BACKGROUND
Alopecia is an autoimmune condition that results in hair loss, mainly from the scalp. There are three specific types of autoimmune alopecia: alopecia areata (AA; small patches of hair loss), alopecia totalis (AT; total hair loss from the scalp) and alopecia universalis (AU; total hair loss from the scalp and body). Whilst research has explored the experiences of White women living with alopecia, there is a lack of research exploring the impact of alopecia on women in the Black community. The current study aimed 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.

PARTICIPANTS AND PROCEDURE
Seven Black women (age range: 37-68 years; mean age: 51 years) were recruited purposively through alopecia support group organisations and social media to participate in a semi-structured interview; four participants were diagnosed with AA, two participants were diagnosed with AU, and one participant was diagnosed with AT. One-to-one interviews were conducted online, and interpretative phenomenological analysis was used to guide data collection and analysis.

RESULTS
Participants discussed the significance of hair specifically within the Black community and the complex relationship between psychological wellbeing, coping and seeking support.

CONCLUSIONS
This novel area, specific to Black women’s psychological experience of alopecia, acknowledges the influence of cultural and ethnic differences. The findings suggest that proactive awareness from health professionals and social support groups are needed due to the nuances of Black women’s alopecia experience to provide better support and to enhance the quality of life for Black women to manage their alopecia.

KEY WORDS
alopecia; Black women; culture; psychosocial; identity
BACKGROUND

Alopecia is an autoimmune condition where the immune system attacks the hair follicles, resulting in the partial or complete absence of hair (Alkhalfah et al., 2010; Jabbari et al., 2016). There are three specific types of autoimmune alopecia: alopecia areata (AA; small patches of hair loss) (Fricke & Miteva, 2015), alopecia totalis (AT; total hair loss) and alopecia universalis (AU; total hair loss from the scalp and body) (Hordinsky, 2013). Alopecia can occur during any age, though the onset and diagnosis of AA are likely to occur during childhood (mean age: 5-10 years) and during adulthood (mean age: 25-36 years) (Fricke & Miteva, 2015). Males and females are equally susceptible to the condition and no statistically significant differences between ethnic groups have been found (Fricke & Miteva, 2015).

A genetic predisposition (Jabbari et al., 2013) and environmental factors such as stress (McElwee et al., 2013) are linked to the cause and progression of AA, AT, and AU (Fricke & Miteva, 2015; Islam et al., 2015; Pratt et al., 2017). The variability of alopecia makes it difficult to predict how much hair loss or regrowth individuals will experience, with some individuals experiencing well-defined patches to total hair loss (Alkhalfah et al., 2010). Currently, there is no cure for alopecia, though there are treatments such as steroid injections or creams, light treatment, hair transplant and immunotherapy to aid hair growth, with higher efficacy rates for AA (Alsantali, 2011; Pratt et al., 2017). In addition to the physical symptoms of alopecia, research has indicated the significant psychological impact of alopecia. Individuals with alopecia may experience poor mental health such as depression, anxiety, or social phobias (Barkauskaite & Serapinas, 2020; Marahatta et al., 2020; Marks et al., 2019; Tucker, 2009). Psychological distress has been linked to the unpredictability of alopecia (Alkhalfah et al., 2010; Islam et al., 2015), the perceived and public stigma of hair loss (Goh, 2021; Schielein et al., 2020; Temel et al., 2019) and the change in appearance (Hunt & McHale, 2005; Rodgers, 2018; Winnette et al., 2021). Hair loss may distort an individual’s self-image (Ng et al., 2017) and in some cases lead to creating a new identity (Davey et al., 2019; Welsh & Guy, 2009). In assessing how individuals cope with circumstances that challenge or threaten their body-image experiences, Cash et al. (2005) identified three strategies: avoidance, appearance fixing, and positive rational acceptance. It has been reported that appearance fixing strategies or concealment in the form of wearing a wig that reflects the individual’s identity before hair loss may contribute to feelings of inauthenticity, thus creating psychological pressures (Dinh & Sinclair, 2007; Aldhouse et al., 2020; Saed et al., 2016). Due to the complex and often unpredictable nature of alopecia, it has been reported that social support can play a significant role in the individual’s psychological wellbeing and emotional coping when dealing with hair loss (Davey et al., 2019; Rafique & Hunt, 2015; Siedlecki et al., 2014). There is a variety of social support systems that individuals can interact with such as family, friends, religion, and alopecia support groups, which may depend on their ethnic origin, culture, religion, or age. Rafique and Hunt (2015) found differences in how Pakistani adolescents with alopecia seek support, with females more likely to seek support from their mothers whilst males were supported by their friends.

Research has also examined the value of support group systems to help individuals cope by sharing experience of the condition with others (Barkauskaite & Serapinas, 2020; de Vere Hunt et al., 2020). This was especially the case in circumstances where the individual perceived there to be low specialist psychological support available (Davey et al., 2019). Receiving psychological support can reassure individuals and can act as a buffer against the psychological impacts of alopecia (Welsh & Guy, 2009). The social relationships formed can help to increase one’s well-being (Siedlecki et al., 2014) to help reduce the emotional impacts of alopecia. However, it is vital that the support is tailored to the individual, so a “one size fits all” model is not utilised (Aldhouse et al., 2020; Rajoo et al., 2019).

Prior research has focused on White individuals’ alopecia experience and the importance of hair (Davey, 2020; de Vere Hunt et al., 2020; Lundin et al., 2014; Montgomery et al., 2017; Piérard-Franchimont et al., 2013), with little research exploring the experiences of women from other backgrounds (Rafique & Hunt, 2015), especially women within the Black community. Hair for Black women symbolises femininity, sexuality and beauty (Manning, 2010; Rooijakkers, 2018; Weitz, 2001), which highly resonates within the Black culture. Historically, short/shaven hair was used to punish enslaved Black women to disregard their culture and reduce physical attraction (Byrd & Tharps, 2014; Donahoo, 2019). Rooted in history, the significance of hair amongst the Black community has been instilled from birth and ingrained within the culture (Moore, 2014; Okazawa-Rey et al., 1987) with individuals adopting different hairstyles, such as Afro’s, Cornrows, Locs, Bantu Knots, and Box-Braids (Johnson, 2013; Mercer, 2000; Rodriguez, 2003). Also dating back to Madam C.J. Walker, 1905, products to maintain and promote hair growth (Thompson, 2009).

During the 21st century, there has been a gradual shift in how Black people perceive and style their hair. Previously, it was common for Black people to conform to westernised standards of beauty such as straight hair (Okazawa-Rey et al., 1987; Sekayi, 2003) as opposed to an individual’s naturally thick and curly texture (Jeffries & Jeffries, 2014). Recently, with the aid of the natural hair movement (NHM) creating...
Black women’s experiences of living with alopecia – a qualitative study

Awareness (Metcalf & Spaulding, 2016; Moore, 2014; Ndichu & Upadhyaya, 2019) there have been positive shifts towards Black people, if they wish, to maintain their afro-textured hair to redefine the essence of beauty (Henderson, 2015; Ndichu & Upadhyaya, 2019). However, alopecia can cause conflict with a person’s identity as hair can be a characteristic used to define oneself (Hunt & McHale, 2005). Therefore, hair loss for Black women may pose additional challenges due to the cultural importance of hair and the psychological impact of trying to understand “who and what I am” when processing and coming to accept their new identity due to hair being significant (Hunt & McHale, 2004; Tatum, 2000).

The aim of this study is to gain an understanding of Black women’s lived experience of alopecia (AA, AT, or AU), with a particular focus on the impact of alopecia and individuals experiences of support groups. The study addressed the following research question: What are Black women’s experiences of living with alopecia?

PARTICIPANTS AND PROCEDURE

PARTICIPANTS

Adults aged 18 years or above who identified as a Black female and had a diagnosis of alopecia (AA, AT or AU but not induced by chemotherapy) for a minimum of three months were eligible to participate (Malkud, 2015). Eligible participants were recruited purposively through alopecia support group organisations (Alopecia UK and Bald Girls Do Lunch USA) and social media, and recruitment ran until data saturation occurred. Seven participants (age range: 37-68 years; mean age of participants: 51 years) were recruited (see Table 1).

MATERIALS

The semi-structured interviews investigated the impact alopecia has had upon participants’ lives, focusing on the psychological implications associated with alopecia, coping mechanisms, experiences with support systems, and the NHM. The qualitative methodology allowed for exploration of the defined areas, and elaboration by participants on other related topics (Braun & Clarke, 2013).

The semi-structured interview schedule was informed by existing literature (Duvey et al., 2019; Iliffe & Thompson, 2019; Rafique & Hunt, 2015). All interviews were conducted by the first author via Microsoft Teams/Skype, lasting a maximum of 72 minutes (mean: 48 minutes).

PROCEDURE

Ethical approval for the study was granted by the Birmingham City University Research Ethics Committee (reference: PSY_MScH_Mar20_001). Participants used an online link where they provided consent and all participants read through the information sheet that outlined the inclusion and exclusion criteria. Also, participants were made aware of their rights to withdrawal and how to do this at any time during the study. Once participants had given consent they were granted access to the demographic form where participants filled out generic information about themselves such as how long they had had alopecia for, the onset and whether they were seeking any treatment. Then participants contacted the researcher to arrange the one-to-one interview. Pseudonyms were used in replacement of participants’ real names to protect their anonymity. At the end of the interview, participants were e-mailed the debrief sheet that out-

Table 1

<table>
<thead>
<tr>
<th>Participant demographics</th>
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<tbody>
<tr>
<td><strong>Pseudonym</strong></td>
</tr>
<tr>
<td>Faith</td>
</tr>
<tr>
<td>Kiki</td>
</tr>
<tr>
<td>Bebe</td>
</tr>
<tr>
<td>SpecialT</td>
</tr>
<tr>
<td>Cassie</td>
</tr>
<tr>
<td>Red</td>
</tr>
<tr>
<td>Veronica</td>
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</tbody>
</table>

Note: Participants’ names have been replaced with a pseudonym. AA – alopecia areata; AT – alopecia totalis; AU – alopecia universalis.
lined how to access relevant support services, their unique withdrawal date as well as the researcher’s contact details.

ANALYSIS

Interview recordings were transcribed using orthographic transcription (Halcomb & Davidson, 2006) and analysed using interpretative phenomenological analysis (IPA; Smith, 2007) to explore how individuals make sense of their alopecia experience, which is encapsulated by the world around them (Willig & Rogers, 2017), whilst also acknowledging the researcher’s conceptions of the world (Alase, 2017; Rafique & Hunt, 2015; Smith et al., 2009).

IPA has a dynamic and idiographic focus based on the first-hand lived experience of the individual, rather than generalising to the alopecia community (Larkin et al., 2006). IPA is an inductive approach (Pietkiewicz & Smith, 2014), with a methodological process allowing for an open dialogue of new topics to arise without pre-existing theoretical frameworks (Smith, 2004). IPA is impactful as it allows an exploration of an individual’s alopecia trajectory such as the diagnosis, support, and identity, reiterating the suitability of IPA (Iliffe & Thompson, 2019; Montgomery et al., 2017; Welsh & Guy, 2009). The analytic approach provides a holistic understanding of the research question (Nizza et al., 2021; Smith, 2003). IPA is frequently used in cultural and health psychology as it provides an insight into the complexity of an individual’s perception of their health condition and how they make sense of their experiences (Osborn & Smith, 1998; Smith, 2004).

As a reflexive researcher (Alase, 2017; Nizza et al., 2021), the first author applied an insider perspective in designing, conducting, and analysing data due to identifying as a Black woman who is also diagnosed with alopecia. The first author was cognizant about her insider positionality, which aided the study. The cultural and gender representation helped to increase the authenticity to allow participants to be detail-oriented about their experiences. Moreover, sharing intersectional characteristics (ethnicity, gender and health status) helped the author to gain a rapport with participants to ask complex and appropriate questions as well as allowing participants to feel relaxed and comfortable sharing emotional aspects of their life. The double-hermeneutic nature of IPA allowed the researcher to create an idiographic understanding of the participants’ social reality of how they live with alopecia as a Black woman (Willig, 2007).

RESULTS

Three superordinate themes were identified within the data set (see Table 2), providing an exploration into participants’ attitudes, beliefs and experiences of living with alopecia.

Table 2

Master table of themes

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
<th>Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theme one: Symbolic nature and perception of hair within the Black community</td>
<td>• Importance of hair – “Hair is your crown and glory”</td>
<td>Culture, importance, beauty, crown and glory, appearance, education, knowledge, shared consensus, pride</td>
</tr>
<tr>
<td></td>
<td>• The wave of the natural hair movement</td>
<td>Natural hair movement, different wig styles/textures, bald, embracing self, involvement, replicating, understanding, culture</td>
</tr>
<tr>
<td>Theme two: Identity: Who am I? The new me!</td>
<td>• Me, myself, and I</td>
<td>Identity, self, new self, body image, self-esteem, unsure of self</td>
</tr>
<tr>
<td></td>
<td>• Concealment… My double life</td>
<td>Hiding, masking, identity, fraud, self-perception, self-image</td>
</tr>
<tr>
<td></td>
<td>• The psychological roller-coaster of alopecia</td>
<td>Depression, identity, anxiety, self-esteem, cultural barriers, mental health norms, not understood, emotions, loneliness Validation, similar experiences, confide in, trust</td>
</tr>
<tr>
<td>Theme three: The power of connectivity... “Who can I rely on?”</td>
<td>• Bonded by similar experiences</td>
<td>Understanding, tips, acceptance, caring, sharing, knowledge, online access, support</td>
</tr>
<tr>
<td></td>
<td>• Representation of support groups</td>
<td>Diversity, inclusion, representation, culture, similar experiences, mutual understanding, support, confide in</td>
</tr>
</tbody>
</table>
THEME ONE: SYMBOLIC NATURE AND PERCEPTION OF HAIR WITHIN THE BLACK COMMUNITY

The theme captures the cultural perspective and symbolic nature of hair within the Black community. Individuals expressed how their experience of hair loss due to alopecia was influenced by their culture.

**Importance of hair – “Hair is your crown and glory”**. Participants reported the significance of hair as representing culture, beauty, femininity, and identity. SpecialT, who has lived with alopecia for more than 40 years, illustrated how hair is linked to an individual’s sense of identity and can impact how individuals feel about having alopecia.

In the Black community, hair is your crown and glory [...] that cultural thing does play a part in how I feel about alopecia and not having hair (SpecialT, 53 years old, alopecia duration > 40 years).

Due to the impact alopecia can have upon an individual’s identity, some individuals, such as Cassie, explained how this influenced their decision to wear wigs.

I’ve substituted it [my hair] with wigs, it’s [hair is] very important [...] I suppose I just think hair is a woman’s crown and glory (Cassie, 51 years old, diagnosed with AT, duration > 10 years).

The majority of participants repeatedly used the phrase “Hair is your crown and glory” signifying how hair is viewed as a powerful symbol of femininity, representing their cultural identity, pride, self-esteem, and a sense of regality. Red illustrated how keeping updated with hairstyles increases one’s confidence.

Especially my [Black] people because we take pride in our hair and I’m not looking like the other girls of colour going to school with ponytails, Afro puffs (Red, 68 year old, alopecia duration > 58 years).

Red conveyed that due to alopecia she was unable to express her cultural identity through hairstyles, which were worn by other children her age. Along with Red, several other participants discussed the desire of having a “normal identity” that matched the norms of their cultural environment.

**The wave of the natural hair movement.** The natural hair movement (NHM) can be positive and empowering to highlight the variance of hair within the Black community (Moore, 2014; Ndichu & Upadhyaya, 2019). Some participants reflected on how the NHM has impacted their alopecia experiences such as having the opportunity to embrace and accept various hairstyles, no matter the length, style, or thickness, both with their natural hair but also using wigs and weaves.

In the natural hair community [...] it-it’s helping people in general have a better level of acceptance that hair is a very broad spectrum erm in terms of how people approach it, how they style it [...] everyone doesn’t have to have hair of a certain colour or certain length or a certain cut, hair is all over the place (Kiki, 45 years old, diagnosed with AA, duration > 10 years).

The NHM is seen to normalise various hairstyles that Black women can have; for Bebe, the NHM represents how individuals from an African or Caribbean background can “embrace” their appearance, with Red highlighting that Black women are innovative with their hairstyles and appearance.

There is this wave of consciousness where we’re telling women of African American origin and those from African origin and Caribbean origin to embrace the way they look and I’ve been seeing that resonate more now (Bebe, 35 years old, alopecia duration 1-4 years).

I love people to be creative, including seeing a woman wearing the bald look but their female features are just emphasised with the eye shadows, eyebrows and earrings [...] I love how Black women expressed themselves through their hairstyles or with no hairstyle (Red).

As a consequence of the NHM, individuals can embrace being bald regardless of whether one chooses to shave their hair or due it being a result of alopecia.

To shave your hair all the way off is definitely natural and I think it’s more acceptable and people love it, they seem to love it yano so I think it’s a positive move (SpecialT).

The NHM allows for individuals with alopecia to feel included as it promotes inclusivity of different hairstyles. The NHM can also help promote self-love for Black women to feel comfortable how they desire to have their hair.

THEME TWO: IDENTITY: WHO AM I? THE NEW ME!

Hair is symbolic culturally and religiously in the westernised society. Hair loss can distort individual’s self-image whereby individuals feel that are leading a double life (e.g., when hiding their hair loss from others), in which some participants expressed the psychological distress it causes.

Me, myself, and I. Hair can shape an individual’s appearance and form part of their identity including links to culture, ethnicity, gender, and how they wish to express themselves. Faith and Veronica outlined the daily struggle of adapting to their new appearance.

I didn’t feel empowered, I didn’t feel beautiful, I didn’t feel great (Faith, 46 years old, diagnosed with AA for 29 years).

Veronica spoke about how people can take their hair for granted until they experience hair loss, with Veronica viewing her reflection (following hair loss) as something other than how she saw herself.

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 in the mirror because it was like an alien looking at me (Veronica, 57 years old, diagnosed with AU, duration 1-4 years).

Participants explained how their reflections were “abnormal” and not reflective of their perception of who they are, with participants fearing social rejection due to their identity.

I always pride myself in having good hair and losing it has just changed my outlook on life completely, i.e., relationships, I don’t even try, I don’t bother [...] when they see the real me without all the extras on they probably gonna be scared off (Bebe).

All participants discussed the challenges of their new identity, with some participants explaining how their new self-identity resulted in social avoidance that has subsequently made it harder for them to seek intimate relationships.

Concealment... My double life. Many participants valued invisibility towards their alopecia, often hiding their condition from others, due to a lack of confidence, negative public perception or lack of comfortability. However, concealing hair loss can perpetuate feelings of inauthenticity.

SpecialT conveyed that she made efforts to conceal her alopecia to keep it a secret from others.

At one time I didn’t want anyone to find out my secret so I wouldn’t put myself out there and so I found a way to mask again, I found a way to hide (SpecialT).

However, Bebe expressed her concern about presenting herself in an inauthentic way despite her discomfort and dislike at her appearance without a wig. The battle between presenting an authentic appearance and managing her happiness when wearing a wig resulted in feelings of leading a “double life”:

Worried that I’m putting a false front to members of the public but inside this is what I look like and I don’t like it, I don’t like what I see [...]. You have one person who’s outside with the wig and when I put it on I look good, I really do, and it makes me happy but knowing it’s not my hair inside [...] I just feel that I’m leading a double life (Bebe).

Similarly, Faith described 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, I didn’t feel like I was being honest when people would say ‘oh your hair looks great,’ ‘I remember your hair from when you was younger and it was really nice’ (Faith).

The psychological roller-coaster of alopecia. Alopecia can impact psychological wellbeing, particularly due to the unpredictability of hair loss and the condition having no known cause. Many participants, such as Faith, discussed the impact alopecia has had upon self-esteem.

My self-esteem has suffered but because I just get on with things mmm it’s almost like I’m just putting all the time, I’m just masking it because nobody sees mmm how-how it made me feel (Faith).

The unpredictable nature of alopecia led some participants to express a sense of helplessness. Both Kiki and Cassie spoke about experiencing psychological distress.

I didn’t know if it was something that you know in three months I could be completely bald or if it was just gonna be a progressive loss of hair over the years so it was extremely stressful and I would say probably you know put me in a bit of a state of depression because of just not knowing what was gonna happen (Kiki).

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 (Cassie, diagnosed at 14 years old).

The change in identity and self-esteem that participants experienced due to alopecia did result in Cassie experiencing depressive and suicidal thoughts where she explained that she did not want to live every day with the struggles of having alopecia, clearly demonstrating the need for psychological support within this community.

Nonetheless, whilst the psychological impact of living with alopecia is clear, there are cultural barriers to acknowledging and seeking support for psychological wellbeing.

Mental health is so important, don’t you give me that crap talking about ‘oh that’s only White people’s problem’ talk to the hand, it’s Black people’s problem [...] No shame in talking about getting counselling (Red).

Normalising mental health is pertinent within Black communities, as the cultural stigma makes it difficult for some individuals to receive support to cope with the psychological impacts of alopecia.

THEME THREE: THE POWER OF CONNECTIVITY... “WHO CAN I RELY ON?”

Support can manifest in numerous ways such as the assistance given by support groups, family/friends, medical professionals, and those in wider society such as hairdressers.

Bonded by similar experiences. Alopecia support groups, whether face-to-face or online, are a space for individuals to interact with those who have a shared identity and truly understand the experience of living with alopecia.

My opinion is that they are an invaluable resource because you know those groups are available online, 24/7, 365 and so there is that immediate ability to share whatever it is that you’re going through and whatever
it is that you’re thinking and have some sense of validation (Kiki).

The support groups provided participants such as Kiki with the ability to connect with others without any time constraints. Being able to share experiences and feelings with others also living with alopecia enables individuals to have a sense that their experiences and feelings are validated and provides a sense of togetherness. It is also a place to learn from others’ experiences and enhance one’s own knowledge.

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 (Veronica).

Support groups can also be a safe space for individuals to be their authentic self without fear of judgement or rejection.

One of my first times I went without it [wig] and let me tell you it was wonderful, I loved it, it’s just like ‘I’m free, I can be me, I don’t have to cover up’. There was no one there to make fun of me, they accepted me [...] it was really exhilarating (Red).

Participants, such as Red, explained how their support group increased their self-confidence without wearing a wig, resulting in them now being comfortable without wearing a wig.

Representation of support groups. Whilst participants truly valued support groups, it was acknowledged that support groups lack diversity and representation of culturally and ethnically diverse (CED – encompass Black, Asian and Mixed heritage) individuals on their social media pages.

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 wasn’t any women of colour and that kinda put me off [...] sometimes you just want to see people who look like you (Faith).

Participants mentioned that CED individuals need to be signified in support groups, with representation being crucial for individuals to be able to share their experiences.

I didn’t know any other Black person that was suffering with alopecia, and I’ve just got this thing about support groups. I want to see people that reflect me and sometimes in terms of hair loss well with anything actually, the cultural responses are different, and I didn’t fancy sitting in a room with a bunch of White ladies to be honest (Cassie).

The lack of diversity and representation of CED groups can deter individuals from attending support groups.

Participants who did attend support groups noted the importance of receiving in-group support, but highlighted that diversity needs to improve. Bebe explains that although she would not want a divide in the support group because everyone is dealing with the same condition, it would be helpful to have diverse cultural insights.

I wouldn’t like to see that split, we should all come together, and share our common issues but diversify in the solution [...] I tend to skip it, particularly if it’s geared towards European, British audience but I hardly see any African, Afrocentric tips on there, so if they do more of that and if they had more representatives (Bebe).

It is important that individuals feel that support groups are accessible and inclusive for all, particularly in terms of representation and the information that is provided.

DISCUSSION

The data provide insight into life with alopecia, focusing on the psychosocial and cultural impacts of alopecia. All participants articulated the significance of hair for women in the Black community, and how the impact of alopecia is deeply rooted in an individual’s culture and cultural identity. Hair is an important characteristic amongst most cultures – besides certain groups of people such as monks for cultural/ritual reasons (Karthal cyan, 2009). Individuals from different cultural backgrounds have varying attitudes to the importance of hair; for example, in the Sikh community having uncut hair (Kesh) is a promise to the Will of God (Trieb, 2017). For White individuals hair represents sexuality and femininity (de Vere Hunt et al., 2020).

For Black people hair has been linked to oppression where historically, Black enslaved women were punished by having their hair cut short/shaven (Byrd & Tharps, 2014; Donahoo, 2019). Even to this current day Black women experience discrimination and are scrutinised for their naturally textured Afro hair where they are referred to as “ugly” and “unprofessional” (Clarke-Jeffers, 2022; Green, 2016) – which are cultural experiences unique to Black individuals. This study has showcased a novel perspective of why hair is significant within the Black community which is due to cultural attributions and ethnic identity. Participants attributed hair as their “crowning glory”, which is a typical label used within the Black community (Brooks & McNair, 2015; Campbell, 2020). The symbolic nature of referring to hair as their “crown” suggests that Black women have taken ownership of their hair which they take pride in and hold in high regard. With Black people continuously being subjected to hair discrimination, there are now recognised campaigns and policies such as World Afro Day and the Halo Code aiming to stop hair discrimination, which can allow Black people to embrace their hair and express their identity without feeling judged (De Leon, 2023; Jackson, 2022). Hence, as participants in-
In studies with White participants they have spoken about feeling feminised and related the significance of their hair to femininity and sexuality (Davey, 2020; de Vere Hunt et al., 2020). Thus, the loss of hair had impacts on how they could express themselves in a feminine manner and trying to retain a sense of evoking sexual desire. Gender identity was a strong symbolic message portrayed amongst White participants (Davey, 2020; de Vere Hunt et al., 2020). Whilst the connection between hair and sexual desire was not evident in this study, femininity was identified by participants where they related hair to having a sense of regality. Participants also indicated that the association between hair and femininity was linked to their cultural experience of being able to be creative with their hairstyles. However, due to alopecia it resulted in participants not being able to integrate with the common hairstyles (Afros, braids and locks) shared within the Black community (Johnson, 2013; Rodriguez, 2003). Thus, the varying hair attributes reflect the different experiences between Black and White individuals with alopecia. It needs to be acknowledged in research and alopecia interventions/support groups that cultural values can result in subtle differences in how individuals cope and manage with alopecia, as seen in other health conditions (Gopalkrishnan, 2018; Taylor & Richards, 2019). Additionally, this study acknowledged the impact of the NHM in which Black women with alopecia can replicate wigs of similar textures/styles or choose to be bald (Ndichu & Upadhyaya, 2019). With the participants emphasising the importance of hair linking to their culture the NHM can be beneficial to allow Black women to embrace their beauty with or without hair that may increase individuals’ self-esteem to cope and manage their alopecia (Ellington, 2014; Moore, 2014; Ndichu & Upadhyaya, 2019). With the participants emphasising the importance of hair linking to their culture the NHM can be beneficial to allow Black women to embrace their beauty with or without hair that may increase individuals’ self-esteem to cope and manage their alopecia (Ellington, 2014; Moore, 2014).

The findings also shed light on the salience of identity as alopecia results in a new appearance that can be difficult for individuals to adapt. Individuals can feel “abnormal” due to their appearance changing and not fitting the physical attractiveness norms of society (Davey et al., 2019; 2020; Hunt & McHale, 2004). The women in this study articulated that hair is a woman’s “crown and glory” showing how valuable hair is to them and their culture, being an expression of their identity (Thompson, 2009). These findings contribute to alopecia research in that hair for Black women forms a crucial part of their identity (Rodriguez, 2003; Thompson, 2009), and why hair loss may be challenging for Black women to accept as hair forms part of their lifestyle and cultural identity (Henderson, 2015).

The notion of concealment or having to camouflage one’s identity is a common theme within alopecia literature (Dinh & Sinclair, 2007; Montgomery et al., 2017; Wiggins et al., 2014) and was present within this research, resulting in individuals feeling they are living a “double life”. The NHM can be beneficial to allow Black women to embrace their beauty with or without hair, which may increase individuals’ self-esteem to cope and manage their alopecia (Ellington, 2014; Grey et al., 2013; Moore, 2014; Ndichu & Upadhyaya, 2019).

The fear of negative evaluation (in response to their changed identity; Goh, 2021) can decrease an individual’s self-esteem and perpetuate psychological distress (Aldhouse et al., 2020; Davis & Callender, 2018; Saed et al., 2016). However, Black individuals may experience a “double stigma” (Gary, 2005), relating to their ethnic origin and the negative connotations of mental health which may deter CED individuals from seeking support (Grey et al., 2013). This suggests that having alopecia, paired with poor mental health, may be a barrier for Black individuals to seek psychological support for their condition. There is a need for services to be sensitive to these cultural differences and acknowledge individuals’ beliefs and values and have representation to increase inclusivity and participation in alopecia/mental health services (Grey et al., 2013).

Previous research has highlighted how alopecia support groups are valuable in providing a space in which individuals can share experiences of their hair loss journey, treatment, and coping mechanisms (Davey et al., 2019; de Vere Hunt et al., 2020; Welsh & Guy, 2009). The current study, however, illustrates how support groups should be enhanced by promoting diversity to increase membership from diverse groups. Social identity theory (Tajfel, 1974) states that membership in a group (e.g., ethnic identity) and having a sense of belonging to the in-group increase self-esteem. However, the participants expressed how much of the support provided in the groups reflected White individuals and therefore led to feelings of being disconnected. This may inhibit individuals from seeking support due to the impression of there being a “them” and “us” divide because of cultural differences (Tajfel & Turner, 1979). The evidence of a lack of relatability in support groups suggests a strong need to increase diversity, inclusion, and accessibility that may help Black individuals feel more represented.

LIMITATIONS

There are a few limitations to the study that need to be addressed. First, participants included in the
study were from the UK and USA, where there are socio-economic health differences (Martinson, 2012). In comparison to the UK, medical healthcare is privatised in the USA (Villa & Kane, 2013), which was acknowledged in some interviews. Thus, individuals’ experiences of alopecia in the USA may differ because of the additional pressures of paying for treatment and wigs (Li et al., 2019; Roseborough, 2018). Second, the participants were predominantly recruited online through alopecia support groups and social media posts. Future research may consider a variety of recruitment methods to ensure that a range of experiences are captured rather than individuals already engaging in social support groups.

CONCLUSIONS

This research acknowledged how Black women with alopecia perceive their alopecia experience, the psychological issues, the social support, and the significance of hair within the Black community. The findings from this study can inform healthcare, with it being imperative that alopecia support is diversified to recognise and value the diverse cultural and ethnic differences and experiences between individuals. Acknowledging how an individual’s culture and ethnic background can influence experiences of living with alopecia will enable a tailored approach to be utilised rather than a “one size fits all” model.

DISCLOSURE

The authors declare no conflict of interest.

REFERENCES


