part in this study.**

The points you need to understand and consent to are these:

- I have read and understand the study information (see attached document) and have had the opportunity to email the researcher (Amrit) with any questions I have about the study.
- I understand that my participation is voluntary and that I can withdraw at any time during the interview without giving any reason, and up to one month after the interview has taken place.

- I understand withdrawing will not affect any support or information provided to me by Alopecia UK.
- I understand that direct quotes may be used in resulting research reports/publications, but that my identity will be protected using a false name and my personal information removed, and that no information that could lead to me or anyone else being identified will be included.
- I understand that all information disclosed within the interview will be kept confidential, in line with the Data Protection Act 1998, unless indicated that myself or anyone else is at risk of serious harm. I give permission for the researcher to get in touch with the appropriate authority if I tell her about harm to myself or others.
- I understand that the information collected will be kept in secure conditions for a period of ten years in a password protected email system and that no other person apart from the researcher will have access to this.

Once I receive your consent, I will send you a short form asking you a few questions about yourself and then we can start the study.

Thanks again for your time and interest in taking part in this study. Looking forward to hearing from you soon.

Amrit

## Appendix 8: Enquiry for Age

Hello XXXX

Thank you for emailing me and being interested in my study, I would love for you to take part.

I have just attached you the information about the study, including what the study is about, the criteria and you will have to do.

Could I please ask what age you are? If you are under 16, I would also need your parent/guardian to email me and tell me that they are happy for you to take part.

I have attached the info sheet for you to read.

If you are happy to take part in my study, you would just need to send me your consent.

If you have any further questions, don't hesitate to contact me

Look forward to hearing from you.  
Best wishes,

Amrit

--

**Amrit Bhatti**

PhD student

School Of Human & Health Sciences

University of Huddersfield

Queensgate, Huddersfield

HD1 3DH

Email: Amrit.Bhatti@hud.ac.uk

**From:** XXX  
**Sent:** Tuesday, February 28, 2017 12:28:14 PM  
**To:** Amrit Bhatti (Researcher)  
**Subject:** Alopecia study

Hello,

I have alopecia and I would like to be involved in your study. How can I apply?  
Kind Regards,

#### Appendix 9: Example of Consent From a Parent of an Adolescent Under 16 Years Old

**Subject:** Re: Alopecia study

Hello XXX

Thank you for getting back with me about your interest in taking part in the study and for your consent.

Would it also be ok for me to receive consent from your son, as it would be him who I would be interviewing? I have attached the information sheet for him to read, and if he want's to take part he would just need to give me consent for this interview to proceed.

Thank you and look forward to hearing from you

Best wishes,

Amrit

--

**Amrit Bhatti**

PhD student

School Of Human & Health Sciences



University of Huddersfield

Queensgate, Huddersfield

HD1 3DH

Email: Amrit.Bhatti@hud.ac.uk

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**From:**

**Sent:** Thursday, January 12, 2017 6:51:03 PM

**To:** Amrit Bhatti (Researcher)

**Subject:** Alopecia study

'I, XXXX confirm that I have read and understood the information provided and that I consent to taking part in this study on behalf of my 15 year old son.

## Appendix 10: Example of Consent From an Adolescent Over 16 Years Old

From:

> Sent: Wednesday, September 28, 2016 9:04 PM

> To: Amrit Bhatti U1154113

> Subject: Alopecia

>

> Hi,

> My name is XXX, and I'm 16 years old. I saw that you were looking for teenagers with alopecia to email, and I am writing to say that I, XXXX confirm that I have read and understood the information provided and that I consent to taking part in this study.

>

> Hope I can help!

>

> xxx

## Appendix 11: Adolescent Demographic and Introduction to study

Hello XXX!

Thank you for emailing me and being interested in taking part in my study.

Just so you know a little about me, (and it doesn’t feel like you are talking to a robot!) I just thought I would introduce myself. So I am Amrit and I am a PhD student at the University of Huddersfield, I am interested in doing this study because I have a family member with alopecia, and I noticed that there is not much research out there which looks at what it is like for teenagers to have alopecia.

But in my spare time, I like to dance and listen to music. I hate the thought of going to the gym so I try other things like rock climbing, swimming and ballet dancing (although I’m rubbish at it!). I love watching films, and I LOVE eating food so I am always eating out with my friends.

Thank you for giving me your consent!

Before I start with your first question, would you be able to fill in below? I have attached you the document if it is easier for you to do it on there.

Your name:

Date of birth:

Age of first onset of alopecia

Is this the first onset of alopecia? If not, can you tell me how many cycles you have had?

Where you live (area):

Your Ethnic group:

Are you in full time education?

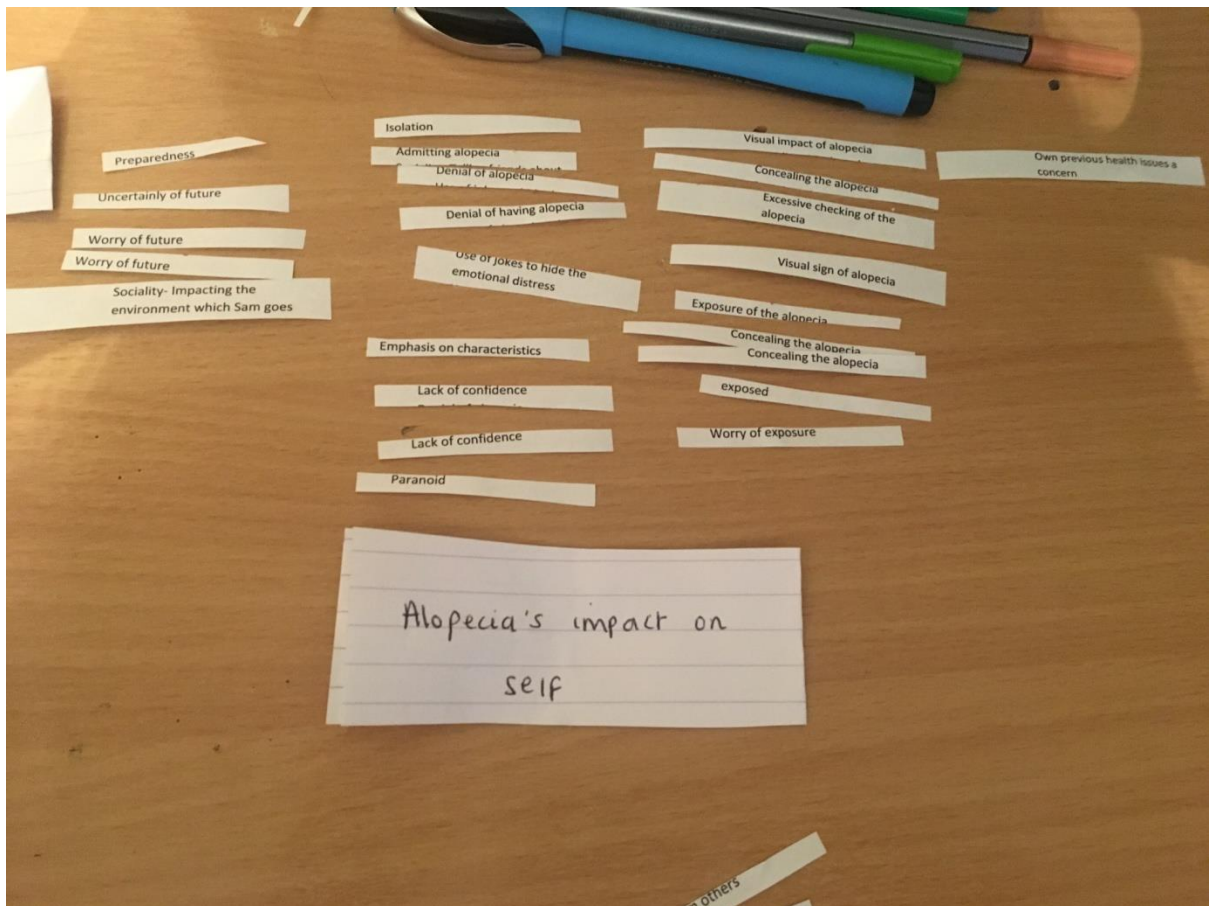
If there is anything else you think I would need to know about (including physical and mental health problems) that you think could affect the study then please let me know.

You can also tell me a little bit about yourself if you want to :)

Once you have filled this in, we can start the study!

Thank you,  
Amrit

Appendix 12: Diagram of cut out themes



Appendix 13: Theme development description

Themes- Parent's experiences of having a child with alopecia

Super-ordinate theme	Description	Sub-ordinate themes	Description
<b>1. A whole series of events: The all encompassing nature of alopecia</b>	A pivotal moment in time- shock and sadness and a lack of understanding to why their child has alopecia. The super ordinate theme captures their world experienced as turning 'upside down' from the initial moment their child started to lose their hair. This moment in time started a 'whole series of events' following the moment in which this occurred as they discuss how the impact of alopecia (living with the unpredictability of alopecia, and the cycle) is still everlasting in their present day experience of alopecia.	1.1. The hair is coming out!	The theme 'hair is coming out' explores the moment in which the parents first see the physical hair coming out, the emotional effect this has had on them and their sense of urgency. A temporal underpinning of time is found in these theme in which time is experienced as slowing down or up following the initial shock and panic of hair loss.
		1.2. The difficulty of not understanding the condition	The subtheme 'the difficulty of not understanding the condition' captures the experience of participants struggling to make sense of the condition and their journey of trying to identify a cause. This again captures the all encompassing nature of alopecia, as the difficulty of not understanding the condition is still occurring in the present day. Parent's still struggle to understand why their child has alopecia and what caused the onset of hair loss.
		1.3 Living with the Unpredictability	The unpredictability of the condition often led the participants to feel anxious about the loss of hair, not knowing when the hair will fall out, how quickly it will fall out and whether all the hair would eventually be lost.
		1.4. Living the cycle of regrowth	This includes the sense of living a 'ground-hog day' and the repeated loss of hair being equally, if not more distressing for parents. This theme captures the 'whole series of events' as participants re-live the same events of hair loss and the same (if not worse) emotional impact that comes with this. The all encompassing nature follows the notion that this cycle of regrowth still occurs (or could occur) in participant's lived present day experience.
<b>2. Alopecia taking over self: The emotional melt down</b>	This theme comes from the quote 'Alopecia has taken over my whole life' to capture the psychological impact of alopecia and the impact this	2.1. Alopecia dominating worry	How they felt worried, not only for their child, but for their own health as an individual without the condition. This sense of worry is something which is something they are unable to

Super-ordinate theme	Description	Sub-ordinate themes	Description
	has had on self. More specifically, the personal realm of the experience will explore how the alopecia has been viewed as taking over self in terms of embodiment and highlights the 'emotional melt down' some participants experience from having a child with alopecia.		control as these internal thoughts occur on a daily basis as they think about how their child is coping with their alopecia.
		2.2. The experience of heartbreak	The experience of heart break also includes the 'dark place' experienced by participants.  All of these highlight the emotional melt down experienced by the participants.
		2.4. The emotional need to accept: Making best of the condition	A large contributor to growth of self is the acceptance of the condition and trying to 'make best of' the situation as much as they could. Many parents tried to explore the positive aspects of their adolescent child having alopecia, by stating how they have grown in strength and focused on other qualities of life.
<b>3. The social dimensions of managing the condition: wanting a sense of normality</b>	For most parents, it is 'others', in particular seeing what 'others' do to their child (name calling and bullying), that gives the participant's experience of alopecia a particular meaning. Parents express how the importance of 'others' such as friends and family become a central part of their life-world, especially as the impact from them in the participant's selfhood is so direct. However, other external sources such as peers bullying their child also became central to their lived world as they describe how social dimensions has created their experience into a negative manner. The pressures from social dimensions result in the strive to be 'normal as possible' not only for the child, but the participants themselves.	3.1. Bullying	All participants alluded to bullying as being an issue which had caused them to have a deep feeling of worry, which in turn left them feeling emotional and helpless. Participants discuss how bullying has become one of their main struggles in their experience as they try to support their child whilst dealing with the emotional and psychological impact it had on them.
		3.2 The complexities of the visibility of the condition	As well as the impact of bullying from external sources, the visibility of the alopecia heightens the participant's sense of panic when the patches of baldness appear. This is because participants tend to worry about how others in the social dimension will react if they saw the alopecia. Parents attempt to manage the alopecia by hiding these patches in order to limit the pressures placed by their social dimensions and to gain a sense of normality.

Super-ordinate theme	Description	Sub-ordinate themes	Description
			The theme also includes preparing others prior to meeting the child because of the perceived social pressure placed on both the child and the parent. The sense of normality is further established here by giving their child a sense of normality through preventing a negative reaction of others.
<b>4. Shifting roles of Medical health professionals</b>	There seemed to be an expectation of roles placed prior to the appointment which was contrasting from their actual experiences. 'Feeling let down', 'lack of empathy' and 'lack of support' was commonly used by parents to describe their experience of seeing the medical health professionals. Most parents felt unprepared to deal with the loss of hair of their adolescent child and the reality of how little support they perceived to have. The expectations and roles of medical health professionals provided different experiences for all participants. Because of this, parents had resorted to taking on these roles themselves, often searching for support for self and child, and exploring alternative medicines and information. During this process of taking on this particular role, their awareness of alopecia grew, but still experienced a lack of control and frustration due to the lack of support received from others.	4.1. The roles of medical health professionals	There is a divergence in which participants are trying to make sense of the roles expected by the medical health professionals versus how they were actually treated in reality. Participants often discussed what professionals should have done, and the problems they faced when dealing with medical health professionals. To coincide with the difficulties they faced dealing with medical health professionals, parents also described the loss of faith with the GP, and lack of support received from others within this profession as disappointing (feeling let down and observed lack of empathy).
		4.2. Needing to become experts	The subordinate theme 'needing to become experts' refers to the perceived perception of roles experienced by participants. It is apparent that the roles and identity within parents' experiences had been questioned as they come to terms with the expectations of medical health professionals not being what they had thought.  This theme includes the need to becoming dominant in professional parent exchanges, in becoming the information gatherer and sharer and balancing a new identity of expert against the need to be supported and reassured.
<b>5. Change in family roles and identity</b>	The change in family roles and identity captures how the parents view themselves within their lived world and their identity. The theme highlights parental roles as well as the roles within the family unit. The roles within	5.1. Remaining strong as a parent	The need to remain strong is perceived to be something which must be done in order to be perceived as supportive of their child. Remaining strong highlights the parental identity that parent's view of themselves as a member of the family unit. There is also a strong indication of the 'motherly' bond between parent and child.

Super-ordinate theme	Description	Sub-ordinate themes	Description
	the family unit include protecting the child, decision making and emotional coping that all form the notion of changing to reunite as a family.	5.2. Pressures of protecting the child 5.2.1 Feeling inadequate as a parent	<p>The participant's sense of identity has been displayed in this particular theme as they describe the daily need to protect their child, but the sense of helplessness they inhibit as they are unable to do so.</p> <p>The pressure of protecting the child not only comes from the parent themselves, but the child's siblings. This pressure however has enabled the participants to develop a sense of pride towards how the family have coped and protected their child that develops a sense of reuniting as a family.</p> <p>Another change in family roles includes the sense of feeling inadequate as a parent. A feeling of inadequacy also illustrates what participants define as a parent, as they begin to question their roles in helping their child and questioning of self.</p>
		5.3. Confused identity	The theme of identity confusion refers to the change participants feel towards their child, which often results in them feeling guilty. Parents discussed how they struggled to make sense of their child's new form of identity through the physical appearance change.
		5.4. Decision making as a family 5.4.1 Emotional coping as a family	Decision making defines the roles of what it means to come together as a family and what is expected of a family.
			Emotional coping is another theme which is found as they provide support for one another in order to get through this emotional experience.