Portfolio Volume 1: Major Research Project

A qualitative exploration of Alopecia: impact, coping and interactions with professionals

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List of Abbreviations

AA = Alopecia Areata
AU = Alopecia Universalis
AT = Alopecia Totalis
AO = Alopecia Ophiasis
AGA = Androgenetic Alopecia
FFA = Frontal fibrosing Alopecia

Language and key terms

Language is an important part of our understanding. Therefore, Appendix A (pg. 145) summarises key terms referred to in this thesis.

Abstract

Background: Alopecia relates to hair loss. This thesis focuses on types of Alopecia mainly believed to be triggered by an autoimmune response, such as Alopecia areata (AA). Although Alopecia is not a life threatening condition, it can be a life changing condition. Hair is often described as an important part of our identity. Therefore, Alopecia can have devastating effects on overall quality of life and, for the majority, negatively impact both psychological and social functioning. Despite the literature on the psychological and social impacts of Alopecia, many medical professionals still view it as a 'cosmetic condition', which affects how those with Alopecia experience interactions with medical professionals**.**

Method: A critical realist research position was used to qualitatively explore Alopecia in relation to its impact, coping and interactions with professionals. This study engaged in semi-structured interviews with 23 adults with Alopecia. Data were analysed using Reflexive Thematic Analysis (RTA).

Results: An inductive RTA was used to develop three themes; '*Navigating Alopecia: A rollercoaster of change', 'Surviving Alopecia: With or without you'* and *'Understanding patient-professional relationships'.* Participants described experiencing several fluctuations in identity, a range of negative emotions and struggles with the ongoing uncertainty. Participants voiced how Alopecia can limit social interactions and impact engagement in activities or hobbies they enjoyed prior to Alopecia. A range of coping strategies were highlighted including camouflaging or use of humour. Participants voiced how they felt understood by some of those close to them but also acknowledged that not everyone knows what to say or do, leaving them feeling misunderstood. However, participants indicated that others with lived experience of Alopecia tended to be more understanding which helped normalise the difficult experiences. Factors that affect help-seeking decision-making were highlighted and participants shared their experiences of professional interactions and suggested improvements.

Conclusions & Implications: The impacts of Alopecia go well beyond the 'cosmetic' or medical realms. This study adds to the body of evidence indicating the psychological and social impacts of Alopecia and the need for medical professionals to treat people more holistically. Support and care recommendations made by those with lived experience of Alopecia should be taken seriously to avoid exacerbating an already distressing condition. Implications exist for medical professionals, clinical psychologists, wider Alopecia treatment guidelines, and for those who experience Alopecia. Several recommendations are made that aim to move Alopecia support and care forward.

Keywords: Qualitative, Interviews, Reflexive Thematic analysis, Alopecia Areata, Psychological well-being, Psychosocial impact, Medical professionals.

1. INTRODUCTION

1.1 Chapter overview

In this chapter, I begin by positioning myself as a researcher; following this, I review the literature and evidence base relating to Alopecia. This chapter concludes with my systematic literature review (SLR) entitled: *What is the psychological and/or psychosocial impact of experiencing Alopecia areata (including universalis and totalis) among adults: a qualitative meta-synthesis.*

1.2 Positioning of the researcher

The concept of research rigor in quantitative and qualitative research differs. Qualitative research is contextual and occurs within a certain place and time between people (Dodgson, 2019). In qualitative research, the concept of reflexivity is important; it relates to the researcher acknowledging their role in the research and requires critical self-evaluation. Reflexivity plays a crucial role in enhancing the transparency, credibility, and trustworthiness of qualitative research by allowing researchers to critically examine their own role in shaping the inquiry and ensuring that their interpretations are grounded in an awareness of their own subjectivity or viewpoint (Olmos-Vega et al., 2023). Patnaik (2013, p. 101) argues that "reflexivity acknowledges the role of the researcher as a participant in the process of knowledge construction and not merely an observer of a phenomenon".

The concept of positionality reflects the stance a researcher has chosen to adopt within a research study" (Savin-Baden & Major, 2023 pg.71). Rowe (2014) argues that a researcher's positionality impacts various aspects of the research study including how a study is conducted or designed, as well as its outcomes and results. Researcher positioning as either an 'insider' or 'outsider' is imperative in qualitative research when considering shared experiences, similarities, and differences between the researcher and the participants (Berger, 2015). Asselin (2003) stated that an insider researcher is someone who can relate to community experiences and understand processes, identity, or language. This can create a sense of increased trust towards the researcher. However, it also means the researcher needs to be mindful of not making assumptions, particularly while interviewing but also during data analysis which could impact participants' meaning-making (Atfield et al., 2012). Despite being someone with a shared experience of Alopecia in relation to my participants, and therefore an ‘insider’ researcher at first glance, I am also an ‘outsider’ researcher in some respects. A researcher is considered an ‘outsider’ when they do not belong to the group of participants they are researching (Braun & Clarke, 2013). Upon initial observation, I, like the participants, have Alopecia; however, Alopecia affects people to varying severities, and my participants may be affected more or less than me. Moreover, they likely have differing social graces from me (Burnham, 2013).), e.g., age, gender, ability, ethnicity, and culture; thus, their experiences of living with Alopecia differ from mine. I will use “I” to position myself as the researcher in acknowledgment of my active role and refer to participants as “participants” when discussing them.

1.3 Personal Relationship with this research project

I am an Irish-South African white female, born in the US but predominantly growing up in the south of Ireland. Being a teenage girl was a time of change and many ups and downs, one of which was noticing around age 14 years that my hair was falling out, which led to a diagnosis of Alopecia areata. This came with mixed emotions and uncertainty. A diagnosis of Alopecia was always going to be challenging. However, it was made harder because I was 14, which is considered a developmental milestone, where, like most young people, I was starting to take more interest in my appearance, heavily influenced by what Western society deems “beautiful”.

My insider position (Kanuha, 2000; Berger, 2015) has influenced my investment and passion in this research. Yet, my close relationship with the research topic has also presented challenges. I did experience some doubts (Appendix K). Doubts over whether I could emotionally manage this topic and sit with hearing participants’ experiences. Nevertheless, following discussions with the research team and my own initial investigations into the literature, I found my belly fuelled with a burning desire to proceed with this research topic and use my voice to further develop this area of inquiry for the wider Alopecia community.

1.4 Epistemological position

Understanding my epistemological position is vital when considering how it impacts my research study's methodology, analysis, and quality assurance (Carter & Little, 2007). Epistemology is the philosophy of knowledge or ‘the study of the nature of knowledge and the methods of obtaining it’ (Burr, 2003, pg. 202). Ontology, on the other hand, is the study of ‘being,’ which concerns itself with the structure of reality and what is possible to know about the world (Crotty, 2003). This thesis adopted a critical realist (CR) perspective, which informed my thinking throughout this thesis and influenced my research methodology. CR is compatible with qualitative research as social inquiry and can be considered through understanding individual experiences and what occurs within society (Manicas, 2009; Danermark et al., 2019). CR claims a realist ontology and a subjective epistemology; it agrees that there is a reality that is independent of us but also acknowledges that knowledge of this reality is negotiated through a filter of individual human experience and interpretation (Fletcher, 2017). Braun and Clarke (2022) argue that “reality and representations of reality” are different (Braun & Clarke, 2022, pg.168-170). In other words, CR accepts that there are enduring features of reality that exist independently of human conceptualisation. However, differences in the meanings individuals attach to experiences are considered possible because they experience different parts of reality. I was drawn to a CR perspective not only because it supports qualitative research but also because it aligns with my worldview or positionality. That is, CR acknowledges the existence of this autoimmune condition known as Alopecia in reality, while recognising that aspects of it are socially constructed experiences influenced by broader societal norms or beliefs as well as varying individual experiences across different social or cultural contexts.

1.5 How I may have impacted this study

My positionality and epistemological stance have impacted key decisions along the journey of this research. To better understand my participants' experiences of Alopecia in reality as well as how they vary across contexts, in line with a critical realist perspective, I felt that approaching this research from a qualitative perspective was best. My insider positionality, or awareness of my own experiences and of times when I felt unheard by medical professionals, influenced a desire to ensure my research was designed in a way that would focus on participants having their voices heard; however, I was mindful that Alopecia is a very personal and sensitive topic which led to my decision to utilise individual semi-structured interviews as part of this study. Reflexive TA was deemed to be an appropriate method of analysis as it aligned with my critical realist stance and the use of semi-structured interviews and encouraged me to engage in reflexivity while navigating my insider-outsider positionality. In relation to my results, I have reflected in Appendix K that my insider position made it at times hard to remove themes that I felt personally resonated with me. However, stepping back into my outsider position and reflecting with my supervisor allowed me to remain curious about broader participant experiences while also allowing me to ensure I returned to the actual research questions regularly when exploring my data.

1.6 Literature review

1.6.1 Hair, its meaning and societal expectations

Throughout history, the relationship between individuals and their hair has been intricate. Firth (1973) posited that hairstyles are not just personal choices but significant cultural statements, visible to all, biologically linked to the body, and tailored to cultural preferences. Hair, therefore, transcends its physical nature to become an integral part of human self-concept and identity (Gorden, 1968; Thompson & Shapiro, 1996). Moreover, physical appearance has been argued to influence identity formation (Shilling, 1993; Gill et al., 2003). Numerous studies have demonstrated that in Western society, hair plays a substantial role in shaping perceptions of physical attractiveness (Terry, 1977; Gilbert & Thompson, 2002; Jackson, 2002; Grimalt, 2003) and is a valued characteristic of both genders (Cash 1999, 2001; Ricciardelli, 2011). Hair symbolises beauty, individuality, or belonging to a particular social or cultural group (McDonagh et al., 2002).

Hair, like many other facets of appearance, is intertwined with social and gender norms and stereotypes. According to Cislaghi et al, (2018), social norms are the rules of action shared by people in society that are considered normal. Social norms also relate to people's beliefs about how others perceive them (Chalub et al., 2006; Gintis, 2010). Norms encompass gender roles and gender socialisation and tend to be deeply held (Hyde, 2014). Historically, gender norms dictated what hairstyles are “appropriate” for men and women in society (Ricciardelli, 2011). Alopecia-related hair loss may be interpreted as an abnormality or failure to conform to social norms, gender norms, or wider beliefs relating to physical appearance (Bull et al., 1988). Cash (2001) found that women with hair loss have less positive body image than women without hair loss. Men are also concerned with hair loss and, similarly, experience body image difficulties (Cash, 2001; Phillips et al., 2006).

Cultural differences and meanings further add to the complexity of society's relationship with hair; for example, in African cultures, hair and hair styling, including braiding or adding beads, have importance in terms of expressions of cultural identity, spirituality, and beauty (White & White 1995; Banks, 2000; Jere-Malanda, 2008; Thompson, 2009; Johnson & Bankhead, 2014). In the Sikh community having uncut long hair symbolises a promise to the Will of God (Trüeb, 2017). Given that those from global majority backgrounds are often underrepresented in research, further work is needed to understand the impact of hair loss on different ethnicities.

Consequently, given the societal value placed on hair, it is not surprising that hair loss often has a profound negative impact on the quality of life of individuals who experience it.

1.6.2 Alopecia types, causes, and prevalence

Alopecia means hair loss. The exact cause of Alopecia is not always known (Sonmez & Hocaoglu, 2022). This thesis focuses on types of Alopecia believed to be triggered by an autoimmune response, such as Alopecia areata (AA). Autoimmune disease is when “the body’s immune system mistakenly attacks its own healthy cells” (Johns Hopkins University, 2024). In the case of Alopecia areata, this immune system malfunction leads to the loss of scalp and/or body hair. There are several types of AA, including patchy Alopecia areata, Alopecia areata universalis (AU), Alopecia areata totalis (AT), and Alopecia areata ophiasis

(AO), among others. Frontal fibrosing Alopecia (FFA) and Androgenetic Alopecia (AGA) are two additional types of Alopecia thought to likely have autoimmune, genetic, or hormonal origins (Alopecia UK, 2018).

Research indicates that genetic, autoimmune, hormonal, environmental factors, or certain medical interventions (e.g., chemotherapy-induced hair loss) contribute to the development of various types of hair loss, although the precise cause is not always clear (Sonmez & Hocaoglu, 2022). There is also some evidence that stressful life events may play a role in triggering episodes of Alopecia (De Waard-van der Spek et al., 1989; Garcia-Hernandez et al.,1999; Hunt & McHale, 2004).

AA prevalence rates vary. Studies have found that approximately 2% of the global population is affected by AA (Lee et al., 2020; Mirzoyev et al., 2014; NICE, 2023), with AA subtypes, although rarer, found with a prevalence rate including AT (0.08%), AU (0.03%) and AO (0.02%) respectively (Lee et al., 2020; Mirzoyev et al., 2014). Other research has estimated a lifetime prevalence of between 1.7% - 2.1% (Kalish et al., 2003; Sonmez & Hocaoglu, 2022), while a UK-based study found that approximately 1 in 4000 of the population develop AA annually (Harries et al., 2022). AA affects males and females of all ages and ethnic backgrounds (Alopecia UK, 2018). Rangu et al., (2019) estimated that approximately 40% of individuals have AA by age 20, and 20% of all cases of AA occur in childhood.

AGA (also known as male-patterned or female-patterned hair loss) is another prevalent type of Alopecia (Villasante Fricke et al., 2015; Vañó-Galván et al., 2019). AGA can also affect both males and females, but it a common type of hair loss, affecting approximately 50% of males over the age of 50 and around 50% of females over the age of 65 (Alopecia UK, 2018). Lastly, FFA is understood as a form of scarring Alopecia (Alopecia UK, 2018). The exact prevalence of FFA appears unclear (Chew et al., 2010; Ladizinski et al., 2013; Vano-Galvan et al., 2014).

1.6.3 Alopecia and Stigma theory

In Society, people are often categorised based on their characteristics or attributes deemed to be ordinary or natural within society (Goffman, 1963). Therefore, stigma relates to identity gone wrong from

Goffman's perspective, when something has happened or we have a characteristic that, in some sense, spoils our identity (Goffman, 1963;2009). The literature discusses different types or levels of stigma, including social stigma, self-stigma, and professional stigma. Social stigma is embedded in the social framework and often creates a sense of inferiority (Ahmedani, 2011). Social stigma can lead to people being labelled, stereotyped, discriminated against, or treated separately by others who hold ordinary or naturally accepted characteristics or attributes by wider society (Ahmedani, 2011). Crocker (1999) defines self-stigma, indicating that stigma is not only held among others in society but can also be internalised by a person with a difference or condition. Moreover, despite an abundance of training, the literature highlights that health professional stigma can also exist. Liggins et al., (2005) found that patients felt labelled and/or 'marginalised' by their health care professionals. This may be because health professionals are exposed to the same rhetoric as the general public, which often views visible differences negatively.

From Goffman's perspective, Alopecia may be considered an example of a spoilt identity, like other characteristics such as scars or deformities (Goffman, 1963;2009). Moreover, individuals with Alopecia are likely to experience varying levels of stigma, including social, self, and from professionals. Davey et al., (2019), stated that people with Alopecia often experience impaired quality of life (QOL) as a result of perceived disease-related stigma. In relation to self stigma, research by Kacar et al., (2016) found that AA leads to high levels of self-stigmatisation. Moreover, in relation to social stigma, Creadore et al. (2021), in a cross-sectional online survey, found stigmatizing attitudes of laypersons toward patients with Alopecia exist across varying social and professional scenarios. Nevertheless, Sonmez & Hocaoglu (2022) argue that with support from medical treatments for Alopecia as well as wigs, the severity of stigma can be alleviated.

1.6.4 Identity, QoL and psychological impact

Additionally, and similarly to the concept of social stigma, a further theory likely impacted by a person's experiences of stigma is Social Identity theory (Tajfel & Turner, 1979), which posits that people derive a portion of their self-concept, including a sense of belonging and identity from their membership in social groups. According to Schwarts, et al., (2013), identity plays a role in promoting well-being and psychosocial functioning. Hair constitutes an integral part of our self and our identity, which is why hair loss may cause a broad range of psychological difficulties related to our identity (Schmidt et al., 2001; Fox, 2003). Consistent findings related to the negative impacts AA has on identity have been demonstrated in the literature. Those with AA struggled with how they viewed themselves due to appearance changes, reporting ‘fluctuating’ or ‘unstable’ identities due to their hair loss as well as negative changes to ‘social’ identity in terms of how they were perceived by others because of AA (Hunt et al., 2004; Barkauskaite et al., 2020; Aldhouse et al., 2020). Furthermore, hair loss may distort self-image (Ng et al., 2017) and can lead to new identity formation (Davey et al., 2019).

The impact of hair loss on quality of life (QoL) varies and is often underestimated but nevertheless is significantly negatively impactful (Sonmez & Hocaoglu, 2022). Mesinkovska et al., (2020) found that coping with AA is a daily challenge and burden on those who experience it. Similarly, a systematic literature review by Muntyanu et al., (2023) found impairments to QoL in over 75% of individuals with AA, with up to one-third reporting extremely severe QoL impairments. Moreover, Newell (2002) estimated 39,000 people in the UK have some form of visible difference in their appearance, with related negative consequences for their QoL, psychological well-being, and social interactions.

AA is considered to be a non-life-threatening or harmless physical condition (Shapiro, 2000) with treatments that exist with varying success rates to help promote hair regrowth. However, studies demonstrate that Alopecia does not just impact sufferers physically due to loss of hair; it can also lead to a range of negative personal, psychological, social, and medical experiences (Hunt et al., 2004). Moreover, Hunt et al. (2004) argue that the psychological distress related to Alopecia can be considered both as a possible precursor and consequence of Alopecia.

AA has been associated with psychological distress, with depression, anxiety, and social difficulties, found to be more prevalent in those with AA compared to the general population (Hunt et al., 2005; Montgomery et al., 2017; Vallerand et al., 2019; Macbeth et al., 2022). Higher rates of depression and anxiety among AA suffers is also consistent across systematic literature reviews (SLR) (Lauron et al.,2023;

Mahadewi et al., 2023; Okhovat et al, 2023). Despite the significant amount of literature consistently finding links between AA and depression and/or anxiety, Gulec et al. (2004) found no significant difference between adults with AA and a control group (age and sex-matched).

Aside from depression and anxiety, Alopecia areata can lead to a range of other negative feelings.. Fox et al. (2003) found that individuals with AA experience reduced self-esteem, feelings of anger, and isolation due to their hair loss. Welsh et al. (2009) highlighted the disruptive impact that AA or AU had on self-image and self-esteem, also leading to feelings of shame about appearance. Moreover, Davey et al. (2019) and Iliffe et al. (2019) found the impact of AA extends beyond the physical body to negatively affect self-confidence, self-esteem, shame, and guilt and could lead to loneliness, isolation, and embarrassment. Moreover, the Food and Drug Administration (FDA) (2018) found that hair loss led to a loss of a part of one's identity and was described as “traumatic.” Additionally, documented experiences of grief and loss following hair loss have been consistently documented (Egele & Tauschke,1987; Davey et al, 2019; Barkauskaite et al., 2020).

Although there is less research on AGA and FFA at present, like AA and its subtypes, the negative psychological and/or psychosocial impacts of AGA and/or FFA, may be significant among those who experience it. Aukerman et al. (2023) concluded that individuals with AGA, not unlike those with AA, reported experiencing a reduced QoL and suffering from feelings of anxiousness, depression, helplessness, and diminished self-esteem. In relation to FFA, Katoulis et al. (2015) found that FFA negatively impacted QoL, including higher rates of anxiety and depression. A further study by Cook et al. (2022) concluded that experiences of a loss of identity, self-consciousness, worry, and fear of judgment were present among participants experiencing FFA. When it comes to comparisons across several types of Alopecia, research by Titeca et al. (2020) that analysed the psychosocial burden of both AA and AGA found those with AA had a worse QoL compared to those with AGA. There does not appear to be literature that compares the psychological impacts of FFA with either AA or AGA.

1.6.5 Impact on social functioning

Not only does AA and other types of Alopecia impact emotional and psychological functioning, but it has also been found to impact physical, social, and familial functioning negatively, leading to impaired social functioning or avoidance of social relationships (Wiggins et al., 2014; Montgomery et al., 2017; Lie et al., 2018).

Aldhouse et al. (2020) found that AA negatively affected familial relationships as well as the development and maintenance of friendships due to fears that family or friends would be unsupportive. Some participants also reported challenges in romantic relationships, such as finding dating difficult or feeling like they should avoid it entirely due to fears of judgment or rejection (Aldhouse et al., 2020). Fear of social rejection leading to social avoidance appears to be a consistent finding, impacting both females and males across different cultural backgrounds (Davey et al., 2019; Barkauskaite et al., 2020; Zucchelli et al., 2022; Katara et al., 2023; Rafique et al., 2024; Clarke-Jeffers et al., 2024).

Individuals with AA have been found to be less likely to engage in physical activity (Olsen et al., 2004) or to feel their daily activities were negatively affected by their AA (Aldhouse et al., 2020). Such activities were affected by fears about being stared at or about wigs not staying on securely, as well as feeling self-conscious or embarrassed (Aldhouse et al., 2020; Rajoo et al., 2020)

Moving to consider the functioning implications of AGA and FFA, it appears these types of Alopecia have similar negative impacts on individuals to AA. AGA impacted social outings which became less frequent and less enjoyable, reducing daily leisure activities; in turn this reduction in social functioning also negatively affected searches for a romantic partner (Gupta et al., 2019; Aukernan et al., 2022). Similarly, Cook et al. (2022) found that FFA also had a detrimental effect on social functioning.

1.6.6 Coping and support

To date, a clear understanding of what helps or hinders Alopecia sufferers in coping with their Alopecia is still developing. Cartwright et al. (2009, pg. 1034) argues that the negative impacts of Alopecia are determined by several factors, including “disease-related factors (e.g., visibility of hair loss), demographic factors (e.g., gender), psychological factors (e.g., beliefs about illness), and behavioural factors (e.g., coping)”. Hunt et al. (2004) acknowledged that coping with AA is likely to be challenging due to the unpredictability of the cycle of hair loss, regrowth, and possible loss again, leading to identity shifts and reconfigurations. Hunt et al. (2004) also argued that coping with or accepting appearance changes that come with AA was seen more frequently in males than females (Hunt et al., 2004). One rationale put forward for this was that females with Alopecia often felt that baldness is more socially acceptable in males than in females (Hunt et al., 2004).

Wig-wearing is one method of coping with Alopecia-related hair loss detailed in the literature. Hunt et al. (2004) concluded that some participants with AA felt that wearing wigs was a positive way to cope with their Alopecia, stating that it allowed them to feel that their hair always looked lovely. For others wig wearing came with its own challenges that sometimes led to distress negotiating windy weather or hobbies/activities that made wig wearing tricky. Similarly, Montgomery et al. (2017) found that although wearing wigs increased social confidence, the concealment reportedly maintained some anxiety, with participants stating that while wearing a wig had a positive impact on everyday life, fears of the wig being noticed were still experienced by those with AA. Nevertheless, it appears that wigs are used as a coping mechanism to reduce the likelihood of experiences of stigmatisation and improve confidence in social settings (Montgomery et al., 2017).

Receiving social support from others is another way individuals cope with their Alopecia, particularly as changes in physical appearance can be associated with social challenges (Rafique et al, 2024). Social support has been found to reduce psychological distress related to stressful life events (Barrera, 1988; Aldwin, 1994). Welsh et al. (2009) argued that good social support can alleviate some of the psychological distress associated with Alopecia. Similarly, Davey et al. (2019) found that the level of support within the environments individuals with AA have access to plays an imperative role in the acceptance process. Support may come from a range of sources, such as family, friends, partners, medical professionals, and others. However, the literature indicates that those with AA experience both positive and negative reactions from friends, family, partners, and wider society in relation to their Alopecia (Hunt et al., 2006; Welsh et al., 2009; Aldhouse et al., 2020; Katara et al., 2023; Rafique et al, 2023) which in turn had an impact on coping.

Alopecia UK and the National Alopecia Areata Foundation (NAAF) are two organisations dedicated to supporting those with Alopecia. Both organisations offer a range of services, including support groups and access to online forums. Turning to peer support from others with a shared lived experience of Alopecia, reports are mixed. For example, Welsh et al. (2009) report that some participants with AA found support groups negative and depressing, whilst others found them to be positive, beneficial, and uplifting. Kalabokes (2011) argued that support groups often provide individuals with a sense of understanding, acceptance, and a space where thoughts and feelings about Alopecia can be normalised. These groups also often provide attendees with a space to share varying coping strategies (Kalabokes, 2011). Iliffe et al. (2019) found that participants with AA who engaged with Alopecia UK's online Facebook group indicated the group supported the development of effective coping styles, increased feelings of being understood, and a greater sense of belonging, which in turn positively impacted acceptance. Similarly, Zucchelli et al. (2022) report that men with AA found accessing Alopecia UK's Facebook group helpful as it provided an opportunity for shared experiences to be explored. Moreover, Clarke-Jeffers et al., (2024) also found that group support boosted self-confidence. However, Clarke-Jeffers et al., (2024) points out that support groups can lack diversity and cultural representation and therefore can be experienced negatively by minoritised groups.

When considering research on other types of Alopecia, such as AGA and FFA, Cash et al. (1993) found that with AGA, coping was more negatively impacted in females than in males. Varghaie et al. (2022) found that FFA generally also negatively impacts psychosocial functioning. Although there is less literature on AGA and FFA, individuals with this type of Alopecia also appear likely to benefit from increased social support to boost coping (Cash et al, 1993; Varghaei et al., 2022).

1.6.7 Help-seeking

The concept of help-seeking is complex, and its definitions vary. Rickwood, et al. (2005, pg. 4) defined help-seeking as 'the behaviour of actively seeking help from other people.' A review of the literature in relation to help-seeking and Alopecia revealed that research in this area is scarce at present, with two exceptions. Tang et al. (2000) found that help-seeking depends on beliefs and attitudes toward Alopecia and whether or not the individual considers it a difficulty for them. Han et al. (2023) highlighted barriers to access to Alopecia support, such as a lack of access to health care or a lack of transparency about Alopecia and the treatment options. Information about AA was often sought from the internet, as well as medical professional recommendations (Han et al., 2023). Help-seeking has been explored further for mental health conditions and has been broadly divided into two categories of 'informal help' from social networks such as family and friends or 'formal help' from professionals (e.g., specialist, generalist, and primary health care providers) that can support people by giving advice, and/or treatments (Rickwood et al., 2005; Rickwood et al., 2012; Thomas et al., 2018; van Weeghel et al., 2019). Moreover, in recent years, help-seeking has also encompassed assistance via the internet (Rickwood et al., 2012). Van Bergen et al. (2023) argue that stigma among dermatology patients can affect help-seeking and, therefore, needs to be better understood and addressed. Literature on other autoimmune conditions, such as Vitiligo, reports that how people access information or seek help for vitiligo is likely influenced by how they cope with the psychosocial impacts of the condition. Reluctance to access support tended to occur when patients felt their condition was dismissed as 'trivial' or 'cosmetic' (Talsania et al., 2010; Ezzedine et al., 2015), therefore it is thought that this may occur with conditions such as Alopecia.

1.6.8 Professional interactions

According to Harries et al. (2022), in the year after diagnosis, people with AA visited their GP 70% more frequently than average, and 1 in 4 patients were referred on to a specialist dermatologist. Of those who visited their GP, 46% were not prescribed any medication (e.g., topical corticosteroids), while in the US one-quarter of Alopecia patients were prescribed treatment within a week of diagnosis, increasing to over half after 12 months. However, to date, satisfaction following seeking professional support has been mixed.

Participants with AA described being told it is ‘only hair’ by healthcare professionals, which increased feelings of loss, grief, and emotional devastation, as well as a sense of not being entitled to those feelings or to support (Davey et al., 2019). Generally, GP and dermatology encounters were found to be insensitive, contributing to feelings of hopelessness (Davey et al., 2019). However, although the psychological impact was rarely considered, participants in Davey et al., (2019) expressed that when it was it was valued.

Several studies echoed an overall negative experience, where respondents reported feeling that their GP or dermatologist were frequently ‘only interested in treating the disease and not the impact the disease on psychological wellbeing’ and had been either ‘minimising or trivialising’ the condition, stating that it is ‘just Alopecia’ or ‘just hair’(Hunt et al., 2004; Bhatti, 2019; Davey et al., 2019; De Vere Hunt, 2021; Macbeth et al., 2022)

Zucchelli et al. (2023) explored patients' experiences of primary healthcare and dermatology provision for Alopecia (AA, AU, AT, AGA & FFA). Results indicated mixed experiences, some positive with GPs and dermatologists displaying caring responses and providing helpful information, with a larger proportion of negative experiences, such as uncaring or unkind responses or inadequate information (Zucchelli et al., 2023).

1.6.9 Treatment and intervention considerations

According to the National Institute of Care and Excellence (NICE, 2023) the following should be considered in relation to the management of AA; no treatment, topical corticosteroid treatment in adults, specialist referral to dermatology, cosmetic options to camouflage hair loss including wigs, dermatography (medical tattooing), and false eyelashes, the use hairpieces and wigs if required, support from Alopecia UK such as information, support groups or psychological support if needed and appropriate. This guidance outlines the treatment options which should be available to those with AA as well as other types of Alopecia, including the option of no treatment if the patient decides not to pursue medical intervention. However, despite wigs and psychological support being options in the guidance, it appears some Dermatology departments will not fund wigs (Zucchelli et al., 2024). Moreover, while psychological support is referenced as a treatment intervention in the AA clinical guidance by both NICE and BAD, few Dermatology departments provide access to psychology, with patients often having to be re-referred to primary care and go via their GP (Messenger et al., 2012). Nevertheless, a 2013 report by the All-Party Parliamentary Group on Skin (APPGS) called for psychodermatology services to be expanded UK wide to better support the mental health of those with skin conditions, including Alopecia. Despite this recommendation, again in 2020, it was concluded that 'many primary care practitioners do not have access to training in dermatology to support patients with skin disease and psychological distress, and fewer have had training in psychodermatology' (APPGS, 2020, pg. 5).

According to Hussain et al., (2017), satisfaction rates with medical treatments for AA vary, and it appears that individuals may be more likely to seek alternative care, such as mental health services, including therapy, due to their dissatisfaction with traditional medical treatments (Hussain et al., 2017). While medical treatments may be of benefit to individuals with Alopecia to support hair regrowth from AA, AU, AT, AO, AGA or FFA, a lack of consideration for Alopecia being more than 'just hair' or a physical condition still appears to be a peripheral concern in treatment guidelines. In line with this, Welsh et al. (2009) argued that participants with Alopecia often indicated that treatments offered by health services tend to be biomedically focused (e.g., topical creams), even when the challenges patients faced were psychologically based.

Davey et al. (2019) reported that very few individuals were offered *'NHS counselling or psychological support'* (Davey et al., 2019, pg. 8) despite feeling that early on in their Alopecia journey, it would have been helpful. Nevertheless, for those who did access psychological therapy, experiences were varied, but when they were positive, therapy was seen to contribute to better coping and acceptance. Moreover, Cartwright et al. (2008) maintained that due to strong relationships between individuals' beliefs about their Alopecia and QoL, health professionals should pay more attention to the psychological impact of Alopecia and offer onward referral for psychological support to address negative beliefs and emotions.

Despite the well-documented negative impacts of Alopecia on psychological well-being outlined in the literature above, training to better consider the mental health aspects of skin conditions and an understanding of what types of psychological interventions are of benefit to individuals with Alopecia is still a developing area.

Few studies have explored the impact of specific interventions on the negative psychological consequences of Alopecia. Kuty-Pachecka (2017) concluded that CBT could play a role in changing maladaptive views about oneself, the world, and the disease, while Hart (2020) who ran a 12-week CBT group, found a significant difference in psychological and physical symptoms associated with AA for people who received the intervention. However, the results should be interpreted in light of the small sample size and not assumed to benefit all. Gallo et al. (2017) found some improvement in QoL due to mindfulness-based work. A study on compassion-focused therapy (CFT) to address feelings of self-criticism, guilt, and shame among those with auto-immune disorders such as AA was found to be positive (Rasouliisini et al., 2019). Additionally, in the USA, acceptance, and commitment therapy (ACT) (Woods et al., 2006) was utilised with some positive effect to treat other hair-related conditions such as trichotillomania. Similarly to the studies presented on AA, Auckerman et al. (2021) found that those with AGA would benefit from psychological support. Like other types of Alopecia, the psychological impacts of FFA may be significant. Therefore, although there is less literature on FFA, individuals with this type of Alopecia are also likely to benefit from psychological intervention (Varghaei et al., 2022).

Finally, the biopsychosocial model considers the biological, psychological, and environmental or social factors associated with developing, maintaining, and treating illnesses (Engel, 1980). The biopsychosocial model often does not appear to be considered in relation to Alopecia, which is arguably consistent with the neglect of psychological and social factors in the intervention considerations outlined above. The biopsychosocial model has been acknowledged within the field of psychodermatology when treating people with skin conditions (Picardi & Pasquini, 2007) and thus should be considered in relation to Alopecia as a more holistic way to support people, given the aetiology and effects of Alopecia, where research highlights genetic, autoimmune, hormonal, or environmental factors at play and negative psychological and social impacts. These impacts are further explored in the systematic literature review (SLR).

1.7 Conclusion

In this chapter so far, I have provided an overview of my relationship to this thesis, and my positioning as an insider researcher. I have stated and discussed my epistemological and ontological perspectives and highlighted my rationale for adopting a critical realist position. I have also provided an overview of the Alopecia literature and highlighted the impacts of Alopecia. The next part of this chapter contains a systematic literature review (SLR) which examines the literature relating to the psychological and/or psychosocial impact specifically of Alopecia Areata (including patchy Alopecia, universalis and totalis) from a qualitative perspective.

1.8 Systematic literature review (SLR)

Systematic literature reviews (SLR) are considered the gold standard of literature reviews (Smith & Noble, 2016). An SLR includes a comprehensive search to locate relevant published work on a particular topic and is methodical, comprehensive, transparent, and replicable (Siddaway et al., 2019), adhering to clear guidelines (Smith & Nobel, 2016). According to Siddaway et al. (2019), an SLR can be quantitative (meta-analysis) or qualitative (narrative review, meta-synthesis). SLRs aim to highlight knowledge gaps and provide recommendations for practice and future research (Fink, 2005). This SLR aimed to identify and critically evaluate qualitative studies exploring the psychological and/or psychosocial impacts of Alopecia Areata (AA). Specifically, it sought to answer the following question: *'What are the psychological and/or psychosocial experiences of Alopecia areata (including patchy, universalis, and totalis) among adults?'*

The psychological and/or psychosocial impacts of AA thus far appear to have been researched and reviewed predominantly from a quantitative perspective or mixed methods standpoint, with at least five quantitative SLRs exploring the psychological and/or psychosocial impacts of AA published in the last 12 months. SLRs by Bahashwan et al. (2024), Okhovat et al. (2023), Lauron et al. (2023), Muntyanu et al. (2023), and Mahadewi et al. (2023) all conducted quantitative SLRs focused on AA across a range of ages. These SLRs predominantly utilised quantitative studies and concluded that AA had a negative impact on quality of life and is associated with consistently higher rates of anxiety and depression, in comparison to the general population.

Less is known about the psychological and/or psychosocial impacts of AA from a qualitative perspective. This is crucial as qualitative research focuses on understanding the individual's experiences of AA, how they make sense of it, and how they manage the condition in their daily lives. While quantitative approaches help us understand rates of anxiety and depression apparent from the results of recently conducted SLRs (Okhovat et al., 2023; Lauron et al., 2023; Muntyanu et al., 2023, Mahadewi et al., 2023; Bahashwan et al., 2024), qualitative approaches provide a unique opportunity to understand how it affects individuals. Therefore, this SLR aims to synthesise published qualitative literature to provide an understanding of the overarching themes and complement the existing quantitative or mixed methods SLRs that exist in the published Alopecia literature.

1.8.1 SLR Method

1.8.1.1 SLR Study selection and search strategy

The literature review included studies predominately with qualitative data only or the qualitative aspect of mixed methods studies. This SLR focused on studies whose entire sample, or the majority of the sample had AA only (including patchy, AU, or AT). Patchy Alopecia Areata, Alopecia Totalis (AT includes a total loss of scalp hair), and Alopecia Universalis (AU includes total loss of hair on the scalp and body) are predominant types of Alopecia Areata which all have an autoimmune aetiology. While other types of Alopecia exist, their aetiologies, symptoms, and impact vary. Moreover, many other types of Alopecia are not autoimmune in origin. Therefore, for this reason, I decided not to include other types of Alopecia as I wanted to allow for comparison of impacts across autoimmune-related Alopecia. The review focused on studies with adult populations, of any gender, sexuality, or ethnicity, to capture a broad range of studies. I decided to focus this SLR on only adult or predominantly adult studies. Although consideration was given to including papers across the lifespan, the National Alopecia Areata Foundation (NAAF) (2024) reported that experiences of AA as an adult are usually different from child experiences, therefore they both warrant their own review. Included studies focused on the psychological and/or psychosocial impacts of adults with AA; however, of note is that definitions of ‘psychological’ and ‘psychosocial’ and what factors are included under these headings appear to vary from study to study. My review of the literature indicated that ‘psychosocial’ and ‘psychological’ are two words often confused as words that hold the same meanings. This made it more difficult to decide on my search terms and required some additional searches and reflection. According to the literature, the lived experiences of Alopecia can affect the psychological or emotional, social, or occupational aspects of an individual’s life, and the repercussions of this on quality of life due to AA are often underestimated. Psychological impacts, sometimes referred to in the literature as emotional impact, focus on the human mind, feelings, thoughts, and/or behaviours (Cambridge Dictionary, 2024). Psychological or emotional distress includes difficulties such as depression, anxiety, social anxiety, anger, low self-esteem, loneliness, shame, and guilt (Hunt et al., 2005; Rencz et al., 2016; Davey et al., 2019; Mesinkovska et al.,2020; Aldhouse et al., 2020), which are all associated with hair loss, often leading to a diminished quality of life. 'Psychosocial' is another commonly used term, which relates to the influence of social factors on an individual's feelings, and to the interrelation of behavioural and social factors (Vizzotto et al., 2013). AA also negatively impacts interpersonal relationships, intimacy, social interactions, and occupational functioning (Chartier et al., 2002; Ross et al., 2005; Gorbatenko-Roth et al., 2023). No date limitations were placed on the included studies for this review to capture as many appropriate studies as possible. Studies written in a non-English language were excluded due to time constraints and a restricted research budget to commission the services of professional translators (Neimann et al., 2018).

A scoping search on the psychological and/or psychosocial impacts of AA was conducted to better understand what SLRs have already been completed on AA. This included an examination of published studies in Google Scholar as well as databases such as Scopus, PubMed, Medine, Cinahl Plus and PsycArticles through the University of Hertfordshire (UH) library. This yielded several predominantly quantitative as well as a few mixed methods SLRs. PROSPERO's database was also checked to see whether any similar SLRs were in progress. This yielded one relevant review, which was noted as ongoing and entitled *'The experience of living with Alopecia: a qualitative meta-synthesis'* by Hurrell et al., registered in August 2022. However, aside from this review on PROSPERO, which has not yet been published, my searches revealed an absence of SLRs on AA, with a particular focus on the meta-synthesis of qualitative studies. Therefore, this SLR literature search followed a meta-synthesis approach, which seeks to integrate findings from multiple qualitative studies, to provide an interpretative account of the available research to understand underlying phenomena and synthesise overarching narratives or constructs regarding AA (Jensen & Allen, 1996; Sandelowski et al., 1997). Methley et al., (2014) SPIDER (sample, phenomenon of interest, design, evaluation, research type) criteria were utilised and can be found below in Table 1. SLR search terms, including key terms like 'Psychological' and 'Psychosocial,' were operationalised for this SLR based on exploration of similar published reviews' key words/terms which indicated the utilisation of variations of my key terms, for example, 'Psychological' discussed as 'well-being'; this led to the creation of my included SPIDER search strategy below. SPIDER presents a structured approach to exploring qualitative and mixed-methods research studies. According to Cook et al. (2012) the "design" and "research type" categories incorporated into the SPIDER tool were intended to further increase the ability of this tool to identify qualitative studies. SPIDER is like other tools such as PICO (population, intervention, comparison, outcome); however, the SPIDER tool enhances research rigor by defining essential components of non-quantitative research studies (Cook et al., 2012).

The literature search for this SLR was conducted during January 2024. Search strategies were adapted to the varying databases that were searched and included for this SLR. Details of the search processes and databases used can be found in Appendix B. Searches were conducted using Scopus, Medline, Cinahl Plus, PubMed, PsychArticles, and Google Scholar. Scopus, Medline, Cinahl Plus, PubMed and PsychArticles were chosen due to their likelihood of having psychological or allied health-related studies. Google Scholar was also checked to see whether the other databases may have missed anything relevant. Only the first 50 results found in Google Scholar were included as an additional database which is known to be less systematic. While debates about whether to include grey literature are ongoing, a key question for consideration is whether the addition of grey literature adds to the quality of the review (McAuley et al., 2000; Cook et al., 2001; Hopewell et al., 2004). The decision was made to exclude grey literature databases such as OpenGray due to the absence of the use of peer review for unpublished literature (Godlee, 2003; Benzies et al., 2006) as well as the potential for bias (Egger 2003).

All papers were screened for inclusion and exclusion criteria (see Table 2). Finally, this protocol was registered in the PROSPERO database for systematic reviews (registration number: CRD42024555973).

Table 1: Overview of the SLR search strategy

SPIDER criteria:		Examples of search terms:
Sample	Adults (Female/Male)	
Phenomenon of interest	Alopecia Areata	"Alopecia Areata" OR "Alopecia Universalis" OR "Alopecia Totalis" OR "Patchy Alopecia Areata"
Design	Qualitative data collection and analysis or mixed methods data collection and analysis (qual aspect only included).	
Evaluation	Psychological, Psychosocial,	Psychological OR Well-being OR Wellbeing OR Psychosocial OR "Body image" OR Emotional OR Appearance* OR "Quality of life" OR QOL
	Impact, effect, experience, lived experience	Impact* OR effect* OR Experience* OR "Lived experience*"
Research type	Primary research either qualitative method or mixed methods (qual aspect only included)	

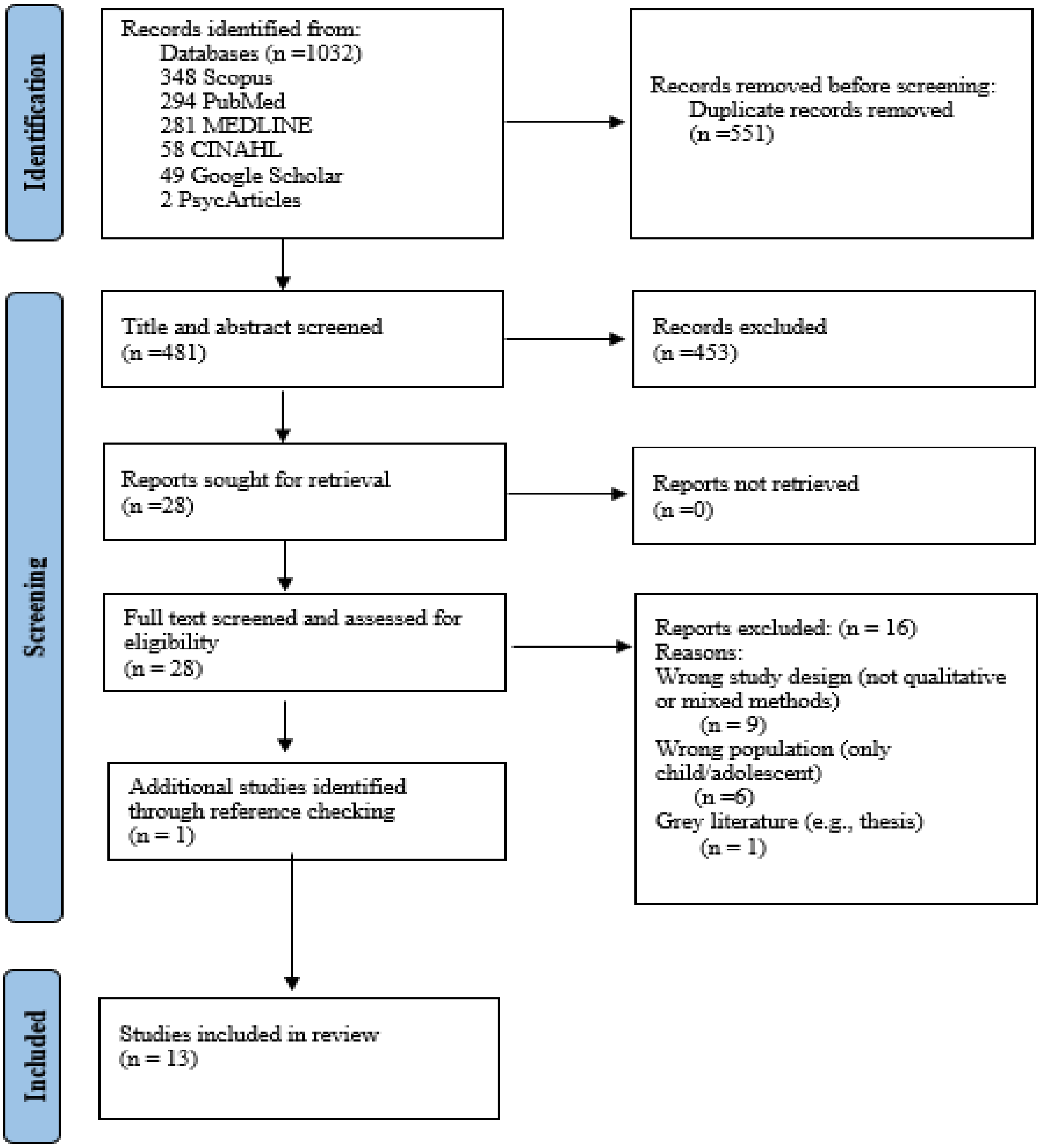
Table 2: Overview of SLR eligibility criteria

SLR inclusion criteria:	SLR exclusion criteria:
Studies that focus on accounts or experiences of individuals or adults (18+yrs) or with a majority adult sample.	Studies that focus on accounts or experiences of only individuals under 18yrs (adolescents, child, children).
Studies focusing on Alopecia Areata (AA), including patchy Alopecia Areata, Alopecia Universalis (AU) and Alopecia Totalis (AT) only or a majority sample of AA.	Accounts or experiences of individuals/adults living with other types of Alopecia other than AA, patchy, AU or AT.
Studies which focus on psychological and/or psychosocial impacts of AA.	Quantitative studies.
Qualitative studies (e.g., interviews, focus groups, qualitative surveys) as well, as the qualitative aspects of appropriate mixed methods studies.	Exclude anything other than primary empirical journal papers (other SLRs, commentaries, book chapters, grey literature, thesis).
Studies in English language only.	Studies not in English language.

1.8.1.2 SLR screening procedure

The searches were based on the criteria set out above, and all relevant studies were moved into Covidence software (Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia, 2024), a screening and data extraction tool for conducting systematic reviews. Duplicates were removed. First, myself and a colleague who acted as a co-rater completed a title and abstract screen against all SLR inclusion and exclusion criteria in Covidence, removing any studies that did not meet the criteria. Where any discrepancies occurred between the two reviewers in the title and abstract screen, these were discussed, and an agreement on inclusion/exclusion was reached. I then reviewed full-text studies independently against the criteria to ascertain the final set of studies included in this SLR. Full-text studies that did not meet the criteria were removed. Additionally, I reviewed the references of all the included full-text studies to ensure nothing else applicable was missed. Figure 1 displays a flowchart of the study selection process 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (PRISMA) statement (Page et al., 2021). PRISMA was utilised as it supports researchers in developing high-quality, efficient, and transparent SLRs (Swartz, 2011).

Figure 1 PRISMA flowchart of the study selection process



1.8.1.3 SLR quality assessment tool

Studies included in this review employed either qualitative or mixed methods research design. In mixed methods studies, only the qualitative aspect was evaluated. Qualitative studies were evaluated using the Critical Appraisal Programme Tool (CASP) qualitative tool checklist. Critical appraisal in qualitative research involves thoroughly examining research studies to assess their credibility, significance, and applicability within a given context (Burls, 2015). It is a comprehensive tool comprised of ten items assessing three broad categories: rigor, credibility, and relevance, which are viewed as cornerstones of trustworthy qualitative research (CASP, 2024). According to Long et al. (2020), CASP is the most commonly used tool for quality appraisal in health-related qualitative evidence syntheses, is described as user-friendly and has support from the Cochrane Qualitative and Implementation Methods Group, who published guidance for conducting qualitative and mixed method synthesis (Harden et al., 2018; Noyes et al, 2018). Table 3 summarises how each included study met the CASP checklist: 10 questions to assess qualitative research. The response to each of the ten CASP questions is either ‘yes’, ‘somewhat/can't tell’, or ‘no.

Table 3: Overview of CASP quality assessment tool for qualitative research

CASP questions	Clarke Jeffers et al., (2024)	Katara et al., (2023)	Rafique et al., (2024)	Zucchelli et al., (2022)	Aldhouse et al., (2020)	Rajoo et al., (2020)	Barkauskaite et al., (2020)	Davey et al., (2019)	Iliffe et al., (2019)	Montgomery et al., (2017)	Welsh et al., (2009)	Hunt et al., (2005)	Fox (2003)
1. Clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2.Qualitative methodology appropriate?	Yes	Somewhat/ can't tell	Yes	Yes	Yes	Yes	Somewhat / can't tell	Yes	Yes	Yes	Yes	Somewhat/ can't tell	Somewhat/ can't tell
3. Research design appropriate to address the aims of the research	Yes	Somewhat/ can't tell	Yes	Yes	Yes	Yes	Somewhat/ can't tell	Yes	Yes	Somewhat/ can't tell	Yes	Somewhat/ can't tell	Somewhat/ can't tell
4.Recruitment strategy appropriate to the aims of the research?	Somewhat/ can't tell	Yes	Somewhat/ can't tell	Yes	Somewhat/ can't tell	Somewhat/ can't tell	Yes	Somewhat/ can't tell	Somewhat/ can't tell	Somewhat/ can't tell	Yes	Somewhat/ can't tell	Somewhat/ can't tell

5. Data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat/ can’t tell	Yes	Yes	Yes	Somewhat/ can’t tell	Somewhat/ can’t tell
6. The relationship between researcher and participants been adequately considered?	No	No	No	Yes	No	No	No	Yes	No	No	No	Somewhat/ can’t tell	No
7. Ethical issues been taken into consideration?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat/ can’t tell	Somewhat/ can’t tell	Yes	No	No	Somewhat/ can’t tell
8. Data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat/ can’t tell	Yes	Yes	Yes	Yes	Somewhat/ can’t tell	Somewhat/ can’t tell
9. Clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
10. Research value?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

1.8.1.4 SLR synthesis method

Narrative synthesis is a method for systematically reviewing and merging results from various studies. A key feature of narrative synthesis is the adoption of a narrative rather than a statistical summary of the findings; in other words, it uses text to summarise and explain the synthesised findings (Popay et al., 2006). Narrative synthesis was chosen for this SLR due to the level of heterogeneity or diversity across the included qualitative or mixed methods studies. The current synthesis was informed by the framework and guidance developed by Popay et al. (2006), who outline four components of narrative synthesis. The first component aimed at developing a theory of whether an intervention is effective, was not used because intervention is not applicable here. The other three components described by Popay et al.'s (2006, pg. 7) framework include 'developing a preliminary synthesis,' 'exploring relationships within and between studies', and 'assessing the robustness of the synthesis.' Developing a preliminary synthesis included 'tabulating the data or textual descriptions', which includes extracting data from the included primary studies in tabular form to provide initial study descriptions, including aspects such as the participants, outcomes, country of origin, duration, the context in which intervention was delivered, or results (Popay et al., 2006). Exploring relationships within and between studies, this component sought to move beyond description by exploring relationships and included concept mapping (Popay et al., 2006). Assessing the robustness of the synthesis included an assessment of the strength, appropriateness, relevance, or impact of the synthesis based on critically appraising the methodological quality of included studies (Popay et al., 2006).

Table 4: Overview of studies included in the SLR

Title, author, year, and location	Study aim(s)	Study characteristics	Study methodology	Reported psychological or psychosocial impacts	Study Themes	Study strengths & limitations
1. Title: "Hair is your crown and glory" –Black women's experiences of living with Alopecia and the role of social support by Clarke-Jeffers et al. (2024). **Location:** UK & USA.	To explore Black women's experience of living with autoimmune types of Alopecia with a focus on the cultural importance of hair within the Black community and the impact of social support.	**Sample size:** N=7 **Population:** Adult Females **Ethnicity:** Black Caribbean or African American. **Aged:** 37-68yrs. **Type of Alopecia:** Alopecia Areata. **Ethics:** Ethical approval sought from Birmingham City University Research Ethics Committee.	**Study design:** Qualitative. **Sampling:** Purposive sampling. **Data collection:** Semi-structured interviews. Interviews were conducted online via Skype and Microsoft Teams and recorded. Interviews lasted an average of 48 minutes. **Data analysis:** Interpretative phenomenological analysis.	Psychological or psychosocial impact including impact on females, self-esteem, depression, anxiety, loneliness, identity, hiding or masking self, body image, society, cultural standards or barriers, and social support.	**Theme 1:** Symbolic nature and perception of hair within the Black community Subtheme: Importance of hair – "Hair is your crown and glory", The wave of the natural hair movement **Theme 2:** Identity: Who am I? The new me! Subtheme: Me, myself, and I, Concealment… My double life, The psychological roller-coaster of alopecia **Theme 3:** The power of connectivity… "Who can I rely on?" Subtheme: Bonded by similar Experiences, Representation of support groups	**Strength:** This study explored an often under-researched ethnic minority as there is more research on white females, which makes this study more unique. **Strength:** IPA appears to be an appropriate analysis method. **Limitation:** No clear rationale for why participants were recruited from support groups across two different countries. **Limitation:** There are likely to be differences in the experiences of black females with Alopecia in the UK vs the USA. **Limitation:** The study recruits from a support group, wonder about those who don't seek social support.
2. Title: The Lived Experience of Women with Alopecia: A Qualitative Study Investigating the Psychological, Social and Emotional Impact of Alopecia a Sample of Greek Women by Katara et al., (2023). **Location:** Greece.	To investigate the changes in the socio-emotional world of women with Alopecia and their adaptation to all aspects of everyday life.	**Sample size:** N=10. **Population:** Adult Females. **Ethnicity:** unclear. **Aged:** 20-55yrs. **Type of Alopecia:** Alopecia Areata. **Ethics:** Ethical approval sought from the Ethics Committee of the SCG College.	**Study design:** Qualitative. **Sampling:** Purposive sampling. **Data collection:** Semi-structured interviews. Interviews were conducted online via Skype and Viber and recorded. Interviews lasted an average of 50 minutes. **Data analysis:** Thematic analysis.	Psychological or psychosocial impact on well-being, impact on females, interactions with family, partners, work, and social life.	**Theme 1:** Functionality and adaptability Subtheme: In social life, using a wig, feelings about wearing a wig. **Theme 2:** Environmental attitude and expectations Subtheme: Family and partner, Social environment, Expected reaction from the social environment and partner **Theme 3:** Attitude towards treatment Subtheme: Continuous treatment, distancing, Willingness for stabilised treatment.	**Strength:** The study acknowledges that it only includes females and there are likely gender and societal differences between males and females in their perception of Alopecia. **Strength:** TA appears to be an appropriate analysis method. **Limitation:** This study did not state the ethnicity of the women involved, other than they were Greek so it is unclear if they were all white for example.

					Theme 4: Effect of the disease Subtheme: In the psyche, at work, in social relations, in social life.	**Limitation:** Utilised quotes could not always be understood alone without the preamble paragraph before them.
3. Title: Self in the darkness seem to me no more real than a dream: Experiences of living with Alopecia Universalis across two cultures by Rafique et al., (2024). **Location:** Pakistan and UK.	To gain some meaningful insights into cross-cultural explanations of psychosocial consequences of AU.	**Sample size:** N=12 **Population:** Adult Males **Ethnicity:** Pakistani and British. **Aged:** Over 18yrs. **Type of Alopecia:** Alopecia Universalis. **Ethics:** Ethics was sought from the regional committee for medical and health research ethics.	**Study design:** Qualitative. **Sampling:** Convenience sampling. **Data collection:** Semi-structured interviews. Interviews were conducted face to face. Interviews lasted an average of 50 minutes. Interviews in Urdu were translated to English. **Data analysis:** Interpretative phenomenological analysis.	Psychological or psychosocial impact including personal reactions, psychological impacts such as anxiety, depression, loss of self-confidence, low self-esteem, feelings of uselessness or worthlessness, social reactions, understanding hair culturally, and impacts such as social rejection, loss of friends, reluctance to initiate new relationships, loss of leisure activities, role of faith. Coping strategies.	**Theme 1:**Immediate Reactions (personal and social) Subtheme: Reactions personal. Reactions social. **Theme 2:** Impact (psychological and social) Subtheme: Psychological impact. Social Impact. **Theme 3:** Coping (cognitive and behaviour) Subtheme: Cognitive Coping. Behavioural Coping **Theme 4:**Adjustment and Rehabilitation Subtheme: Adjustment & rehabilitation. **Theme 5:** Equilibrium /Growth (Psychological and Spiritual) Subtheme: Psychological Growth. Spiritual Growth.	**Strength:** Few studies consider varying cultural perspectives, which adds to this study's uniqueness. **Strength:** The study acknowledges it only focused on males and future studies could include females. **Limitation:** The generalisability of convenience samples is unclear and may not be representative of the general population with AU. **Limitation:** The study does not provide much in the way of descriptives for the participant sample. **Limitation:** TA may have been a better method than IPA due to the likely heterogeneity in a sample across two cultures. **Limitation:** Interpretation of a translation may not fully capture cultural differences relating to AU in Pakistani participants.
4. **Title:** Men's Experiences of Alopecia areata: A qualitative study by Zucchelli et al., (2022).**Location:** UK.	To explore men's experiences of living with AA via semi-structured interviews.	**Sample size:** N=18 **Population:** Males Adults & Adolescents. **Ethnicity:** White, Asian British, Multiple/Mixed ethnic groups. **Aged:** 17-71yrs. **Sexuality:** Straight & Gay. **Type of Alopecia:** Alopecia Areata, including patchy, universalis, and barbae.	**Study design:** Qualitative, **Sampling:** Sample for interview obtained from a wider survey conducted previously/ separately. **Data collection:** Semi-structured interviews. Interviews were conducted via phone or online audio service, and eight via Microsoft Teams.	The psychological or psychosocial impact on males, social challenges, well-being, identity, and engaging in public activities.	**Theme 1:** The unknown man Subtheme: The unseen man, The unheard man, The disguised man **Theme 2:** The man in context Subtheme: Male pattern baldness, similar but different, Recognising the whole man: different and different again, It's harder, yet easier for women **Theme 3:** The burdened man	**Strength:** This study acknowledges experiences of Alopecia for males who are often an underrepresented group. Strength: RTA appears to be an appropriate analysis method for the research question and sample size. **Strength:** Study recruited both straight and gay males. Gay males are not always represented in research.

		Ethics: Ethical approval sought from the University of the West of England Faculty Ethics Committee, Participants were offered a £20 online shopping voucher to compensate for their time (though we did not specify the amount in the participant information to avoid any potential for coercion).	Interviews lasted an average of 63 minutes. **Data analysis:** Reflexive Thematic analysis.		Subtheme: The private weight, The public cost, Being less of a man.	**Strength:** This study acknowledges its limitations by not representing ethnic minority males. **Limitation:** 1 participant had Androgenetic Alopecia and well as Areata, they possibly should have been excluded as all other participants specifically have types of Alopecia Areata. **Limitation/strength:** Debates on the use of remuneration, may be considered a limitation or strength. The ethics of payment may entice participants for the wrong reasons, on the other hand it may be argued as more ethical to compensate participants for time.
5. Title: "You lose your hair, what's the big deal?' I was so embarrassed; I was so self-conscious. I was so depressed:" a qualitative interview study to understand the psychosocial burden of Alopecia areata by Aldhouse et al., (2020).**Location:** USA & Canada.	To explore the symptom experience and psychosocial burden of living with AA.	Sample size: N=45 **Population:** Females & Males Adults & Adolescents. **Ethnicity:** Asian, Black, or African American, White, Hawaiian, or Pacific islander, Hispanic, Other. **Aged:** 15-72yrs. **Type of Alopecia:** Alopecia Areata. **Ethics:** Ethical approval sought from the Western Institutional Review Board. Patients received an honorarium of $150 USD/CAD.	**Study design:** Qualitative, however, utilizes the Severity of Alopecia Tool (SALT) in participant selection. **Sampling:** Unclear, possibly purposeful. sampling. **Data collection:** Semi-structured interviews. Interviews were conducted in two rounds, interim analyses were completed after 30 interviews (Round 1). Following the first 30 interviews, eligibility criteria were modified to focus on the experiences of adults with severe hair loss (SALT ≥50%) at the time of recruitment in Round 2. Interviews were conducted face to face.	Psychological or psychosocial impact including emotional and psychological impact, and perceived/actual stigma, relationship impacts and social/lifestyle impacts.	**Theme 1**: Psychosocial impact of AA. Subtheme: Emotions – emotional impact, psychological impact, perceived/actual stigmatisation. Functioning – Relationship impacts, social and lifestyle impacts. **Theme 2:** Physical impact of AA. Subtheme: Physical impacts – eye irritation, sunburn, nasal irritation, poor thermoregulation. Signs/symptoms – hair loss, nails, scalp skin, scalp sensations.	**Strength:** Study includes relatively similar numbers of females (n=26) to males (n=19), likely leading to greater reliability relating to the psychosocial burden of living with AA. **Strength:** TA appears to be an appropriate method for the research question; however, this study does have an unusually large sample size. **Limitation:** Sample size for a qualitative study refers to "saturation," which is a widely debated concept. It goes on to state this was reached after interview 24 and begs the question why recruitment continued. **Limitation:** Unclear why the study sought to include adolescents and

			Interviews lasted an average of 90 minutes. **Data analysis:** Thematic analysis.			adults, it states a predominant focus on adults and given the large sample size, it does not appear adolescents were necessary. **Limitation:** I wonder if this study is doing too much by ‘collapsing’ perspectives from a wide age range / developmental stage **Limitation:** Themes not clearly labelled. **Limitation:** Results relate to those with a certain SALT score and therefore the effects of milder AA was not investigated. **Limitation:** Debates on the use of remuneration.
6. Title: Perceived barriers and enablers to physical activity participation in people with Alopecia Areata: a constructivist grounded theory study by Rajoo et al., (2020). **Location:** Australia.	To identify the perceived barriers and enablers to physical activity (PA) participation in individuals with AA by using grounded theory to inform subsequent PA intervention designs.	**Sample size:** N=16 (8 focus group & 8 telephone interviews). Those who partook in the focus group were different from those who completed interviews. **Population:** Adult Males & Females. **Ethnicity:** Unclear **Aged:** 18-65yrs **Type of Alopecia:** Alopecia Areata **Ethics:** Ethical approval sought from the Human Research Ethics Committee of RMIT (Royal Melbourne Institute of Technology) University, Australia.	**Study design:** Qualitative, **Sampling:** Sequential/selective sampling. **Data collection:** Focus group and semi-structured telephone interviews. **Data analysis:** Constructivist grounded theory	Psychological or psychosocial impacts self-conscious, embarrassed, scared, anxiety, shame, self-motivation, being stared at, conversations with new people, incentive encounters, not wanting to leave the house, engaging in PA is harder, illness perceptions, acceptance, social support groups.	**Theme 1:** Barriers to physical activity Subtheme: Being stared at, Body image, Managing the noticeability of the wig, Restricted dress code, Psychosocial – being self-conscious and embarrassed, Extreme temperature **Theme 2:** Enables physical activity Psychosocial – acceptance of the condition, psychosocial – social media and support groups, Building resilience from a young age, Self – motivation, Degree of hair loss.	**Strength:** GT was used appropriately to develop a model of enablers and obstacles to engaging in PA with AA. **Strength:** Offering varied methods to participants to ensure they feel comfortable participating. **Strength:** The researchers do acknowledge that the sample size is small. **Limitation:** Lack of descriptive detail on participants and unaware of ethnicity for example. **Limitation:** Given small sample size could be challenging to compare focus groups and interview data. **Limitation:** Larger sample likely to make a developed model more generalisable.

7. Title: Therapeutic implications of psychological state in patients with Alopecia areata: A qualitative study by Barkauskaite et al., (2020). **Location:** Lithuania	To explore the lived experience of people with Alopecia areata in Lithuania	**Sample size:** N=6 **Population:** Adult Males & Females. **Ethnicity:** White, Asian British, Multiple/Mixed ethnic groups. **Aged:** 23-33yrs. **Type of Alopecia:** Alopecia Areata, including Totalis & universalis **Ethics:** Ethical approval sought from the Faculty of Organizational and Clinical Psychology at Vilnius University	**Study design:** Qualitative, **Sampling:** Unclear, from a specific group so appears to be purposive sampling. **Data collection:** Unstructured interviews. Interviews were conducted in person Interviews lasted an average of 60 minutes **Data analysis:** Colaizzi's phenomenological approach also known as descriptive phenomenology.	Psychological or psychosocial impact including anger, fear, anxiety, blaming, and grief, interaction with others, illness perceptions.	**Theme 1:** Devastating loss of perceived self Subtheme: Acute balding immerse in the painful chaos of self-perception, Gender differences, In the process of the fluctuating identity **Theme 2:** Grieving and the process of acceptance Subtheme: Shock and denial, Anger, fear, anxiety and blaming, The relative acceptance **Theme 3:** The Grown Man Subtheme: Coming to terms with alopecia, Personal growth through adversity.	**Strength:** The study successfully recruited both males and females. **Limitation:** It is unclear why the researchers used Colaizzi's phenomenological approach instead of IPA. **Limitation:** There is a risk of lots of variation in an unstructured interview; a semi-structured interview allows for flexibility while still being more comparable. **Limitation:** We do not have any additional descriptive information on the ethnicity of the participants. **Limitation:** Recruitment was specifically from the National Alopecia Association (NAA) of Lithuania, I wonder whether those who do not engage in the NAA would respond similarly. **Limitation:** This study does not reflect on its own study limitations.
8. Title: Living with Alopecia areata: an online qualitative survey Study by Davey et al., (2019).**Location:** UK.	To explores how meanings associated with hair and hair loss influence on experiences of living with AA. To identify how this understanding might inform practice by healthcare professionals to best support patients to cope with the condition.	Sample size: N=95 **Population:** Adult Males & Females. **Ethnicity:** White, British, Scottish, British Asian, South Asian, Black British, Middle Eastern, British Welsh. **Aged:** 18-79yrs. **Sexuality:** Straight, Bisexual, Gay, Lesbian. **Type of Alopecia:** Alopecia Areata, including Totalis & universalis **Ethics:** Ethical approval sought from the Health and Applied Sciences	**Study design:** Qualitative, **Sampling:** convenience/ volunteer sample **Data collection:** Online qualitative survey with 10 questions. **Data analysis:** Thematic Analysis	Psychological or psychosocial impact emotionally devastating, depression, suicidal thoughts, self-esteem, self-confidence, self-worth, lonely, bereavement, loss of identity, bullying, interactions with professionals.	**Theme 1:** It's (not) just hair Subtheme: Hair loss is emotionally devastating, Pace and unpredictability of hair loss, Hair loss is like a bereavement, Hair loss is like losing a limb, a breast, or part of the self, Feeling or looking monstrous or alien, Feeling ugly and unfeminine, Being bullied, Significance of hair loss dismissed by healthcare professionals, Not entitled to be upset **Theme 2:** A restricted life Subtheme: Unable to participate in leisure	**Strength:** Use of TA appropriate to the study aims and questions. **Strength:** The study acknowledges its limitations including predominance of white women among the participants. **Limitation:** The justification for the sample size is unclear. 95 participants for a qualitative study are rather large and unusual, likely unnecessary. **Strength:** Clear rationale given for the use of a qualitative survey over other more regularly used

Faculty Research Ethics Committee of the University of the West of England.			activities, exercise and playing sports, Avoiding leaving the house or socialising, Affecting career choices or feeling able to work, Cost of concealment, Concealment and inauthenticity in relationships, Restricted opportunities for and in intimate relationships, Loss of the mundane pleasures of femininity or gendered grooming, The ultimate freedom is being bald and proud and authentic in public **Theme 3:** Abandon hope all ye who lose their hair Subtheme: Even if my hair grows back, I fear losing it again, (False) hope of treatment, Exploitative businesses, Dismissive or insensitive doctors, Lack of empathy from psychologists/counsellors, There is no option but to get on with my life **Theme 4:** Seeking support is a highly personal journey Subtheme: An individual journey towards coping and acceptance, Anger and frustration at a lack of signposting to psychological and peer support in medical contexts, Counselling or psychological therapy needs to be offered early on and therapists need to understand what it's like to live with alopecia, Counselling and psychological therapy help, Support from family and friends helps coping and self-acceptance,	qualitative methods such as interviews, due to the sensitive nature of the topic. **Limitation:** Nothing mentioned about informed consent or right to withdraw, what consents were attached to the online survey.

					Learning from others with Alopecia how to manage hair loss, Contact with others who have Alopecia helps coping and self-acceptance, Hearing other peoples' experiences of Alopecia makes things worse, Post-traumatic growth.	
9. Title: Investigating the beneficial experiences of online peer support for those affected by Alopecia: an interpretative phenomenological analysis using online interviews by Iliffe et al., (2019).**Location:** UK	To gain an experiential account as to how online support provides benefit to people living with alopecia.	Sample size: N=12 **Population:** Adult Females, 1 person under 18yrs. **Ethnicity:** Unclear **Aged:** 30-59yrs (11 out of the 12 participants. **Type of Alopecia:** Alopecia Areata. **Ethics:** Ethical approval sought from the University of Sheffield.	**Study design:** Qualitative, **Sampling:** Purposive sample **Data collection:** Semi-structured interviews. Interviews lasted approx. 60 minutes. Interviews were conducted via Facebook messenger. **Data analysis:** Interpretive Phenomenological Analysis.	Psychological or Psychosocial impact going to a dark place, shame, depressed, isolating, how others cope with alopecia, what others think, withdrawn, attending events/hobbies, family.	**Themes:** Gradual healing, Expressing emotions, Image concerns, Practical support and knowledge, Tips on coping, Belonging, Connecting, Shared experiences, New identities and self-acceptance, Social life and openness.	**Strength:** IPA appears to be appropriate method for the research question and sample size. **Strength:** This acknowledges that the transferability of the findings may be limited in part due to the investigation of a single charity source. **Limitation:** For consistency it would have been better for all participants to be Alopecia suffers and all over 18yrs rather than including 1 parent experience with an under 18yr old child. **Limitation:** It remains unclear whether all participants with Alopecia had the same type of Alopecia. Alopecia Areata is discussed in the literature section, but this is not re-confirmed in the participant section.
10. Title: A mixed methods survey of social anxiety, anxiety, depression and wig use in Alopecia by Montgomery et al., (2017).**Location:** UK.	To examine levels of social anxiety, anxiety, and depression reported by people living with Alopecia, associations between wig behaviours and psychosocial distress and experiences of wearing wigs in social situations.	Sample size: N=338 **Population:** Adolescent & Adult Males & Females. **Ethnicity:** White, Asian, Black, other. Aged13-65yrs (49.4% between 35-54yrs, only 1.5% between 13-17yrs.	**Study design:** Mixed methods. **Sampling:** Purposive volunteer sample **Data collection:** Survey with closed & open ended questions. **Data analysis:** Quantitative - independent samples t-	Psychological or psychosocial impact interacting with people, illness perceptions, impact on going to new places or trying new activities, attractiveness, confidence, distress, negative views of appearance, being stared at or shouted at, pity from strangers, depressing,	**Themes:** wearing a wig impact on confidence during social situations, wearing a wig affected everyday life, Worries about not wearing a wig.	**Strength:** CA appears to be suitable for this mixed methods study, used when large amounts of textual data is present with less focus on comparing or contrasting. **Strength:** This study acknowledges limitations such as it had a

		Type of Alopecia: Alopecia Areata, including Universalis, Totalis, Frontal fibrosing, Androgenic, Male pattern balding, Female pattern balding, Scarring Alopecia, Linchen planopilaris, chemically induced or unknown. AA, AU & AT counted for 279 of the 338 participants. **Ethics:** Ethical approval sought from the University of Sheffield Psychology Department Ethics Committee.	tests and Pearson correlation. Qualitative – Content analysis.	self-conscious, impact on work or social life, worried, feeling ugly.		predominantly white female sample. **Strength:** This study acknowledges limitations such as a number of responses could not be coded into themes as the responses did not relate to the question suggesting some participants may have experienced problems interpreting the questions. **Strength:** This study acknowledges recruiting a participant sample just from Alopecia UK who are seeking support rather than widening it out to those not involved with a charity may also impact generalisability of the results. **Limitation:** It may have been better to pick either an adolescent or adult sample and pick a certain type of Alopecia rather than opening it out to so many types which may impact them differently. **Limitation:** While the study states 338 participants completed the survey, it does not further state what number of participant responses were included in the qualitative CA section.
11. Title: The lived experience of Alopecia areata: A qualitative study by Welsh et al., (2009). **Location:** UK	Explored experiences of individuals living with Alopecia areata (AA) and Alopecia universalis (AU) and investigated their accounts of adjusting to, and coping with, such conditions.	Sample size: N=12 **Population:** Adult Males & Females. **Ethnicity:** Unclear **Aged:** 20-59yrs. **Type of Alopecia:** Alopecia Areata, including universalis	**Study design:** Qualitative, **Sampling:** Purposive sample **Data collection:** Biographical semi-structured interviews in person. Interviews lasted 30-60 minutes.	Psychological or psychosocial impacts including shame, embarrassment, depression, sadness, less going out, social support, work, hobbies, family.	**Theme 1:** Coping with the initial impact of alopecia. Subthemes: Pragmatic coping 1; social dimensions; treatments and social support. **Theme 2:** Living with the unpredictability of alopecia.	**Strength:** IPA appears to be a suitable method to answer the aims and research question. **Strength:** Sample size appears appropriate for IPA. **Strength:** The study acknowledges that the varying ages of onset may impact views and

		Ethics: Ethical approval sought from the University of Teesside.	**Data analysis:** Interpretive Phenomenological Analysis.		Subthemes: Time to adjust; pragmatic coping 2; putting things into perspective and positive thinking.	participants are likely to be at different points with coping and acceptance meaning results may not be generalisable. **Limitation:** Lack of descriptive on participants and unaware of ethnicity for example. **Limitation:** In relation to participants in written text it states participants aged 31-59 but in the participant information summary box it states they were aged between 20-59. Age inconsistencies.
12. Title: Reported experiences of persons with Alopecia areata by Hunt et al., (2005).**Location:** UK	The aim of the current research is to explore the areas of concern that people with Alopecia have, rather than provide predetermined categories.	Sample size: N=162 (part 1), 34 (part 2). **Population:** Adolescent or Adult Males & Females. (80% described experiences in adulthood). **Ethnicity:** Unclear **Aged:** 12-93yrs. **Type of Alopecia:** Alopecia Areata, including Universalis and Totalis. **Ethics:** Ethical approval specifics unclear.	**Study design:** Qualitative, **Sampling:** Purposive volunteer sample **Data collection:** Part 1 - spontaneously generate accounts of the psychological impact on their personal and social lives of their experiences of alopecia. Part 2 – email interviews from a different sample of participants. **Data analysis:** Grounded theory approach.	Psychological or Psychosocial impacts include negativity about appearance, stress, lonely, shame, upsetting, suicidal ideation, worry, public opinion on baldness, sex differences, explaining to friends and family, becoming reclusive, less socialising, loss of self-esteem and confidence, impacts at work or relationships, bullying, social support, treatments, and professional attitudes.	**Theme 1**: Personal: physical effects, causes, psychological distress, and coping. **Theme 2:** Social: work, relationships, sex differences, children and adolescents, and social support **Theme 3:** Medical: treatment and doctors' attitudes.	**Strength:** This study acknowledges that limitation of its techniques is that it is unlikely to generate a representative sample of people with alopecia; it being more likely to access those with problems who are seeking solutions. **Limitation:** The sample size for a qualitative GT study is rather large. **Limitation:** It is also not clear why GT was utilised to analyse the data; creation of a model was not clear. TA may have been more appropriate. **Limitation:** This study could have provided more information about its participants such as ethnicity.

13. **Title:** Case study of Alopecia universalis and web-based news groups by Fox (2003). **Location:** Online – UK, USA & elsewhere in the world.	The aim of the study was to explore the nature and themes of discourse within a net-based support group as a basis for gaining a greater appreciation of the experiences and concerns of individuals with Alopecia universalis.	**Sample size:** Based on episodes of communication rather than numbers of participants. Total of 228 episodes on the net-based group over 18months. Appears to be from 12 net-based group members. **Population:** The web-based group included males & females. Unclear the breakdown of who was willing to be involved in the study. **Ethnicity:** Unclear **Aged**: Unclear **Type of Alopecia:** Alopecia Universalis **Ethics:** Details of ethics unclear, but researcher from the University College Worcester.	**Study design:** Qualitative, **Data collection:** Online extracts from a group. **Sampling:** Unclear, from a specific group so appears to be purposive sampling. Content from interactions on a web-based Alopecia group. **Data analysis:** Content or cognitive mapping.	Psychological or psychosocial impact on self-confidence, self-esteem, emotional roller coaster, sadness, professionals not listening, work environment, identity changes, relationships including partners, family & friends.	**Themes:** Powerlessness as opposed to advocacy, Practical support and advice, Self-grief in terms of loss of self-identity and esteem and the search for a new self, Emotional survival and encouragement, Life changing or change opportunity for self-acceptance and personal growth.	**Strength:** Exploring communications on a web-based group is a unique way to explore the experiences of AU. **Strength:** This study does make attempts to attend to the ethical considerations relating to internet research. **Strength**: It appears the researcher did share a declaration, which appears to relate to study information and consent and pulled conversations from the 12 who responded. **Strength:** The study does acknowledge its limitations such as the potential bias of the sample must also be acknowledged, as individuals who participated in any web-based discussion are self-selected and may therefore have a predisposition to discussing their life experiences and hence may share attributes or values. **Limitation:** Very little information was collected from participants, limited sense of age, gender, ethnicity, etc. **Limitation:** it is not clear why concept mapping was chosen over other methods like TA. **Limitation:** The decision of the researcher in this study to initially 'eavesdrop' and then finally declare a research interest, while in accord

with the emerging literature surrounding web-based research ethics, is arguably contentious in the context of the continuing debate regarding ethical issues specific to web-based research (netiquette).

1.8.2 SLR Results

1.8.2.1 SLR study selection

A total of 1,032 studies were initially identified through database searches. These were imported into Covidence software, which removed 551 duplicate studies. Following the removal of duplicates, myself and a colleague who acted as a co-rater screened 481 study titles and abstracts against the SLR eligibility criteria. 28 studies were included for a full-text review. Following the full-text review, 16 studies that did not meet the criteria were removed, and 12 studies were included in the review (see Table 4 above). One additional study was identified by engaging in reference and citation checking. Therefore, a total of 13 studies have been included in this SLR.

1.7.2.2 SLR study characteristics

Table 4 above provides an overview of the study characteristics and methodology, a summary of the reported psychological and/or psychosocial impacts, as well as study strengths and limitations. The 13 included studies for this SLR totalled to include 779 participants. Sample sizes varied from 7 to 338 participants. Twelve of the 13 studies were qualitative, and one study was mixed methods, however, I only focused on the qualitative aspect of this mixed methods study. Studies were conducted across different locations, predominantly the UK (n=5), with 3 studies based across 2 locations, including the UK and USA, the UK and Pakistan, and USA and Canada jointly. The remainder of the studies took place in Greece, Lithuania and Australia. Studies focused predominantly on adult populations (n = 8), with four that focused mainly on adults while also including children or adolescent age groups. In one, the exact population age ranges were unclear. All studies focused on AA, including its subtypes AU or AT. One study had a broader focus, and while it predominantly focused on AA, it also included Frontal fibrosing, Androgenetic, Male pattern balding, Female pattern balding, Scarring Alopecia, Lichen planopilaris, or chemically induced Alopecia. Studies used a range of sampling methods, mainly either purposive or convenience. Data collection methods included semi-structured interviews (n = 7), online qualitative survey (n= 2), focus groups and/or interviews (n= 1), unstructured interviews (n= 1), email interviews (n= 1) and online extracts from a group (n= 1). Study analyses similarly varied depending on research aims and included thematic analysis or reflexive thematic analysis (n= 4), interpretive phenomenological analysis (n= 4), grounded theory (n= 2), content analysis (n= 1), descriptive phenomenology (n= 1) or content or cognitive mapping (n=1). Finally, all 13 studies included aspects of the psychological and/or psychosocial impact of AA.

1.8.2.3 SLR quality of included studies

The relevant qualitative studies were inspected using the Critical Appraisal Programme Tool (CASP) qualitative tool checklist. Table 3 above summarises how each of the included studies met the CASP Checklist: 10 questions to assess qualitative research. All studies identified a clear research aim or question. Most of the studies used an appropriate methodology with a clear rationale for the study design. Nine studies used either Thematic analysis, Reflexive Thematic analysis, Interpretative Phenomenological analysis, Grounded theory or Content analysis in line with the study research questions and aims (Welsh et al, 2009; Montgomery et al., 2017; Iliffe et al.,2019; Davey et al., 2019; Rajoo et al., 2020; Aldhouse et al., 2020; Zucchelli et al., 2022; Katara et al., 2023; Clarke-Jeffers et al., 2024). However, for four of the thirteen studies, it was unclear if the methodology was appropriate and there was insufficient detail regarding the justification of their study design (Fox, 2003; Hunt et al., 2005; Barkauskaite et al., 2020; Rafique et al., 2024). A further critique of Rafique et al., (2024) study is that I felt TA may have been a better method than IPA due to the likely heterogeneity in a sample across two cultures/countries (UK & Iranian). A variety of sampling strategies were used across the studies (e.g., purposive, convenience, or sequential), with purposive being the most frequently used in at least eight of the included studies. However, it was noted that specifics on sampling were not highlighted in all studies. The majority of studies utilised adult samples only, but a few collected data from both adults and/or adolescent or child samples within the same study without a clear rationale as to why (e.g., Montgomery et al., 2017). Most of the studies stated that they intended to recruit samples with AA or its subtypes; however, some of the study results then indicated other Alopecia types (e.g., Montgomery et al., 2017). Most of the studies took ethical issues into consideration sufficiently and clearly stated where they obtained ethical approval from, but studies by Hunt et al., (2005) and Fox (2003) did not have enough detail in relation to ethical considerations. Several studies acknowledged a lack of diversity that often occurs in research (e.g., typically more white females) and therefore made attempts to increase this in relation to ethnicity, gender and sexuality (Montgomery et al., , 2017; Davey et al., 2019; Barkauskaite et al., , 2020; Adlhouse et al., 2020; Zucchelli et al, 2022) which is important for the transferability of results, especially in qualitative research. Many of the qualitative studies did not adequately consider the relationship between the researcher(s) and participants or mention the reflexivity important in qualitative research, other than Davey et al. (2019) and Iliffe et al. (2019). Given the sensitivity of the research topic and difficulties some may have speaking about their lived experience of Alopecia, some studies offered varying data collection methods in a bid to make potential participants get involved in a way that they felt most comfortable with (e.g., Zucchelli et al., 2022). Moreover, Davey et al. (2019) also clearly discussed the sensitive nature of discussing Alopecia and therefore opted for an online survey rather than interviews to make participants more comfortable. As discussed above the terms 'psychological' and 'psychosocial' were used interchangeably across studies but often highlighted similar things in relation to the negative impacts of AA on everyday life (e.g., psychological distress, social isolation, interpersonal and occupational difficulties). Finally, none of the thirteen studies were excluded from this SLR because of poorer quality as it was felt that even though the older included studies did not meet as many CASP criteria as more recent ones, they still likely added to this SLR as they were all nevertheless publishable, peer-reviewed studies. Moreover, there are fewer qualitative published studies in this area generally. However, the results of this SLR did seek to prioritise the stronger papers in the synthesis that met more of the CASP criteria and were therefore deemed to be of better quality.

1.8.2.4 SLR synthesis study findings

I utilised Popay et al.'s (2006) narrative synthesis framework to identify the main themes, patterns and commonalties across the 13 included SLR studies to better understand the psychological and/or psychosocial experiences of AA among adults. The four main themes are presented below*: An emotional rollercoaster, Who am I now and do I fit in, Alopecia is good at telling you what you can and can't do,* and *The impact of supportive or unsupportive responses.*

1. An emotional rollercoaster

There was an acknowledgment by many studies of the existence of continuous apprehension, uncertainty and unpredictability experienced by those with Alopecia, with cycles of greater or lesser hair loss and regrowth (Fox et al., 2003; Welsh et al, 2009; Davey et al., 2019; Rojoo et al, 2020; Aldhouse et al., 2020; Rafique et al., 2024; Clarke-Jeffers et al., 2024). Participants expressed the following:

> *"It's the unpredictability that's hard to deal with a bit of growth then you lose it again that the bit that's difficult, the roller coaster" (Fox, 2003, pg. 7).*
>
> *"The uncertainty of not knowing which way it was going to go and why and anticipating that I was going to be completely bald was the most horrific part of the whole experience"* (Aldhouse et al., 2020, pg. 5).

Moreover, feelings of a lack of control over hair, with impacts on appearance were reported by several studies (Fox et al., 2003; Welsh et al, 2009; Davey et al., 2019; Rojoo et al, 2020; Aldhouse et al., 2020; Rafique et al., 2024; Clarke-Jeffers et al., 2024). Participants stated the following:

> *"Unpredictable patterns of hair loss can result in feelings of apprehension, uncertainty, and feeling unable to control one's appearance and regain self-confidence and self-esteem"* (Rafique et al., 2024, pg. 13).

Evident across all the papers was the fact that Alopecia comes with emotionally or psychologically devastating impacts, which were even described by some as a traumatic life event (Fox et al., 2003; Hunt et al., 2005; Welsh et al., 2009; Davey et al., 2019; Montgomery et al, 2017; Iliffe et al., 2019; Rojoo et al, 2020; Aldhouse et al., 2020; Barkauskaite et al., 2020; Zucchelli et al., 2022; Rafique et al., 2024; Karata et al., 2023; Clarke-Jeffers et al., 2024). Psychological trauma may be a precursor to or a consequence of Alopecia (Hunt et al., 2005). Higher levels of anxiety and depression or low mood compared to the general population was the most consistent finding when exploring the emotional impact of Alopecia. Suicidal ideation was also detailed in a few studies. Participants stated the following:

> *"I am anxious very conscious about how I look; I keep staring at myself in the mirror to try reduce my anxiety"* (Rafique 2024, pg. 9).
>
> *"I look back now and it was depression, I had depression, I definitely had depression, the sense of just wanting to die [...] the sense of helplessness and despair that day, this scarf just wouldn't work and just thinking I wanna die, I want to die because if this is what I gotta face I can't do it anymore and I don't want to do it"* (Clarke-Jeffers et al., 2024, pg. 6).

However, a range of other negative emotional experiences were also highlighted across the SLR papers, such as isolation, embarrassment, anger, social anxiety, low self-esteem, helplessness, worthlessness, shame, guilt, irritability, loneliness, and grief (Iliffe et al, 2019; Aldhouse et al., 2020; Zuccheilli et al., 2022). Participants stated the following:

> *'It's very isolating. . . Alopecia is very good at telling you "you can't", so you don't"* (Iliffe et al, 2019, pg. 5).
>
> *"I was so embarrassed, I was so self-conscious, I was so depressed about it. I concealed it, concealed it, concealed it"* (Aldhouse et al., 2020, pg. 5).
>
> *"so, it's been like a life of being angry at my own appearance and the psychology effect was really, really big"* (Zuccheilli et al., 2022, pg. 7).

Hair loss and appearance changes due to Alopecia were described and compared to grief, loss, or bereavement, where individuals often described needing to mourn the loss of their hair to reach some level of possible acceptance (Davey et al., 2019; Aldhouse et al., 2020; Rafique et al., 2024). Rafique et al., (2024) specifically describes hair loss as it relates to Worden's (2009) four stages of grief. Participants shared the following:

> *"losing hair is a grieving process and the emotions felt mirror those experienced by those suffering a bereavement." (Davey et al., 2019, pg. 5).*
>
> *And it took me about two years. I really – I really had to mourn the loss of my hair." (Aldhouse et al, 2020, pg. 5).*

2. *Who am I now and do I fit in?*

The impact on managing identity due to appearance shifts was mentioned in almost all the papers (Fox et al., 2003; Hunt et al., 2005; Welsh et al, 2009; Davey et al., 2019; Montgomery et al, 2017 ; Iliffe et al., 2019; Rojoo et al, 2020; Aldhouse et al., 2020; Barkauskaite et al., 2020; Zucchelli et al., 2022; Rafique et al., 2024; Karata et al., 2023; Clarke-Jeffers et al., 2024). Clarke-Jeffers et al. (2024) made specific reference to the role of social identity theory (Tajfel, 1974), which relates to how people think of themselves as an individual or group member in relation to the presence or absence of shared characteristics of others. Identity appeared to be affected by those with Alopecia when it came to how individuals saw themselves, experiencing feelings of being different or not being the same person anymore when they look in the mirror, in relation to how they saw themselves in old photographs as well as how they perceived other people saw them due to their hair loss. Participants reported:

> *"sometimes I look at the old photographs and I cannot recognize me anymore.. (crying) I miss my eyelashes, I want everything back, as it was…sometimes I think even if the hair will grow back, I will never be the same person and the wound will always be there…"* (Barkauskaite et al., 2020, pg. 4).
>
> *"I cannot find myself when I look in the mirror, I am no longer there… Mike has gone …gone forever, wish I could be Mike again"* (Rafique et al.,, 2024, pg. 9).
>
> *"I guess hair is just part of your identity and you take it for granted that you've got hair on your head [...] it's a daily struggle looking in the mirror and not seeing anything and I think what made it worse*

> *was when I actually lost all my eyelashes and my eyebrows, and I couldn't look at myself"* (Clarke-Jeffers et al., ,2024, pg. 5).

Identity and appearance changes seem related to a perceived deviation from what society considers 'normal' or 'attractive'. Gender-based assumptions were mentioned in relation to males suffering less than females when experiencing Alopecia due to differing gender norms and expectations compared to females. There was also a reference to females being better able or more likely to conceal Alopecia than males. Moreover, females reported feeling unfeminine, less attractive, and not womanly anymore because of Alopecia, while similarly males reported feeling less masculine, not attractive, and weak.

> *"I get quite upset when I see myself bald. There is a reason monsters are portrayed bald. In Lord of the Rings when Gollum was a Hobbit he had hair when he turned evil – bald. Then of course there is Nosferatu, Voldemort, Trolls and Orcs"* (Davey et al., 2019, pg. 5).
>
> *"… society demands that [women] have hair and … you know, certain qualities and they look a certain way. I think men are much luckier"* (Zucchelli et al., 2022, pg. 7).
>
> *"With AA I absolutely felt less masculine… I felt like a worm… not attractive for sure"* (Zucchelli et al., 2022, pg. 8).
>
> *It has ruined my life to a certain degree as when a woman loses her hair, which is her crowning glory, it is devastating and one feels like dying* (Hunt et al., 2005, pg. 9).

Changes in identity and appearance related to concerns about public perceptions, misconceptions, and reactions to those with Alopecia. Several studies reported those with Alopecia felt they often experienced funny looks or were stared at or even received negative comments by members of the public. A lack of public understanding in relation to why someone may experience hair loss was also evident. Illness perceptions from society led to the misconception that Alopecia sufferers were likely to be experiencing a serious illness such as cancer before considering other causes for baldness such as Alopecia related hair loss. Participants reported:

> *"People never really look at me like a full human being sometimes. They always look at me like in a weird way, like, 'he doesn't have eyelashes and eyebrows, and he doesn't have hair"* (Aldhouse et al., 2020, pg. 8).
>
> *"I will remember it forever". The comment is quoted in the following quote: "what did you go and shave your hair like that dude, you look like a Mongolian?" This phrase will never leave my head because it was the first time I cried when someone insulted me so badly"* (Katara et al., 2023, pg. 5).
>
> *"I get embarrassed when people especially girls in my university stare at me…though they don't ask me what happened"* (Rafique et al, 2024, pg. 9).
>
> *"[My supervisor] noticed that I was wearing a wig, and she thought I had like some kind of chemo […]. I mean like it all came from good intentions. She wanted to care for me but then it's like 'oh yeah I didn't have chemo,' and I didn't want to be looked like a person who was really sick"* (Aldhouse et al., 2020, pg. 8).

Attempts to manage identity and appearance shifts often entailed concealment of hair loss, which led to a mixture of feelings with some feeling better as a result while others felt like a fraud by utilising a wig or make-up to alter themselves. Participants reported:

> *"Feeling like a fraud in relation to people's comments about how good her hair looks (whilst wearing a wig - other people were none the wiser that her hair was falling out).My self-esteem hasn't been great for years because it gets to the point that I hated looking at myself in the mirror cuz I felt like a fraud (wearing a wig)"*(Clarke-Jeffers et al., 2024, pg. 6).
>
> *"It's (wigs) given me a lot more confidence in just leaving the house and being in front of other people"* (Montgomery, et al 2017, pg. 4).

3. Alopecia is good at telling you what you can and can't do

Many studies found that functioning was affected not just psychologically but also in other domains such as social functioning (Hunt et al., 2005; Welsh et al, 2009; Montgomery et al., 2017; Rojoo et al, 2020; Aldhouse et al., 2020; Zucchelli et al., 2023; Rafique et al., 2024; Karata et al., 2023; Clarke-Jeffers et al., 2024). Social avoidance due to fears related to social rejection was found to impair relationships and activity engagement and led to those with Alopecia often living a limited lifestyle and experiencing social isolation.

Participants detailed not going out as often, missing social activities such as weddings, and engaging in fewer hobbies or sports:

> *"I guess AA makes you self-conscious in social setting. So, I find it hard to have conversation to new people. that fear of them asking what you look like things like that and the feeling you must explain them is quite difficult"* (Rojoo et al, 2020, pg. 5).
>
> *"I don't even know how I'd do if I didn't have to constantly [be] thinking about, [...] 'can I [do that activity] with my wig?" (*Aldhouse et al., 2020, pg. 8).
>
> *"I'd never go anywhere new or unfamiliar. I'd always ... if I was having a drink it'd be a drink after work where I work, you know? or I'd be like, go to a mate's house. I'd never to ... town, I'd never go somewhere where I'd feel uncomfortable"* (Zucchelli et al., 2022, pg. 8).
>
> *"My favourite hobby was swimming, I loved to swim but I no longer want to swim, I would rather read a book and watch TV. I feel more comfortable when I am at home with family"*(Rafique et al., 2024, pg. 9).

4. The impact of supportive or unsupportive responses

Support from family, friends, partners, or potential partners was evident, with greater social support from significant others found to lead to greater acceptance of Alopecia. Participants voiced the following in relation to positive interactions with family, friends, or partners:

> *"I personally have had a very great support from my husband, family, and all of my friends"* (Hunt et al., 2005, pg. 10).
>
> *"I got lots more support from my work friends than from anyone else really and that helped a lot"* (Welsh, 2009 et al., pg. 4).
>
> *My family was always around me, they supported me emotionally…my wife has been the biggest support for me during this period"* (Rafique et al., 2024, pg. 10).

Participants also detailed interactions with family, friends, or partners who were unsupportive and lacked understanding. Some studies indicated that Alopecia could lead to fears and challenges in the development and maintenance of intimate relationships. Overall, negative interactions with others often further compounded distress and isolation among those with Alopecia:

> *"Now I know the true colours of my friends, they think losing hair is a joke…they can't feel the pain the pain I am going through…I am better off without them, they don't deserve to be in my thoughts…my life"* (Rafique et al., 2024, pg. 10).
>
> *"I told a guy on my first date, never saw him again now I have learnt to wait and build a relationship"* (Fox, 2003, pg. 7).

Healthcare professionals seemed to hold similar social and cultural assumptions and discussions about hair as their patients face in society. A few studies reported those with Alopecia became distressed by the negative or unsupportive interactions with doctors and dermatologists, who, it appears, were more concerned with the physical disease, while often failing to consider the psychological impact. Participants voiced:

> *'The physicians have a way of minimizing patients' complaints. Another statement of the sort is that it's only a cosmetic condition'* (Fox, 2003, pg. 6).
>
> *"I was just told to wear a wig. "After all it's only your pride that's hurt," said one doctor* (Hunt et al, 2005, pg. 13).
>
> *"The consultant was totally obnoxious and made me cry – his attitude was, it's only hair"* (Davey et al., 2019, pg. 6).

Finally, several studies detailed the role of social support from others with lived experience of Alopecia; this tended to be in the form of in-person or online support groups. Generally, groups were reported to be positive, understanding, helpful, sought to normalise experiences, and provided emotional reassurance and helpful sources of practical information about managing hair loss. Participants who found them helpful stated:

> *"I think that was my lifesaver to meet other people like me because um yes I heard of alopecia, I didn't know anybody that had it [..] it's just been a lifesaver for me, an eye-opener as well to hear other people's stories what they're going through um and I didn't even realise that I didn't have hair in my nose or ears"* (Clarke-Jeffers et al., 2024, pg. 7).

> *"I think the [Alopecia UK] Facebook group has helped me a lot… because you're seeing, you know, a lot of other people going through exactly the same sort of things that you've been through..."* (Zucchelli et al, 2022 pg. 5).

> *"It feels more normal now I see others who look like me whereas before this group the only bald person I saw was me at home alone in front of a mirror"* (Iliffe et al., 2019, pg. 5).

However, in contrast, one study by Clarke-Jeffers et al. (2024) highlighted one drawback being a need for support groups to be more culturally diverse to support those from various ethnic backgrounds:

> *"There was a support group that I looked up myself, the only problem with that when I've looked into their website and looked at all the information they had, but there weren't any women of colour and that kinda put me off […] sometimes you just want to see people who look like you"* (Clarke-Jeffers et al., 2024, pg. 7).

1.8.3 SLR conclusion

Four main themes were identified in relation to the SLR question; *'What are the psychological and/or psychosocial experiences of Alopecia areata (including patchy, universalis, and totalis) among adults?'*. All four themes highlight the significant negative impact that Alopecia has on overall quality of life. The first theme, *'An Emotional rollercoaster,'* detailed the level of unpredictability and lack of control often experienced by those with Alopecia, along with a wide range of negative emotions, of which depression and anxiety were most frequent. Feelings of loss, grief, and bereavement were also frequently experienced. The second theme *'Who am I now and do I fit in"*, highlighted the impact that Alopecia has both on identity and appearance which had negative impacts on how those experiencing Alopecia saw themselves as well as how others in society perceived them. An expression of feeling less feminine or masculine due to hair loss situated Alopecia into wider gender norms or expectations within society of what is 'normal or accepted.' Societal assumptions such as cancer often being thought of as a rationale for hair loss before Alopecia highlight a lack of public awareness, further stigmatising those with Alopecia. The third theme, *'Alopecia is good at telling* *you what you can and can't do'*, evidenced the negative impact Alopecia can have on being in social settings with others and engaging in hobbies/activities. Finally, the fourth theme, '*The impact of supportive or unsupportive responses'*, demonstrated a mixture of supportive and unsupportive responses to Alopecia from family, friends, and either current or potential romantic partners. Healthcare professionals were also frequently found to be unsupportive, unsympathetic and dismissive. Finally, there was a sense that others with Alopecia tended to be more understanding and supportive about Alopecia via support groups, messaging forums, or social media and tended to make those with Alopecia feel more normal and understood. However, of note was a call for more diversity in relation to support groups going forward.

This SLR demonstrates the significant impact of Alopecia on the psychological and social functioning of adults which has clinical and future research implications. It demonstrates the need for further consideration to be given to the development of psychological interventions to mediate the negative emotional consequences of Alopecia, which at present are underdeveloped and have only begun to be researched in the UK. Given that engaging in social support groups has a positive impact, specifically peer support from others with lived experience of Alopecia, further research could seek to better understand the benefits of peer support, which in turn may also point to group-based psychological support being a worthwhile research endeavour. Further research could be conducted to further recognise the identity shifts that occur related to living with Alopecia. Health professionals should take the time to consider psychological support or the role of social support alongside possible referral to dermatology as a more standard part of their practice. Finally, research on wider societal understandings of hair loss could be of use in a bid to further educate those without Alopecia about Alopecia, likely reducing stigmatisation.

1.8.4 SLR critical reflection

To the best of my knowledge, this is the first systematic review that critically examined the psychological and/or psychosocial impacts of Alopecia Areata among adults from a qualitative perspective, making this SLR a valuable contribution to the current evidence base. A comprehensive search strategy was adopted for this SLR. A strength of this SLR is that the abstract and title screen was completed with a co-rater in a bid to reduce biases and any risk of errors in the screening process. However, this review is not without its limitations. There was variation when it came to the terminology and definitions utilised in papers to describe the psychological/psychosocial impact of AA. This had several implications; it affected how I defined these broad terms for the purposes of this review. Moreover, it made decisions around search terms more difficult, so search terms were kept open and broad as a result. Therefore, one recommendation is that moving forward, more consistency in relation to these terms should be sought in this field. It could be a limitation of this SLR, as variability regarding these terms could mean some studies did not come up through the final search for this SLR. Grey literature was not included in this SLR, which means literature such as dissertations and conference papers were not included. Therefore, a limitation may relate to my decision to exclude grey literature, which may mean valuable results have been missed (Paez, 2017).One of the included studies was mixed methods and for the purpose of this SLR only the qualitative data was explored; despite it being still considered of value to the SLR, there may be limitations to not appraising a study in its entirety. Due to a lack of time and resources, studies published in a non-English language were excluded from this study, so it is possible that my search strategy excluded potentially important literature. Similarly, the decision was made to exclude grey literature and theses, so it is again possible that this SLR missed some published qualitative studies on AA. Furthermore, the quality assessments also identified variation in the quality of the SLR studies included, particularly as the studies got older it became evident that they tended to meet less of CASPs quality checklist criteria. The findings from this review should therefore be considered with these limitations in mind.

1.9 Gaps in the literature

The literature review and SLR highlight the considerable negative impacts of Alopecia on QoL, social functioning, and psychological well-being. Yet medical professionals, e.g., GPs, and dermatologists, still often do not acknowledge the psychological impact of Alopecia on those who experience it, and access to psychological support for those with Alopecia is still often not considered.

Little has been done qualitatively to understand what helps or hinders those with Alopecia to cope with the psychological impacts of Alopecia, to support more useful interactions with medical professionals as well as possible interventions, psychological or otherwise.

There is some evidence in the literature that those with Alopecia report that medical professionals such as GPs and dermatologists minimise the negative impacts of Alopecia in their interactions with patients. Therefore, more in-depth exploration of what helps or hinders help-seeking (e.g., going to a professional for support) is needed, as well as what those with lived experience of Alopecia want professionals to know, do, and understand to make interactions as beneficial and supportive as they can be.

1.9.1 Rationale for the current research project

I have highlighted the significance of, and meanings attached to hair in wider society, the negative impact of Alopecia related hair loss on QoL and psychosocial well-being and functioning, which medical professionals often still fail to acknowledge, and the challenges and lack of satisfaction experienced by those with Alopecia when engaging with medical professionals. This was followed by a SLR of the literature focusing on the psychological and/or psychosocial impact specifically of AA (including patchy Alopecia, AU and AT) on adults from a qualitative perspective. The findings of the SLR reinforce the significant detrimental impacts of experiencing Alopecia on daily functioning and well-being, something medical professionals should consider further in their interactions with those who have Alopecia.

1.9.2 Aims and research questions

This study aimed to support medical professionals to better understand the impact of living with Alopecia on QoL, psychological well-being and identity, what helps or hinders coping with the psychological impact of Alopecia, and what individuals want from interactions with medical professionals around their Alopecia. Specifically, this study aimed to answer the following research questions:

1. What do medical professionals need to know about how living with Alopecia affects QoL, psychological well-being, and identity
2. What do Alopecia sufferers want medical professionals to understand about what helps or hinders them to cope with the psychological impact of Alopecia?
3. What affects help-seeking when deciding whether to seek professional support for Alopecia?
4. How do individuals experience interactions with medical professionals about their Alopecia (GPs or dermatologists)?

2. METHOD

2.1 Chapter overview

This chapter outlines the method chosen to investigate the research topic and questions. The study design is discussed, including a rationale for using semi-structured interviews and Reflexive thematic analysis. I highlight the recruitment process, participant information and reflect on ethical considerations relevant to this study. Finally, I discuss the data collection and analysis process and assess the quality of this study's methodology.

2.2 Design

2.2.1 Qualitative methodology

Qualitative research methodology aims to delineate, interpret, and comprehend human experiences, elucidating the significance these experiences hold for the participants involved (Kazdin, 2021). Willig (2013) argued that qualitative research explores the quality and texture of people's subjective experiences. Researchers utilise a qualitative methodology to focus on the meanings people attribute to events (Talyor & Ussher, 2001). This contrasts with quantitative approaches where the 'voice' of the individual or group tends to be hidden beneath statistics (Roberts, 2014).

2.2.2 Rationale for a qualitative design

A qualitative research design was deemed the most appropriate approach to address the study aims. The purpose was to capture and understand the meaning or sense-making of the impact Alopecia has on the participants, which is less quantifiable with numerical data.

2.2.3 Reflexive thematic analysis (RTA)

I selected RTA because it allows for flexibility around dataset composition and size and includes transparent guidelines to follow. Moreover, it considers the researcher's position and contribution as part of the process more explicitly than ordinary TA, and given I am an insider researcher, this felt important.

The method of qualitative analysis needs to be compatible with the epistemological position (Willig, 2013). Braun and Clarke (2006) reported that TA can be conducted from different epistemological positions (e.g., realist, social constructionist etc). RTA can align with a CR stance that the meanings individuals make from their experiences of reality are influenced by the context (language and culture) in which they are situated, as well as the limits and constraints of the world they exist in (Maxwell, 2012). From a CR perspective, RTA "provides access to situated, interpreted realities, not simple, decontextualised truths", which the researcher then interprets through the lens of their own cultural contexts or language (Braun & Clarke, 2022, p. 171). Interpretation is central to both a CR epistemology and RTA.

RTA is an interpretative approach to qualitative data analysis that facilitates the identification and analysis of patterns or themes in a data set (Braun & Clarke, 2022). It is considered a flexible approach that allows researchers to tailor the approach to their study needs (Willig, 2013; Braun & Clarke, 2022). RTA is a method of identifying and analysing patterns of meaning in a qualitative dataset (Braun & Clarke, 2022). RTA illustrates these patterns in detail with interpretations used to make sense of diverse subjects (Boyatzis, 1998). RTA can be used to analyse smaller and larger datasets as well as homogenous and heterogenous samples (Braun & Clarke, 2022).

RTA allows for an inductive approach, where "the analysis is located within, and coding and theme development are driven by, the data content" (Braun & Clarke, 2022, p. 10), or a deductive approach, which draws on codes shaped by pre-existing theories and/or literature (Crabtree & Miller, 1999; Boyatzis, 1998; Braun & Clarke, 2022). Coding of themes can be at semantic (explicit/surface meaning) or latent (implicit/interpretive) levels (Braun & Clarke, 2022). For this study, I chose to analyse primarily from an inductive 'bottom-up' or 'data-led' approach to allow fluid interpretation of the data with minimal pre-conceptions, and understanding that inductive, semantic and CR approaches tend to cluster together (Braun

& Clarke, 2022). In RTA analysis, I engaged in semantic level and latent level analysis/coding, utilising interpretation at all levels.

Braun and Clarke (2022) detail a transparent 6-stage process to do RTA. The stages include familiarising yourself with the data, coding, generating initial themes, developing and reviewing themes, redefining, defining and naming themes, and writing up. These phases are iterative, and analysis often involves moving bac and forth between them (Braun & Clarke, 2022).

To increase rigour regarding qualitative quality criteria, I kept a reflective diary, as I was aware that in Braun and Clarke's RTA, the researcher always impacts the analysis, and reflexivity makes RTA what it is. The reflexive approach to TA highlights my active role as a researcher in knowledge production (Braun & Clarke, 2022) which I felt strongly about as an insider researcher. RTA considers the reflection of the researcher’s interpretive analysis of the data conducted at the intersection of the dataset, the theoretical assumptions of the analysis, and the analytical skills/resources of the researcher (Braun & Clarke, 2022).

2.2.4 Strengths and weaknesses of RTA

According to Braun and Clarke (2022) RTA is relatively flexible. A strength of RTA is that it can be underpinned by a variety of ontological and epistemological positions, which lends itself to a wide range of research enquiries. RTA can be utilised with various analytical orientations such as inductive, deductive, sematic, or latent (Braun & Clarke, 2022). Another strength of RTA is that it can be used to analyse smaller and larger datasets as well as homogenous and heterogenous samples (Braun & Clarke, 2024). Finally, it allows for both ‘social and psychological explanations of the data’, in other words, thoughts, feelings, and behaviours in relation to a social context (Braun & Clarke, 2022, pg. 261).

Braun and Clarke (2022) discuss that one difficulty to be aware of with RTA is the concept of ‘analytic paralysis’, the notion that there is so much data to analyse and the meaning making process can feel overwhelming, especially for novices to RTA. Another challenge discussed by Finlay (2021) relates to the challenge of 'bad' RTA where themes are not sufficiently informative, clear, or distinctive or the process of obtaining themes lacks adequate reflexive transparency by the researcher. A further limitation Braun and Clarke (2024) put forward is the complexity of exact guidance for the more interpretive level of RTA; they argue it is a skill that comes with time.

2.3 Data collection

2.3.1 Semi-structured interviews

Semi-structured in-depth interviews are often utilised in qualitative research (DeJonckheere et al., 2019). Semi-structured interviews allow conversations to be guided rather than prescriptive (Walton et al., 2021). They explore participants' thoughts, feelings, and beliefs about a particular topic and can delve deeply into sensitive subjects (DeJonckheere et al., 2019). According to Aldridge (2016), semi-structured interviews also position the participant as an 'expert' of their experiences. Semi-structured interviews employ closed- and open-ended questions accompanied by why or how questions (Adams, 2015). Questions can be adapted and changed depending on the respondents' answers, and the interviewer can probe or seek clarification (Adams, 2015). However, they also have limitations, including being time-consuming (Adams, 2015). Nevertheless, it was believed to be the most appropriate data collection method.

2.3.2 Virtual Zoom interviews

Interviews were held over Zoom, meaning they were virtual and video based. Therefore, I reviewed the BPS Ethics guidelines for internet-mediated research to ensure I was aware of the key considerations, e.g., confidentiality, privacy, and social responsibility (Kaye et al.,2021, BPS). This method of interviewing was chosen because it meant that interested participants could get involved from anywhere in the UK (England, Scotland, Wales, or Northern Ireland) without considering any additional travel or cost. Another rationale for interviews via Zoom was that previous studies had commented on the sensitivity of the topic of alopecia, and therefore, it was hypothesised that participants might feel more at ease engaging in interviews in their own homes. Research suggests that virtual interviews can be positively perceived, increase accessibility, and can be conducted productively without substantially compromising on content or depth (Sturges et al., 2004; Irani, 2019; Gray et al., 2020). However, holding in mind that not all participants are competent with technology to the same level which is a potential disadvantage to doing virtual Zoom interviews, I provided a step-by-step guide on how to join and access Zoom to help ensure all participants had access to it and to mitigate anyone feeling apprehensive about using Zoom. In line with BPS (Pote et al., 2020, BPS) recommendations, I was also prepared to offer a tutorial to support participants to navigate Zoom if requested. However, as with any online mode of data collection, you can risk technological issues that may influence the information gathered (Walton, 2021). Nevertheless, the practical advantages outweighed the disadvantages for the purposes of this study.

2.3.3 Devising the interview schedule

I discussed possible semi-structured interview topic areas with my research supervisors and brainstormed possible interview questions based on the literature and research questions. Following some refinement, I sent an updated interview schedule to my supervisors, and feedback was gained from them. One of my supervisors is affiliated with Alopecia UK so she also shared and discussed it with their experts by experience (EbE) panel members and Alopecia UK's Research and Liaison Manager. This feedback was incorporated into the interview schedule. As I began interviewing, research participants were also asked for their feedback on the interview process to see whether anything else needed to be considered. This led to small changes in how I invited people to the interview and how I worded leaving additional time at the end of the interview to discuss the research topic or my own experiences with Alopecia in more detail rather than any changes to the actual questions themselves (See reflections, Appendix K). The interview schedule can be found in Appendix D.

2.4 Experts by Experience (EbE)/Professional Consultation

Initial research ideas: Before deciding what avenue of Alopecia research to go down, I sent out a brief survey online with a list of several topics they wished to gain feedback on. This survey was shared on social media and sent via one of my supervisors to their experts by experience (EbE) panel members and Alopecia UK's Research and Liaison Manager. It asked those with lived experience of Alopecia to give me their thoughts on which of the topics felt important or a priority to them. There was also a box for additional comments and considerations in case my ideas did not encompass what Alopecia suffers deemed important. Six individuals provided feedback via this online survey, which helped me narrow down my research focus to considering interactions those with lived experience of Alopecia have with professionals. This can be found in Appendix C.

Interview schedule, participant information sheet, and recruitment poster: Given one of my supervisors is affiliated with Alopecia UK, she also shared and discussed the interview schedule, participant information sheet, and recruitment poster with EbEpanel members at Alopecia UK and Alopecia UK's Research and Liaison Manager who provided me with additional feedback and minor suggested tweaks. This feedback is not contained in the appendix as it was minimal such as slight re-wordings in the information sheet and poster, but the suggestions were taken on board.

2.5 Participants

2.5.1 Inclusion and exclusion criteria

The inclusion and exclusion criteria are set out in Table 5. This study focused on adults' experiences, and therefore, an age limit of 18 years + was set. Participants were expected to be fluent in English as I did not have the resources to access interpreters. Participants were expected to reside in the UK in the hope they would have access to medical professionals such as GPs or dermatologists operating similarly from a UK-based healthcare system. However, I was aware of some variation being likely in the support offered by the region (e.g., England vs Scotland or Wales). Finally, this research focused specifically on types of Alopecia understood to have an autoimmune aetiology rather than those whose Alopecia had other aetiologies, as specific causes are likely to mediate the impact on experiences and psychological well-being (e.g., chemotherapy induced Alopecia).

Table 5: Participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
All genders.	Aged under 18 years.
Aged 18 years and over.	Not living in the UK.
Living in the UK.	Not fluent in English.
Fluent in English.	Diagnosed with a type of Alopecia that is not understood to have an autoimmune cause, e.g., Alopecia as a result of chemotherapy, pregnancy-related Alopecia, or due to trichotillomania.
Diagnosed with a type of Alopecia that is thought to have an autoimmune cause, e.g., Alopecia areata including patchy alopecia, Alopecia universalis or Alopecia totalis or else androgenetic Alopecia or scarring Alopecia.	

2.5.2 Participant recruitment

Purposive sampling was used to recruit participants for this study. This was deemed appropriate, as it enabled participants with suitable qualities to choose to participate (Etikan et al., 2016). According to Patton (2002), purposive sampling ensures that participants willing to take part were likely to hold experiences, beliefs, and understandings relevant to the research aims. Study recruitment posters seeking participants were advertised on social media accounts set up for this study, such as X (formally Twitter) and Instagram. One of my supervisors also sent research posters to Alopecia UK, who advertised the study on their website via their research page and shared it in their Alopecia Facebook group. The study recruitment poster can be found in Appendix E. Participant recruitment ran between August – December 2023. The anticipated sample size for this study was estimated at 20 participants. I reviewed several Alopecia studies which utilised either TA or

RTA to get a sense of sample size, studies included various sample sizes ranging from 10 to 18 to 95 participants (Davey et al., 2019; Zucchelli et al., 2022; Katara et al., 2023). An estimated number of 20 participants was decided based on consideration for previous research, researcher resource and Braun and Clarke's (2022) notion of no one right dataset size when engaging in qualitative research highlighted below.

Sample adequacy in qualitative inquiry pertains to the appropriateness of the sample composition and size and is an important consideration in evaluating the quality and trustworthiness of qualitative research. Fusch et al., (2015) argues in favour of the idea that there is 'no one-size-fits-all' method to reach data saturation' when undertaking qualitative research (Fusch et al., 2015). Moreover, Braun and Clarke (2021) state there is no simple way to take all data-related elements, e.g., richness or complexity, to determine the right size of the dataset, and as such recommend avoiding claims of 'saturation.' Arguably more fitting is Malterud et al., (2016)'s notion of 'information power' as a justification for sample size, in other words the more pertinent information a sample holds, the fewer participants are needed described as an alternative to data saturation in relation to RTA.

Thirty-one expressions of interest to participate in this study were received. One interested individual did not meet study criteria. Seven of the interested 31 did not respond to my email following initial expression of interest. Twenty-three individuals provided consent and engaged in interviews which deemed an adequate number of participants.

2.5.3 Participant demographics

The sample consisted of 23 participants: females (n=18), males (n=4), and other/self-identified (n=1). Participant ages ranged between 19-69 years old. The mean age was 36 (SD = 13.60). Participants identified as English, Welsh, Scottish, or Northern Irish (n=18), White other (n=3), Black Caribbean (n=1), and Indian (n=1). Participants reported the following types of Alopecia diagnosis: AA (n=3), AT (n=8), AU (n=7), AO (n=1), AGA (n=1), FFA (n=1), and Alopecia unspecified type (n=2). The age at which participants' Alopecia began/was diagnosed ranged between 5 years and 54 years. All 23 participants ticked ‘Yes’ to whether they had ever sought medical professional support for their Alopecia. Furthermore, 13 of the 23 specified they had seen a GP/doctor, and 14 of the 23 reported they had been referred to a dermatologist. Others reported they had also seen other professionals, such as a trichologist or a counsellor, in relation to their Alopecia. Participants were all given pseudonyms to preserve confidentiality and anonymity. A participant-by-participant breakdown table was not included to protect participant confidentiality.

2.6 Data collection procedure

Participants were recruited between August-December 2023. I shared the recruitment poster via social media (e.g., X and Instagram). The recruitment poster (Appendix E) and participant information sheet (Appendix H) were also shared via one of my research supervisors to Alopecia UK; they shared it online with their Facebook group and added the study to the research section of their website. Interested participants contacted me via email or social media in response to the recruitment calls. If I was contacted via social media, I asked participants for their email addresses to continue correspondence. An initial screening email assessed participants’ suitability for the study. Participants were then sent the information sheet and a consent form (Appendix H & I) to read and complete if they wanted to continue with an interview. The consent form, along with some demographic questions (Appendix D), was sent in the email as a link to Qualtrics, which was used to collect this information. I also expressed to interested participants that I was happy to answer any questions they may have had about the study or any of the information sent via email. If participants wanted to set up an interview, they were reminded to complete the information in Qualtrics, and then a convenient time to complete the research interview was agreed. I set up a Zoom appointment which was sent via email, and participants were also emailed the day before with a reminder. Interviews were all scheduled as 60-minute slots but lasted between approximately 40 minutes and 75 minutes.

At the start of the Zoom interview, participants were reminded of the aims of the research, information about data collection, re-asked about consent, and I talked about confidentiality. It was also explained that the interviews were being recorded to help me with transcription. Participants then were allowed to ask questions before we got started. Finally, participants were advised that if we had any technical issues with the Zoom link we could leave and then rejoin on the same link. One interview had to be rescheduled due to a participant having an internet connection/power outage issue due to bad weather. At the end, I explained the rough timeline and submission steps to participants and asked if they were happy for me to keep in touch regarding the study; all participants verbally consented to this and expressed they were looking forward to reading a copy of this study. They were also reminded about their right to withdraw and given the cut-off date for this, after which data analysis would have begun.

Furthermore, a slight change was made following interview number four; as an insider researcher, which participants were made aware of in my information sheet (*This research area holds a lot of importance and meaning to me. Therefore, transparency with potential participants is essential. I myself have lived experience of Alopecia since age 14.*), I noticed that participants often asked about my rationale for deciding to research this topic. I was mindful that sharing this at the beginning of the interview, prior to participants answering questions, could lead to my responses influencing what participants shared. Therefore, I decided to change this and say that I was happy to leave time for further questions about the broader research topic or my experiences with Alopecia toward the end, which everyone seemed happy with going forward.

2.7 Ethical considerations

The University of Hertfordshire Health, Science, Engineering Technology Ethics Committee granted ethical approval for this project; Protocol number: *LMS/PGR/UH/05424*. A copy of this ethical approval is attached in Appendix G. The Code of Human Research Ethics (British Psychological Society, 2021) was used to ensure the project adhered to ethical guidelines.

2.7.1 Internet mediated research

Given that interviews took place via Zoom, I reviewed the BPS Ethics guidelines for internet mediated research to ensure they were aware of the key considerations, e.g., confidentiality, privacy, and social responsibility (Kaye et al., 2021, BPS).

2.7.2 Informed consent

According to the BPS Code of Human Research Ethics (Oates et al., 2021, pg. 12, BPS) informed or valid consent relates to the researcher 'ensuring that every participant from whom data are gathered for the purposes of research consents freely and voluntarily to participation, having been given sufficient information to enable them to make an informed choice'. Therefore, a participant information sheet, with information about the study was shared with participants via email prior to their participation. This included key information about the study, the study eligibility criteria, their right to withdraw, the study procedure, information about the potential benefits and risks of taking part, and how participant information would be handled, including details about confidentiality. It also included details about dissemination. A screening email assessed participants' suitability for the study. In the screening, I went through the study criteria and consent form with participants, which was sent to them via Qualtrics, and obtained consent prior to their interview. All consent forms were downloaded, password protected and stored securely in line with the University's ethical guidelines, separate from participants' interview data.

2.7.3 Confidentiality/anonymity

According to the BPS Code of Human Research Ethics (Oates et al., 2021, BPS), the Data Protection Act (2018), states that "information obtained from and about a participant during an investigation is confidential unless otherwise agreed in advance" (Oates et al., 2021 pg. 21, BPS). Participants have a right to expect that information they provide will be treated confidentially and, if published remain anonymous or not be identifiable. The principles of confidentiality and anonymity were explained to participants in the information sheet provided to participants. I protected participants' confidentiality by using pseudonyms. I also ensured the data was stored securely and password-protected to protect confidentiality.

2.7.4 Right to withdraw

Participants were reminded of another important ethical principle: their right to withdraw from the study. This was outlined in the consent form on Qualtrics, and participants were reminded at the end of the interview. The latest date to withdraw from the study was stipulated as 26.01.24, as once data transcription began, data could not be removed from the analysis.

2.7.5 Risk of physical and psychological harm

It was hypothesised that some of the topics raised in the interview could potentially cause psychological distress for participants. Participants were asked personal and sensitive questions about their experiences of Alopecia. Therefore, participants were informed at the start of the interview that they could skip questions if they did not feel comfortable. Furthermore, with participant safety in mind, contact details of appropriate services in the event of any distress were included in the consent form. Participants were reminded about these at the end of the interview.

2.7.6 Compensation / remuneration

According to the BPS Code of Human Research Ethics (Oates et al., 2021, BPS), participants can be compensated for their time through a small payment or gift voucher. However, it is also important for researchers to hold an awareness of how this may impact participation and take steps to avoid coercion. Therefore, the decision was made to state that a raffle would be held for a Love2Shop voucher, which participants could opt in to take part in, but the amount it was for was not stated. The winning participant later found out this was for a Love2shop voucher worth £30.

2.8 Reflexivity

There is a dance that the researcher often engages in between the research process and the participants, describing multiple tensions about what to focus on throughout the research study (Finlay, 2008). Being aware of assumptions, prejudices, and biases is an important part of being a researcher, and I was even more mindful of this in my position as an insider researcher. To support my reflexivity, I discussed aspects of the research and my relationship to it with my research supervisors and in the Thematic analysis (TA) research methods workshops I attended. I also kept a reflective diary (Appendix K) and made notes after many of the research interviews, during my SLR, and throughout my RTA data analysis, documenting content that stood out, as well as my emotional responses and any curiosities

2.9 Data analysis

Descriptive statistics analysis was carried out via SPSS for demographics collected from all 23 participants with lived experience of Alopecia. Following this, RTA was employed as my data analysis method. The process of analysing the data followed the six phases outlined by Braun and Clarke (2022). To support my data analysis, the transcriptions were inputted into NVivo software. Below, I outline the six stages of RTA followed in line with Braun and Clarke (2022). These phases are iterative, and analysis often involves moving back and forth between them (Braun & Clarke, 2022).

Phase 1: Data familiarisation

Having conducted the interviews, I came to the analysis with some knowledge of the data. I utilised Zoom’s transcription function to support my transcription of all 23 interviews, this supported what Braun and Clarke call the ‘process of immersion’ (Braun & Clarke, 2022, pg. 35). It includes moving through several iterations of data familiarisation. I listened back to each interview, once with audio only whilst reviewing and tidying up the transcriptions, and then reread each participant’s transcript without audio, this review was done in a more ‘active way’ (Braun & Clarke, 2006), they were then moved into NVivo. I then noted down some initial thoughts.

Phase 2: Data coding

Following familiarisation, I began to code each transcript in turn. As Braun and Clarke (2022) note, this marked a move to a more ‘systematic’ process. The researcher used NVivo to code all transcripts, coding what was of interest or important in relation to the research questions. I took an inductive stance as much as possible, choosing to be led by the data instead of the literature (Braun & Clarke, 2022). But I was aware of my own experiences, meaning I already held a higher level of knowledge than average without deep diving into the literature. Both ‘semantic’ (explicit) and ‘latent’ (interpretative) codes were utilised (Braun & Clarke, 2022, pg. 35). The researcher also included some surrounding data not to lose the wider context (Bryman, 1998), which my supervisors reminded me was important. I tried to code both a diversity of perspectives and the meaning from the interviews (Braun & Clarke, 2022). Excerpts from several coded transcripts can be found in Appendix J. Given the amount of data collected, I stopped after the first 10-11 interviews to review, combine, and delete duplicate codes in NVivo before continuing.

Phase 3: Initial theme generation

In this phase of the analysis, I started to identify shared patterns of meaning across the dataset. I formed initial ‘clusters of codes that appeared to share a core idea’ (Appendix L) and then constructed initial themes and subthemes, which were an initial representation of the patterns I saw in the dataset (Appendix M for Thematic map) (Braun & Clarke, 2022, pg.35). Following this, I began to consider the data in light of the research-related questions.

Phase 4: Developing and reviewing themes

In this phase, I sought to ‘assess the fit’ of initial themes and/or subthemes to the data (Braun & Clarke, 2022, pg. 35). This development and review phase aimed to determine whether themes made sense in relation to coded extracts as well as the full dataset. I wanted to ensure that each theme communicated an important pattern of meaning in relation to the dataset and wider research questions. The research held in mind that this may lead to themes collapsing together, being split into other themes, or alternatively, if appropriate, staying the same (Braun & Clarke, 2022). See Appendix M for Thematic map

Phase 5: Refining, defining and naming themes

This phase was concerned with ‘fine turning’ themes to ensure they were clear (Braun & Clarke, 2022, pg. 36). A synopsis of each theme was written, and data extracts were chosen to support the themes. This phase resulted in the final analysis, represented on the thematic map in Appendix M and in the results chapter below.

Phase 6: Writing pp RTA

The final stage of reflexive TA is writing descriptions of each theme, which, according to Braun and Clarke (2022), seeks to ‘weave analytic narrative and data extracts to tell the reader a meaningful narrative about the dataset’ that also answers your research questions (Braun & Clarke, 2022, pg. 36).

3. RESULTS

3.1 Chapter overview

In this chapter, I present the results of the reflexive thematic analysis. In line with a critical realist epistemology, the results are my interpretation of participants' experiences of Alopecia influenced by my own interacting experiences and contexts. Three main themes were developed in relation to what medical professionals need to know to better support those with lived experiences of Alopecia. See Table 6 below.

Table 6: RTA List of Themes and Subthemes

	Theme	**Subtheme**
1.	Navigating Alopecia: A rollercoaster of change	Identity and hair
		Emotional and physical unpredictability
2.	Surviving Alopecia: With or without you	A more limited existence
		Coping: There is more to contend with
		Sometimes, you'll get it, but you'll never fully understand
		The power of shared experience
3.	Understanding patient-professional relationships	To seek help or not to seek help
		Professional interactions: A mixed bag that could be improved

3.2 Theme 1: Navigating Alopecia: A rollercoaster of change

The first theme captures the diverse range of changes, those with Alopecia often go through, from fluctuations or shifts in identity to experiencing a wide range of negative emotions, to living with a sense of unpredictability and lack of control over their hair loss and regrowth. This theme encompasses two subthemes.

3.2.1 Subtheme 1: Identity & hair

One of the first changes detailed in the rollercoaster of change theme relates to identity and hair. Some participants voiced how hair was integral to their identity and thus was a characteristic used to describe themselves or used by others to describe them. Hair is important in society, and therefore, due to expectations and understandings of the wider societal meanings attached to hair, participants highlighted how they were defined, identified, or discussed in relation to their hair. Phoebe discusses how often others in society refer to or define people by their hair. She also goes on to comment on how even technology, her iPhone, viewed her differently because of her hair loss:

> *Phoebe: "I just feel like you almost completely lose your identity, because even little things like you'll notice at work and things people describe people by their hair, they'll say, oh, the girl with the brown hair there or the girl with the red hair or, you know… or when my Alopecia started, I couldn't get into my bank account because it used my face ID. My ID must have changed so much, you know cos I had quite dark features. I had dark eyelashes, dark eyebrows, dark hair. So then when I was trying to get into my phone using my face ID, I was like ohh it's not working because my face looks so different and then my phone wouldn't work. I don't know if you have an iPhone, but it has little circles of different people's faces, and I had like a selection of pictures of me before Alopecia. That's obviously lumped me into that group as a person and then all my other pictures with my Alopecia, it's lumped me into another person".*

Simon expressed how he was known by others before his Alopecia as the guy with the hair and how he then saw his hair as a big part of himself and his identity:

> Simon: "*So I had that long hair like in my late twenties, thirties, early forties, and so I was always quite defined by my hair. But people would be like Oh, yeah, the guy with the hair, you know. That's the way that I saw myself ……. so yeah, my hair is or was a massive part for me so not having it, it's definitely been a change and transition".*

In contrast to what Phoebe and Simon described, where hair was a defining feature of their identities, others talked about viewing their identity as being more than their hair and how losing their hair does not define who they are. These participants described other ways of defining themselves such as in relation to their hobbies or interests. David highlights how sports, specifically running was a big part of who he was in terms of his identity formation and as a result felt his hair loss did not affect his ability to run as one of the fastest in his school:

> David*:"....it always helps that I've always been really athletic, and I was really good at sports. So, I was on the track or running team track in school and I was one of the fastest kids in the school. So, I guess my framing was I'm not any slower or anything or any less good at sports because I don't have hair, I'm still the same and so it doesn't matter….Everyone knew that I was, really fast….And , they weren't gonna think I was any less good at it because I didn't have hair or anything. It was still something that, I guess, is a positive trait for me".*

Alison pointed out that she could express her identity and who she is in other ways and does not need her hair to do that:

> Alison: *"It's definitely impacted the way I think people perceive me, but I don't think that my own perception of myself now is impacted. I think my identity, I can express that in many ways. It doesn't have to, or I don't have to have hair…"*

In relation to changes in identity, some participants felt their hair loss had led to a sense of no longer feeling or seeing a familiar version of themselves in the mirror but rather someone different. Kate described her experiences of Alopecia as an identity shift:

> Kate: *"...I've got to put like a wig on and I've got to get that ready and it doesn't look like me and so you're constantly kind of looking at yourself in the mirror being like, oh that's not quite who I am. So, I guess it's this constant feeling of not feeling like you look like yourself as well, that I think has been really, really difficult...and very much an identity shift…"*

Participants also described feelings of loss or that a part of themselves was missing, and how not having hair led to feelings of a loss of or change in identity, as described by Leah below:

> Leah: *"There's a sense of no longer feeling like myself. I feel as though I've completely and actually lost who I am when I look in the mirror... without my hair on it's not me that I see, it's somebody else……"*

Participants also voiced how hair loss can be influenced by culture, as a result of certain hair practices and, in turn, how this may impact or change their ability to express their cultural identity. Hair in Black Caribbean and Indian culture holds meaning and is an expression of beauty or health, this can be negatively impacted by experiencing Alopecia. Some participants also pointed out how in the Western world, wigs are less accepted compared to in other cultures where regularly changing hair is part and parcel of cultural expression. Niamh talks about an interaction with someone from another culture who she felt did not understand why Niamh was struggling with the idea of having to wear a wig:

> Niamh: *"….if you come from a culture where covering your hair or wearing wigs is what most people do, it's quite difficult to understand why that (wig wearing) would be a big deal to somebody else".*

Sienna discussed how in Black Caribbean culture hair is a symbol of beauty which is important particularly to women, and how having Alopecia can therefore affect your sense of cultural identity:

> Sienna: *"…it's just to kind of once again highlight the cultural side of things, race, ethnicity, all of that stuff and how things are received or felt differently across cultures, I think. women and hair across cultures, it's seen as for the most part, part of their beauty or what not. But what that can mean culturally as well and think to the identity."*

Gina pointed out the impact of Alopecia-related hair loss in Indian culture where luscious long thick hair is a symbol of health and almost expected of South Asian women:

> Gina: *"…in South Asian culture and the importance of long, luscious hair and even if you have short hair, it's something that is a bit more like ohh, you don't have really, sort of, thick healthy hair…."*

3.2.2. Subtheme 2: Emotional and physical unpredictability

Moving from changes relating to how we perceive ourselves or how we are perceived by others in society, participants expressed the emotional and physical changes they experienced. Participants described the rollercoaster of generally negative emotions e.g., depression, anxiety, feeling self-conscious, issues with confidence, feelings of loneliness, as well as feelings of loss or bereavement, while also feeling guilty or bad for being upset about their hair loss. Many participants experienced depression and anxiety due to Alopecia;

sometimes, this was formally diagnosed, other times, it was not, and for some, medication was offered to manage these difficult emotions. Leah shared about her experiences with depression and anxiety due to Alopecia to highlight this:

> Leah*:" I have had severe anxiety and depression for as long as I can remember, but only sought diagnosis in my 20s…I was bullied at school for my hair loss and for looking different. I've never really felt as though I fit in, and the mood impacts that has on me daily are huge. I have tried lots of different antidepressants and anti-anxiety medication, but nothing touches the root of the problem. So, living with chronic Anxiety and depression is a daily battle. It's a decision to get up in the morning every day".*

Many participants detailed periods of feeling self-conscious about their appearance, here Ruby describes how her experiences with Alopecia made her self-conscious and how difficult this was:

> Ruby: *"…obviously again on like the mental side of things. I mean, being a young person in this world is hard enough in terms of people's body image and feeling self-conscious. But being a young person with Alopecia, in this world ... like I respect anyone who's gone through Alopecia, honestly, because it is such a difficult thing, and especially because of the kind of uncontrollable nature of it…."*

Similarly, Kevin described how his Alopecia made him feel self-conscious and it also negatively affected his confidence:

> Kevin: *"I'm just very self-conscious about it. Yeah, that kind of sums up being very self-conscious and affecting my confidence…."*

Below Kate details how Alopecia affected her self-confidence to the point that it made her feel as if she should not be going out:

> Kate: *"…I think I definitely still withdraw myself, don't really do as much as what I would do. It's a confidence thing, I think. I think I've always been quite a confident person, but now that this has happened, now that Alopecia has happened, it does kind of make you feel maybe like you shouldn't be going out…."*

Aaron described how his confidence was impacted by Alopecia especially when he would look in the mirror and see himself bald or when he would look back at old pictures from when he had hair:

> Aaron: *"I would say confidence is probably the biggest thing. Just in general, let's say specific to something, I would just say my confidence a little bit, and I guess when I'm looking in the mirror, I'm looking at pictures, it's that, so I don't know if the word is self-doubt …."*

Several participants described Alopecia as a lonely condition or a lonely journey to go through. Ruth stated the following to demonstrate this:

> Ruth: *"It's quite a lonely journey, isn't it?"*

Similarly, Kaitlyn described her experiences of Alopecia as a lonely condition:

> Kaitlyn: *"It's a very lonely condition, that's the only way I can describe it and I think that might be what affects people more…I think there's not enough support in that sense to make it whatever the opposite of lonely is like yeah"*.

Experiences of Alopecia-related hair loss was voiced by participants as a bereavement or loss, and there was a sense that participants needed to grieve the loss of their hair or the person they were before they were affected by Alopecia. This is highlighted in the quotes below by Ruth and Gina who talk about Alopecia as a bereavement and there being a sense of loss of the person you were before Alopecia:

> Ruth: "… *It is like a bereavement I think Alopecia I feel like I'm going through another loss with my hair…I feel like I can allow myself to grieve and feel a bit compassionate for the person I am who is going through this…."*

> Gina: *"…I wanna not feel like this, but I don't think my identity has fully accepted it, if that makes sense. I'm still kind of grieving my old person…"*

Participants also described a great sense of guilt for feeling bad or upset about Alopecia, a condition often referred to as 'cosmetic' rather than something that makes you ill such as cancer, leading them to question whether it was acceptable to feel negative emotions because it could be worse. Sienna describes the guilt for complaining about her Alopecia while also stating that although it may not be life-threatening, it is nevertheless traumatic:

> Sienna: *"…I had felt at first, I felt quite guilty about complaining about this cos it's not as if I'm a cancer patient who's going through chemotherapy that's caused them to lose their hair, you know, so kind of feeling like, oh, it could be worse. But like how dare I belittle my trauma. It's still trauma,*

> *right? It's still something, so just having to be able to explain to them, there's also that battle too, at least for me, there was that battle of war. Well, I mean, it's not lethal. It's not life threatening. So how dare I be sad? But also yes, like it can be sad and just yeah, just kind of naming that as well".*

In addition to the identity changes and psychological impacts of Alopecia, participants discussed how Alopecia can lead to feelings of uncertainty and loss of control due to the unpredictability of Alopecia, which symbolises further changes, adding to the burden of the condition. Participants described a strong sense of uncertainty and loss of control that can further exacerbate negative experiences already felt due to the unpredictable nature of people's hair going through cycles of falling out and growing back. Below Meave highlighted the negative impact of the unpredictability of living with Alopecia:

> Meave: *"...I think for me being bald and having bald spots, I don't find upsetting, and I'm not self-conscious about itself. For me, the thing that does sometimes affect me psychologically is the unpredictableness of it, because I don't know when it's coming. I don't know what triggers it. I don't know if it's something I can help or control it or have any sort of effect on…."*

Similarly, Leah discussed the uncertainty that comes with living with an auto-immune condition such as Alopecia:

> Leah: *"…the uncertainty that you live with a chronic, relapsing remitting autoimmune condition, you don't know any point in your life when your hair's going to fall out or when it's going to grow back and that's a huge psychological burden".*

3.3 Theme 2: Surviving Alopecia: With or without you

The second theme describes various ways people are affected by, manage, and cope with Alopecia. It underscores the profound social impact of Alopecia and experiences of increased isolation, e.g., less socialising and fewer hobbies/activities. This theme then moves to capture things participants detailed that impact their ability to cope with their Alopecia or the additional things people need to consider. Broadly, coping includes practical coping strategies (e.g., wigs, scarves, wearing hats, microblading, or checking on

Alopecia) and internal coping strategies (e.g., using humour or working on mindset). This theme explored social support from family, friends or partners and is broken down into supportive and/or unsupportive others. Finally, this theme captures the positive and powerful value of social support, specifically from others with lived experience of Alopecia who participants reported tended to understand and normalise Alopecia experiences better than anyone else could. This theme encompasses four subthemes.

3.3.1 Subtheme 1: A more limited existence

This subtheme delves into the general decrease in social interactions, for example, being with friends, and highlights specific instances where activities, events, or hobbies have been adversely affected by Alopecia, such as swimming. Ciara discusses how she socialises with others a lot less due to her Alopecia:

> Ciara: *"You know, I don't socialise really at all. I've got a friend that I meet in town, but that's all, so someone from work that knows all about it (Alopecia) anyway".*

Similarly, Eva highlights how since her Alopecia she is less social generally, enjoys socialising less, and when she does socialise may drink to feel less self-conscious around others:

> Eva: *"…but obviously we're going in situations we feel self-conscious and it's a social situation and there's alcohol involved. You drink more things like that. I mean that's a very loose connection, but you know there's just that kind of to feel a bit more comfortable so, I think there's that. I also haven't socialised as much or haven't enjoyed socialising as much, going out with my core friends as much as I had done……It could be COVID whatever…. But Alopecia definitely hasn't helped…"*

Participants also provided examples of the hobbies, activities, or events that Alopecia has affected or the things they are either more reluctant to do or have stopped altogether because of their Alopecia. Below Harper talks about how her Alopecia has affected her ability to go swimming in the UK:

> Harper: *"Probably the biggest thing is I always have to think about what I'm going to do in terms of activities, so I don't think I've been swimming in this country, probably twice since I've had Alopecia, I've had it for 13 years…"*

Similarly, Kevin highlighted how his Alopecia made him more reluctant to attend formal suit and tie events where he felt he couldn't hide his Alopecia:

> Kevin: *"...I didn't wanna go out. I remember my dad had, a big corporate event, but he wanted to go to and he was able to bring a guest and he picked me to take, which I hated so much, because obviously it was like a suit and tie then I couldn't wear a hat or anything...But that was, the only time I actually went out without, my comfort of, like, the hat or hood and everything. So that time was really stressful, really affected my confidence..."*

3.3.2 Subtheme 2: Coping: There is more to contend with

Moving to how people cope with Alopecia, there was a sense that participants have more to contend with to survive on a daily basis as a result of their Alopecia. Some participants detailed how they camouflage their Alopecia, either with a wig, a hat, or a scarf, or procedures such as microblading and how these things are important to them which implies more thinking, organising and planning by those with Alopecia. Harper explains below how wearing her wig helps her manage and almost forget about her Alopecia:

> Harper*: "...I don't know how I cope. I suppose it's covering it up. Here's how I cope with it, when I've got my wig on, I can sort of forget about it."*

For Simon, even though other people may have known about his Alopecia, he felt better wearing a hat:

> Simon: *"When I work now, I wear a hat pretty much every day at work now, not because I have to. Everyone knows that I've got Alopecia and I've got a bald head, but I just wanna wear a hat. It just makes me feel bit better".*

Ruth described buying scarves to cover her Alopecia as she felt they suited her better than hats:

> Ruth: *"One very practical thing is I think I feel I'm lucky that I feel like I look okay in scarves, and so that's been a plus for me, you know.....I have so many of these, kind of every time I see a scarf I can buy it. Yeah, that's helped me".*

For Phoebe, losing her eyebrows made her realise their importance to her appearance, and using microblading or eyebrow transfers helped her manage her Alopecia, particularly when going out:

> *Phoebe: "…I did get microblading on my eyebrows so that I've got, you know, eyebrows there and which again, I would have day-to-day. And then if I was going out somewhere more fancy or something? I would put my transfers on and like fake eyelashes and things like that, and, but yeah, I'd say they're really important because I just think I didn't realise till I lost my eyebrows how much your eyebrows actually kind of shape your face…"*

Participants shared various things they would do to check their hair loss which in the context of having more to contend implies more effort and energy by those with Alopecia to ensure hair is in place or to check whether it is growing or falling out, likely using both mental and physical energy. For Ruth, this was checking to make sure her hair was still in place; for Kevin, this checking was about monitoring progress with photos:

> Ruth: *"…The first thing I do when I go indoors from being outside is try and look in a mirror. I always carried for the hand mirror, and I try and sort out my fringe. And I still, before I go anywhere, I still have a little mirror that's you know".*

> Kevin: *"…I tried to take a picture of it every day so I could monitor its progress, and obviously, if I see it's getting better, I feel better about it…."*

People highlighted the role of humour and how it helped to support them on their Alopecia journey, nevertheless it is another thing those with Alopecia consider. Simon talks about how in an example of gallows humour his friends personalised his bald patch and named it 'Barry' which for him made checking on this Alopecia patch easier on nights out:

> Simon: *"…And the good thing about friends is that they know how to deal with a situation…How can I put it… a bit like gallows humour, if you like. They'll bring you back to Earth and put you in perspective and try and try to make things easier to deal with. And that's why we named him Barry, that was my mates. I think they named him Barry just so they didn't use the word, bald patch, or Alopecia… We'd be on a night out and I'd be like, could you just check Barry for me…"*

Kaitlyn also described using humour to manage her Alopecia in interactions with other people:

> Kaitlyn: *"…Whereas like with Alopecia it's sort of like, it makes me funny because I have a very dark sense of humour. I say stuff and I've had people actually tell me that they found it offensive. People without Alopecia have told me that making jokes about like if it's windy and I'm with somebody, I'm like Ohh, find me a hat before my hair blows away…"*

Some participants described how they became more focused on mindset and engaged in things such as mindfulness, meditation, or therapy. While therapy was not necessarily specifically for their Alopecia some participants sought to increase their awareness of their thoughts and feelings related to their Alopecia due to the negative impacts it had on their well-being and quality of life. Ruby explained how she was more aware of her mindset while experiencing Alopecia and thought back to her previous experiences of CBT, which she felt helped her approach it more positively:

> Ruby: *"...so a lot of the things with like mindset and stuff. I've always had an interest in that. So, I think in that sense, I know a lot better how to kind of manage. I also did cognitive behavioural therapy when I was younger. So, I know that thinking in a certain way will lead you to feel a certain way and that will rapidly cycle. So, I think for me personally it's been having that knowledge of how your psychology kind of can affect like how you feel about things".*

Similarly, Alison spoke about how she focused on spirituality, meditation and mindfulness which supported her to have a more positive outlook on her Alopecia:

> Alison: *"... I think more generally kind of broader learnings of life and like spirituality and meditation and mindfulness and these kind of wider understandings of like what humanity is, what being a human is and stuff like that. It's kind of really took me away from that space of aesthetics and like what something looks like as opposed to going more deeper and being more focused on like the character of a person, their qualities and stuff like that".*

3.3.3 Subtheme 3: Sometimes, you'll get it, but you'll never fully understand

This subtheme denotes experiences of being supported or feeling misunderstood by important others. Firstly, participants discussed times when others important to them, such as family members, friends, or partners, have been supportive or understanding of their experiences. Kaitlyn provided an example of when a family member, her nan was supportive and understanding of her Alopecia:

> Kaitlyn: *"... My nan, she was the most supportive because she'd had a brain operation, so she'd had to have all of her head shaved. So, she sort of was the one that was like, it's your choice. Like if you wanna be totally bald, be totally bald. If you wanna walk around with three hairs, walk around with three hairs. If you want a wig, wear a wig like...."*

Harper highlighted supportive friends in her life who she feels understand and agree that Alopecia can be awful:

> *Harper: "…probably my closest friends are, you know, they still will say to me just it is shit. It is, it's horrible…"*

This sentiment was echoed by Chloe who stated:

> Chloe: *"…and I think also my best friend. I don't really know how it happened, but like we joke about it now, which does make me feel so much more comfortable about it…."*

Niamh mentioned the following in relation to the benefit of a supportive partner, in this example she discusses her husband and how he understands that with Alopecia even doing simple things can be hard:

> Niamh*: "My husband has been amazing through it. I mean, he's never questioned any decisions I ever make, or what I choose to do which that's just having that, and he does now, maybe not the beginning, but he does now understand, like just sometimes just doing, the simplest of things is hard. It's taken a few arguments, few tears to get there. But that's probably helped just knowing that he's there..."*

In contrast to the positive or supportive experiences described above, some participants also detailed examples of times when they felt misunderstood or when those close to them did not always understand them or the impact of Alopecia on their life. Niamh discussed below an example of when her mom has struggled to know what to say or do, and this has strained their relationship:

> Niamh: *"…the relationship with my mom has been difficult, strained, and I find myself…. My mom has not, she's not been unsupportive, that's not fair, but she obviously struggles to know what to say and what to do. So sometimes she does the wrong thing. I'm not particularly capable of telling her that she's done the wrong thing".*

Similarly, Kendall highlighted when she hasn't felt her partner, or her mother have understood the effect of Alopecia on her:

> Kendall: *"…They really don't understand and sometimes I know that, even like I said, my partner or my mum and they look at me and they're like, it's okay. It's not okay, you know, it's not okay for me. I'm telling you, it's not okay…"*

3.3.4 Subtheme 4: The power of shared experience

Although support from family, friends, and/or partners was a mixture of supportive or unsupportive, some participants detailed examples of support that came explicitly from those with lived or shared experiences of Alopecia. This was experienced as a more consistently positive source of support and there was a powerful sense of being accepted in shared experiences. Support either came from the charity Alopecia UK's online Facebook group or from an in-person support group or Individuals with Alopecia via Instagram. There was a sense that this helped to combat the sense of loneliness felt by those with Alopecia in the first theme. Simon spoke about his experience of being able to support someone else via Alopecia UK's online Facebook group and states how this platform is a game changer in terms of support:

> Simon*: "…There was a guy the other day, and he was told, I can't remember if it was his eyebrows or eyelashes that he was talking about and both of mine, my eyelashes…. they all just went, and it looked… it just looked really weird. But they come back relatively quickly, not as thick in quantity but they come back full to me… So, you know the fact that I could say to him that might is obviously, it's an individual thing but mine went and then they just seem to grow really quickly, whereas nothing else has. I could offer that little bit of support and people have done that to me as well. You know, when you've when you shared stuff and that's a game changer. Really, it's a game changer…it's great when someone that you don't know can tell you something positive that you can hold onto..."*

Similarly, Harper details how her experience of utilising one of Alopecia UK's in-person groups was life-changing due to the power of shared experiences of wig wearing:

> Harper: *"It's kind of was life changing because I remember the first meeting was quite intimidating because I think all of us, apart from our group leader, all of us wearing wigs. But I remember at one point somebody just took their wig off and I was like ohh like that's weird. But then six months down the line, I was the person doing that. You know, somebody asked me about my wig and what it was like inside. So, I just took it off. I wouldn't have done that anywhere else probably".*

Participants also expressed how connecting with others that have Alopecia via Instagram was helpful. Both Zelda and Eve discuss the benefits of linking with the Alopecia community online:

> Zelda: *"Straight away, just the community on Instagram. Like there's too many people that I've met that have Alopecia or you know, like the child or somebody has Alopecia and some of the girls that I've met on there have become real friends, there's been events that have been surrounding Alopecia, where it's just like a whole new group of friends that you probably wouldn't have ever met had this particular thing not brought you together. I think there's always somebody on there that's like, going through a similar emotion that day or has tips and tricks and is reviewing products and all of that and I think that has been a massive, massive positive impact on having Alopecia for me".*
>
> Eve: *"I guess kind of, I watch Alopecia UK, Instagram and kind of seen all of those stories and things like that and, because it's obviously when I was 15, I don't even know if Instagram was or maybe it was just starting, but social media wasn't much there and I didn't really connect with anything else, whereas now, that's been helpful to see kind of other people's journeys etc. and how also positive other people can be…."*

3.4 Theme 3: Understanding patient-professional relationships

This theme captures the help-seeking decision-making of those with Alopecia and the factors influencing people's decisions to seek support. It also explores interactions with a range of professionals, mainly medical and some non-medical, including GPs, dermatologists, trichologists, wig professionals, etc. These have been described as a mixture of positive and negative experiences or a mixed bag. Participants also detailed various things they felt professionals may want to consider in their patient interactions going forward to make these interactions more beneficial for those with alopecia. This theme encompasses two subthemes.

3.4.1 Subtheme 1: To seek help or not to seek help

Here, some of the factors that may influence people to seek help and support or choose not to were spoken about. For example, experiences with GPs, access to dermatology, seeing a trichologist, exploring the internet, and discussing things with family were all mentioned as factors that influenced decisions relating to seeking further support for Alopecia. Satisfaction levels with experiences with medical professionals also appear to impact decision-making around whether people decide to work with NHS or private medical professionals. Gemma highlights how her experiences with a GP acted as a factor that influenced her help-seeking decisions. She expressed that in a consultation a GP voiced there was nothing they could do, there was also a general sense that her past experiences of bringing up Alopecia led to a negative response by professionals which in turn led to her deciding not to bring up her Alopecia or seek support:

> Gemma: "*my doctor is all perfectly nice, but it's got to the stage now where, if I go to the doctor's I don't even mention the Alopecia, you know, I'm so conditioned to not bring it up as a subject because, you know not, let say, a negative reaction. But more there's nothing we can do all these years down the line. So, I think, what's the point in even mentioning it…"*

For Sienna, it appears there were multiple things that factored into her decision-making around seeking support for Alopecia including discussions with family members who had experienced hair loss themselves or others, such as a trichologist, as well as looking online. For Sienna this supported her positively to access what she felt would support her with her Alopecia:

> Sienna*: "…just having conversations with my family experienced similar things. So yeah, just that and then the actual healthcare professionals and trichologists. The information that they've shared with me has also impacted it. Before that it was just talking to family and Googling, looking up on the Internet, I know what's out there and reading research on the treatment that I'm having and stuff like that".*

3.4.2 Subtheme 2: Professional interactions: A mixed bag that could be improved

This subtheme explores how interactions with professionals were essentially a mixed bag filled with both positive and negative experiences, with room for improvement. Some participants discussed experiences where professionals have been supportive, sympathetic, and helpful, allowing patients the time they need in consultations. Simon detailed his positive interactions with an NHS GP. He highlighted how the GP gave him time and appeared to know someone himself with lived experience of Alopecia and as a result appeared more understanding of what Simon was going through:

> Simon: *"…we probably get half an hour chat about someone that he knew about the information that he had and the knowledge that he had which again wasn't a lot, but he could offer me a bit of reassurance if you like. Even though I'd experienced Alopecia …But I do think there is definitely still a long way to go, because not everyone's like that, you know. Maybe if I've seen a different GP, they might have been or they might not have been to understand…."*

Ruth voiced a positive experience seeing an NHS dermatologist, stating the dermatologist she saw was sympathetic and gave her time:

> Ruth: *"…I went to see another dermatologist. I think she was more like a proper dermatologist, and she was so different, she was so sympathetic. She, I mean, I don't know if it's because she was a woman or just a nice person. She just gave me time…".*

Both Harper and Sienna had positive experiences with professionals they opted to see privately:

> Harper: *"I was in such a state my mum paid for me to see a private dermatologist. Who was lovely, really, really nice and totally honest and did blood tests. Explained everything and said you know, well, we're looking for iron, thyroid, anything abnormal. Depending on what that, then we'll look at the next steps…"*
>
> Sienna: *"Actually, the NHS have been helpful, which is that I have had good experiences. I mean wait lists, but you know, but I have had good experiences from services and also, I accessed some private support as well, so those trichologists they've been incredibly supportive as well…"*

Harlow praised the support of other types of professionals such as those who have supported them with wigs which provided a sense of reassurance:

> Harlow*: "I mean, I think (wig supplier) in terms of the kind of the support they give me when I go and get a wig and the first time I went, they, kind of held my hand through the whole process and kind of reassured me that it was going to be okay".*

In contrast, some individuals with Alopecia have found professionals to be dismissive, leaving patients feeling unheard, unseen, or invalidated. Ciara detailed below how the GP she saw for her Alopecia was not understanding and appears to have not even given her any information or support about wigs on prescription:

> Ciara: *"You would have thought another woman would understand, wouldn't you? But I don't think she did. I think it was a case of, now I've seen you, and another one, another one after her, you know, not much we can do, discharge. That's it. It was someone else that told me about the wigs that I could get on prescription, not that lady".*

Similarly, Harper details a dismissive interaction with her GP who told her to look up her Alopecia on Wikipedia if she wanted more information on it:

> *Harper: "…You know what they say to somebody in that first consultation, you know, makes big impact. I can still see his face 13 years on and the way he was so dismissive and telling me to look it up on Wikipedia and I barely knew what Wikipedia was then".*

Kevin voiced his experience with a dismissive dermatologist, who appeared to not understand the importance of him of having access to steroids to treat his Alopecia:

> Kevin: *"Right, in my experience, they've always been quite dismissive of it. I guess this is also cos my case is quite minor at the moment, but when I went to go get my steroids for this one, she kind of seemed like confused as to why I would want them. I almost seemed like I was annoying her a bit, as if like, this is like unnecessary ….it meant a lot to me.…"*

Participants highlighted times when they felt unheard, unseen, or invalidated by professionals they saw. For example, Ruby details how an invalidating interaction with a GP made her alopecia feel worse:

> Ruby: *"I remember coming away from doctor's appointments has probably been the one thing that has made it feel worse to me because I just feel like the problem is so invalidated and just not seen as that important at all, when I know to me it's huge, like it's a really big thing".*

Many participants voiced concern for the lack of consideration and understanding for the mental health impacts of Alopecia. Kendall highlighted how no medical professional has ever asked how she is coping which she felt indicated a lack of consideration for the mental health impacts of Alopecia:

> Kendall: *"…I've never had anybody say to me, are you coping? Are you like, you know how are you mentally? How are you? It's almost like, well, we can't grow the hair back. We can't stop the patch. There's no medication we can give you. So therefore, there's nothing we can do…."*

Similarly, Harlow voiced a lack of consideration for mental health support as well as signposting to Alopecia support groups:

> Harlow: *"…They don't say how are you actually or do we need psychological interventions? Here's a support group or anything like that. There's just nothing…."*

Due to their mixed experiences with professionals regarding Alopecia, participants made suggestions to help professionals better understand things and things they could adopt in their practice. Participants were clear they felt professionals did not understand what it is like to experience or live with Alopecia leading to calls for professionals to understand Alopecia as a condition that is not just 'cosmetic' but also significantly impacts mental health.

Gina highlighted just how much of an impact Alopecia can have on life generally and going through appointments related to Alopecia can be stressful and professionals should be more aware of this:

> Gina: *"The impact in your life actually cos I think that could just, you know, it's really so stressful. The whole experience of finding out and doing tests and you know; you're going into that appointment but you're dealing with it every day in your life"*.

Niamh pointed out how Alopecia affects a lot more than the hair on your head and that all hair whether it be head hair, eyelashes, or nose hairs have a function and not having them can make life more uncomfortable:

> Niamh: *"…As often your GP would be your first port of call. I think maybe they should be a little more educated to understand that it's not just about the hair on your head first of all, that having no eyes and no eyebrows, can make life pretty miserable …When I had nothing my eyes were just so sore all the time…. and my eyelids were sore, and my nose was sore….so I think they possibly need to be made aware of actually, it's not, you're not moaning, well you are moaning but you're not there because you don't look good…. you feel uncomfortable"*.

Harper stated that professionals need to be more aware that Alopecia is not a cosmetic issue but actually has a lot of negative psychological impacts that are long-lasting:

> Harper: *"It completely changes the idea of self, it's not a cosmetic thing. I think that's the biggest thing, it's not cosmetic because I think they tend to or certainly the guy that I saw just thought it was. Oh, it's a cosmetic thing. You can cover it up. It's fine. It's not. I think they need to understand it's not just a physical thing. It's a mental thing. It's a psychological thing. It doesn't matter whether it was two months ago that you lost it or two years or 20 years, it still affects you…"*.

Lastly, participants detailed a range of things that professionals may want to consider which those with lived experience feel would improve their experiences of professional interactions. These included treating people holistically, asking people how they are feeling and/or what they want from a consultation, checking with patients more, onward referral, more leaflets, resources, and signposting, whether that be to general Alopecia info, to Alopecia UK support groups or to mental health resources or interventions. Nevertheless, while many things appear to require improvement and development, individuals acknowledged that the NHS is currently stretched.

Leah called for professionals to treat those with Alopecia more holistically, provide people with options and take the time to explain the benefits and drawbacks of treatments:

> Leah: *"It's your job to treat the person holistically in front of you and you lay out the options and you work together through the options, the pros and cons of each of the options. Potential side effects, you know, impact your quality of life and daily life for each of the treatments. And then you say, what would you think fits best with you? And that is something that patients really, really benefit from is having plural options now for severe Alopecia".*

Gemma expressed that more signposting would be useful, signposting to treatment options, emotional support, and support groups such as Alopecia UK:

> Gemma: *"I think, signposting on treatments that are available that can manage or stop it getting worse…I was gonna say, it was just general signposting to the emotional support. So, Alopecia UK or other support groups that may be available. Maybe I don't even know about you know, or even forums where people with lived experience can actually just sit and have a moan together. A local support group that kind of thing that would have been helpful to me, never happened, and I sort of like moved away from even thinking about that now. But I wish that had been there for me".*

Sienna stated that more knowledge, resources, onward appropriate referral to services including mental health, or linking people in with people in their communities with similar experiences such as an Alopecia UK group would be helpful:

> Sienna: *"I think if they had knowledge and resources, first of all, I'd say like mental health resources…even a referral to the service, mental health support, you know, anything like that would have been helpful or just, you know, inquiring a little bit more illness and they're not mental health professionals, but kind of getting an understanding of what's going on and trying to, yeah, point people in the right direction…I think community is really powerful, really important, and although I haven't connected with like I know there's, I think it's Alopecia UK or whatever…"*

Similarly, David echoed the need for the mental health side of things to be considered further by professionals, something that was not there when he was younger and first experienced Alopecia:

> *David: "I think it would just be the sort of more on the mental health support side of it that at least 20 years ago was non-existent. I would hope, given the fact that mental health is a lot more in the mainstream now, that it is something that is pursued."*

Finally, Harlow voiced wanting professionals to check in more after initial consultations to feel less like a tick box but, like others who were interviewed, did acknowledge that the NHS is currently stretched:

> Harlow: *"...I think just talking to us, checking in, being more than just a tick box. Like, Yep, you've got Alopecia off you go. But you know it's the NHS and they're really stretched, and I understand why they don't follow up with people..."*

4. DISCUSSION

4.1 Chapter overview

This chapter summarises the results of this study in relation to the research aims and how they sit within the existing literature. I will also discuss the strengths and limitations of this study, as well as the clinical implications and make suggestions for future research. I will attempt to critically evaluate this study before presenting my conclusions.

4.2 Summary of study results

This study aimed to explore Alopecia in relation to its impact, coping, and interactions with professionals. Specifically, it aimed to address the following research questions:

1. What do medical professionals need to know about how living with Alopecia affects QoL, psychological well-being, and identity?
2. What do Alopecia sufferers want medical professionals to understand about what helps or hinders them to cope with the psychological impact of Alopecia?
3. What affects help-seeking when deciding whether to seek professional support for Alopecia?
4. How do individuals experience interactions with medical professionals about their Alopecia (GPs or dermatologists)?

This study interviewed 23 adults with Alopecia, predominantly of an autoimmune aetiology such as AA, AT, AU, AO, and FFA as well as one participant with AGA, likely caused by both genetic and hormonal factors, which are not fully understood yet. The interview data was analysed using RTA, and I developed three main themes and several subthemes. To address research question number one, participants with Alopecia highlighted the significant shifts and fluctuations experienced in relation to identity; they evidenced the negative impact that Alopecia has on psychological well-being and detailed how they are affected by the unpredictability of hair loss and regrowth that is part and parcel of Alopecia, all important for medical professionals to hold in mind, demonstrating that Alopecia extends beyond being the purely physical condition that professionals tend to see it as. To address research question number two, participants expressed how Alopecia leads to restrictions in life, both in socialising with others and when it comes to engagement in activities, hobbies, or events. The various ways people cope with Alopecia were detailed and are essential for medical professionals to consider as coping strategies likely to impact those with Alopecia, either helping or hindering those with lived experience of Alopecia. Participants voiced how they feel understood by some of those close to them but also acknowledged that not everyone knows what to say or do, leaving them feeling misunderstood by either family, friends, or partners. However, participants indicated others with lived experience of Alopecia tended to be much more understanding and this helped normalise the difficult experiences. Participants highlighted some of the factors that influenced their decision-making when deciding whether to seek support for their Alopecia, including professional support from medical professionals; this addressed research question three. Finally, to address question number four, professional interactions (e.g., GPs, dermatologists) were explored and found to be mixed; some were positive, while others were negative, which further impacted an already complex situation. As a result, participants highlighted ways in which medical professionals could improve patient – professional interactions by increasing their understanding of the psychosocial impact of Alopecia, leading to more positive outcomes for those with the condition.

4.3 Discussion of findings in the context of the wider literature

The themes and subthemes from this study will now be situated in the existing literature on Alopecia and will be discussed in the context of the SLR and the current study research questions. The first theme was *Navigating Alopecia: A rollercoaster of change.* The subtheme *Identity and hair* encompasses how hair constitutes an integral part of our self and identity (Schmidt et al., 2001; Fox, 2003). Identity in the context of Alopecia has been described in the literature as ‘fluctuating’ or ‘unstable’ due to hair loss (Hunt et al., 2004;

Barkauskaite et al., 2020; Aldhouse et al., 2020). The results of this study support previous research in demonstrating changes in identity and/or appearance due to Alopecia (Barkauskaite et al., 2020; Rafique et al., 2024; Clarke-Jeffers et al., 2024). Aspects of these shifts can be understood in the context of social identity theory (Tajfel, 1974), relating to how people think of themselves as an individual or group member in relation to the presence or absence of shared characteristics, e.g., hair. Other theories applicable when understanding Alopecia's impact on identity relate to the concepts of social stigma and self-stigma (Crocker, 1999; Ahmedani, 2011; Kacar et al., 2016), understood as the ways in which people are labelled, stereotyped or treated differently by society or internally by themselves based on holding different characteristics or attributes, such as ., Alopecia, described by Goffman as relating to "identity going wrong" (Goffman, 1963;2009). This study reinforces the results of previous studies and builds on understandings of how identity shifts may occur due to Alopecia. Changes concerning identity firstly reflected participants' perceptions of how they were seen or identified by others. This likely relates to wider societal expectations, understandings and meanings attached to hair. For example, participants shared being described by others, Ms. X with brown hair, long hair, curly hair, or nice hair, or Mr X with a bald head or being known prior to Alopecia for one reason or another in relation to their hair. The ways in which others perceive and/or describe those with Alopecia-related hair loss differently to previous versions of themselves with hair is in line with literature detailing how physical appearance, including hair, can influence identity (Shilling, 1993; Gill et al., 2003). People with Alopecia can also experience negative changes to their social identity, creating the sense that they are somehow abnormal or failing to conform to traditional social norms, gender norms, or wider beliefs relating to physical appearance, making them vulnerable to different types of stigma (Goffman, 1963;2009; Bull et al., 1988; Hunt et al., 2004; Barkauskaite et al., 2020; Aldhouse et al., 2020), which in turn is likely to impact their well-being negatively. A novel finding worth further exploration relates to one participant who pointed out how technology, namely her face ID on her iPhone, would not work due to the appearance changes that occurred due to her wearing a wig due to her hair loss. This negatively impacted her ability to do daily life tasks such as access her bank account on her phone, which added to her emotional distress and negative sense of self.

Another shift in identity related to perceptions of self. Many participants reported feeling they had lost a part of themselves or did not feel like themselves when they looked in the mirror or at old pictures, again demonstrating the link between hair, self-concept, identity, and self-stigma for many people (Gorden, 1968; Thompson & Shapiro, 1996; Crocker, 1999), a finding echoed in papers presented in the SLR (Barkauskaite et al., 2020; Rafique et al., 2024).

In contrast to studies that predominantly highlight the negative consequences of Alopecia on identity, some participants in this study voiced how they felt their hair did not define them and expressed that identity could be conveyed in other ways, such as being known as a fast runner, something hair did not impact. This idea within this subtheme was enlightening and positive but goes against much of the current evidence. This might relate to what Moss et al. (2012;2014) found, which was that when high value is placed on appearance, there is a greater impact on QoL compared to those who place less value on appearance or in this case hair. Another reason may relate to personality traits, beliefs about illness, or coping strategies, which Cartwright et al. (2009) argue can mediate responses to conditions such as Alopecia.

Additionally, a few participants reported a possible added layer of complexity regarding Alopecia and culture. While there is some literature on the cultural experiences of Alopecia (Rafique et al., 2015; Rafique et al., 2024; Clarke-Jeffers et al., 2024), this is an area in need of further development. Participants from Black Caribbean and Indian cultures voiced that hair relates to beauty and health in these cultures. Some studies, for example, report how hair for Black women symbolises femininity and beauty (Manning, 2021; Clarke-Jeffers et al., 2024). Therefore, experiences of Alopecia may affect people’s ability to style or wear their hair in a manner that expresses cultural identity and belonging in the same ways as other members of their community (White & White 1995; Banks, 2000; Jere-Malanda, 2008; Thompson, 2009; Johnson &

Bankhead, 2014). In turn, leading to experiences of social stigma (Ahmedani, 2011) by a specific culture or even internalised self-stigma (Crocker, 1999) for feeling like you are failing to be able to express yourself through your hair.

The subtheme *Emotional and physical unpredictability* details the range of negative psychological emotions and unpredictability of Alopecia. In line with other studies, including the SLR, this study concluded that Alopecia is associated with depression and anxiety. Higher rates are found among those with lived experiences of Alopecia compared to the general population (Hunt et al., 2005; Miller et al., 2015; Montgomery et al., 2017; Vallerand et al., 2019; Macbeth et al., 2022). Several other SLRs also corroborate this finding (Lauron et al., 2023; Mahadewi et al., 2023; Okhovat et al., 2023; Bashashwan et al., 2024). Difficulties with feeling self-conscious, a lack of self-confidence, guilt, and loneliness reported by participants in this study are also echoed in the literature (Fox et al., 2003; Welsh et al., 2009; Davey et al., 2019; Iliffe et al., 2019). Moreover, participants in this study, as seen in other studies and my SLR, pointed out a sense of bereavement, loss, and grief, describing their Alopecia as a loss of a piece of themselves (Egele & Tauschke, 1987; Davey et al., 2019; Barkauskaite et al., 2020). Emotional distress was often highlighted by participants in relation to seeing their hair falling out. Emotional distress was noted to also occur when trying to engage socially due to fears that hair loss or wig-wearing would be noticed. These difficult emotions are not surprising given the wider societal meanings attached to hair outlined above in relation to identity and appearance. Moreover, it is likely that stigma (Goffman, 1963;2009) exacerbates the impact that Alopecia has on psychological well-being for many, with Kacar et al., (2016) concluding that those with AA have high levels of self-stigmatisation. This indicates the importance of providing psychological support services as a standard part of care for those with Alopecia, which many studies have previously called for (Hunt et al., 2005; Davey et al., 2019; Zucchelli et al., 2023). The results reiterate the devastating psychological effects of Alopecia which still largely appear not to be considered by professionals such as GPs or Dermatologists working to support those with Alopecia, discussed further below.

The second theme, *Surviving Alopecia: With or without you*, has four subthemes that broadly explores Alopecia and coping. In the subtheme, *A more limited existence*, participants detailed how experiencing Alopecia can lead to socialising less. This finding is in line with the literature, which states that those with Alopecia often experience impaired social functioning or avoidance of social relationships, increasing isolation (Wiggins et al., 2014; Montgomery et al., 2017; Lie et al., 2018). Participants in this study also described the negative impacts that Alopecia can have on willingness to engage in activities, hobbies, and events, also likely increasing feelings of isolation. According to the literature, individuals with Alopecia are also less likely to engage in physical activity (Olsen et al., 2004) or feel their daily activities were negatively affected by their Alopecia (Aldhouse et al., 2020). This limited engagement in socialising with others and activities is thought to be a result of fears around social judgment or rejection, concerns about being stared at, or feelings of self-consciousness and/or embarrassment around Alopecia (Davey et al., 2019; Aldhouse et al., 2020; Barkauskaite et al., 2020; Rajoo et al., 2020; Zucchelli et al., 2022; Katara et al., 2023; Rafique et al., 2024; Clarke-Jeffers et al., 2024). Moreover, fears of or actual experiences of stigma (Goffman, 1963;2009), particularly social stigma (Ahmedani, 2011) from others, are likely to contribute further to impaired social functioning in relation to the lived experience of Alopecia. Unfortunately, social stigma can be very real; for example, Creadore et al. (2021) found that laypeople were stigmatising those with Alopecia across a range of social situations. Reduced social functioning and reduction in engagement in activities has multiple implications, including but not limited to impaired relationships with friends, partners, or family members, a limited lifestyle with fewer things that bring a sense of satisfaction or fulfilment, further maintaining feelings such as low self-confidence, depression, anxiety, loneliness, and isolation (Aldhouse et al., 2020). Moreover, avoidance of social interactions, hobbies or activities may also maintain difficult emotions such as social anxiety (Turk et al., 2001). In light of this, it may be worth including a group element as part of psychological support for those with Alopecia not to feel stigmatised, similar to some of the supports provided already by the charity Alopecia UK.

Moving to consider coping, this subtheme is entitled *Coping: There is more to contend with*, underpins the various ways people cope with Alopecia and the additional things they may consider when coping with their Alopecia. Participants broadly discussed Coping in two ways: practical coping, which included camouflaging or checking, and more internal coping around humour and mindset. Camouflaging Alopecia included wigs, hats, scarves and/or microblading. In this study, wig-wearing appeared largely positive, with participants feeling it allowed them to get on with life. Wig-wearing is a common method of camouflaging or coping with Alopecia well documented in the literature. However, wig-wearing in the wider evidence base has mixed reviews. In line with this study, Hunt et al., (2004) concluded that those with Alopecia felt that wearing wigs was a positive way to cope with their Alopecia, stating it allowed people to feel that their hair always looked good. Similarly, Montgomery et al. (2017) and Sonmez and Hocaoglu (2022) found that wearing wigs increased social confidence and often alleviated stigmatisation in social settings. However, wigs can also maintain some anxiety related to Alopecia by increasing fears that others may find out someone was wearing a wig and have a negative reaction (Montgomery et al., 2017). Other means of camouflaging Alopecia mentioned by participants included scarves, hats, or microblading, with hat-wearing and microblading reported to be used by both female and male participants. These are less well documented in the literature than wig-wearing but are practices which those with Alopecia likely engage in to manage appearance-related concerns or to mitigate feelings of loss of identity or self-confidence. Camouflaging Alopecia-related hair loss is an often used coping strategy but can lead to its own anxieties about hair loss being discovered (Montgomery et al., 2017).

Checking Alopecia, wig placement, and photographing hair loss or regrowth were detailed by those with Alopecia as coping mechanisms and appear less well documented in the Alopecia literature. Engagement in regular appearance-checking can be understood in relation to the wider societal meanings of hair, resulting from a perceived need for self-preservation in social interactions (Wiggins et al., 2014). Checking may also occur as a result of the psychological distress associated with Alopecia due to the unpredictability of Alopecia for many who experience it or as a result of experiencing stigma, as documented above.

Moving to more internal coping strategies, the first mentioned by several participants was humour. Little evidence currently exists of the relationship between Alopecia and humour in the literature. One study on Alopecia and adolescent coping found that humour was more frequently used by males than females (Rafique et al., 2015). Males reported making fun of themselves in front of friends before their friends could (Rafique et al., 2015). In contrast, the results of my study suggest that both males and females use examples of humour in relation to coping with Alopecia. In line with Rafique et al. (2015) one participant in this study stated that she made fun of herself to deter others from making fun of her. Borg et al. (2012) hypothesised that the use of humour for some may conceal real emotions, which seems possible given the negative psychological impact well documented in the literature and emphasised in this study.

Participants in this study also reported on the use of mindfulness, meditation, or CBT to support coping due to the difficulties that come with Alopecia. Much of this appears to have resulted from participants' interest and own research rather than more formal therapy via a GP referral. Other participants developed a more positive mindset when attending therapy. However, therapy still rarely seems to be recommended directly because of Alopecia but rather comes up during therapy for other difficult life events. Psychological intervention directly for Alopecia or illness-specific therapy is still a developing area. A few studies have reported on the efficacy of therapeutic interventions for Alopecia. Kuty-Pachecka (2017) concluded that CBT could play a role in changing maladaptive views about oneself, the world, and the disease, while Hart (2020) who facilitated a 12-week CBT group, found a significant difference in psychological and physical symptoms associated with AA for people who received the intervention, versus controls. Gallo et al. (2017) found some improvement in QoL following mindfulness-based work, while consideration has also been given to CFT or ACT principles, which, for some, have demonstrated positive changes (Woods et al., 2006; Rasouliisini et al., 2019). Whilst findings of the intervention studies discussed suggest mindfulness and CBT based interventions show promise, further studies are required to replicate the findings and determine how and why these interventions are effective for people with alopecia.

The third subtheme, *Sometimes you'll get it, but you'll never fully understand* relates to participants receiving social support or feeling misunderstood by those close to them in interactions. According to the literature, receiving social support from others is another way individuals cope with Alopecia, particularly as Alopecia can be associated with social challenges (Rafique et al., 2024). Good social support from loved ones can alleviate some of the psychological distress associated with Alopecia, reduce stigma, and move toward acceptance (Barrera, 1988; Aldwin, 1994; Welsh et al., 2009; Davey et al., 2019). Both positive and negative reactions from friends, family, partners, and wider society in relation to their Alopecia have an impact on coping (Hunt et al., 2006; Welsh et al., 2009; Aldhouse et al., 2020; Katara et al., 2023; Rafique et al., 2024). Examples of both positive and negative interactions with friends, family, and partners were found in the current study. Participants expressed that those who were supportive expressed that how they managed their Alopecia was up to them, e.g., being bald or wearing a wig, while others said loved ones were supportive by acknowledging that Alopecia is challenging to deal with. Those who felt unsupported or misunderstood expressed that this occurred when those close to them said things like everything is okay despite the person with Alopecia trying to voice that they did not feel this way. Therefore, social support and understanding from loved ones are essential in aiding coping and likely reduce both social stigma and self-stigma (Crocker, 1999; Ahmedani, 2011).

Subtheme four of theme two relates to *The power of shared experiences*. In line with the literature, this finding suggests that peer support from others with lived experience of Alopecia is largely beneficial in supporting coping with Alopecia. Kalabokes (2011) argued that support groups are beneficial in providing individuals with a sense of understanding and acceptance, and creating a space where thoughts and feelings about Alopecia can be normalised. Moreover, studies on Alopecia UK's online Facebook group indicated the group supported the development of effective coping styles, increased feelings of being understood, and a greater sense of belonging, which in turn positively impacted acceptance (Iliffee et al., 2019: Zuchelli et al., 2022). Participants in the current study voiced how Alopecia UK's Facebook group and in-person support groups, as well as support from the Instagram community, were mostly life-changing and normalising, adding to the existing literature on the advantages of community and peer support.

In summary, themes one and two explore the impact of Alopecia on psychological well-being and social functioning. Findings point to the impact of hair loss on quality of life in line with Newell (2002) and Muntyanu et al. (2023). Therefore, perceived support and understanding from others are an important consideration when examining coping, particularly given the psychosocial implications of Alopecia.

The final theme *Understanding patient-professional relationships*, explored help-seeking decisions and understandings of patient-professional relationships regarding Alopecia. Several participants discussed the first subtheme*, To seek help or not to seek help*, highlighting various factors that affected their help-seeking decisions. Participants detailed negative and positive experiences that subsequently influenced their decisions to seek further help. Negative experiences of attempting to seek formal help when they tried to bring up Alopecia to their GP were in line with the literature and led to participants feeling a lack of support as well as disease-related or professional stigmatisation (Liggins et al, 2005;Rickwood et al., 2005; Rickwood et al., 2012; Thomas et al., 2018; van Weeghel et al., 2019; Davey et al., 2019). In contrast, other participants had more positive interactions, allowing them to feel heard and supported, thereby affecting their subsequent help-seeking decisions. This came from a combination of 'informal help' via family, 'formal help' from a trichologist, and assistance via the Internet (Rickwood et al., 2005; Rickwood et al., 2012; Thomas et al., 2018; van Weeghel et al., 2019). While the results of this study align with the limited literature available about Alopecia and help-seeking decisions, further research would be of use delve into the factors that affect help-seeking specifically in relation to Alopecia in the way it has been explored for other autoimmune disorders, such as Vitiligo (Talsania et al., 2010; Ezzedine et al., 2015) as help-seeking decisions likely impact people's ability to cope with Alopecia and feel greater levels of satisfaction with treatment or support options as well as professional interactions.

The second subtheme of theme three relates to the mixed bag of interactions and satisfaction rates, in line with Zucchelli et al. (2023), who highlighted negative and positive patient interactions with GPs and dermatologists. The findings in relation to the negative experiences people have had with professionals, often described as 'dismissive,' are in line with the literature on Alopecia and professional interactions and emphasises that insensitive GP and dermatology encounters can contribute to feelings of hopelessness (Davey et al., 2019). Participants went on to voice how many professionals referred to Alopecia as an 'a cosmetic condition' or 'just hair,' which, understandably, for those living with the negative daily QoL impacts of Alopecia, was seen as devastating, minimising their experiences (Hunt et al., 2004; Bhatti, 2019; Davey et al., 2019; De Vere Hunt, 2021; Macbeth et al., 2022). Unfortunately, this may relate to what Liggins et al. (2005) pointed out: that healthcare professionals may also stigmatise others as they are exposed to the same rhetoric as the general public. Moreover, there appears to be an apparent gap in the knowledge held by professionals on the real impacts of Alopecia (Zucchelli et al., 2023), which is likely to reinforce stigma, or feeling misunderstood and harm psychological well-being. Although less literature exists, this study also found positive interactions with professionals; leading to participants feeling more heard and understood and in turn likely more willing to seek support and consider treatment or support options, which may mediate the negative psychological impacts of Alopecia.

Zucchelli et al., (2023) concluded that many of those with Alopecia are currently dissatisfied with the psychological support for Alopecia, something that this study echoes and called for ways to 'optimize overall patient experience' (Zucchelli et al. 2023, pg. 10). In light of this, to further the current evidence base, this study explored what participants want professionals to understand or do that would make patient-professional interactions more beneficial.

Participants want professionals to understand just how much of an impact Alopecia can have on life generally, and how going through appointments related to Alopecia can be stressful. Participants pointed out how Alopecia affects more than the hair on your head and that all hair, whether head hair, eyelashes, or nose hairs, have a function. Participants also reiterated that professionals need to understand that Alopecia is not a cosmetic issue but has a lot of negative psychological impacts that are long-lasting.

Participants also made some recommendations for professionals to consider in their practice. They called for professionals to treat them more holistically, seek out treatment options or drug trials, explain the pros and cons of treatments better, enhance their understanding, knowledge, and resources on Alopecia for patients, and provide appropriate referral to specialist services or mental health services. Finally, participants also called for more leaflets and better signposting to support groups such as Alopecia UK and/or mental health services. Additionally, participants voiced a desire to be checked in on more after initial consultations to feel less like a tick box, but also acknowledged how stretched the NHS is.

In response to both what participants wanted professionals to understand and what they would like them to do differently that would be more beneficial, a consistent lack of consideration for the mental health aspect of Alopecia and referral to psychological interventions was raised. This is in line with the literature stating that the psychological impact of Alopecia was rarely considered in GP or Dermatology encounters (Davey et al., 2019). Moreover, despite considerations for psychological support being referenced as a treatment for Alopecia in clinical guidance by NICE (2023) and BAD (2012), GPs or Dermatologists do not regularly consider onward mental health referrals. It is unclear whether this is due to a lack of knowledge and understanding by GPs and Dermatologists (Zucchelli et al., 2023), who still seem to view Alopecia via a medical lens rather than a biopsychosocial lens, or due to the current state of the NHS or both. Nevertheless, there still appears to be rather large gap in the way we view and treat conditions that transcend both the physical and mental health spheres. Perhaps this indicates newer roles for Clinical Psychology professionals in GP practices and Dermatology departments, which seems apparent when you explore the literature despite largely remaining unimplemented. The BPS (Marks, 2022, pg. 5, BPS) published a report that called for Clinical psychology to be "routinely embedded into primary care", while this is not necessarily in relation to Alopecia but rather encompasses other long-term health conditions where people also have mental health needs, those with Alopecia would likely benefit from this. Moreover, the British Skin Foundation (2019) reported that "87% of dermatologists agree that people with skin conditions in the UK do not have sufficient access to psychological support", meaning psychological well-being in Dermatology departments is also currently lacking. Despite, reports in 2013 and 2020 by the All-Party Parliamentary Group on Skin (APPGS) that called for psychodermatology services to be expanded UK wide to better support the mental health of those with skin conditions, including Alopecia. Therefore, despite calls for changes that would likely optimise overall patient experience between 2013-2020 not much has changed as those with lived experience of Alopecia still call for similar things in 2024.

4.4 Strengths and limitations

In terms of strengths, this study sought to explore the impacts, coping, and interactions with professionals in relation to Alopecia with a participant pool on the slightly large side for a qualitative study while also attempting to include varying genders, age groups, and ethnicities to capture a more robust range of Alopecia experiences.

This study appears to be one of the first that delves further into teasing out the various shifts and changes those with Alopecia experience in relation to identity. It adds to the evidence base on the psychological and social impacts of Alopecia, demonstrated in the SLR and the main study findings, which reinforces the need for these to be considered further. This is important as our sense of self and identity play a role in promoting well-being and protecting against negative psychosocial functioning (Schwartz et al., 2013).

It takes our understanding of patient-professional interactions a step further than only ascertaining if the interaction was positive or negative and sought to hear what those with lived experience of Alopecia want or need to improve interactions with professionals about Alopecia.

Furthermore, I am aware that there are both strengths and limitations to being an insider researcher. I made attempts to address situations in this study that may have led to my own experiences impacting it, such as changing the structure of the interviews slightly, so my experiences of Alopecia were not shared before interviewees had a chance to answer questions. Therefore, another strength relates to my being an insider researcher, which positively facilitated participants to feel comfortable enough to attend interviews, contributing to the rich data I received in this study.

However, this study is not without its limitations. Although my study criteria sought to only include those with Alopecia that is autoimmune in nature, I did include those with AGA, which I am aware has several likely causes not all of which are autoimmune. Nevertheless, whether participants described experiences of AA or AGA, there was a sense that the overall QoL was negatively impacted.

This study only included those who spoke fluent English; therefore, it is likely that the findings of this study are not fully transferable of the experiences of those who are non-English speaking more globally. Moreover, although this study did include non-white participants, they were in a minority and therefore the theme surrounding identity and culture is likely underdeveloped.

4.5 Implications, recommendations, and future research

This study has implications for how Alopecia is understood and viewed by professionals (e.g., GPs and dermatologists) and for how professionals practice in relation to Alopecia. Both my SLR and my main study findings highlight from a qualitative perspective the significant impacts Alopecia has on QoL, namely impacting people's social functioning and psychological functioning. However, it also points to things such as the impact of negative interactions on help-seeking decision-making. Therefore, Alopecia should not be a 'cosmetic condition' or viewed from a medical model lens but should rather be understood through a biopsychosocial lens. While the biopsychosocial model has been acknowledged more widely in the field of psychodermatology when treating people with skin conditions (Picardi & Pasquini, 2007), current treatment or support for Alopecia does not appear to be viewed in this way by professionals.

This study has implications for Clinical Psychologists who should consider whether existing psychological models and interventions are sufficient to support those with Alopecia, or whether consideration should be given to a more targeted illness-specific intervention. Consideration could be given to the role of social support outlined in this study and how this could be interwoven into psychological support, possibly indicating that a group-based rather than one-to-one intervention model could be fruitful. Clinical psychologists with an interest and/or understanding of the psychological impacts of Alopecia could provide consultation and training to either trainees or qualified GPs and/or dermatologists to support them to view Alopecia as more than a 'cosmetic issue'. Finally, Clinical Psychologists could work within primary care with GPs or in specialist Alopecia dermatology departments to test the feasibility of the role of a 'clinical psychologist' in these types of services in the parts of the UK where this is not already being done as recommended by the BPS and APPGS.

Current Alopecia guidelines set out by the National Institute of Care and Excellence (NICE) and the British Association of Dermatologists (BAD) require an update as well as possible consultation from psychological professionals as they both currently refer to "provision of psychological support if needed and appropriate" (NICE, 2023) or "psychological-based treatments" (BAD, 2024) as more of a vague afterthought, despite the overwhelming evidence for the psychological impact of Alopecia.

If medical professionals were to view Alopecia from a biopsychosocial lens when considering impact and, therefore, treatment or support options, and/or if Clinical Psychologists provided additional teaching and training to medical professionals and/or if Clinical Psychologists embedded themselves in primary care and/or dermatology departments, this would all have implications for those with lived experience of Alopecia. Hopefully optimising patient's overall experience.

It is recommended that professionals hear the voices of those with lived experience of Alopecia and pay more attention to what they want professionals to understand and do, likely improving satisfaction levels in relation to patient-professional interactions. Sharing a study summary via a leaflet or blog via places like Alopecia UK, the Royal College of General Practitioners and the British Association of Dermatologists would support this.

Participants recommended professionals give more consideration and understanding to:

1. Alopecia can affect many facets of life generally, and going through appointments related to Alopecia can be stressful.

2. Alopecia affects a lot more than the hair on your head and that all hair, whether head hair, eyelashes, or nose hairs, all have a function

3. Alopecia is not only a physical condition but one that has significant, long-lasting effects on mental health.

4. In interactions or medical appointments about their Alopecia, participants in my study expressed they want to be treated more holistically; they want treatment options, they want the pros/cons of treatments to be explained to them, they want access to leaflets, signposting, and/or onward referral to social support or mental health support services.

Future research should consider developing the following areas based on the results presented in this study. Research is needed to develop further and consider psychological intervention options to support those with the rollercoaster of changes that often come with Alopecia. While the results of Hart's (2020) CBT trial appear positive, further consideration should be given to replicating the results with a larger sample size and considering options such as CFT or ACT. The results of this study indicate that Alopecia leads to difficult identity fluctuations for many and also demonstrates the importance of social support, particularly from peers with lived experience of Alopecia. Therefore, both should be considered in relation to the development of psychological interventions.

Given the negative impact Alopecia has on social functioning, future research may wish to consider whether social support or peer support groups could be more targeted, perhaps to those at the beginning of their Alopecia journey versus those further along.

Help-seeking, specifically in relation to Alopecia, would likely benefit from further exploration as it may lead to increased access to resources and support, thus improving mental health and may support us in understanding what barriers arise and how to address them.

Finally, although some literature exists on the relationship between Alopecia and culture, further research could be conducted to explore this further across a variety of cultures.

4.6 Critical evaluation of this study

Critical appraisal in qualitative research involves thoroughly examining research studies to assess their credibility, significance, and applicability within a given context (Burls, 2015). To critically appraise the current study, I evaluated it using the Critical Appraisal Programme Tool (CASP) qualitative tool checklist as I did with my SLR. It is a comprehensive tool comprised of ten items assessing three broad categories: rigor, credibility, and relevance, which are viewed as cornerstones of trustworthy qualitative research (CASP, 2024). Table 7 summarises how I feel this study met the CASP checklist: 10 questions to assess qualitative research.

Table 7: Critical review of the current study

CASP questions	CASP Criteria	Was it met? (yes, no, somewhat)	How was the criteria met?
1. Clear statement of the aims of the research?	What was the goal of the research? Importance? Relevance?	Yes	The research aims and research questions were clearly presented for this study. I provided an overview of where the literature is at and the current gaps this study sought to address.
2.Qualitative methodology appropriate?	Is qualitative research the right methodology for addressing the research goal?	Yes	A qualitative research design was deemed the most appropriate approach to address the study aims, where the purpose was to capture and understand the meaning or sense-making of the impact Alopecia has on the participants, which is less quantifiable with numbers data.
3. Research design appropriate to address the aims of the research	The researcher has justified the research design (e.g. have they discussed how they decided which method to use)?	Yes	Yes, this is presented in my method chapter, which outlines my rationale for RTA, the strengths and weakness of RTA, my use of semi-structured virtual interviews, and my interview schedule.
4.Recruitment strategy appropriate to the aims of the research?	If the researcher has explained how the participants were selected? If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study? If there are any discussions around recruitment (e.g. why some people chose not to take part)?	Yes	My participant recruitment strategy was outlined in my method chapter, it includes the participant inclusion and exclusion criteria as well as how participants were recruited for this study.
5. Data collected in a way that addressed the research issue?	If the setting for the data collection was justified? If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)? If the researcher has justified the methods chosen?	Yes	The decision to conduct online interviews was discussed in the method chapter. The rationale for the use of semi-structured interviews for this study was also clearly presented in the method. An explanation for the number of interviews conducted for this

	If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)?		study was situated in the context of other qualitative research.
6. The relationship between researcher and participants been adequately considered?	If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location?	Somewhat	I provided a clear positionality statement at the beginning of this study and documented my engagement in reflexivity. During data collection, I changed aspects of the interview after interview 4 to ensure my own experiences and, therefore, possible biases did not influence participants. In relation to considering bias in research question development, I could have done more, e.g., include more EbE. However, I did put forward possible overall research topics, which were reviewed by the Alopecia panel at Alopecia UK.
7. Ethical issues been taken into consideration?	If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained? If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)? If approval has been sought from the ethics committee?	Yes	The research was explained in the participant information and consent forms. My method chapter clearly outlines my ethical considerations, including those related to informed consent and confidentiality. The method chapter and my appendices present a clear statement of ethical approval from the UH ethics committee.
8. Data analysis sufficiently rigorous?	If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process? If sufficient data are presented to support the findings?	Yes	Thematic maps have been included to demonstrate how initial clusters, categories, and themes were devised. Quotes from the data have been included in the research findings/results section to demonstrate examples of data in relation to the findings.

9. Clear statement of findings?	If the findings are explicit? If there is adequate discussion of the evidence both for and against the researcher's arguments? If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)? If the findings are discussed in relation to the original research question?	Yes	My results chapter is clear, and my discussion is clearly presented and written in light of the research questions originally set out.
10. Research value?	If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature? If they identify new areas where research is necessary? If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used?	Yes	Yes, this is addressed in the Implications, Recommendations, and Future Research section.

5. Conclusion

This study explored Alopecia in relation to its impact, coping, and interactions with professionals. Four research questions were addressed. Twenty-three participants engaged in semi-structured interviews as part of this study. An RTA constructed three main themes: Navigating alopecia: A rollercoaster or change, Surviving Alopecia: With or without you, and Understanding patient-professional relationships. The outcomes of this study demonstrate the psychological and social impacts Alopecia has on functioning, some of the coping strategies those with Alopecia use, the mixed bag of experiences in relation to patient-professional interactions, and recommendations to professionals that should be considered in their practice going forward, including but not limited to more consideration and support for the mental health impact of Alopecia. Together, these findings point to a greater need for Alopecia to be considered by professionals from a more holistic biopsychosocial lens rather than medical alone, moving us away from previous assumptions that Alopecia is a ‘cosmetic’ issue as well as an urgent need for appropriate psychological support. Alopecia research like that conducted in this study is important due to the many facets of QoL that Alopecia can negatively impact, e.g., mental health, relationships, social belonging, and the freedom to engage in activities or hobbies that enrich a sense of pleasure and mastery. Finally, implications have been outlined for current Alopecia treatment guidelines (e.g., NICE & BAD), for professionals (e.g., GPs and dermatologists), for clinical psychologists, and, importantly, for those with lived experience of Alopecia who seek better care. I want to end with a participant quote that I feel sums up the importance and relevance of doing research in this area better than I ever could:

Ruth: *You're not dying, but actually, it's life changing. It's a life-changing condition…*

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7. Appendices

Appendix A – Key terms and language

Language is an important part of our understanding. Therefore, the table below summarises key terms referred to in this thesis.

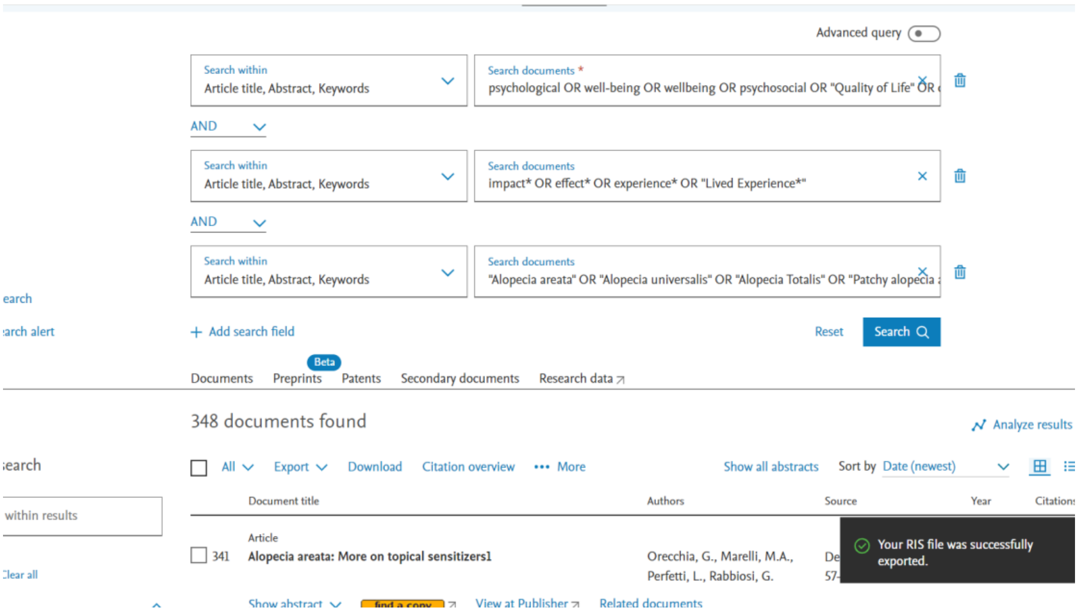
Term	**Definition**
Alopecia	Alopecia means hair loss. There are lots of different types of hair loss, and the causes can be genetic, autoimmune, environmental, or be a result of medical intervention (e.g., chemotherapy-induced hair loss). The exact cause of Alopecia is not always known (Sonmez & Hocaoglu, 2022).
Autoimmune condition/ disease	This type of condition/disease develops when your immune system mistakes a part of your body as foreign and attacks it. For example, if an individual has Alopecia areata, then their immune system mistakenly attacks their hair follicles (American Academy of Dermatology Association, 2024).
Alopecia Areata (AA)	Alopecia Areata (AA) is an autoimmune disorder. The word “areata” means patchy, given it often causes patchy hair loss, it is usually called Alopecia Areata. With AA, the body’s immune system mistakenly attacks healthy hair follicles (American Academy of Dermatology Association, 2024). AA often starts with isolated patches of hair loss, commonly in one or more coin-sized (usually round or oval) patches on the scalp and/or across the body, including the beard, eyebrows, eyelashes, or body hair, including pubic hair (Alopecia UK, 2018). According to the American Academy of Dermatology Association (2024), this type of hair loss usually begins in children and young adults, but people of any ages, genders and ethnicities can develop AA. Alopecia Areata Universalis and Alopecia Areata Totalis are two varying forms of AA.
Alopecia Totalis (AT)	Alopecia Areata Totalis (known as Alopecia Totalis) is characterized by a total loss of all scalp hair. It specifically relates to individuals whose hair loss extends to all the hair on their scalps (American Academy of Dermatology Association, 2024). This type of hair loss usually begins as typical AA patches. However, some people continue to experience rapid hair loss, and patches are not seen before most of the scalp hair is lost (Alopecia UK, 2018).
Alopecia Universalis (AU)	Alopecia Areata Universalis (known as Alopecia Universalis) is characterised by hair loss which extends across the entire scalp, face (including eyebrows and eyelashes), and the rest of the body (including pubic hair).
Alopecia Areata Ophiasis (AO)	Alopecia Areata Ophiasis has a specific pattern of hair loss, where hair falls out from the sides and lower back of the scalp. It is a rare form of AA (Alopecia UK, 2018).
Androgenetic Alopecia (AGA)	Androgenic Alopecia is a condition thought to be caused by genetic and hormonal factors that affect people of any gender. However, it can present differently in males versus females. Androgenetic

	Alopecia is often referred to as 'Male Pattern Hair Loss' or 'Female Pattern Hair Loss'. Hairs on the scalp grow in tufts, usually of 3-4 hairs. In AGA, the hair tufts gradually shrink, so the number of hairs in each tuft decrease causing the patches of skin on the scalp to be visible (Alopecia UK, 2018).
Frontal Fibrosing Alopecia (FFA)	Frontal Fibrosing Alopecia is a form of Lichen Planopilaris which is understood to be inflammatory in nature. It usually causes slow but progressive hair loss. FFA is a type of scarring hair loss that affects the frontal region of the scalp (i.e. the forehead and sideburns), leaving smooth patches. It tends to affect women more than men but can impact both. Genetic studies of FFA suggest it is an autoimmune condition in which an affected person's immune system mistakenly attacks the hair follicles and destroys them. Although triggers are not yet clear, hormones and other environmental factors are also possibly at play (Alopecia UK, 2018).
Dermatology	Dermatologists treat individuals with a variety of skin, hair, and nail conditions. They see conditions such as skin cancer, eczema, psoriasis, acne, and hair loss etc. In the UK, NHS referrals to dermatologists are made by the General Practitioner (GP). Found at: https://www.healthcareers.nhs.uk/explore-roles/doctors/roles-doctors/medicine/dermatology on 15.05/24.
Trichologist/Trichology	Trichology is the diagnosis and treatment of diseases and disorders of the hair and scalp. Trichologists are not medically qualified (although some Trichologists can be Medical Doctors who specialise in hair and scalp conditions) and therefore do not work within the NHS but receive training of a clinical and medical nature specific to the hair and scalp. The Institute of Trichologists is the regulatory board that manages their standards (The Institute of Trichologists, 2024).

Appendix B – SLR searches

Scopus

Article title, Abstract, keywords
Psychological OR Well-being OR Wellbeing OR Psychosocial OR “Body image” OR Emotional OR Appearance* OR “Quality of life” OR QOL
AND Identity* OR Impact* OR Effect* OR Experience* OR “Lived Experience*”
AND “Alopecia areata” OR “Alopecia totalis” OR “Alopecia Universalis” OR “Patchy Alopecia areata”



Search within: Article title, Abstract, Keywords
Search documents *: psychological OR well-being OR wellbeing OR psychosocial OR "Quality of Life" OR

Search within: Article title, Abstract, Keywords
Search documents: impact* OR effect* OR experience* OR "Lived Experience*"

Search within: Article title, Abstract, Keywords
Search documents: "Alopecia areata" OR "Alopecia universalis" OR "Alopecia Totalis" OR "Patchy alopecia

348 documents found

	Document title	Authors	Source	Year	Citation
☐ 341	Article **Alopecia areata: More on topical sensitizers1**	Orecchia, G., Marelli, M.A., Perfetti, L., Rabbiosi, G.	De 57-		

Your RIS file was successfully exported.

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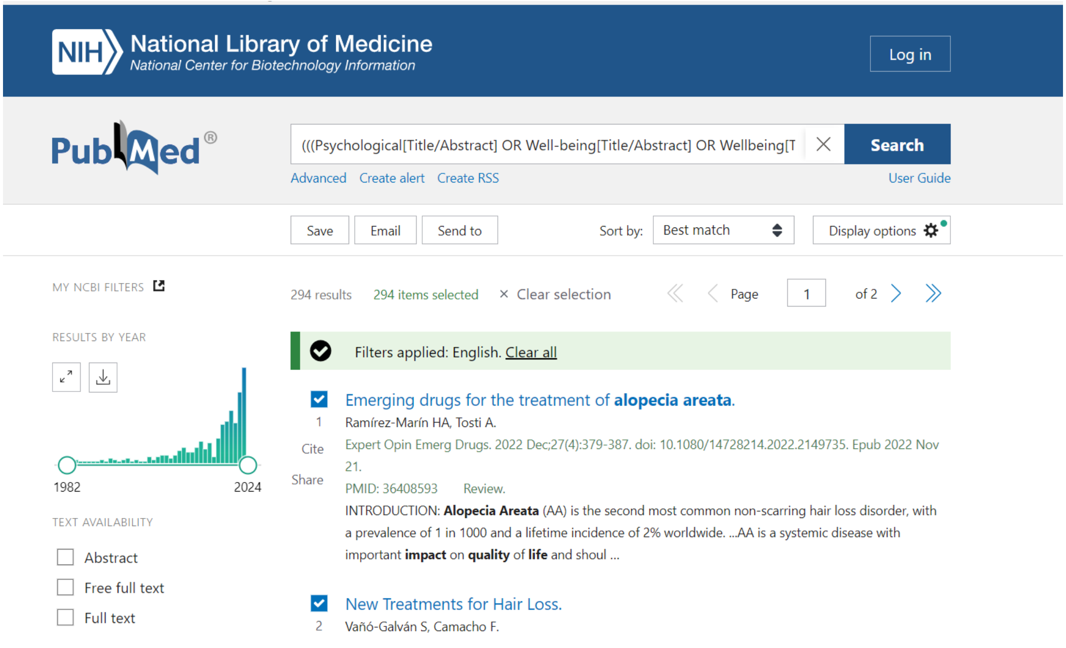
(((Psychological[Title/Abstract] OR Well-being[Title/Abstract] OR Wellbeing[Title/Abstract] OR Psychosocial[Title/Abstract] OR "Body image"[Title/Abstract] OR Emotional[Title/Abstract] OR Appearance*[Title/Abstract] OR Identity[Title/Abstract] OR "Quality of Life"[Title/Abstract] OR QOL.[Title/Abstract]) AND (Impact*[Title/Abstract] OR Effect*[Title/Abstract] OR Experience*[Title/Abstract] OR "Lived Experience*"[Title/Abstract])) AND ("Alopecia areata"[Title/Abstract] OR "Alopecia totalis"[Title/Abstract] OR "Alopecia Universalis"[Title/Abstract] OR "Patchy Alopecia areata"[Title/Abstract]))



(((Psychological[Title/Abstract] OR Well-being[Title/Abstract] OR Wellbeing[T

294 results 294 items selected × Clear selection Page 1 of 2

Filters applied: English. Clear all

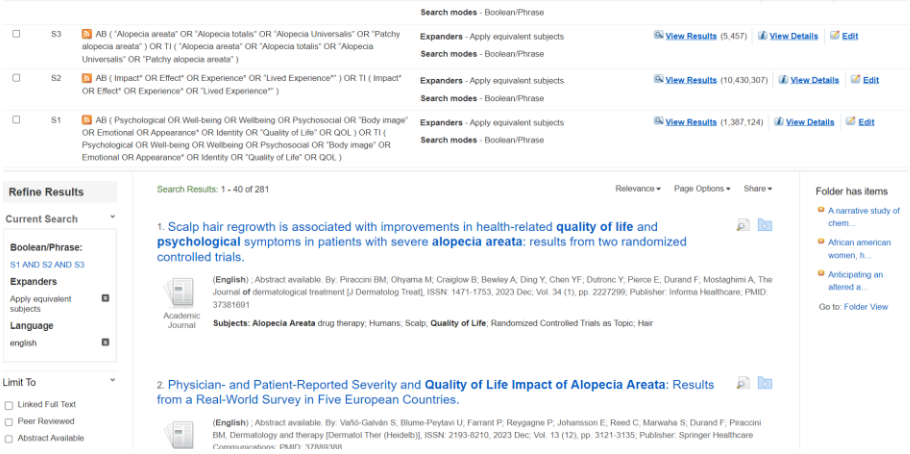
☐ Abstract
☐ Free full text
☐ Full text

☑ 1 Emerging drugs for the treatment of **alopecia areata**.
Ramírez-Marín HA, Tosti A.
Expert Opin Emerg Drugs. 2022 Dec;27(4):379-387. doi: 10.1080/14728214.2022.2149735. Epub 2022 Nov 21.
PMID: 36408593 Review.
INTRODUCTION: **Alopecia Areata** (AA) is the second most common non-scarring hair loss disorder, with a prevalence of 1 in 1000 and a lifetime incidence of 2% worldwide. ...AA is a systemic disease with important **impact** on **quality** of **life** and shoul ...

☑ 2 New Treatments for Hair Loss.
Vañó-Galván S, Camacho F.

Medline

AB (Psychological OR Well-being OR Wellbeing OR Psychosocial OR “Body image” OR Emotional OR Appearance* OR Identity OR “Quality of Life” OR QOL) OR TI (Psychological OR Well-being OR Wellbeing OR Psychosocial OR “Body image” OR Emotional OR Appearance* OR Identity OR “Quality of Life” OR QOL) AND AB (Impact* OR Effect* OR Experience* OR “Lived Experience*”) OR TI (Impact* OR Effect* OR Experience* OR “Lived Experience*”) AND AB (“Alopecia areata” OR “Alopecia totalis” OR “Alopecia Universalis” OR “Patchy Alopecia areata”) OR TI (“Alopecia areata” OR “Alopecia totalis” OR “Alopecia Universalis” OR “Patchy Alopecia areata”)



Search modes - Boolean/Phrase

☐	S3	AB ("Alopecia areata" OR "Alopecia totalis" OR "Alopecia Universalis" OR "Patchy alopecia areata") OR TI ("Alopecia areata" OR "Alopecia totalis" OR "Alopecia Universalis" OR "Patchy alopecia areata")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (5,457)
☐	S2	AB (Impact* OR Effect* OR Experience* OR "Lived Experience*") OR TI (Impact* OR Effect* OR Experience* OR "Lived Experience*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (10,430,307)
☐	S1	AB (Psychological OR Well-being OR Wellbeing OR Psychosocial OR "Body image" OR Emotional OR Appearance* OR Identity OR "Quality of Life" OR QOL) OR TI (Psychological OR Well-being OR Wellbeing OR Psychosocial OR "Body image" OR Emotional OR Appearance* OR Identity OR "Quality of Life" OR QOL)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (1,387,124)

Boolean/Phrase:
S1 AND S2 AND S3
Expanders
Apply equivalent subjects
Language
english

☐ Linked Full Text
☐ Peer Reviewed
☐ Abstract Available

Search Results: 1 - 40 of 281

1. Scalp hair regrowth is associated with improvements in health-related **quality of life** and **psychological** symptoms in patients with severe **alopecia areata**: results from two randomized controlled trials.
(**English**) ; Abstract available. By: Piraccini BM; Ohyama M; Craiglow B; Bewley A; Ding Y; Chen YF; Dutronc Y; Pierce E; Durand F; Mostaghimi A, The Journal **of** dermatological treatment [J Dermatolog Treat], ISSN: 1471-1753, 2023 Dec; Vol. 34 (1), pp. 2227299; Publisher: Informa Healthcare; PMID: 37381691
Subjects: Alopecia Areata drug therapy; Humans; Scalp; **Quality of Life**; Randomized Controlled Trials as Topic; Hair

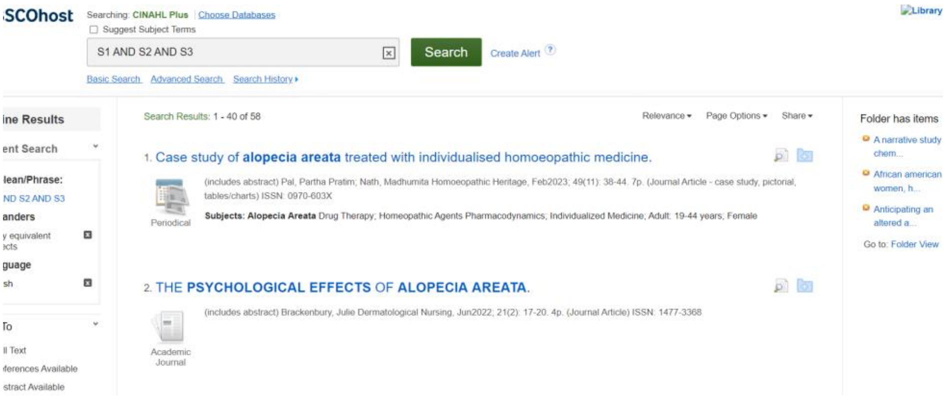
2. Physician- and Patient-Reported Severity and **Quality of Life Impact of Alopecia Areata**: Results from a Real-World Survey in Five European Countries.
(**English**) ; Abstract available. By: Vañó-Galván S; Blume-Peytavi U; Farrant P; Reygagne P; Johansson E; Reed C; Marwaha S; Durand F; Piraccini BM, Dermatology and therapy [Dermatol Ther (Heidelb)], ISSN: 2193-8210, 2023 Dec; Vol. 13 (12), pp. 3121-3135; Publisher: Springer Healthcare Communications; PMID: 37889388

A narrative study of chem...
African american women, h...
Anticipating an altered a...

Cinahl Plus

AB (Psychological OR Well-being OR Wellbeing OR Psychosocial OR “Body image” OR Emotional OR Appearance* OR Identity OR “Quality of Life” OR QOL) OR TI (Psychological OR Well-being OR Wellbeing OR Psychosocial OR “Body image” OR Emotional OR Appearance* OR Identity OR

"Quality of Life" OR QOL) AND AB (Impact* OR Effect* OR Experience* OR "Lived Experience*") OR TI (Impact* OR Effect* OR Experience* OR "Lived Experience*") AND AB ("Alopecia areata" OR "Alopecia totalis" OR "Alopecia Universalis" OR "Patchy Alopecia areata") OR TI ("Alopecia areata" OR "Alopecia totalis" OR "Alopecia Universalis" OR "Patchy Alopecia areata")



S1 AND S2 AND S3

ND S2 AND S3

Search Results: 1 - 40 of 58

1. Case study of **alopecia areata** treated with individualised homoeopathic medicine.

(includes abstract) Pal, Partha Pratim; Nath, Madhumita Homoeopathic Heritage, Feb2023; 49(11): 38-44. 7p. (Journal Article - case study, pictorial, tables/charts) ISSN: 0970-603X

Subjects: Alopecia Areata Drug Therapy; Homeopathic Agents Pharmacodynamics; Individualized Medicine; Adult: 19-44 years; Female

2. THE **PSYCHOLOGICAL EFFECTS** OF **ALOPECIA AREATA**.

(includes abstract) Brackenbury, Julie Dermatological Nursing, Jun2022; 21(2): 17-20. 4p. (Journal Article) ISSN: 1477-3368

Folder has items

A narrative study chem...

African american women, h...

Anticipating an altered a...

Go to: Folder View

PsycArticles (APA)

Title: "Alopecia areata" OR "Alopecia totalis" OR "Alopecia Universalis" OR "Patchy Alopecia areata" *OR* **Abstract**: "Alopecia areata" OR "Alopecia totalis" OR "Alopecia Universalis" OR "Patchy Alopecia areata"

2 Results for **Title**: "Alopecia areata" OR "Alopecia totalis" OR "Alopecia Universalis" OR "Patchy alopecia areata" *OR* **Abstract**: "Alopecia areata" OR "Alopecia totalis" OR "Alopecia Universalis" OR "Patchy alopecia areata"

1. ☐ Journal Article

Adverse childhood experiences, risk factors in the onset of autoimmune diseases in adults: A meta-analysis.

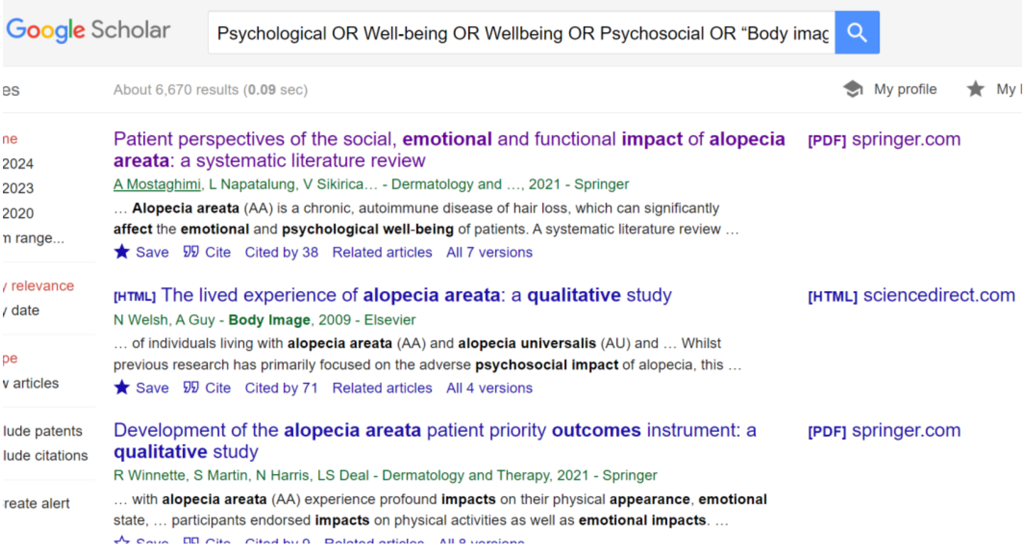
Macarenco, Maria-Magdalena, Opariuc-Dan, Cristian, & Nedelcea, Cătălin

Professional Psychology: Research and Practice, Vol 53(1), Feb 2022, 69-79

https://doi.org/10.1037/pro0000430

Google Scholar (6,670 results – searched / saved first 5 pages (50 results))

Psychological OR Well-being OR Wellbeing OR Psychosocial OR “Body image” OR Emotional OR Appearance* OR “Quality of life” OR QOL AND Identity* OR Impact* OR Effect* OR Experience* OR “Lived Experience*” AND “Alopecia areata” OR “Alopecia totalis” OR “Alopecia Universalis” OR “Patchy Alopecia areata” AND Qualitative



About 6,670 results (**0.09** sec)

Patient perspectives of the social, **emotional** and functional **impact** of **alopecia areata**: a systematic literature review — [PDF] springer.com

A Mostaghimi, L Napatalung, V Sikirica… - Dermatology and …, 2021 - Springer

… **Alopecia areata** (AA) is a chronic, autoimmune disease of hair loss, which can significantly **affect** the **emotional** and **psychological well-being** of patients. A systematic literature review …

Save Cite Cited by 38 Related articles All 7 versions

[HTML] The lived experience of **alopecia areata**: a **qualitative** study — [HTML] sciencedirect.com

N Welsh, A Guy - **Body Image**, 2009 - Elsevier

… of individuals living with **alopecia areata** (AA) and **alopecia universalis** (AU) and … Whilst previous research has primarily focused on the adverse **psychosocial impact** of alopecia, this …

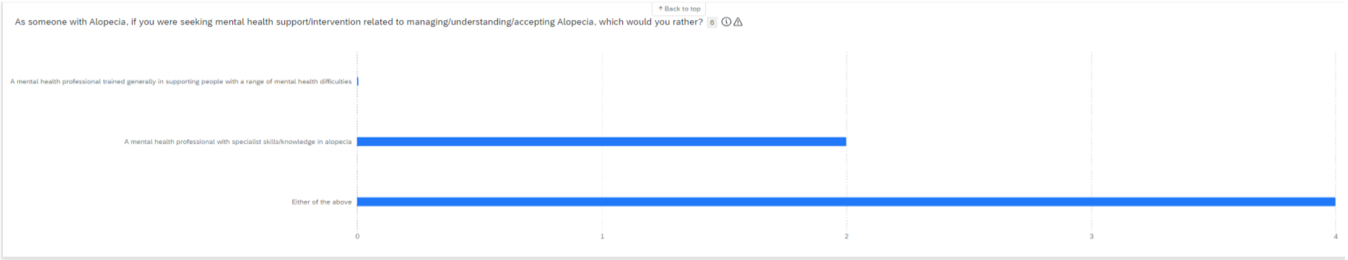
Save Cite Cited by 71 Related articles All 4 versions

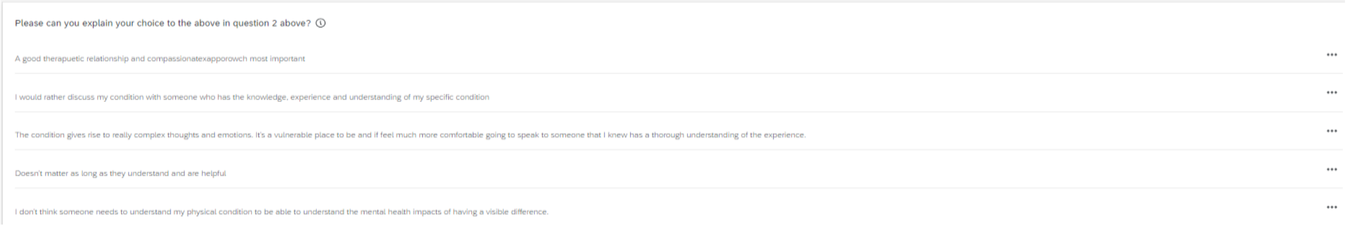
Development of the **alopecia areata** patient priority **outcomes** instrument: a **qualitative** study — [PDF] springer.com

R Winnette, S Martin, N Harris, LS Deal - Dermatology and Therapy, 2021 - Springer

… with **alopecia areata** (AA) experience profound **impacts** on their physical **appearance**, **emotional** state, … participants endorsed **impacts** on physical activities as well as **emotional impacts**. …

Appendix C – Feasibility testing / pilot study (N = 6)


As someone with Alopecia, if you were seeking mental health support/intervention related to managing/understanding/accepting Alopecia, which would you rather?


Please can you explain your choice to the above in question 2 above?

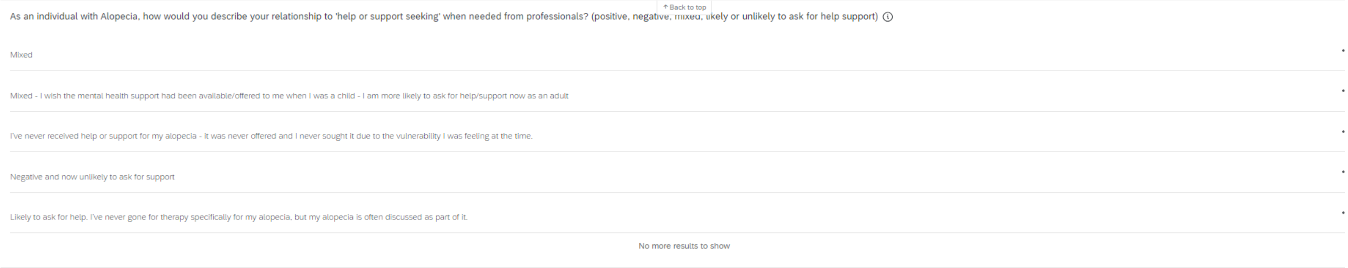
A good therapuetic relationship and compassionatexapporowch most important

I would rather discuss my condition with someone who has the knowledge, experience and understanding of my specific condition

The condition gives rise to really complex thoughts and emotions. It's a vulnerable place to be and if feel much more comfortable going to speak to someone that I knew has a thorough understanding of the experience.

Doesn't matter as long as they understand and are helpful

I don't think someone needs to understand my physical condition to be able to understand the mental health impacts of having a visible difference.


As an individual with Alopecia, how would you describe your relationship to 'help or support seeking' when needed from professionals? (positive, negative, mixed, likely or unlikely to ask for help support)

Mixed

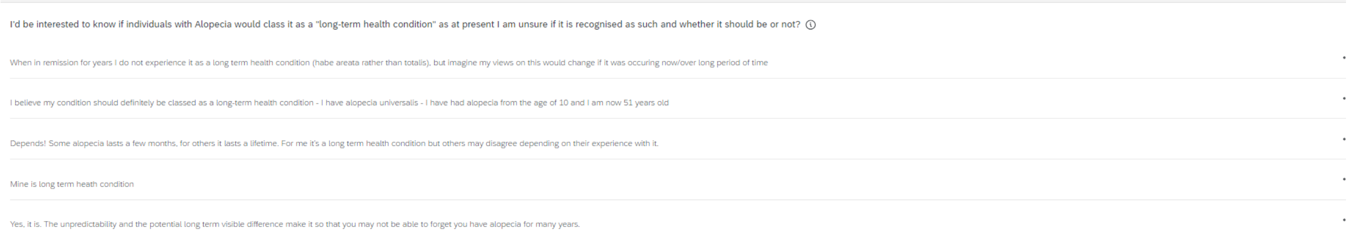
Mixed - I wish the mental health support had been available/offered to me when I was a child - I am more likely to ask for help/support now as an adult

I've never received help or support for my alopecia - it was never offered and I never sought it due to the vulnerability I was feeling at the time.

Negative and now unlikely to ask for support

Likely to ask for help. I've never gone for therapy specifically for my alopecia, but my alopecia is often discussed as part of it.

No more results to show


I'd be interested to know if individuals with Alopecia would class it as a "long-term health condition" as at present I am unsure if it is recognised as such and whether it should be or not?

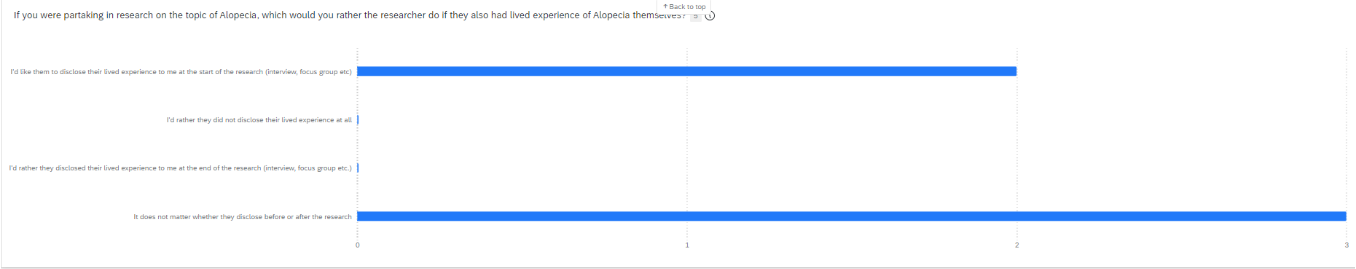
When in remission for years I do not experience it as a long term health condition (habe areata rather than totalis), but imagine my views on this would change if it was occuring now/over long period of time

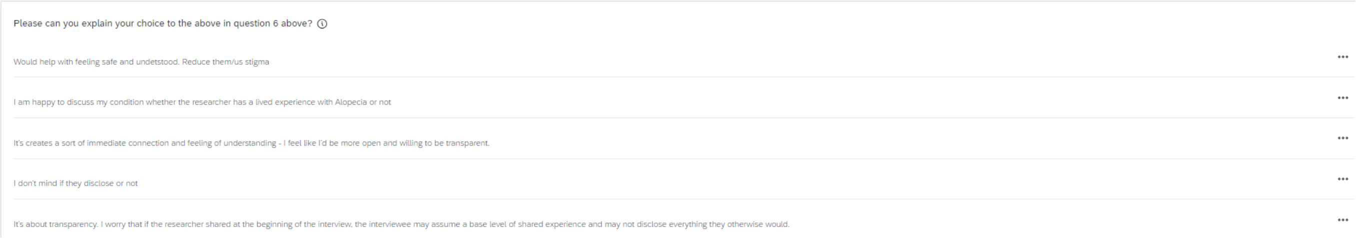
I believe my condition should definitely be classed as a long-term health condition - I have alopecia universalis - I have had alopecia from the age of 10 and I am now 51 years old

Depends! Some alopecia lasts a few months, for others it lasts a lifetime. For me it's a long term health condition but others may disagree depending on their experience with it.

Mine is long term heath condition

Yes, it is. The unpredictability and the potential long term visible difference make it so that you may not be able to forget you have alopecia for many years.


If you were partaking in research on the topic of Alopecia, which would you rather the researcher do if they also had lived experience of Alopecia themselves?


Please can you explain your choice to the above in question 6 above?

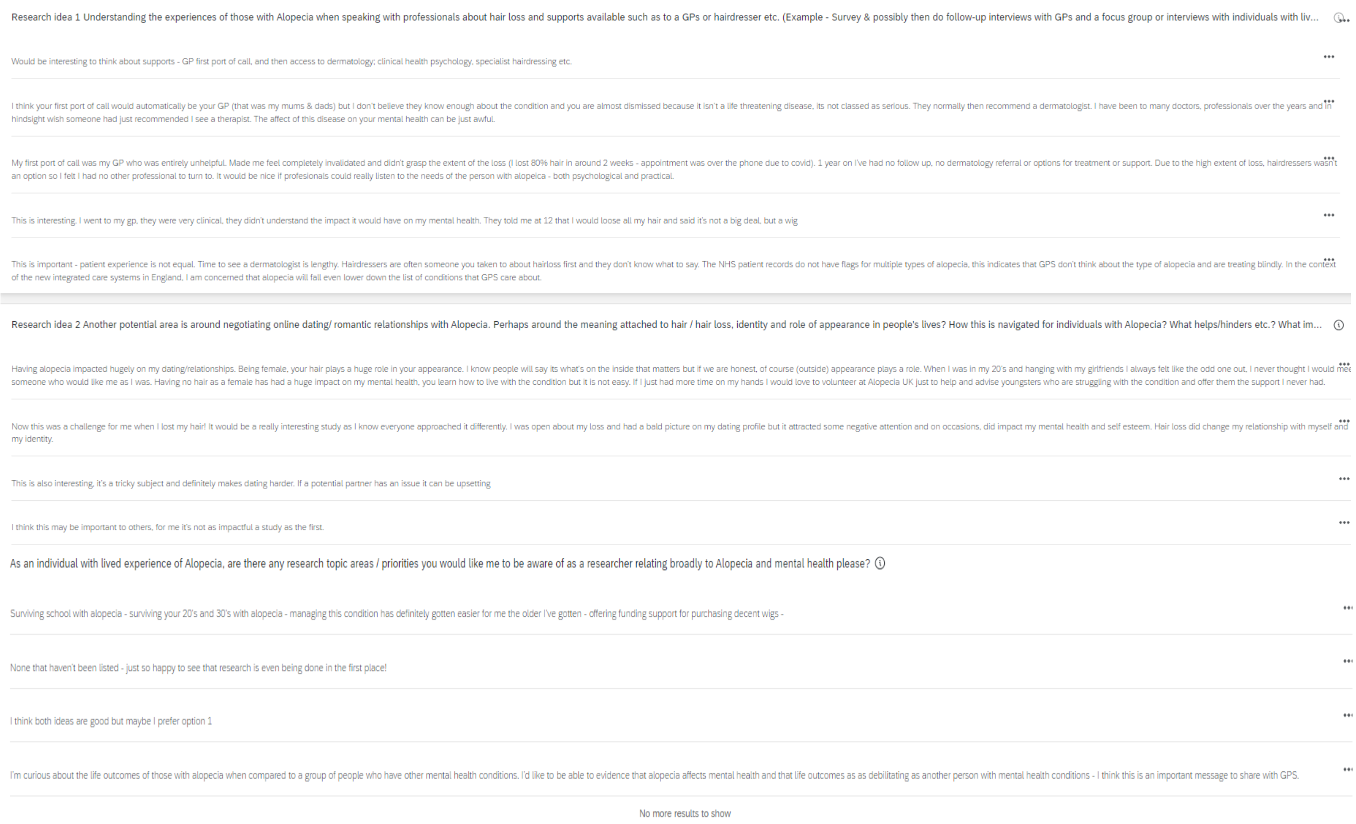
Would help with feeling safe and undetstood. Reduce them/us stigma

I am happy to discuss my condition whether the researcher has a lived experience with Alopecia or not

It's creates a sort of immediate connection and feeling of understanding - I feel like I'd be more open and willing to be transparent.

I don't mind if they disclose or not

It's about transparency. I worry that if the researcher shared at the beginning of the interview, the interviewee may assume a base level of shared experience and may not disclose everything they otherwise would.



Research idea 1 Understanding the experiences of those with Alopecia when speaking with professionals about hair loss and supports available such as to a GPs or hairdresser etc. (Example - Survey & possibly then do follow-up interviews with GPs and a focus group or interviews with individuals with liv...

Would be interesting to think about supports - GP first port of call, and then access to dermatology; clinical health psychology, specialist hairdressing etc.

I think your first port of call would automatically be your GP (that was my mums & dads) but I don't believe they know enough about the condition and you are almost dismissed because it isn't a life threatening disease, its not classed as serious. They normally then recommend a dermatologist. I have been to many doctors, professionals over the years and in hindsight wish someone had just recommended I see a therapist. The affect of this disease on your mental health can be just awful.

My first port of call was my GP who was entirely unhelpful. Made me feel completely invalidated and didn't grasp the extent of the loss (I lost 80% hair in around 2 weeks - appointment was over the phone due to covid). 1 year on I've had no follow up, no dermatology referral or options for treatment or support. Due to the high extent of loss, hairdressers wasn't an option so I felt I had no other professional to turn to. It would be nice if profesionals could really listen to the needs of the person with alopeica - both psychological and practical.

This is interesting. I went to my gp, they were very clinical, they didn't understand the impact it would have on my mental health. They told me at 12 that I would loose all my hair and said it's not a big deal, but a wig

This is important - patient experience is not equal. Time to see a dermatologist is lengthy. Hairdressers are often someone you taken to about hairloss first and they don't know what to say. The NHS patient records do not have flags for multiple types of alopecia, this indicates that GPS don't think about the type of alopecia and are treating blindly. In the context of the new integrated care systems in England, I am concerned that alopecia will fall even lower down the list of conditions that GPS care about.

Research idea 2 Another potential area is around negotiating online dating/ romantic relationships with Alopecia. Perhaps around the meaning attached to hair / hair loss, identity and role of appearance in people's lives? How this is navigated for individuals with Alopecia? What helps/hinders etc.? What im...

Having alopecia impacted hugely on my dating/relationships. Being female, your hair plays a huge role in your appearance. I know people will say its what's on the inside that matters but if we are honest, of course (outside) appearance plays a role. When I was in my 20's and hanging with my girlfriends I always felt like the odd one out, I never thought I would meet someone who would like me as I was. Having no hair as a female has had a huge impact on my mental health, you learn how to live with the condition but it is not easy. If I just had more time on my hands I would love to volunteer at Alopecia UK just to help and advise youngsters who are struggling with the condition and offer them the support I never had.

Now this was a challenge for me when I lost my hair! It would be a really interesting study as I know everyone approached it differently. I was open about my loss and had a bald picture on my dating profile but it attracted some negative attention and on occasions, did impact my mental health and self esteem. Hair loss did change my relationship with myself and my identity.

This is also interesting, it's a tricky subject and definitely makes dating harder. If a potential partner has an issue it can be upsetting

I think this may be important to others, for me it's not as impactful a study as the first.

As an individual with lived experience of Alopecia, are there any research topic areas / priorities you would like me to be aware of as a researcher relating broadly to Alopecia and mental health please?

Surviving school with alopecia - surviving your 20's and 30's with alopecia - managing this condition has definitely gotten easier for me the older I've gotten - offering funding support for purchasing decent wigs -

None that haven't been listed - just so happy to see that research is even being done in the first place!

I think both ideas are good but maybe I prefer option 1

I'm curious about the life outcomes of those with alopecia when compared to a group of people who have other mental health conditions. I'd like to be able to evidence that alopecia affects mental health and that life outcomes as as debilitating as another person with mental health conditions - I think this is an important message to share with GPS.

No more results to show

Appendix D – Demographics & Interview Schedule

Demographic Questions

1. Which of the following best describes your gender?

Male

Female

Non-binary

2. What is your age (in years)?

____

3. Which of the following best describes your ethnicity?

Asian or Asian British
Arab
Indian
Pakistani
Bangladeshi
Chinese
Any other Asian background
Black, Black British, Caribbean or African
Caribbean
African
Any other Black or Caribbean background
White and Black Caribbean
White and Black African
White and Asian
White other
English, Welsh, Scottish, Northern Irish or British
Irish
Gypsy or Irish Traveller
Roma

Any other ethnic group

4. Age of first onset of Alopecia(in years)?

____

5. What type of Alopecia have you do you suffer from?

Alopecia Areata
Alopecia Totalis
Alopecia Universalis
Androgenetic Alopecia
Central Centrifugal Cicatricial Alopecia(CCCA)
Lichen Planopilaris
Frontal Fibrosing Alopecia

6. Have you ever sought professional support for your alopecia? (GP, Dermatologist, Psychological support?

Yes

No

Semi-structured interview questions

Introduction

1. Tell me a little bit about yourself? (Icebreaker)

Experiences/effects of Alopecia

2. Tell me what it is like to live with Alopecia? (physical / psychological / QoL etc.)
3. Does having Alopecia affect your sense of who you are as a person / your identity?
4. What is the emotional/psychological impact of living with Alopecia? (Impact on mood?)

Coping with Alopecia

5. What or who helps you to cope with Alopecia? (family/friends, specific strategies, products, support groups?).
6. Can you think of anything that has negatively impacted or hindered your ability to cope with Alopecia?

Support seeking / experiences of going to a professional (GP/ Dermatologist)

7. When you noticed hair loss, what happened next? What influenced your decision to / not seek help for Alopecia?
8. Who did you seek support from when you first noticed Alopecia? (From GP / dermatology / psychological / other?). If no, explore why? / any referrals made?
9. What has your experience been of seeking information or help around Alopecia? What did you find helpful/unhelpful about the support you received? (From GP / dermatology / psychological?
10. Do you think the impact of Alopecia is currently understood by professionals such as GPs/dermatologists/psychologists? (Could you say more on the / why do you think this is?
11. What would you like professionals (GPs / dermatologists / psychologists) to know / say / do that would make interactions more beneficial / help you or others seeking support in the future?
12. Can you tell me one key thing you would like professionals to understand when working with people who have lived experience of Alopecia?

Support offered / Satisfaction.

13. When you did seek professional support for your Alopecia, what type of supports were offered to you?
14. Were you satisfied with what was offered? (If yes / no then why?)

Anything additional / experience of the interview

15. Is there anything else you feel is important for me to know, that we have not covered in this interview?
16. How have you found the interview experience?

Appendix E – Recruitment poster (shared via social media & Alopecia UK)

RESEARCH PARTICIPANTS NEEDED!

Do you have Alopecia?

This study is looking for people who are:

- Diagnosed with certain types of alopecia (e.g., alopecia areata patchy, totalis or universalis, or androgenetic alopecia, or scarring alopecia).
- Aged 18 and over.
- Fluent in English.
- Living in the UK.
- All genders.

Aims:

We need your help to better understand the impact of living with alopecia. We want to hear about what having alopecia feels like to you, anything that might have helped or has not helped your well-being. We also want to hear about your experiences with medical professionals you have seen about your alopecia to help us understand any challenges and what any positive experiences look like.

What do I have to do to participate?

We are inviting people to participate in an interview for up to 60 minute online via Zoom with Ashley, a trainee clinical psychologist.

About the researcher:

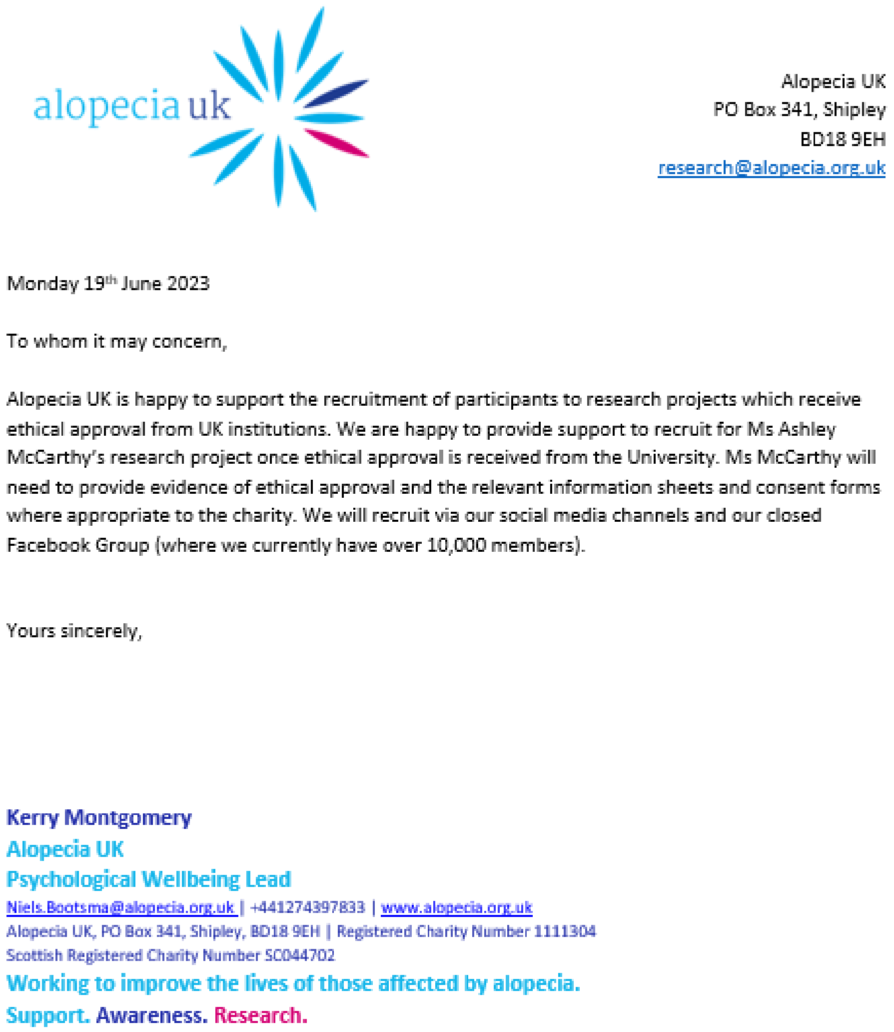
I am Ashley, a trainee clinical psychologist completeing this research as part of my doctorate in Clinical Psychology at the University of Hertfordshire.

How do I sign up for this research project?

Please email *a.mccarthy7@herts.ac.uk* to receive further information, ask questions or arrange a suitable date and time to conduct the interview.

University of Hertfordshire UH

Appendix F – Approval letter Alopecia UK



Alopecia UK
PO Box 341, Shipley
BD18 9EH
research@alopecia.org.uk

Monday 19th June 2023

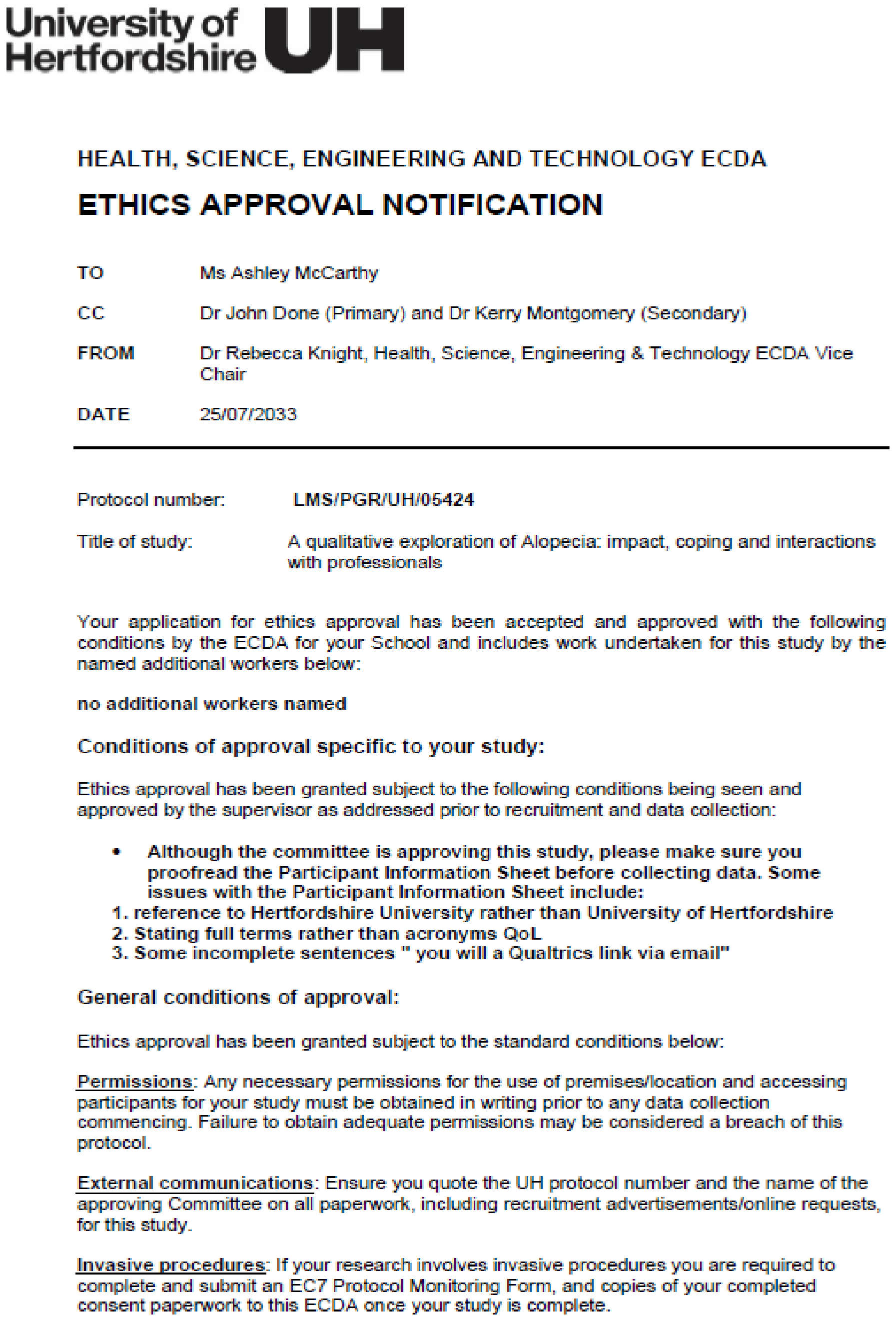
To whom it may concern,

Alopecia UK is happy to support the recruitment of participants to research projects which receive ethical approval from UK institutions. We are happy to provide support to recruit for Ms Ashley McCarthy's research project once ethical approval is received from the University. Ms McCarthy will need to provide evidence of ethical approval and the relevant information sheets and consent forms where appropriate to the charity. We will recruit via our social media channels and our closed Facebook Group (where we currently have over 10,000 members).

Yours sincerely,

Kerry Montgomery
Alopecia UK
Psychological Wellbeing Lead
Niels.Bootsma@alopecia.org.uk | +441274397833 | www.alopecia.org.uk
Alopecia UK, PO Box 341, Shipley, BD18 9EH | Registered Charity Number 1111304
Scottish Registered Charity Number SC044702
Working to improve the lives of those affected by alopecia.
Support. Awareness. Research.

Appendix G – Ethical approval letter



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Ms Ashley McCarthy
CC Dr John Done (Primary) and Dr Kerry Montgomery (Secondary)
FROM Dr Rebecca Knight, Health, Science, Engineering & Technology ECDA Vice Chair
DATE 25/07/2033

Protocol number: **LMS/PGR/UH/05424**

Title of study: A qualitative exploration of Alopecia: impact, coping and interactions with professionals

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

Conditions of approval specific to your study:

Ethics approval has been granted subject to the following conditions being seen and approved by the supervisor as addressed prior to recruitment and data collection:

- **Although the committee is approving this study, please make sure you proofread the Participant Information Sheet before collecting data. Some issues with the Participant Information Sheet include:**

1. reference to Hertfordshire University rather than University of Hertfordshire
2. Stating full terms rather than acronyms QoL
3. Some incomplete sentences " you will a Qualtrics link via email"

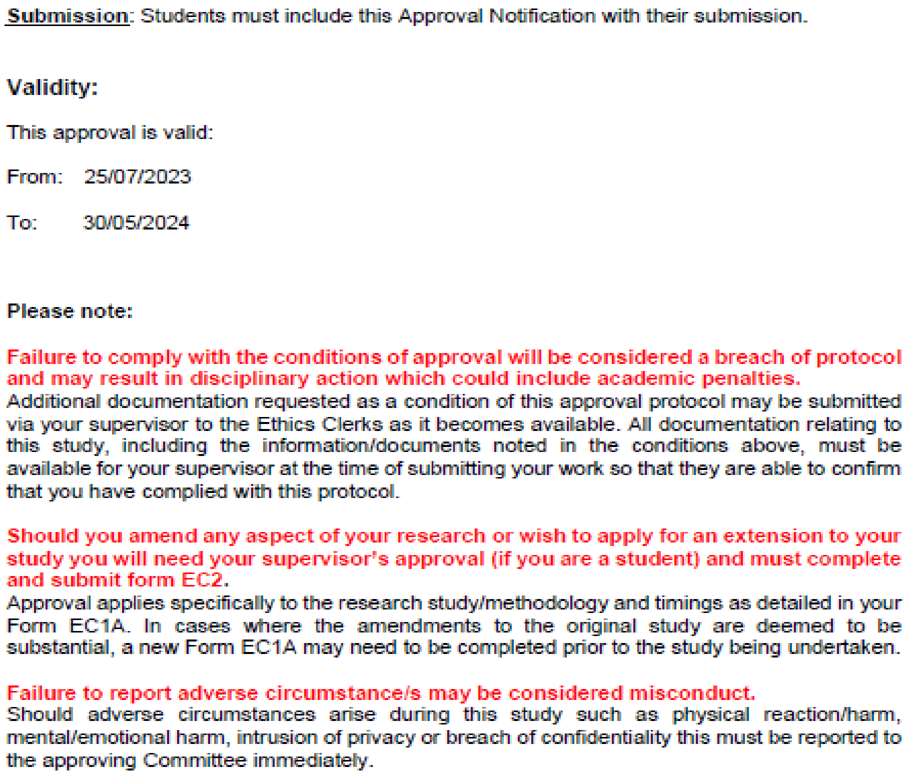
General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.



Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 25/07/2023

To: 30/05/2024

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix H – Participant Information sheet

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS (‘ETHICS COMMITTEE’)

FORM EC6: PARTICIPANT INFORMATION/BRIEFING SHEET

PARTICIPANT INFORMATION/BRIEFING SHEET

Title: *A qualitative exploration of Alopecia: impact, coping, and interactions with professionals*

Introduction
My name is Ashley McCarthy, and I am a trainee Clinical Psychologist. I am conducting my major research project (MRP) as part of my professional doctorate in Clinical Psychology at the University of Hertfordshire. You are being invited to take part in a study on Alopecia. Before you decide whether to do so, it is essential that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask me anything that is not clear or for any further information, you would like to help you make your decision. Please do take your time to decide whether you wish to take part.

The University’s regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link: https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

What is the purpose of this study?
The purpose of this study is to conduct semi-structured interviews to better understand:

1. How does living with Alopeciaaffect identity/well-being/quality of life?
2. What helps/hinders people living with Alopecia cope with the condition?
3. What affects help-seeking when deciding whether to seek professional support for Alopecia?
4. What do those with Alopecia want from interactions with medical professionals (e.g., GPs, Dermatologists)?

My relationship/interest to the research topic:
This research area holds a lot of importance and meaning to me. Therefore, transparency with potential participants is essential. I myself have lived experience of Alopecia since age 14. While it is essential that participants are aware of this when deciding whether to partake, I am also aware that Alopecia is a highly personal journey. Therefore, individual experiences will likely differ, and will be a privilege to hear.

Do I have to take part?
It is completely up to you whether you participate in this study. If you do decide to participate, you will be sent an information sheet, asked a few pre-screening and demographic questions, and asked to sign a consent form. Agreeing to join the study does not mean you must complete it. You are free to withdraw from the study until 26/01/24 without giving a reason; after this date the researcher will have begun data analysis of the interview data making it more challenging to remove your data.

Are there any inclusion or exclusion, age-related or other restrictions that may prevent me from participating?

The study inclusion criteria are as follows: Adults over aged 18, fluent in English, of any gender identification with a diagnosis of a type of Alopecia by a medical professional, Alopecia(including Alopecia Areata such as totalis and universalis, or androgenetic alopecia, or types of scarring alopecia) who reside in the UK.

The study exclusion criteria are as follows: those under the age of 18, or those specifically with Alopecia due to cancer treatment or a diagnosis of Trichotillomania.

How long will my part in the study take?

Initially, you will be sent an information sheet, be asked some pre-screening and demographic questions, and sign a consent form on Qualtrics via email. To participate, a Zoom link will be set up and sent to you for a suitable day and time, agreed between you and the researcher. During the interview, the researcher will ask you a range of questions related to your experiences of living with Alopecia. The semi-structured interview will be recorded. It will last for 45-60 minutes. The interview data will be saved securely and then be analysed by the researcher.

What will happen to me if I take part?

Once you have read the information sheet, if you are eligible for the study, you will complete a Qualtrics link with screening and demographic questions and a consent form. You will be sent a Zoom link via email to engage in the semi-structured interview on an agreed day/time. It will last for 45-60 minutes.

What are the possible disadvantages, risks, or side effects of taking part?

The researcher does not foresee any disadvantages to taking part in this study. In relation to risk, the risk is low but the content of some of the questions may/may not bring up mixed emotions given that you are being asked to speak about a topic that is personal and actively think its impact.

If any distress is caused, please see below for support you can access:

Depending on your experiences of having Alopecia/ hair loss, for some going through the survey may bring up difficult memories, thoughts and feelings. If it gets a bit much, please do feel free to take a break or even stop entirely.

You can also contact any of the below support organisations:

Contact your GP if you are experiencing distress and feel it would help to speak to someone.

Samaritans Helpline: 116 123 (24 hrs, everyday)

You can visit the Alopecia webpage for other sources of support which lists organisations which may be helpful Other sources of help | Alopecia

What are the possible benefits of taking part?

This research project will allow us to better understand the impact of alopecia, how those with Alopecia cope with their lived experience, and how to improve relationships with professionals, namely GPs or Dermatologists.

How will my taking part in this study be kept confidential?

All information provided throughout the research will be kept confidential. The data will be stored electronically on the University of Hertfordshire's secure network in a password-protected file. The results will be presented in a research report as part of the course requirements. The research will also be considered for publication, presented in the form of numbers and quotations. It will be anonymous and careful attention will be made to ensure you cannot be identified.

What will happen to the data collected within this study?

Data will only be seen by the research team. The data will be anonymised before storage. The data collected will be stored electronically, in a password-protected environment until the researcher has completed the Doctorate in Clinical Psychology at the end of September 2024 or until the research has been accepted for publication and subsequently published, after which time it will be destroyed under secure conditions.

Will the data be required for use in further studies?
The collected data will not be used in any further studies.

Who has reviewed this study?
This study has been favourably reviewed by the University of Hertfordshire Health, Science, Engineering Technology Ethics Committee with delegated authority.

The study protocol number is: *LMS/PGR/UH/05424*

Factors that might put others at risk:
Please note that if, during the study, any medical conditions, or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

Will I receive anything if I do this study?
There will be an option to enter a raffle for a Love2Shop voucher. The winner will be notified via email.

Who can I contact if I have any questions?
If you would like further information or would like to discuss any details personally, please get in touch with:

Principal Investigator/researcher:
Ms Ashley McCarthy, Trainee Clinical Psychologist
Email: a.mccarthy7@herts.ac.uk

Primary Supervisor(s):
Dr John Done
Email: d.j.done@herts.ac.uk

Secondary Supervisor(s):
Dr Kerry Montgomery
Email: kerry.montgomery@alopecia.org.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane Hatfield
Herts AL10 9AB

Thank you very much for reading this information and considering participating in this study.

Appendix I – Consent form

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

FORM EC3
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

Informed Consent: Participants with lived experience of alopecia

Consent form

To provide consent please read and tick the following:

- I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed and asked to renew my consent to participate in it. ☐
- I have been assured that I may withdraw from the study, and that I may withdraw my permission to continue to be involved in the study, by the 26.01.24 without disadvantage to myself or having to give a reason. I am aware that after the 26.01.24 data analysis will have commenced. ☐
- I have been given information about the risks of suffering harm or adverse (Please see contacts in information sheet). (Samaritans over 18 / Alopecia UK) ☐
- I have been told how information relating to me (data obtained in the course of the study), will be handled: how it will be kept secure, who will see it and how it will or may be used. ☐
- I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities. ☐
- I consent to being recontacted in the future again in connection with this or another study. ☐

Signature of participant……………………………………..

Date…………………………

Signature of (principal) investigator………………………………………………………

Date…………………………

Name of (principal) investigator [in BLOCK CAPITALS please]

……………………………………………………………………………………………………

Right to withdraw

In the event you wish to withdraw a code will be needed to identify you. Please create your code here in the box below. Initials and date of interview.

Example: Joy Bloggs on 03.02.23 code would be JB030223. Please make a note of your code!

Code: ___________________________

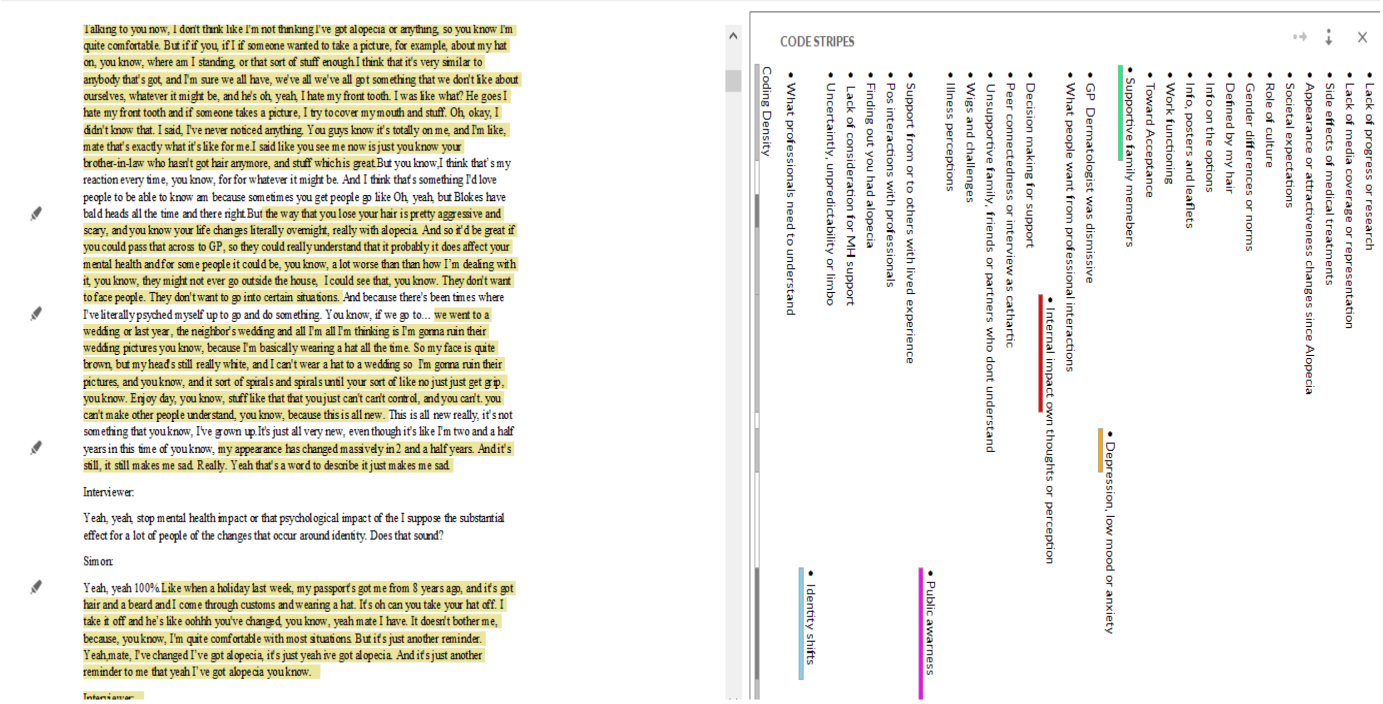
Reminder - Participants must email the researcher by the 26/01/24 with their code if they wish to withdraw.

Email for raffle

If you wish to partake in the raffle for a Love2Shop voucher, please enter your email below:

Email: _____________________________

Appendix J – Example interview transcripts



Talking to you now, I don't think like I'm not thinking I've got alopecia or anything, so you know I'm quite comfortable. But if if you, if I if someone wanted to take a picture, for example, about my hat on, you know, where am I standing, or that sort of stuff enough.I think that it's very similar to anybody that's got, and I'm sure we all have, we've all we've all got something that we don't like about ourselves, whatever it might be, and he's oh, yeah, I hate my front tooth. I was like what? He goes I hate my front tooth and if someone takes a picture, I try to cover my mouth and stuff. Oh, okay, I didn't know that. I said, I've never noticed anything. You guys know it's totally on me, and I'm like, mate that's exactly what it's like for me.I said like you see me now is just you know your brother-in-law who hasn't got hair anymore, and stuff which is great.But you know,I think that's my reaction every time, you know, for for whatever it might be. And I think that's something I'd love people to be able to know am because sometimes you get people go like Oh, yeah, but Blokes have bald heads all the time and there right.But the way that you lose your hair is pretty aggressive and scary, and you know your life changes literally overnight, really with alopecia. And so it'd be great if you could pass that across to GP, so they could really understand that it probably it does affect your mental health and for some people it could be, you know, a lot worse than than how I'm dealing with it, you know, they might not ever go outside the house, I could see that, you know. They don't want to face people. They don't want to go into certain situations. And because there's been times where I've literally psyched myself up to go and do something. You know, if we go to... we went to a wedding or last year, the neighbor's wedding and all I'm all I'm thinking is I'm gonna ruin their wedding pictures you know, because I'm basically wearing a hat all the time. So my face is quite brown, but my head's still really white, and I can't wear a hat to a wedding so I'm gonna ruin their pictures, and you know, and it sort of spirals and spirals until your sort of like no just just get grip, you know. Enjoy day, you know, stuff like that that you just can't can't control, and you can't. you can't make other people understand, you know, because this is all new. This is all new really, it's not something that you know, I've grown up.It's just all very new, even though it's like I'm two and a half years in this time of you know, my appearance has changed massively in 2 and a half years. And it's still, it still makes me sad. Really. Yeah that's a word to describe it just makes me sad.

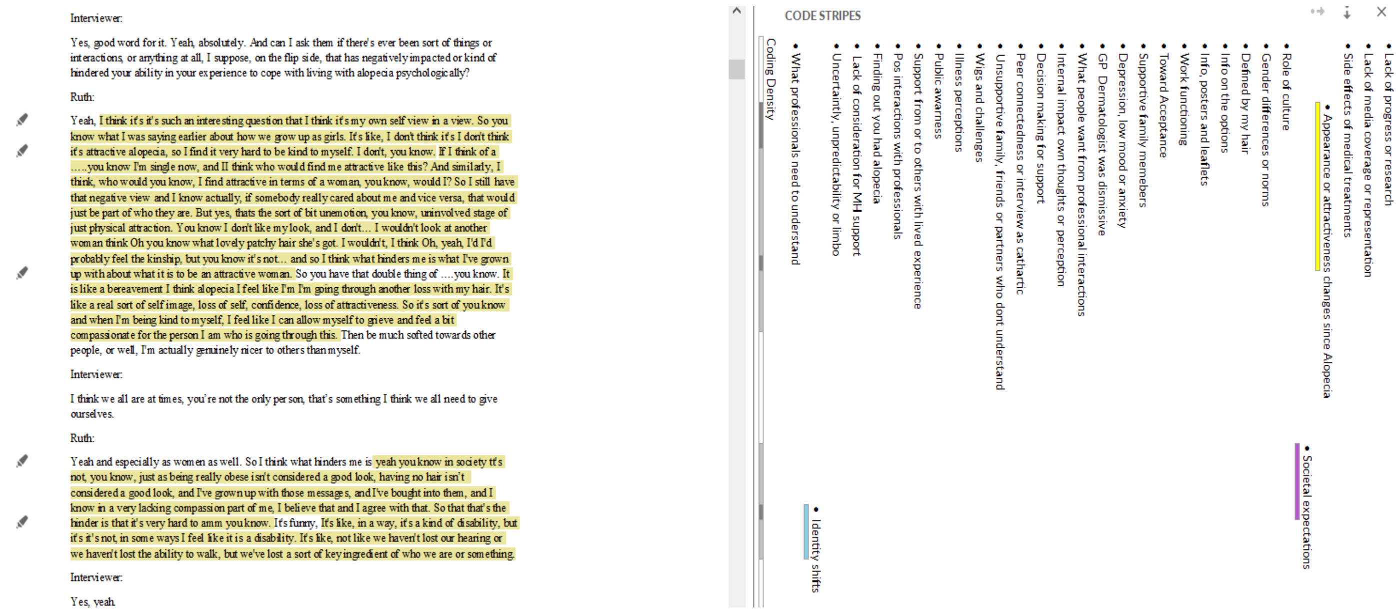
Interviewer:

Yeah, yeah, stop mental health impact or that psychological impact of the I suppose the substantial effect for a lot of people of the changes that occur around identity. Does that sound?

Simon:

Yeah, yeah 100%.Like when a holiday last week, my passport's got me from 8 years ago, and it's got hair and a beard and I come through customs and wearing a hat. It's oh can you take your hat off. I take it off and he's like oohhh you've changed, you know, yeah mate I have. It doesn't bother me, because, you know, I'm quite comfortable with most situations. But it's just another reminder. Yeah,mate, I've changed I've got alopecia, it's just yeah ive got alopecia. And it's just another reminder to me that yeah I've got alopecia you know.

Interviewer:



Interviewer:

Yes, good word for it. Yeah, absolutely. And can I ask them if there's ever been sort of things or interactions, or anything at all, I suppose, on the flip side, that has negatively impacted or kind of hindered your ability in your experience to cope with living with alopecia psychologically?

Ruth:

Yeah, I think it's it's such an interesting question that I think it's my own self view in a view. So you know what I was saying earlier about how we grow up as girls. It's like, I don't think it's I don't think it's attractive alopecia, so I find it very hard to be kind to myself. I don't, you know. If I think of a .....you know I'm single now, and II think who would find me attractive like this? And similarly, I think, who would you know, I find attractive in terms of a woman, you know, would I? So I still have that negative view and I know actually, if somebody really cared about me and vice versa, that would just be part of who they are. But yes, thats the sort of bit unemotion, you know, uninvolved stage of just physical attraction. You know I don't like my look, and I don't... I wouldn't look at another woman think Oh you know what lovely patchy hair she's got. I wouldn't, I think Oh, yeah, I'd I'd probably feel the kinship, but you know it's not... and so I think what hinders me is what I've grown up with about what it is to be an attractive woman. So you have that double thing of ....you know. It is like a bereavement I think alopecia I feel like I'm I'm going through another loss with my hair. It's like a real sort of self image, loss of self, confidence, loss of attractiveness. So it's sort of you know and when I'm being kind to myself, I feel like I can allow myself to grieve and feel a bit compassionate for the person I am who is going through this. Then be much softed towards other people, or well, I'm actually genuinely nicer to others than myself.

Interviewer:

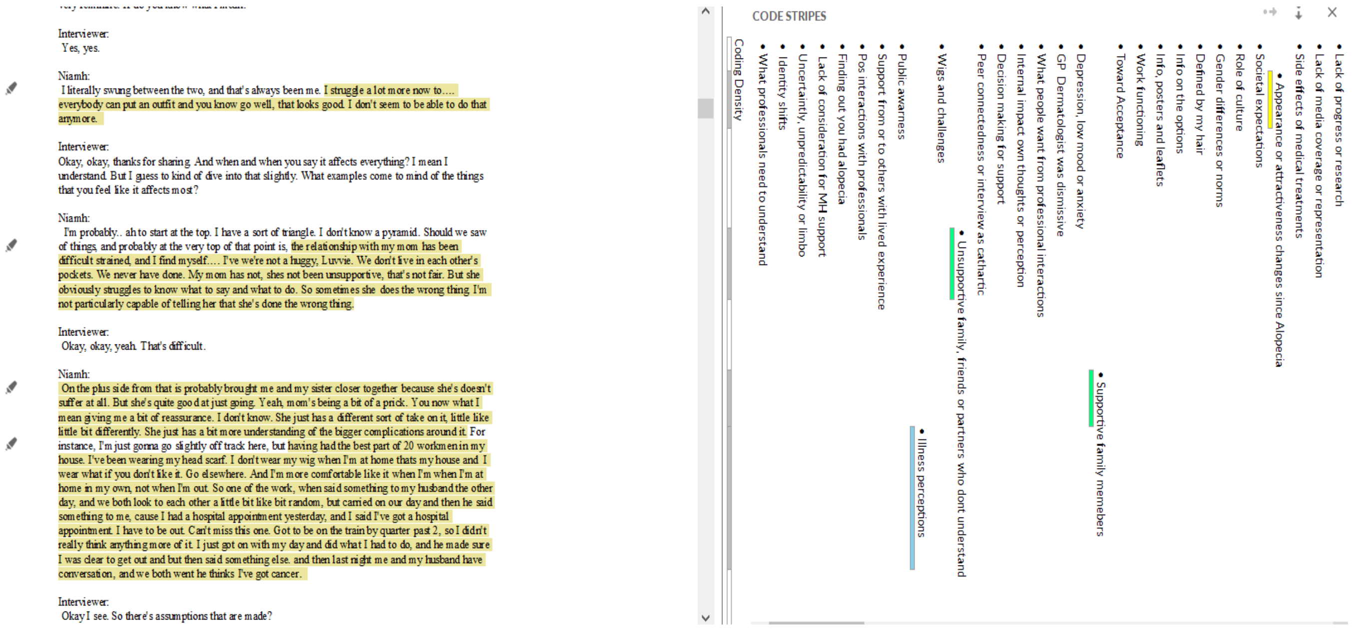
I think we all are at times, you're not the only person, that's something I think we all need to give ourselves.

Ruth:

Yeah and especially as women as well. So I think what hinders me is yeah you know in society it's not, you know, just as being really obese isn't considered a good look, having no hair isn't considered a good look, and I've grown up with those messages, and I've bought into them, and I know in a very lacking compassion part of me, I believe that and I agree with that. So that that's the hinder is that it's very hard to amm you know. It's funny, It's like, in a way, it's a kind of disability, but it's it's not, in some ways I feel like it is a disability. It's like, not like we haven't lost our hearing or we haven't lost the ability to walk, but we've lost a sort of key ingredient of who we are or something.

Interviewer:

Yes, yeah.



Interviewer:
Yes, yes.

Niamh:
I literally swung between the two, and that's always been me. I struggle a lot more now to…. everybody can put an outfit and you know go well, that looks good. I don't seem to be able to do that anymore.

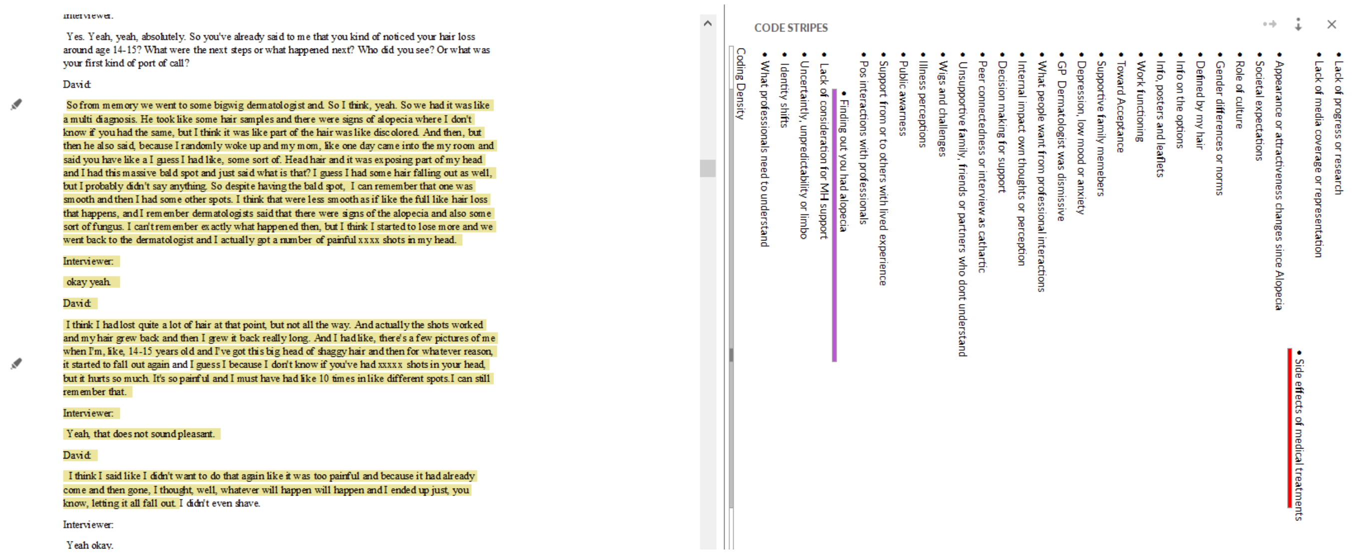
Interviewer:
Okay, okay, thanks for sharing. And when and when you say it affects everything? I mean I understand. But I guess to kind of dive into that slightly. What examples come to mind of the things that you feel like it affects most?

Niamh:
I'm probably.. ah to start at the top. I have a sort of triangle. I don't know a pyramid. Should we saw of things, and probably at the very top of that point is, the relationship with my mom has been difficult strained, and I find myself…. I've we're not a huggy, Luvvie. We don't live in each other's pockets. We never have done. My mom has not, shes not been unsupportive, that's not fair. But she obviously struggles to know what to say and what to do. So sometimes she does the wrong thing. I'm not particularly capable of telling her that she's done the wrong thing.

Interviewer:
Okay, okay, yeah. That's difficult.

Niamh:
On the plus side from that is probably brought me and my sister closer together because she's doesn't suffer at all. But she's quite good at just going. Yeah, mom's being a bit of a prick. You now what I mean giving me a bit of reassurance. I don't know. She just has a different sort of take on it, little like little bit differently. She just has a bit more understanding of the bigger complications around it. For instance, I'm just gonna go slightly off track here, but having had the best part of 20 workmen in my house. I've been wearing my head scarf. I don't wear my wig when I'm at home thats my house and I wear what if you don't like it. Go elsewhere. And I'm more comfortable like it when I'm when I'm at home in my own, not when I'm out. So one of the work, when said something to my husband the other day, and we both look to each other a little bit like bit random, but carried on our day and then he said something to me, cause I had a hospital appointment yesterday, and I said I've got a hospital appointment. I have to be out. Can't miss this one. Got to be on the train by quarter past 2, so I didn't really think anything more of it. I just got on with my day and did what I had to do, and he made sure I was clear to get out and but then said something else. and then last night me and my husband have conversation, and we both went he thinks I've got cancer.

Interviewer:
Okay I see. So there's assumptions that are made?



Interviewer:

Yes. Yeah, yeah, absolutely. So you've already said to me that you kind of noticed your hair loss around age 14-15? What were the next steps or what happened next? Who did you see? Or what was your first kind of port of call?

David:

So from memory we went to some bigwig dermatologist and. So I think, yeah. So we had it was like a multi diagnosis. He took like some hair samples and there were signs of alopecia where I don't know if you had the same, but I think it was like part of the hair was like discolored. And then, but then he also said, because I randomly woke up and my mom, like one day came into the my room and said you have like a I guess I had like, some sort of. Head hair and it was exposing part of my head and I had this massive bald spot and just said what is that? I guess I had some hair falling out as well, but I probably didn't say anything. So despite having the bald spot, I can remember that one was smooth and then I had some other spots. I think that were less smooth as if like the full like hair loss that happens, and I remember dermatologists said that there were signs of the alopecia and also some sort of fungus. I can't remember exactly what happened then, but I think I started to lose more and we went back to the dermatologist and I actually got a number of painful xxxx shots in my head.

Interviewer:

okay yeah.

David:

I think I had lost quite a lot of hair at that point, but not all the way. And actually the shots worked and my hair grew back and then I grew it back really long. And I had like, there's a few pictures of me when I'm, like, 14-15 years old and I've got this big head of shaggy hair and then for whatever reason, it started to fall out again and I guess I because I don't know if you've had xxxxx shots in your head, but it hurts so much. It's so painful and I must have had like 10 times in like different spots.I can still remember that.

Interviewer:

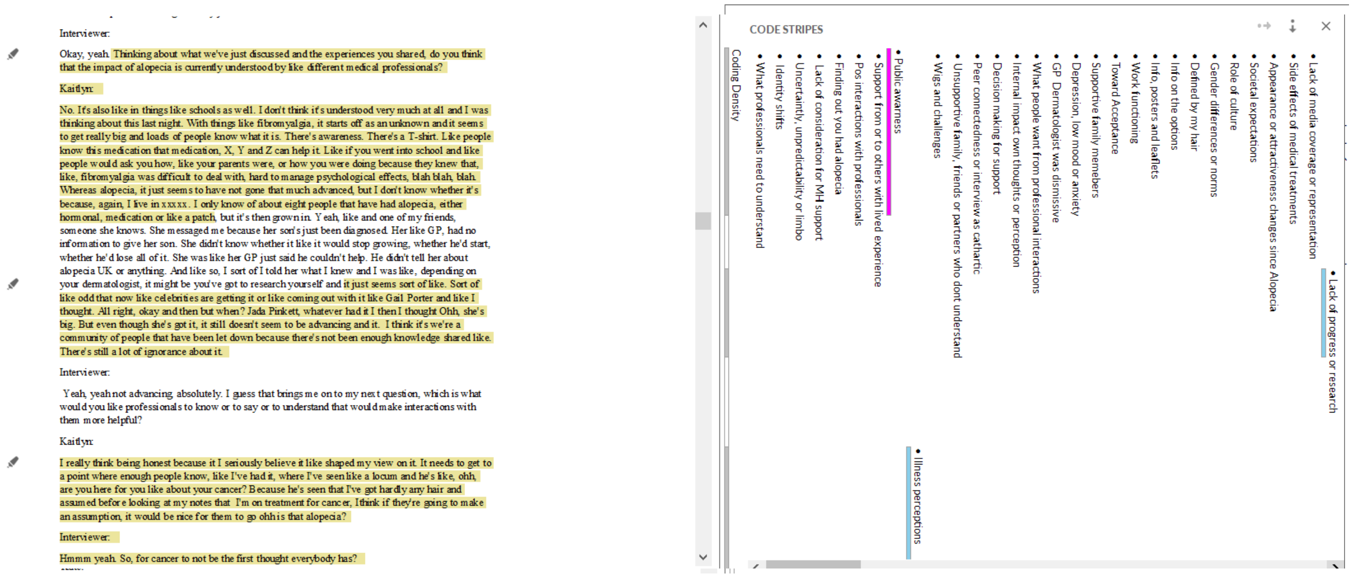
Yeah, that does not sound pleasant.

David:

I think I said like I didn't want to do that again like it was too painful and because it had already come and then gone, I thought, well, whatever will happen will happen and I ended up just, you know, letting it all fall out. I didn't even shave.

Interviewer:

Yeah okay.



Interviewer:

Okay, yeah. Thinking about what we've just discussed and the experiences you shared, do you think that the impact of alopecia is currently understood by like different medical professionals?

Kaitlyn:

No. It's also like in things like schools as well. I don't think it's understood very much at all and I was thinking about this last night. With things like fibromyalgia, it starts off as an unknown and it seems to get really big and loads of people know what it is. There's awareness. There's a T-shirt. Like people know this medication that medication, X, Y and Z can help it. Like if you went into school and like people would ask you how, like your parents were, or how you were doing because they knew that, like, fibromyalgia was difficult to deal with, hard to manage psychological effects, blah blah, blah. Whereas alopecia, it just seems to have not gone that much advanced, but I don't know whether it's because, again, I live in xxxxx. I only know of about eight people that have had alopecia, either hormonal, medication or like a patch, but it's then grown in. Yeah, like and one of my friends, someone she knows. She messaged me because her son's just been diagnosed. Her like GP, had no information to give her son. She didn't know whether it like it would stop growing, whether he'd start, whether he'd lose all of it. She was like her GP just said he couldn't help. He didn't tell her about alopecia UK or anything. And like so, I sort of I told her what I knew and I was like, depending on your dermatologist, it might be you've got to research yourself and it just seems sort of like. Sort of like odd that now like celebrities are getting it or like coming out with it like Gail Porter and like I thought. All right, okay and then but when? Jada Pinkett, whatever had it I then I thought Ohh, she's big. But even though she's got it, it still doesn't seem to be advancing and it. I think it's we're a community of people that have been let down because there's not been enough knowledge shared like. There's still a lot of ignorance about it.

Interviewer:

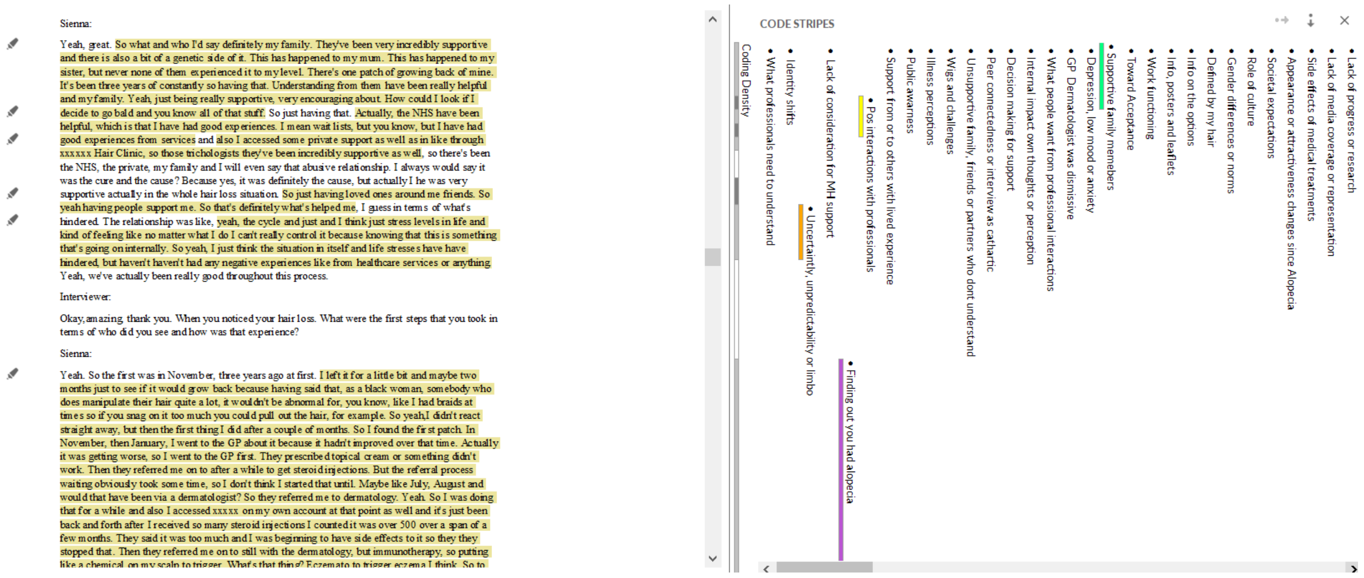
Yeah, yeah not advancing, absolutely. I guess that brings me on to my next question, which is what would you like professionals to know or to say or to understand that would make interactions with them more helpful?

Kaitlyn:

I really think being honest because it I seriously believe it like shaped my view on it. It needs to get to a point where enough people know, like I've had it, where I've seen like a locum and he's like, ohh, are you here for you like about your cancer? Because he's seen that I've got hardly any hair and assumed before looking at my notes that I'm on treatment for cancer, I think if they're going to make an assumption, it would be nice for them to go ohh is that alopecia?

Interviewer:

Hmmm yeah. So, for cancer to not be the first thought everybody has?



Sienna:

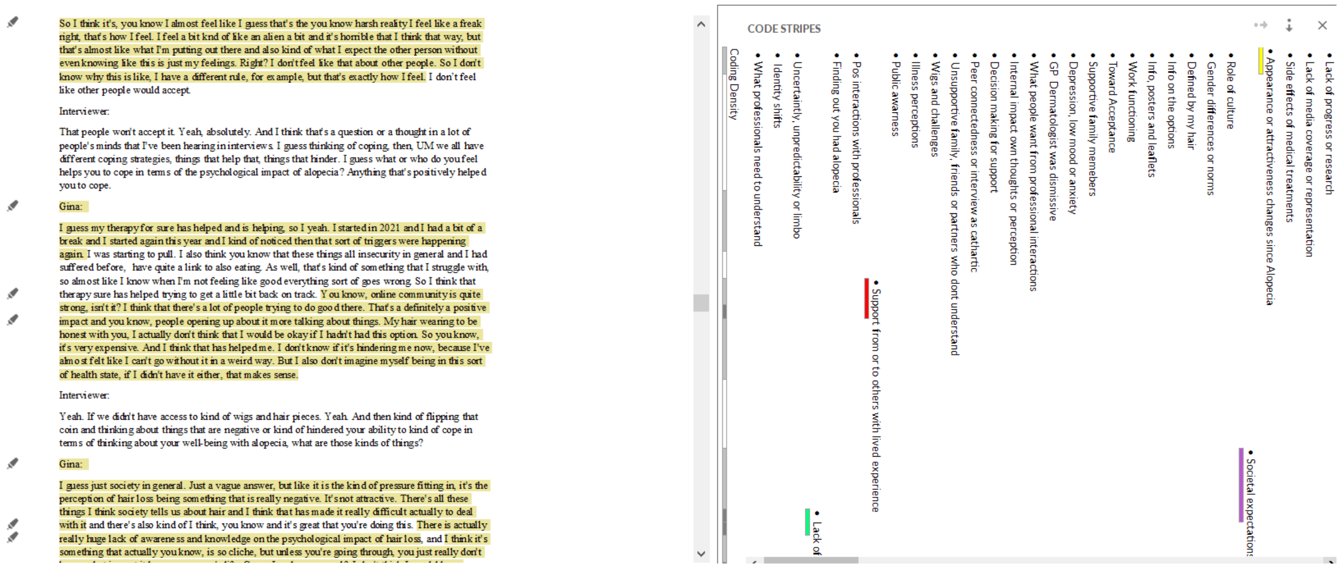
Yeah, great. So what and who I'd say definitely my family. They've been very incredibly supportive and there is also a bit of a genetic side of it. This has happened to my mum. This has happened to my sister, but never none of them experienced it to my level. There's one patch of growing back of mine. It's been three years of constantly so having that. Understanding from them have been really helpful and my family. Yeah, just being really supportive, very encouraging about. How could I look if I decide to go bald and you know all of that stuff. So just having that. Actually, the NHS have been helpful, which is that I have had good experiences. I mean wait lists, but you know, but I have had good experiences from services and also I accessed some private support as well as in like through xxxxxx Hair Clinic, so those trichologists they've been incredibly supportive as well, so there's been the NHS, the private, my family and I will even say that abusive relationship. I always would say it was the cure and the cause? Because yes, it was definitely the cause, but actually I he was very supportive actually in the whole hair loss situation. So just having loved ones around me friends. So yeah having people support me. So that's definitely what's helped me, I guess in terms of what's hindered. The relationship was like, yeah, the cycle and just and I think just stress levels in life and kind of feeling like no matter what I do I can't really control it because knowing that this is something that's going on internally. So yeah, I just think the situation in itself and life stresses have have hindered, but haven't haven't had any negative experiences like from healthcare services or anything. Yeah, we've actually been really good throughout this process.

Interviewer:

Okay, amazing, thank you. When you noticed your hair loss. What were the first steps that you took in terms of who did you see and how was that experience?

Sienna:

Yeah. So the first was in November, three years ago at first. I left it for a little bit and maybe two months just to see if it would grow back because having said that, as a black woman, somebody who does manipulate their hair quite a lot, it wouldn't be abnormal for, you know, like I had braids at times so if you snag on it too much you could pull out the hair, for example. So yeah, I didn't react straight away, but then the first thing I did after a couple of months. So I found the first patch. In November, then January, I went to the GP about it because it hadn't improved over that time. Actually it was getting worse, so I went to the GP first. They prescribed topical cream or something didn't work. Then they referred me on to after a while to get steroid injections. But the referral process waiting obviously took some time, so I don't think I started that until. Maybe like July, August and would that have been via a dermatologist? So they referred me to dermatology. Yeah. So I was doing that for a while and also I accessed xxxxx on my own account at that point as well and it's just been back and forth after I received so many steroid injections I counted it was over 500 over a span of a few months. They said it was too much and I was beginning to have side effects to it so they they stopped that. Then they referred me on to still with the dermatology, but immunotherapy, so putting like a chemical on my scalp to trigger. What's that thing? Eczema to to trigger eczema I think. So to


So I think it's, you know I almost feel like I guess that's the you know harsh reality I feel like a freak right, that's how I feel. I feel a bit knd of like an alien a bit and it's horrible that I think that way, but that's almost like what I'm putting out there and also kind of what I expect the other person without even knowing like this is just my feelings. Right? I don't feel like that about other people. So I don't know why this is like, I have a different rule, for example, but that's exactly how I feel. I don't feel like other people would accept.

Interviewer:

That people won't accept it. Yeah, absolutely. And I think that's a question or a thought in a lot of people's minds that I've been hearing in interviews. I guess thinking of coping, then, UM we all have different coping strategies, things that help that, things that hinder. I guess what or who do you feel helps you to cope in terms of the psychological impact of alopecia? Anything that's positively helped you to cope.

Gina:

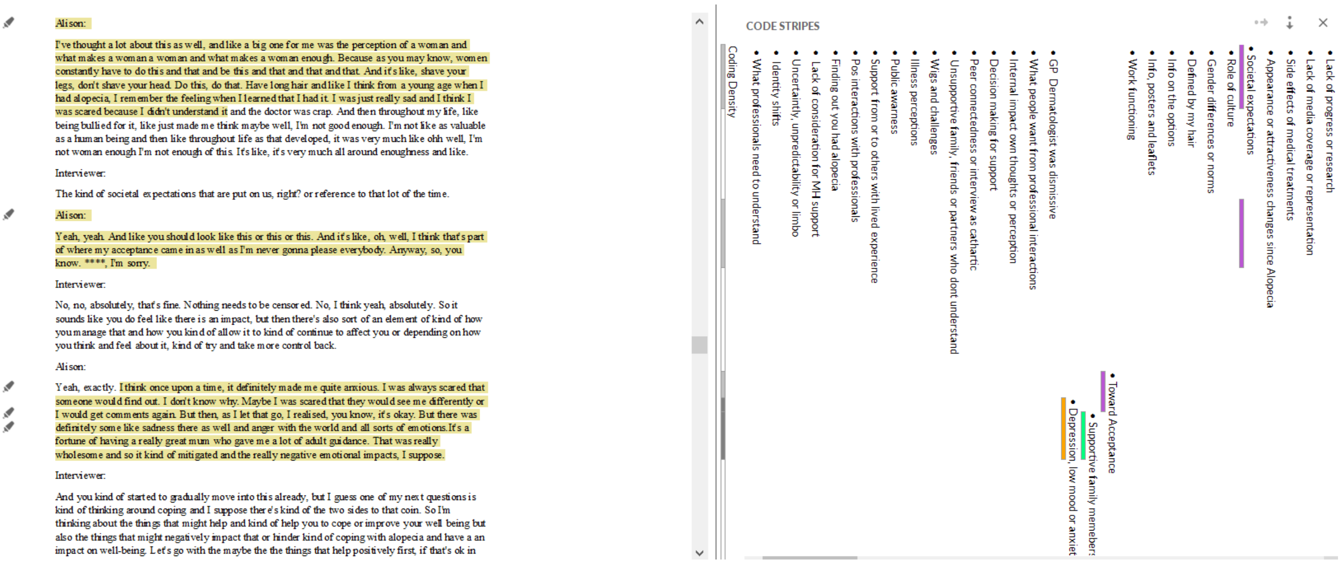
I guess my therapy for sure has helped and is helping, so I yeah. I started in 2021 and I had a bit of a break and I started again this year and I kind of noticed then that sort of triggers were happening again. I was starting to pull. I also think you know that these things all insecurity in general and I had suffered before, have quite a link to also eating. As well, that's kind of something that I struggle with, so almost like I know when I'm not feeling like good everything sort of goes wrong. So I think that therapy sure has helped trying to get a little bit back on track. You know, online community is quite strong, isn't it? I think that there's a lot of people trying to do good there. That's a definitely a positive impact and you know, people opening up about it more talking about things. My hair wearing to be honest with you, I actually don't think that I would be okay if I hadn't had this option. So you know, it's very expensive. And I think that has helped me. I don't know if it's hindering me now, because I've almost felt like I can't go without it in a weird way. But I also don't imagine myself being in this sort of health state, if I didn't have it either, that makes sense.

Interviewer:

Yeah. If we didn't have access to kind of wigs and hair pieces. Yeah. And then kind of flipping that coin and thinking about things that are negative or kind of hindered your ability to kind of cope in terms of thinking about your well-being with alopecia, what are those kinds of things?

Gina:

I guess just society in general. Just a vague answer, but like it is the kind of pressure fitting in, it's the perception of hair loss being something that is really negative. It's not attractive. There's all these things I think society tells us about hair and I think that has made it really difficult actually to deal with it and there's also kind of I think, you know and it's great that you're doing this. There is actually really huge lack of awareness and knowledge on the psychological impact of hair loss, and I think it's something that actually you know, is so cliche, but unless you're going through, you just really don't


Alison:

I've thought a lot about this as well, and like a big one for me was the perception of a woman and what makes a woman a woman and what makes a woman enough. Because as you may know, women constantly have to do this and that and be this and that and that and that. And it's like, shave your legs, don't shave your head. Do this, do that. Have long hair and like I think from a young age when I had alopecia, I remember the feeling when I learned that I had it. I was just really sad and I think I was scared because I didn't understand it and the doctor was crap. And then throughout my life, like being bullied for it, like just made me think maybe well, I'm not good enough. I'm not like as valuable as a human being and then like throughout life as that developed, it was very much like ohh well, I'm not woman enough I'm not enough of this. It's like, it's very much all around enoughness and like.

Interviewer:

The kind of societal expectations that are put on us, right? or reference to that lot of the time.

Alison:

Yeah, yeah. And like you should look like this or this or this. And it's like, oh, well, I think that's part of where my acceptance came in as well as I'm never gonna please everybody. Anyway, so, you know. ****, I'm sorry.

Interviewer:

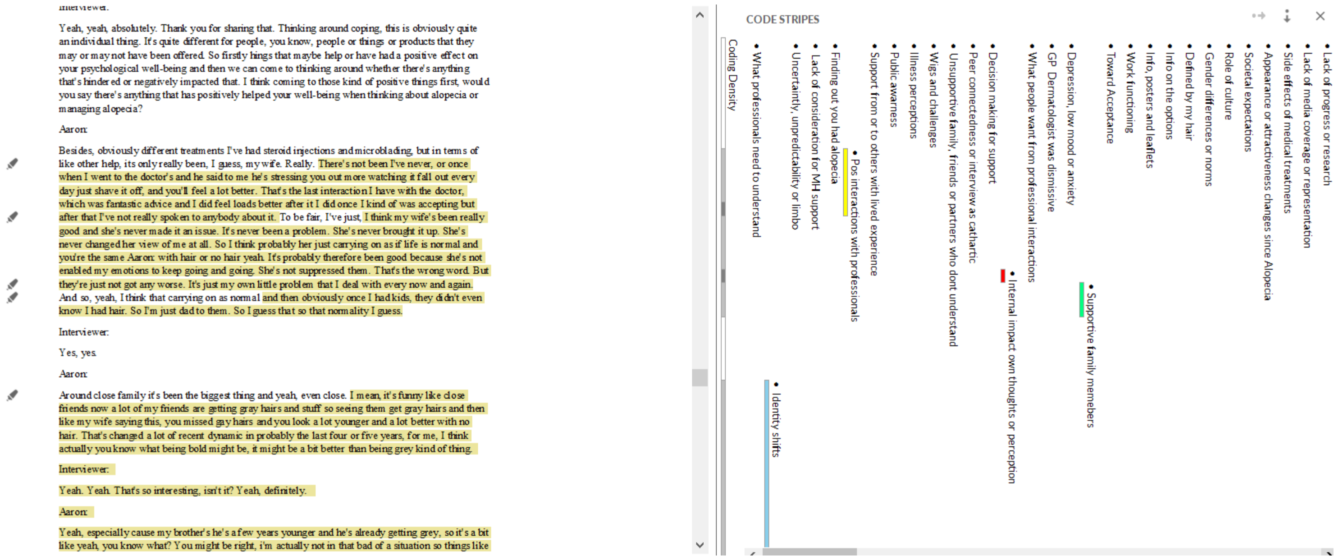
No, no, absolutely, that's fine. Nothing needs to be censored. No, I think yeah, absolutely. So it sounds like you do feel like there is an impact, but then there's also sort of an element of kind of how you manage that and how you kind of allow it to kind of continue to affect you or depending on how you think and feel about it, kind of try and take more control back.

Alison:

Yeah, exactly. I think once upon a time, it definitely made me quite anxious. I was always scared that someone would find out. I don't know why. Maybe I was scared that they would see me differently or I would get comments again. But then, as I let that go, I realised, you know, it's okay. But there was definitely some like sadness there as well and anger with the world and all sorts of emotions.It's a fortune of having a really great mum who gave me a lot of adult guidance. That was really wholesome and so it kind of mitigated and the really negative emotional impacts, I suppose.

Interviewer:

And you kind of started to gradually move into this already, but I guess one of my next questions is kind of thinking around coping and I suppose there's kind of the two sides to that coin. So I'm thinking about the things that might help and kind of help you to cope or improve your well being but also the things that might negatively impact that or hinder kind of coping with alopecia and have a an impact on well-being. Let's go with the maybe the the things that help positively first, if that's ok in



Interviewer:

Yeah, yeah, absolutely. Thank you for sharing that. Thinking around coping, this is obviously quite an individual thing. It's quite different for people, you know, people or things or products that they may or may not have been offered. So firstly hings that maybe help or have had a positive effect on your psychological well-being and then we can come to thinking around whether there's anything that's hindered or negatively impacted that. I think coming to those kind of positive things first, would you say there's anything that has positively helped your well-being when thinking about alopecia or managing alopecia?

Aaron:

Besides, obviously different treatments I've had steroid injections and microblading, but in terms of like other help, its only really been, I guess, my wife. Really. There's not been I've never, or once when I went to the doctor's and he said to me he's stressing you out more watching it fall out every day just shave it off, and you'll feel a lot better. That's the last interaction I have with the doctor, which was fantastic advice and I did feel loads better after it I did once I kind of was accepting but after that I've not really spoken to anybody about it. To be fair, I've just, I think my wife's been really good and she's never made it an issue. It's never been a problem. She's never brought it up. She's never changed her view of me at all. So I think probably her just carrying on as if life is normal and you're the same Aaron: with hair or no hair yeah. It's probably therefore been good because she's not enabled my emotions to keep going and going. She's not suppressed them. That's the wrong word. But they're just not got any worse. It's just my own little problem that I deal with every now and again. And so, yeah, I think that carrying on as normal and then obviously once I had kids, they didn't even know I had hair. So I'm just dad to them. So I guess that so that normality I guess.

Interviewer:

Yes, yes.

Aaron:

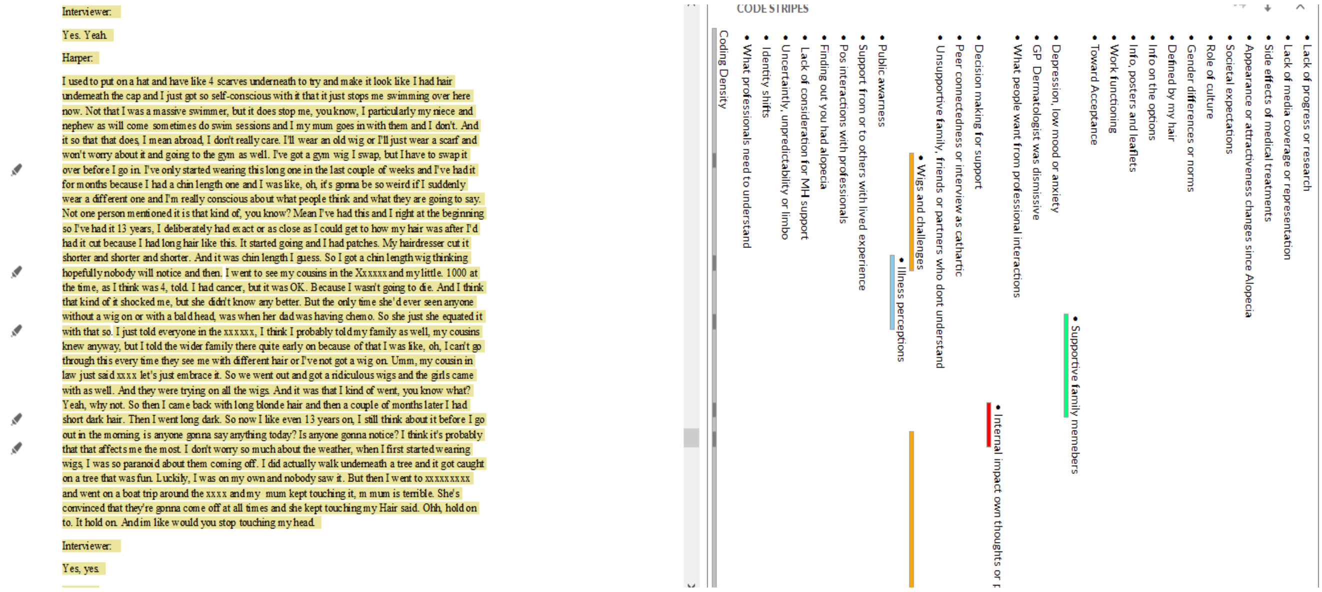
Around close family it's been the biggest thing and yeah, even close. I mean, it's funny like close friends now a lot of my friends are getting gray hairs and stuff so seeing them get gray hairs and then like my wife saying this, you missed gay hairs and you look a lot younger and a lot better with no hair. That's changed a lot of recent dynamic in probably the last four or five years, for me, I think actually you know what being bold might be, it might be a bit better than being grey kind of thing.

Interviewer:

Yeah. Yeah. That's so interesting, isn't it? Yeah, definitely.

Aaron:

Yeah, especially cause my brother's he's a few years younger and he's already getting grey, so it's a bit like yeah, you know what? You might be right, i'm actually not in that bad of a situation so things like



Interviewer:

Yes. Yeah.

Harper:

I used to put on a hat and have like 4 scarves underneath to try and make it look like I had hair underneath the cap and I just got so self-conscious with it that it just stops me swimming over here now. Not that I was a massive swimmer, but it does stop me, you know, I particularly my niece and nephew as will come sometimes do swim sessions and I my mum goes in with them and I don't. And it so that that does, I mean abroad, I don't really care. I'll wear an old wig or I'll just wear a scarf and won't worry about it and going to the gym as well. I've got a gym wig I swap, but I have to swap it over before I go in. I've only started wearing this long one in the last couple of weeks and I've had it for months because I had a chin length one and I was like, oh, it's gonna be so weird if I suddenly wear a different one and I'm really conscious about what people think and what they are going to say. Not one person mentioned it is that kind of, you know? Mean I've had this and I right at the beginning so I've had it 13 years, I deliberately had exact or as close as I could get to how my hair was after I'd had it cut because I had long hair like this. It started going and I had patches. My hairdresser cut it shorter and shorter and shorter. And it was chin length I guess. So I got a chin length wig thinking hopefully nobody will notice and then. I went to see my cousins in the Xxxxx and my little. 1000 at the time, as I think was 4, told. I had cancer, but it was OK. Because I wasn't going to die. And I think that kind of it shocked me, but she didn't know any better. But the only time she'd ever seen anyone without a wig on or with a bald head, was when her dad was having chemo. So she just she equated it with that so. I just told everyone in the xxxxx, I think I probably told my family as well, my cousins knew anyway, but I told the wider family there quite early on because of that I was like, oh, I can't go through this every time they see me with different hair or I've not got a wig on. Umm, my cousin in law just said xxxx let's just embrace it. So we went out and got a ridiculous wigs and the girls came with as well. And they were trying on all the wigs. And it was that I kind of went, you know what? Yeah, why not. So then I came back with long blonde hair and then a couple of months later I had short dark hair. Then I went long dark. So now I like even 13 years on, I still think about it before I go out in the morning is anyone gonna say anything today? Is anyone gonna notice? I think it's probably that that affects me the most. I don't worry so much about the weather, when I first started wearing wigs, I was so paranoid about them coming off. I did actually walk underneath a tree and it got caught on a tree that was fun. Luckily, I was on my own and nobody saw it. But then I went to xxxxxxxx and went on a boat trip around the xxxx and my mum kept touching it, m mum is terrible. She's convinced that they're gonna come off at all times and she kept touching my Hair said. Ohh, hold on to. It hold on. And im like would you stop touching my head.

Interviewer:

Yes, yes.

Appendix K - Reflexivity

Reflections on thinking about MRP topic and proposal

When thinking of topics for MRP and writing a proposal, I had held the idea of researching the psychological impacts and coping with alopecia in the back of my mind for a long time. My other research ideas are topics I am also passionate about which could maybe be left at the door at night a lot easier, e.g., forensic one of which was centred on domestic violence. I have mixed thoughts and feelings attached to this topic - alopecia. On one hand, I am very passionate about it as I have struggled with it daily since I was a teenager. On the other hand, I thought about the other DClin Psychology course requirements and wondered if researching something so close to home could become too taxing. Would it be too emotional, or would it be oddly therapeutic to hear the lived experiences or coping mechanisms of others? I was mindful about whether I share that I have lived experience in my research materials, given that I would tend not to tell strangers about my alopecia in my daily life. But would sharing my lived experience make those with lived experience more willing / comfortable to be involved in any sort of research like this? Lots of questions to discuss with the research team.

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I recently explored the literature for two of my MRP thesis ideas. One is forensic, an area I have done a lot of work in, but I saw a lot of hits on search engines when looking through this. In contrast, there is a lot less research out there on Alopecia. This was somewhat expected but made me equal parts sad and angry. On the Dclin Psychology course, the concept of "positions of power" has arisen many times in the last almost 2yrs. Am I in a unique position to be a lived experience researcher and gather the voices of those with lived experience or will others, do it? Have I already done a lot in the forensic realm, and should I challenge myself to do something more health related like Alopecia? I was mindful I had my own set of experiences and possible bias when it comes to Alopecia. Could I conduct research and keep my own stuff out of it? I am still unsure if this would be too overwhelming?

I am amid MRP proposal writing. After discussion with the research team, and discussions friends and family I have decided to jump in and hopefully do my MRP on Alopecia and I have been put in touch with someone from Alopecia UK. Reviewing the literature made more an aware of the psychological impact but also the mixed experiences people have in their interactions with medical professionals. Could my research interview those with lived experience and survey GPs to see what they know? Unsure if this would be too big a project? I also put some feelers out online and the consensus is sharing my lived experience is likely to make those with alopecia more comfortable. A question for supervisors is how much of my lived experience should I share?

MRP topic chosen and proposal or study refinement

I have had to change some of my original ideas which were felt to be a bit ambitious but am still doing qualitative research on Alopecia, ethics is in and now it's a waiting game, hopefully this does not require much amending. I recently attended a UH conference and spoke to another researcher who has just completed research of something she has lived experience in, I asked what advice she would give another lived experience researcher and she suggested spacing out interviews, so not doing more than two in a day and keeping my supervisors in the loop on the toll it may or may not take on me. I was very thankful for this and need to hold it in mind when scheduling interviews.

Recruitment reflections

Recruitment information was shared with Alopecia UK to put on their website and social media, and I also set up a Twitter and Instagram research account to share it myself to. As emails began to come in from interested possible participants, I was struck by the fact that the first one came from a male. It was not what I expected and challenged the assumption I clearly held but was not actively conscious of which was the expectation to mainly hear from females. In the first week or two, I continued to be surprised (pleasantly!) by the fact that of the 6 interviews booked in, I had not 1 but 2 males and 4 females. I was also amazed to receive participation requests from older people, by that I mean participants in their 50-60s. I not sure why I had assumed my participants would automatically be more likely to be 18-35 sort of age bracket. Of course, older people still struggle with Alopecia, and I guess reflecting on it now, likely had even less support if they were diagnosed when they were teenagers over 40 yrs. ago for example than younger people now. I felt excited at the prospect of having mixed age ranges and genders in my research and I wondered if / how this would impact experiences shared and my analysis?

Interview reflections

In interview 1 was struck by there being something about how being young, single, or looking for a partner, not in a stable job and maybe not owning a home impacted likelihood or willingness to share with others that the participant had alopecia, compared to when the participant was older, had a family, good job and was a homeowner. However, I felt I could relate and it’s a bit sad really, the idea that we are possibly afraid of the rejection maybe or judgement but can manage it better when we know we are going back home to our own family husband/wife and or kids who fully except us already irrelevant of whether we have hair. The other thing that stood out for me here was the participants description of how their friends gave the original alopecia patch a name (Barry), almost its own identity separates from the person with Alopecia, and this seemed helpful or made it easier to talk about it when it was referred to as Barry. It bought to mind how similarly I gave my first hair piece a name (Tracey), while I can’t remember where it came from originally, I do remember my closest friends using it to discuss my hair with me.

Following interview 4, I noticed that participants were asking about my rationale for deciding to research this topic. I was mindful that sharing to much about my rationale at the beginning of the interview, prior to participants answering questions. I was acutely aware it could lead to my responses potentially influencing what participants shared and did not want to influence the interviews in this way where possible. In regard to in interview 4, I did however feel it was appropriate to express my rationale when asked as I felt the participant was almost engaging in some kind of an ‘authenticity’ checking with me to establish my genuineness. I guess I understand this in the historical context of research often being seen as taking from participants and only more recently getting better at giving back. Following this interview, I decided to change this and say that they were happy to leave time for further questions about the broader research topic or my experiences with Alopecia toward the end. I hoped once my rationale for doing this was clearly explained, participants would understand, after all their story was much more pertinent to the research than my own. Nevertheless, I was also aware that I am intertwined in this research, both personally and professionally.

Following the completion of interview 23, I felted on how I was feeling both incredibly grateful for amount of interest I had in this study, but I was as equally scared as I was grateful thinking about beginning my data analysis and wanting to ensure I give meaning to my participants' experiences in a way that truly represents them. I noted I was apprehensive and perhaps slightly avoidant of starting my analysis due to this. Nobody else had put this on me, and I was aware it was solely and internal pressure I placed on myself and something I likely needed to discuss with my supervisors.

SLR reflections

My Systematic Literature review has been a struggle, a struggle to wrap my head around, unsure if this is due to my dyslexia or the research fatigue starting to settle in. I found the full text review and analysis of my 13 included papers tough. It hit me slightly unexpectedly and there have been a few tears over the last few days. I reflected with my supervisors that reviewing SLR papers and SLR analysis hit me far harder than doing my own interviews with participants and I wasn't clear on why this was. It may have been due to personal life things that were going on at the time which made things feel rawer and therefore I decided to use some of my personal therapy sessions to explore this further that I was already engaging in for other reasons.

RTA analysis and coding reflections

Following the initial coding of interviews 1-6, I was reminded and struck by two participants who had a much more positive or glass-half-full attitude toward their Alopecia compared to the rest of my participants and, to be honest, a much more positive outlook on Alopecia compared to what I myself currently hold. I felt I was in awe of these two participants but was struck by one querying whether their positive outlook was normal. It was not something I had expected and found myself toeing the line between my different roles on training; a) as a researcher and b) as a therapist wanting to explore this further but not being sure of the appropriateness which resorted in me saying 'well what's normal anyway?' I reflected after on the wider societal context or norms at play and influential they are in contributing to people's meanings attached to hair and beauty etc.

Interview coding continues, and I am at the halfway point …. NVivo software is coding things painfully slowly and despite several attempts to close tabs, restart my laptop etc. Nothing was helping! Despite NVivo testing my patience (10.45pm on Sunday night), I reflected on how what my participants had shared was so powerful, which I firmly believe is keeping me going. A recurrent area in all my interviews that I had noticed was based on the concept of identity and how this shifted and changed due to Alopecia and just how much hair was a part of that for so many of my participants. In contrast, one participant stated … 'but I can express that in many ways I don't have to have hair to express myself' … I remembered it from the actual interview and in my head thought 'hell yes!' but I am not sure this is my position, rather a position I am working to get closer toward. The same participant reflected the view that 'society causes the unwellness attached to Alopecia because it doesn't impact your health like it doesn't biologically make you sick'. I reflected on this from an ontological/epistemological stance. This research and my positioning are from a Critical Realist stance which I stand by. CR acknowledges the existence of this autoimmune condition, known as alopecia in reality, while recognising that aspects of it are socially constructed experiences influenced by broader societal norms or beliefs whilst as well as varying individual experiences across different social or cultural contexts. However, in contrast, I felt like my participant was leaning more toward a social constructionist stance toward Alopecia.

The process of reviewing and refining codes to look for clusters and what may resemble initial themes, has thus far been equal parts tedious and exciting. Again, the pressure to want to do what my participants have said justice is a thought that has crept into the back of my mind. A re-read of Braun and Clarke reminded me of the importance of reflexivity to acknowledge who we are (me as a researcher) shapes what we notice in the data, and a recent meeting with my supervisors reminded me to just keep going.

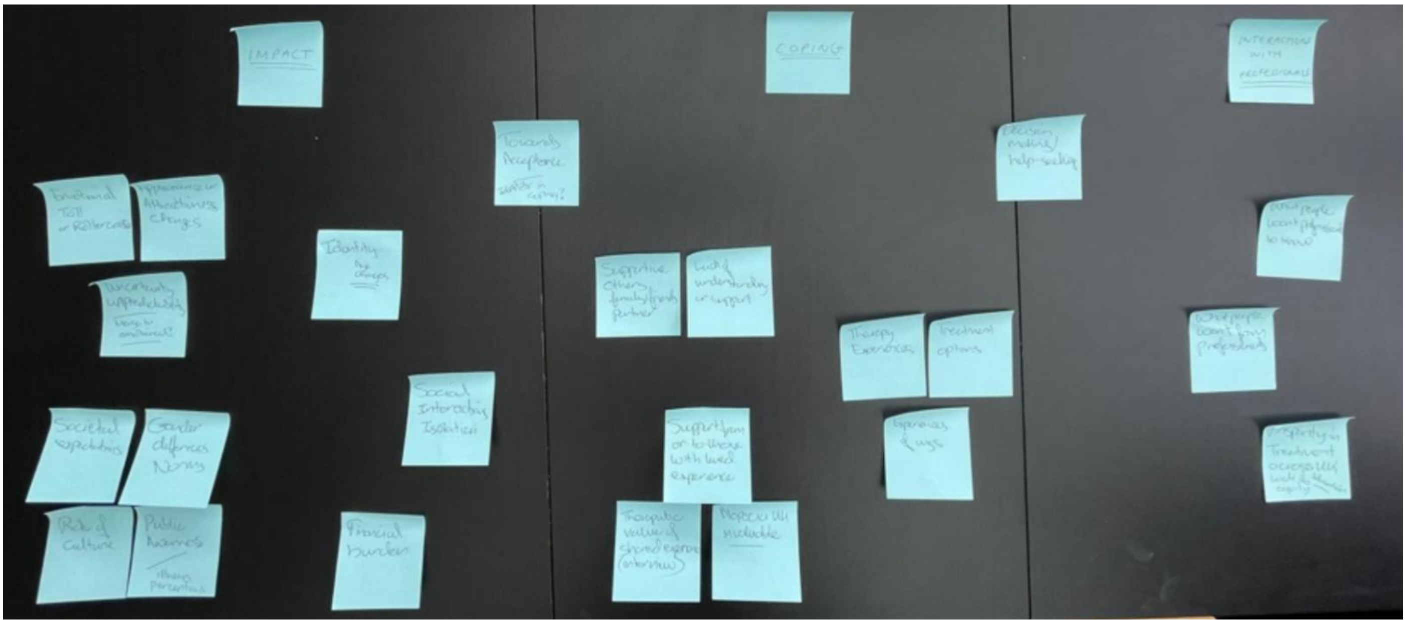
I have been looking at my clusters and refining codes for a while now and they have changed about three times. I had the opportunity to meet one of my supervisors, Debbie, in person and lay out all my post-it notes to review, discuss, and refine my codes further out loud. She was immensely helpful in allowing me to see where my previous experiences, knowledge(s), and assumptions may have been influencing my coding. As well as where my experiences may be influencing my decisions on what to leave in or remove from what I would present in my results.

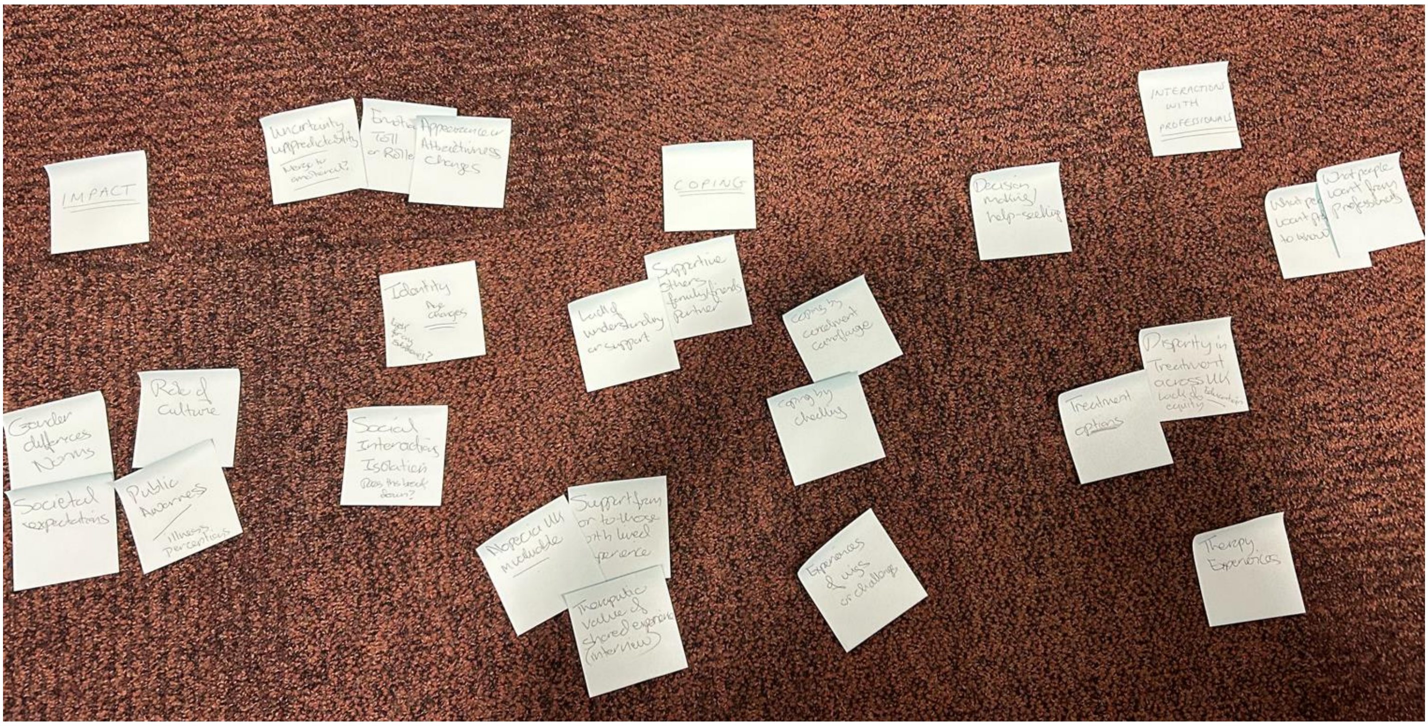
One of the unintended or unexpected ideas that came out of my data but was not included in my results or discussion, as it did not really answer any of my research questions, was the idea that the interviews for the majority of my participants were described as 'cathartic' seeming to almost hold some therapeutic value in and of themselves. I did seek feedback at the end of each interview on how participants found the interview in a bid to check in on whether people felt comfortable, which I think stemmed my not wanting participants to experience the interview as difficult or negative like any of the uncomfortable interactions I have had with both professionals and non-professionals around my Alopecia. I wondered why participants described the interview as 'cathartic'; was it because of my insider positioning and the decision to share this in my information sheet, possibly making participants feel more at ease to share their experiences? Would this have come about anyway, irrelevant of whether I had Alopecia or not? It remains unclear however, this does appear to appear to be an example of where I as the researcher have possibly influenced this research.

Study results reflections

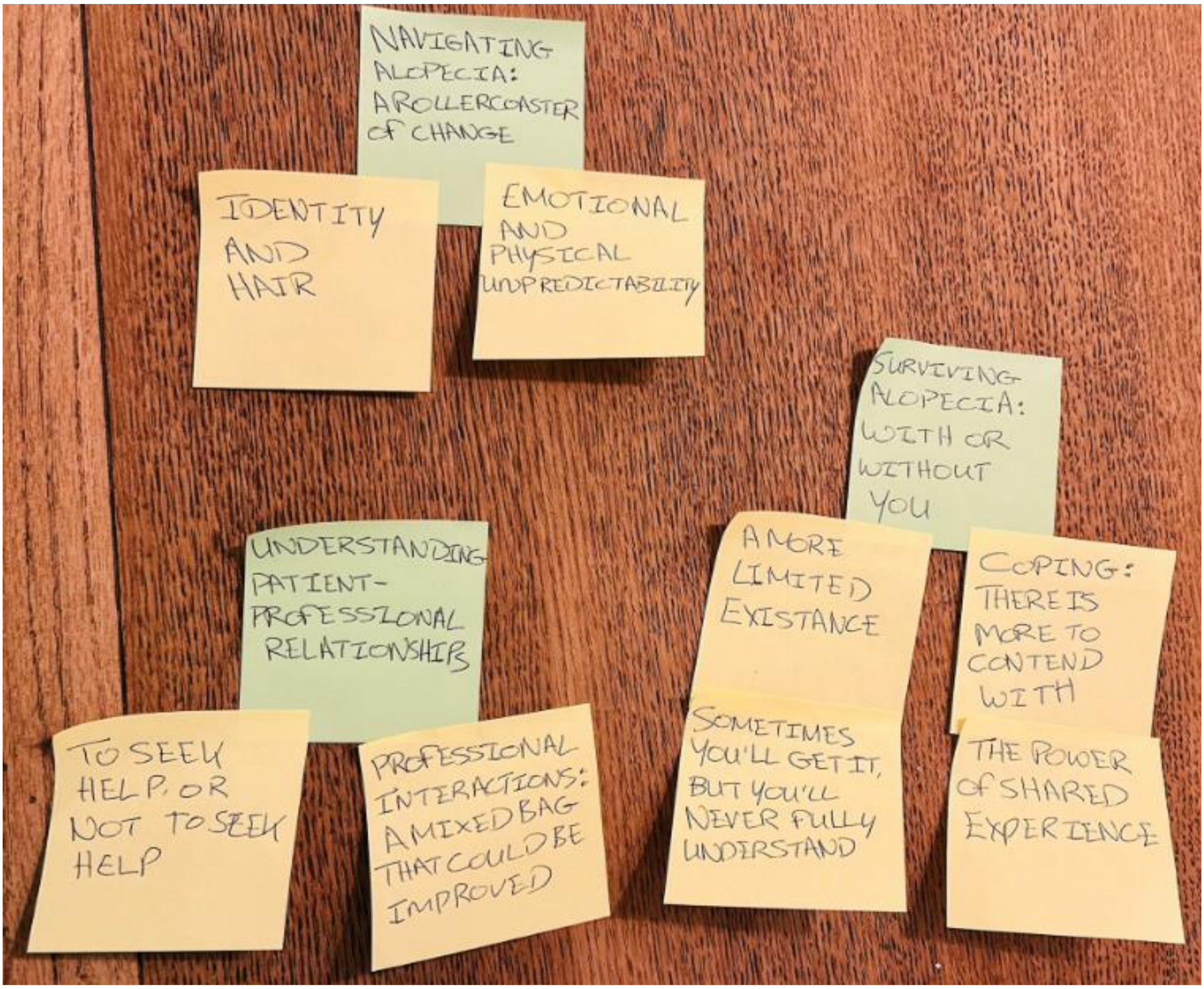
While it was a challenge, I found myself taking great care to ensure that all 23 of my participants were quoted at least once, which, although it wasn't very straightforward, I feel strongly about including everyone's voices. I think this was important for me as I am aware that historically, the relationships between researchers and participants have, at times, been strained, and participants have felt taken advantage of. Therefore, while there is a balance to be struck between writing text and interspersing quotes, I wanted to ensure every participant knew that the interviews they did, the time they gave, and the experiences shared were important to me and this study.

Appendix L – Initial clusters





Appendix M – Thematic maps


NAVIGATING ALOPECIA: A ROLLERCOASTER OF CHANGE
IDENTITY AND HAIR
EMOTIONAL AND PHYSICAL UNPREDICTABILITY
SURVIVING ALOPECIA: WITH OR WITHOUT YOU
UNDERSTANDING PATIENT-PROFESSIONAL RELATIONSHIPS
A MORE LIMITED EXISTANCE
COPING: THERE IS MORE TO CONTEND WITH
TO SEEK HELP, OR NOT TO SEEK HELP
PROFESSIONAL INTERACTIONS: A MIXED BAG THAT COULD BE IMPROVED
SOMETIMES YOU'LL GET IT, BUT YOU'LL NEVER FULLY UNDERSTAND
THE POWER OF SHARED EXPERIENCE