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ARTICLE

A systematic review and meta-synthesis of qualitative studies of alopecia: Managing identity and appearance changes

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Abstract

Purpose: Alopecia is a medical dermatology condition resulting in multiple psychosocial negative consequences in identity and appearence. Despite numerous qualitative studies examining the experience of people with alopecia, a comprehensive synthesis is lacking. This can obscure progress in research and minimize the impact of psychosocial support people with alopecia can receive. This systematic meta-synthesis aimed to critically integrate the existing literature to enhance psychological understanding of how people with alopecia manage issues about identity and appearance changes, and provide some evidence-based recommendations for clinicians working in the area of psychodermatology.

Methods: A systematic search of six databases: APA PsycInfo (OVID), Medline (OVID), Embase (OVID), CINAHL (EBSCO) and Scopus identified 22 eligible studies on the lived experience of alopecia among adults, adolescents and parents. The Critical Appraisal Skills Programme Qualitative Checklist was used to appraise the quality of the studies. Extracted data underwent inductive thematic analysis.

Results: The synthesis, representing 990 people living with alopecia, identified five main themes, focusing on managing identity and appearance changes: (1) coming to terms with a changed identity; (2) the journey to acceptance; (3) complexities of concealing hair loss; (4) social influences in both facilitating and hindering adaptation; and (5) treatment experiences highlighting unmet needs. Findings reveal substantial variation in managing identity and appearance changes, with some individuals achieving acceptance swiftly while others struggle. Social reactions and personal interpretations significantly shape adjustment.

Conclusions: Alopecia profoundly impacts identity, coping, and social interactions, often accompanied by dissatisfaction with health care and treatment options. The reactions of other people and interpretations of these experiences appear to play a key role in adjustment. The review underscores the need for personalized, non-pharmacological interventions that address personal and social challenges. Greater co-production in health care training and intervention development is necessary to improve support for individuals with appearance-altering conditions.

KEYWORDS

Alopecia, coping, dermatology, lived experience, qualitative, skin conditions, stigma, thematic synthesis

Statement of Contribution

What is already known on the subject?

- Alopecia has a significant impact on an individual's quality of life and emotional wellbeing.
- There is a lack of long-term effective treatment options, indicating the need to focus on how people manage identity and appearance concerns.

What does this study add?

- This is the first review of qualitative evidence investigating the lived experience of alopecia, focusing on managing identity and appearance changes.
- The review shows the complexity associated with adjustment to conditions such as alopecia that may affect both appearance and identity.
- Interventions to support people living with appearance-altering conditions need a personalized approach drawn from a range of supra-theories or meta-psychological models encompassing biopsychosocial perspectives.

INTRODUCTION

Alopecia is a dermatological condition affecting people across the lifespan and is characterized by substantial hair loss from the scalp and other body areas, including eyelashes, eyebrows and nose hair (Gilhar et al., 2012). This condition encompasses various types, including alopecia areata, alopecia totalis, alopecia universalis and scarring alopecia, with severity ranging from patchy hair loss to complete baldness. Its progression can be rapid, recurrent and unpredictable (Tosti et al., 2006) and is often associated with cumulative stressful life events in the year preceding onset (Ferentinos et al., 2022; Güleç et al., 2004; Picardi & Abeni, 2001). Notably, hair loss does not solely define the impact of alopecia but can exacerbate stress (Taheri et al., 2012). This indicates that beyond the physical change in appearance, there are other factors contributing to the significant psychological and social impact of the condition (Cartwright et al., 2009; Mesinkovska et al., 2023), underscoring the need for psychosocial support.

The psychological impacts of alopecia have been widely studied, revealing the potential for significant impairments in mental health and quality of life (Rencz et al., 2016). Systematic reviews and meta-analyses highlight higher rates of anxiety and depression among adults with alopecia, compared with healthy controls, with medium to large effect sizes (van Dalen et al., 2022). In children, findings are mixed, with some studies indicating greater psychological distress to some people, while others report no significant differences. Parents of affected children also report lower health-related quality of life (Bilgiç et al., 2014). While quantitative evidence highlights the psychological burden of alopecia, the mixed results emphasize the need for further research, including qualitative research that might help elucidate the nuanced social and contextual elements (e.g., lived experiences) associated with the condition. There are now a number of qualitative studies examining the experience of living with alopecia conducted. Yet, there is an urgent need to synthesize the findings of these studies because such a synthesis will provide a roadmap for clinicians to understand with more sensitivity the interpersonal and contextual implications of managing identity and appearance changes in alopecia.

Understanding the contextual sensitivities of living with alopecia, especially how people manage identity and appearance changes necessitates a focus on its notable social impact, because the degree of alopecia's visible difference in appearance indicates that changes in appearance are a major source of distress for individuals (Mostaghimi et al., 2021). As a visible acquired condition, similar to burns, alopecia impacts self-confidence and body image (Tucker, 2009); both contribute to appearance-related distress and social anxiety (Montgomery et al., 2017; Powell et al., 2023; Russo et al., 2019). In turn, distress often is associated with the use of passive avoidance strategies, for example, social avoidance (Cash, 2001; Montgomery et al., 2017) and camouflage behaviours (Davey et al., 2019). These avoidance behaviours, when used excessively, can have a negative impact on the long-term management of chronic conditions (Karademas et al., 2017; Karekla & Panayiotou, 2011). Further, within the social context, social risk factors, such as urban living and social deprivation, are associated with higher incidences of alopecia, with people in deprived areas less likely to access specialist dermatology services (Harries et al., 2022). Additionally, people with alopecia report higher unemployment rates and frequent work absences, and there may also be influences of ethnicity, which may reflect broader societal challenges linked to the condition (Harries et al., 2021; Macbeth et al., 2022; Thompson et al., 2024) that further strengthen the need for targeted psychosocial interventions.

Another critical contextual factor is the lack of long-term effective treatments and the side effects of existing medications (Delamere et al., 2008; Harries et al., 2024). Recent advancements in pharmaceutical products, such as JAK inhibitors, offer promise (Yan et al., 2022), yet such treatments are not widely accessible, and some people may find them unsuitable or undesirable. Thus, understanding the contextual issues related to distress is paramount for developing non-pharmacological interventions to alleviate the significant psychological, societal and treatment-related burdens of alopecia, irrespective of medical advancements (Messenger et al., 2012; van Dalen et al., 2022).

The urgent need for psychological support for people with skin conditions has been emphasized by the UK's All Party Parliamentary Group on Skin's report on the mental health impact of such conditions (All Party Parliamentary Report on Skin, 2020). The group underscored the importance of investigating the contextual parameters associated with living with a skin condition, especially how people manage identity changes and cope with appearance concerns, to further inform the development of person-centred health services in dermatology (Cowdell et al., 2012; Onselen, 2018; Schmidt et al., 2001; Smeets et al., 2020). Notably, a qualitative meta-synthesis of the experiences of people with alopecia could enable the voices of those impacted to be better considered, assisting understanding of core psychological processes that might be the target of psychological support interventions.

In sum, systematically synthesizing qualitative research at a '*meta*' level, considering authors' interpretations, extends the findings of primary research (Mohammed et al., 2016) in a way that can directly inform health care interventions (Thomas & Harden, 2008). Consequently, this systematic meta-synthesis aimed to investigate the lived experiences of people with alopecia, focusing on managing identity and appearance changes in alopecia. Within this main objective, this systematic meta-synthesis review focused on providing answers to three key questions: (1) What challenges do they face? (2) How do they cope? and (3) What are their treatment experiences?

METHODS

Review protocol

Prior to searches being conducted, we set up and registered a review protocol on PROSPERO (reference: CRD42022352975). The review followed both the Preferred Items for Systematic Reviews and Meta-Analyses checklist (PRISMA; Page et al., 2021) and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research guidelines (ENTREQ; Tong et al., 2012). We carried out a thematic synthesis, using the process outlined by Thomas and Harden (2008).

Information sources and search strategy

We employed a comprehensive search strategy to identify all relevant primary studies (Tong et al., 2012). The Population, Phenomenon of Interest and Context (PICo: Stern et al., 2014) template was used to develop the research question and search strategy (see Table 1).

To define the search terms and strategy, we consulted an information scientist from the Library of Cardiff University. Between October 2023 and December 2024, we searched six databases: APA PsycInfo (OVID), Medline (OVID), Embase (OVID), CINAHL (EBSCO) and Scopus. We decided not to apply any date restriction as there was no prior review of the qualitative literature. We purposefully chose specific databases to include a range of psychosocial and medical journals. No further papers were identified from citation searches or searches of the reference lists of the selected full-text articles. Search terms included '*alopecia*' as well as terms related to qualitative methods and phenomena associated with qualitative research, such as thematic, grounded theory and interpretative phenomenological theory. Finally, we employed two qualitative search filters, including a string of simple free-text terms, to support all relevant articles as described in Rogers et al. (2018). Search strategies were adapted as required for each database; a full list of search terms can be found in Appendix S1.

Eligibility criteria

Studies were eligible if they (a) used qualitative methods for primary data collection, with sufficient data analysis and qualitative data for extraction, including mixed methods, research letters and studies developing patient reported outcome measures (PROMs) on the lived experience of alopecia; (b) studies primarily presenting findings on the experience of living with alopecia, including at least one quote and author interpretation referring to people's challenges, coping and treatment experiences; and (c) included individuals with alopecia and parents/carers of children with alopecia.

Studies were excluded if they (a) focused on other physical health conditions alongside alopecia; (b) were literature reviews; (c) exclusively addressed chemotherapy-induced alopecia (covered in Kocan

TABLE 1 Elements of research question identified using PICo.

Criteria	
Population	People with alopecia or parents of children with alopecia
Phenomena of interest	Qualitative lived experience of alopecia
Context	Any context

et al., 2023); and (d) lacked a sufficient method of qualitative analysis (e.g., reference to inductive/deductive type of analyses without presenting any specific names).

Selection of studies

Figure 1 displays the PRISMA diagram (Moher et al., 2009) and outlines the process of study selection. The primary reviewer (ZH) screened the sources by their titles and abstracts, following the inclusion and exclusion criteria. Then, another reviewer (AT), together with the primary reviewer, screened the full texts of papers. To resolve discrepancies, the two reviewers met with one of the other authors who acted as a moderator (VSV) and discussed the papers with reference to the inclusion and exclusion

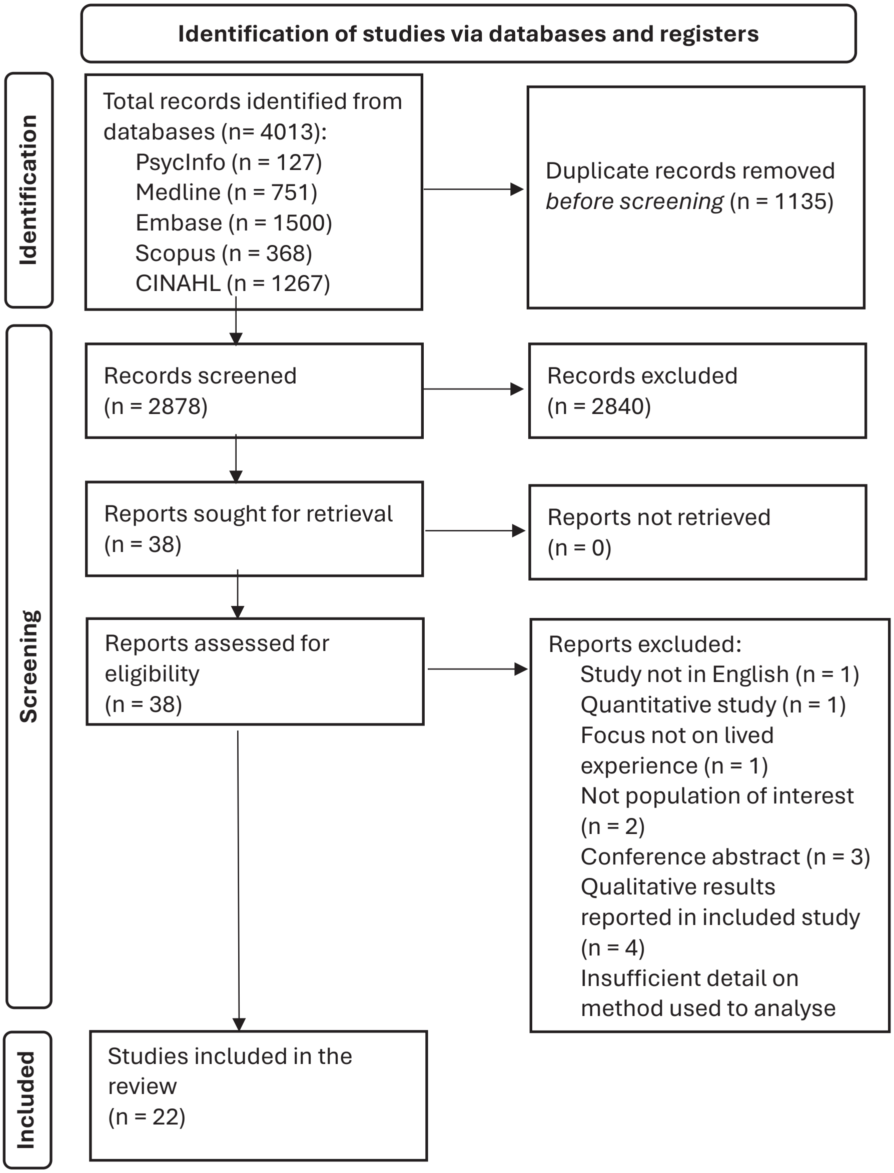

FIGURE 1 PRISMA flow diagram.

criteria until a consensus was reached. There was almost 95% agreement between the reviewers and the moderator. The final data set comprised 22 included studies.

Data extraction

The team developed a data extraction tool using Microsoft Word, guided by the ENTREQ guidelines and the PICO (Tong et al., 2012). The primary reviewer extracted data from the studies and summarized it into the Table 2 with the use of Nvivo software (QSR International Pty Ltd, 2020). An example of a complete detailed data extraction table is included in Appendix S2.

Quality appraisal

We employed the Critical Appraisal Skills Programme 10- items checklist for qualitative studies (CASP: Critical Appraisal Skills Programme, 2018), commonly used in health care (Noyes et al., 2018), to assess the methodological quality, risk of bias, and strengths and limitations of the studies (see Appendix S3). The CASP checklist was selected because it allows reviewers to evaluate primary studies on validity, results and local utility across different qualitative methodologies (Noyes et al., 2018). We decided not to exclude studies based on methodological quality but conducted a critical appraisal of all selected studies (Dixon-Woods et al., 2005). The first author (ZH) completed the quality appraisal while the second author (VSV) appraised a random selection of articles (25%, $n = 6$). Discrepancies occurred on 4 out of 60 checklist items that were discussed with reference to the CASP checklist prompts to resolve ambiguities and reach consensus.

Synthesis of results

Following the suggestions of Downe et al. (2019), we selected thematic synthesis to aggregate findings across the selected studies due to the broad and heterogeneous nature of the data set (Noyes et al., 2018). Prior to synthesis, we transferred the PDF files of each study into NVivo 1.7 for analyses. The thematic synthesis involved three steps. Firstly, the first coder (ZH) read the selected papers repeatedly, coding the result and discussion sections line-by-line to capture authors' interpretations (Thomas & Harden, 2008), and generated an initial code bank. Secondly, the first coder (ZH) organized the initial identified codes into descriptive themes (see the Appendix S4). Thirdly, two coders (AT & VSV) further interpreted the descriptive themes, to develop analytical themes, identifying patterns and relationships across studies in relation to the three specified research questions (Thomas & Harden, 2008). These were then discussed in detail with the other authors, and the final list of themes and subthemes was agreed upon through whole team discussions (see the Appendix S5). In the supplementary file, a summary of the descriptive themes with illustrative quotes is presented, that as well as an example of the codes and descriptive themes contributing to an analytical theme.

Reflexivity and warrantability

The authors sought to consider the role played by personal and professional experiences, recognizing that these could influence the development of the themes. To be transparent about this, the author group held regular meetings to identify specific constructs and experiences that might influence the findings and to check the warrantability of these within the data (Megheirkouni & Moir, 2023).

TABLE 2 Summary of included studies.

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
Aldhouse et al. (2020)	USA	*n* = 45 19 males, 26 females Aged 15–72 AA diagnosis	Dermatology research centres	Semi-structured interviews	Thematic analysis (phenomenological approach)	Descriptions of physical symptoms and their impact Perceived/actual stigmatization Psychological and emotional impact of AA Impact on social functioning
Barkauskaite and Serapinas (2020)	Lithuania	*n* = 6 2 males, 4 females Aged 22–33 AT or AU diagnosis	National alopecia organization	Unstructured interviews	F.P. Collaizi's phenomenological approach	Changes in identity A process of grieving through to acceptance Gendered experience of alopecia Emotional reactions to alopecia
Cook et al. (2022)	USA	*n* = 14 14 females Average age of 67 FFA diagnosis	Dermatology clinic	Semi-structured interviews	Coded using inductive and constant comparison technique	Confusion around cause Delay in getting diagnosed and longing for a cure Disguising hair loss Fatigue and psychosocial difficulties Positive experiences with hair stylists
Davey et al. (2019)	UK	*n* = 95 11 males, 84 females Aged 18–79 AA, AU or AT diagnosis (*n* = 89) No formal diagnosis (*n* = 6)	Online through email, social media, and alopecia charity newsletter	Online survey using open questions	Thematic analysis (critical realist framework)	Emotional and social impacts of hair loss Changes in identity Impact on daily lifestyle and relationships Negative experiences of treatment and health professionals, lack of psychological support Coping, growth and acceptance, importance of social support
de Vere Hunt et al. (2021)	UK	*n* = 21 3 males, 18 females Aged 14–23 AA diagnosis	Young people were interviewed for HealthTalk resources	Semi-structured interviews	Inductive thematic analysis	Health professionals overlooking emotional impact and giving insufficient information

(Continues)

TABLE 2 (Continued)

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
Fox (2003)	UK	228 episodes of web-based communication from group consisting of 138–155 members	Web-based support group	Collection of web-based communication over 18 months	Content analysis and concept mapping	Pursuit for meaning and moving towards acceptance Powerlessness and loss of identity Need for practical support and advice Emotional survival
Haskin et al. (2017)	USA	$n = 10$ 10 females Aged 51–71 SA diagnosis	Dermatology clinics	Semi-structured interviews	Thematic analysis (inductive and semantic level approach)	Emotional impact including self-blame, fear of unpredictability, loss of self-esteem Lack of knowledge about cause and lack of sensitivity from physician Concealing hair loss Experiences of positive and negative support from others.
Hunt and McHale (2005)	UK	Part 1: $n = 162$ 41 males, 121 females Part 2: $n = 34$ 17 males, 17 females Aged 12–93 years Participants self-identified with alopecia 4 parents of children with alopecia	Advertisements in local newspapers, requests on alopecia websites	Part 1: spontaneous written accounts Part 2: email interviews	Grounded theory	Overarching theme of identity Personal impact including physical effects, cause, psychological distress and coping Social impact including work, relationships and social support, different experiences of different ages and genders Treatment experiences and doctors attitudes
Iliffe and Thompson (2019)	UK	$n = 12$ 12 females Aged 30–59 People with alopecia diagnosis 1 parent of a child with alopecia	Alopecia Facebook support group, people that had found the group beneficial were recruited	Semi-structured interviews via Facebook messenger	Interpretative phenomenological analysis	Helpful aspects of online support including opportunity to express emotions, practical support, a sense of belonging, and internal changes leading to self-acceptance

TABLE 2 (Continued)

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
Leow and Lee (2017)	Singapore	$n = 21$ 12 males, 9 females Aged 22–57 AA diagnosis ILK injection ($n = 10$) DCP application ($n = 11$)	National dermatology centre	Interviews	Framework method (inductive, iterative process)	Journey from shock to acceptance Impact of self-esteem Expectations of health care providers Experimenting with complementary and alternative medicine Social support Treatment concerns
Macey et al. (2022)	USA	$n = 11$ 5 males, 6 females Aged 12–17 AA diagnosis	Dermatology research centres	Semi-structured combined concept elicitation and cognitive interviews	Thematic analysis (experiential, realist approach)	Scalp hair loss as most bothersome symptom Resilience, acceptance and social support Impact on emotional and psychological functioning Disturbances in daily living
Matzer et al. (2011)	Austria	$n = 45$ 10 males, 35 females Aged 22–77 AA diagnosis	Dermatology clinic and self-help groups	Survey and follow-up interviews	Coding framework a combination of grounded theory approach and thematic coding Frequency analysis	Varied experience of stress prior to AA Range of emotional reactions to AA Range of coping styles utilized by participants Stress experiences in the AA journey
Montgomery et al. (2017)	UK	$n = 338$ 5 males, 329 females, 1 unknown Aged 13–65+ 11 types of alopecia AA = 82.6%	Social media and alopecia charity mailing list	Survey with inclusion of open-ended questions	Qualitative content analysis (inductive approach)	Positive and negative impact of wig use on confidence Concerns about social judgement when not wearing a wig Challenges associated with wig use

(Continues)

TABLE 2 (Continued)

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
Rafique and Hunt (2015)	Pakistan	*n* = 8 3 males, 5 females Aged 16–19 AA diagnosis	Dermatology departments	Semi-structured interviews	Interpretative phenomenological analysis	Range of coping styles used in experience of AA Loss of self and social loss Concerns about future and physical aspects Negative emotions and thoughts
Rajoo et al. (2020)	Australia	*n* = 16 (8 in focus group, 8 interviews) Aged 18–59 AA diagnosis	Alopecia foundation website and social media	Focus group Telephone interviews	Constructivist grounded theory	Facilitators and barriers to engaging in physical activity Four phase model of AA moving from onset, initial reactions, adjustment and acceptance
Razum and Vukasovic Hlupic (2022)	Croatia	*n* = 11 11 males Aged 23–33 Androgenetic alopecia	Advertisements on social media	Semi-structured interviews	Thematic analysis	Thoughts and feelings associated with hair loss Impact on social and daily functioning Coping with hair loss
Stock et al. (2022)	UK	*n* = 22 22 females Aged 26–56 5 types of alopecia, AU = 72% Undergone medical tattooing	Advertisements on websites, social media and charity newsletters	Interviews	Inductive thematic analysis	Reasons for undertaking medical tattooing Regaining confidence Considerations when seeking treatment Important factors for practitioners to consider
Welsh and Guy (2009)	UK	*n* = 12 5 males, 7 females Aged 30–59 AA/AU diagnosis	Charity newsletter and local newspaper	Biographical semi-structured interviews	Interpretative phenomenological analysis	Coping with initial impact Living with unpredictability of disease Coping style changes over time
Wiggins et al. (2014)	UK	*n* = 23 3 males, 20 females Aged 29–74 AA/AT/AU diagnosis 1 parent of child with AA	Charity websites and newsletters	Focus groups Semi-structured interviews Video diaries	Discursive psychology	Experiences of wig use Importance of noticeability Differences in how strangers, acquaintances and close friends and family notice and react to wig use

TABLE 2 (Continued)

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
Winnette et al. (2021)	USA	*n* = 36 10 males, 26 females Aged 12–70 AA diagnosis	Patient databases from research organizations	Concept elicitation and cognitive debriefing interviews	Thematic analysis	Physical experience of symptoms Emotional impact of diagnostic process and treatments Impact on daily lives
Wyrwich et al. (2020)	USA	*n* = 30 13 males, 17 females Aged 15–72 AA diagnosis	Clinician referral via university dermatology research groups	Semi-structured interviews	Thematic analysis (phenomenological interpretative approach)	Impact of physical symptoms on daily life and psychological wellbeing
Zucchelli et al. (2022)	UK	*n* = 18 18 males Aged 17–71 AA/AU diagnosis	Recruited from broader survey sample	Interviews	Reflexive thematic analysis (critical realist worldview)	Men's experiences of alopecia Feeling unrepresented Importance of hair for men and the impact of hair loss Coming to terms with hair loss and impact on the self

Abbreviations: AA, alopecia areata; AT, alopecia totalis; AU, alopecia universalis; DCP, diphenylcyclopropenone; FFA, frontal fibrosing alopecia; ILK, intralesional Kenalog steroid injection; SA, scarring alopecia.

RESULTS

Summary of included studies

Twenty-two studies were reviewed in full, containing 990 participants, 784 females and 190 males, ranging in age from 12 to 93 years. There were six mixed-methods studies included that related to measurement development. The remaining 16 studies used qualitative methods only. All studies included first-hand accounts of living with alopecia; however, three studies also included participants reporting their experiences from the perspective of being a parent of a child with alopecia. Most studies included participants with alopecia areata, totalis and universalis. The most common data collection method was interviews ($n = 15$); other methods included focus groups ($n = 2$), written accounts ($n = 7$), video diaries ($n = 1$), extracts from online support groups ($n = 1$) and open-ended survey questions ($n = 4$). A range of analysis methods were used including thematic analysis ($n = 9$), grounded theory ($n = 3$), interpretative phenomenological analysis ($n = 6$) and content analysis ($n = 2$). Table 2 provides a summary of the main characteristics of each study. Primary studies were carried out mostly in the USA ($n = 6$), United Kingdom ($n = 5$), followed by Lithuania ($n = 1$), Singapore ($n = 1$), Austria ($n = 1$), Pakistan ($n = 1$), Australia ($n = 1$) and Croatia ($n = 1$). Regarding study population, most studies ($n = 13$) included people with alopecia areata (AA) diagnosis, followed by alopecia universalis (AU) ($n = 6$), alopecia totalis (AT) ($n = 1$), scarring alopecia (SA) ($n = 1$), or others (e.g., androgenic alopecia).

Quality appraisal results

Table 3 presents a summary of the results from the CASP checklists completed for each of the included studies. The first author appraised the quality of each selected article. The second author independently rated five out of 22 randomly selected articles (20%), reaching a high agreement (90%; with 45 out of 50 items) between the raters. Seven studies had '*yes*' answers on all checklist items, indicating a high study quality. The remaining studies had some 'can't *tell*' or '*no*' answers, indicating a moderate to low quality (Scope et al., 2021). One study had mostly 'can't *tell*' answers because it was published as a research letter; therefore, providing limited opportunity for the authors to review details of methodology and the process of analysis. Most of the 'can't *tell*' or '*no*' answers were in response to the question of whether the researchers have sufficiently considered the relationship between the researcher and participants.

Methodological critique of included studies

Several studies in the review lacked transparency in data collection (interview or survey guide) and analysis. Nine studies had a limited description of the analysis process and so received a 'can't *tell*' answer on the CASP checklist for the question related to rigorous data analysis. However, word counts of journal articles can limit authors' ability to give full details of the steps involved in undertaking qualitative analysis, making it difficult to make a firm conclusion on the rigour of analysis in these studies. While more recent studies were of higher quality, only nine papers sufficiently addressed the relationship between the researcher and participants; the other studies tended to lack a description of any reflexive processes, increasing the risk of researcher bias. A small number of the studies ($n = 2$) omitted direct quotations, presenting only narrative accounts. Common limitations included non-diverse, self-selected samples and small sample sizes, all of which affect the transferability of findings.

TABLE 3 Summary of quality appraisal results.

Author (year)	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship & reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research
Aldhouse et al. (2020)	✓	✓	✓	✓	✓	X	✓	?	✓	✓
Barkauskaite and Serapinas (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Cook et al. (2022)	✓	✓	✓	✓	?	?	?	?	✓	?
Davey et al. (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
de Vere Hunt et al. (2021)	?	?	?	?	?	?	✓	?	✓	✓
Fox (2003)	✓	✓	✓	✓	✓	✓	?	?	✓	✓
Haskin et al. (2017)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Hunt and McHale (2005)	✓	✓	✓	✓	?	X	X	?	✓	?
Iliffe and Thompson (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Leow and Lee (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Macey et al. (2022)	✓	✓	✓	✓	✓	✓	✓	?	?	✓
Matzer et al. (2011)	✓	✓	✓	✓	✓	X	✓	?	✓	✓
Montgomery et al. (2017)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Rafique and Hunt (2015)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Rajoo et al. (2020)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Razum and Vukasovic Hlupic (2022)	✓	✓	✓	✓	?	X	✓	?	?	✓
Stock et al. (2022)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓

(Continues)

TABLE 3 (Continued)

Author (year)	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship & reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research
Welsh and Guy (2009)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Wiggins et al. (2014)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Winnette et al. (2021)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Wyrwich et al. (2020)	✓	✓	✓	✓	✓	X	✓	?	✓	✓
Zucchelli et al. (2022)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Note: ✓ = yes; ? = can't tell; X = no.

Thematic synthesis

The thematic synthesis resulted in five overarching themes, each with three or four subthemes. These themes do not reflect the experiences of every participant across the studies but summarize the most prevalent and salient findings focusing on managing identity and appearance changes. We did not find any evidence of significant outlying perspectives from these themes and Table 4 shows which studies contributed to each subtheme. In Figure 2, we illustrate a conceptual model of the analytic themes and subthemes. We then present each one of the themes and subthemes. We conclude with a final descriptive paragraph explaining our data-driven conceptual model, derived from this meta-synthesis.

Overarching theme 1: Who am I without hair?

1.1 **Hair is important.** Participants across the studies emphasized the significance of hair, describing its loss as deeply traumatic and akin to losing a limb, for example, *'it isn't just cosmetic and it can affect people deeply, it is like losing a limb, and you have to adjust'* (Davey et al., 2019, p.1381). Hair received a cultural and symbolic meaning of youth and femininity, and many remained hopeful for a cure, highlighting its profound importance.

1.2 **Loss of and impact on self.** Hair loss significantly affected identity and loss of self-perspective, with participants reporting feeling dehumanized, unattractive and stigmatized. While the importance of hair was reported to be more significant for women, reports from men suggested that the impact in terms of loss of confidence and identity is similar. Both women and men commented on the impact of femininity, masculinity and confidence. Personal characteristics, such as race, sexuality and neurodivergent characteristics interacted with hair loss, further intensifying the feelings of difference and marginalization, as reflected in participant accounts. For example, *'the more attractive you are, the better in the gay community … it's just completely, like … destroyed my confidence … especially being gay, it has been a lot harder having alopecia'* (Zucchelli et al., 2022, p.7).

1.3 Physical changes and challenges. Participants highlighted the physical effects of alopecia, particularly the loss of eyelashes and eyebrows which caused eye irritation, especially when sweating. This typically required daily cleaning to prevent discomfort: *'Dust gets in my eyes. Sweat falls in, and it's more of a nuisance having to clean my eyes out every night. That's my biggest thing. Every night I got to clean my eyes. If I don't, it irritates the hell out of me the next day'.* (Wyrwich et al., 2020, p.S75). Such issues sometimes hindered physical activity. Hair loss varied in rate—rapid for some, gradual for others—but was largely unpredictable, reinforcing feelings of trauma and lack of control.

Overarching theme 2: The (difficult) journey to acceptance

2.1 **Emotional responses to alopecia.** Participants reported feeling shocked and fearful when first diagnosed with alopecia, with some looking for someone to blame either others or themselves: *'My first reaction was very strong. I blamed God for all this, I was angry with him. I kept questioning him why he was so cruel to me. I held him responsible for my condition'* (Rafique & Hunt, 2015, p.7). There was also a sense that people didn't feel they were entitled to feel the way they did because they were not 'ill'. The emotional reactions to losing hair were likened to the feeling of grief: *'Losing hair is a grieving process and the emotions felt mirror those experienced by those suffering a bereavement'* (Davey et al., 2019, p. 1381).

2.2 People cope in varied ways. Coping styles included active strategies such as seeking support, use of medicines, alternative medicines, or wigs. Some turned to distraction to manage psychological distress: "*I was always in the library studying; I suppose I did not want to face the world out there. I got very good grades. I felt comfort in studying; it kept me away from all the thoughts that could bother me.*" (Rafique &

TABLE 4 Contribution of reviewed studies to themes.

	Main themes and subthemes																	
	Who am I without hair			The (difficult) journey to acceptance				The ways in which society helps and hinders				The complexity of concealment				Unmet needs		
Author	1.1	1.2	1.3	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4	4.1	4.2	4.3	4.4	5.1	5.2	5.3
Aldhouse et al. (2020)	●	●	●	●	●	●	●			●	●	●	●	●		●		●
Barkauskaite and Serapinas (2020)	●	●		●		●	●	●			●	●	●	●				
Cook et al. (2022)	●	●	●	●		●	●	●			●	●	●	●			●	
Davey et al. (2019)	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●
de Vere Hunt et al. (2021)	●	●			●	●	●			●		●			●	●	●	
Fox (2003)	●	●	●	●		●	●		●	●	●	●	●	●	●		●	
Haskin et al. (2017)		●		●		●		●			●	●	●	●		●	●	
Hunt and McHale (2005)	●	●	●	●	●	●	●	●			●	●	●	●		●	●	●
Iliffe and Thompson (2019)	●				●	●	●	●	●					●				
Leow and Lee (2017)	●	●		●	●	●	●	●					●			●		●
Macey et al. (2022)	●	●	●	●	●	●	●	●		●	●	●	●	●	●			
Matzer et al. (2011)		●		●	●	●					●					●		●
Montgomery et al. (2017)		●								●	●	●	●	●	●			
Rafique and Hunt (2015)	●	●	●	●	●	●	●	●		●	●	●	●	●				●
Rajoo et al. (2020)	●			●	●	●	●	●	●	●	●	●	●	●				
Razum and Vukasovic Hlupic (2022)	●	●	●	●	●		●				●		●	●				
Stock et al. (2022)	●	●				●	●	●			●	●	●	●		●	●	●
Welsh and Guy (2009)	●	●		●	●	●	●	●	●	●	●	●	●	●	●	●		●

TABLE 4 (Continued)

Author	Main themes and subthemes																
	Who am I without hair			The (difficult) journey to acceptance				The ways in which society helps and hinders				The complexity of concealment				Unmet needs		
	1.1	1.2	1.3	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4	4.1	4.2	4.3	4.4	5.1	5.2	5.3
Wiggins et al. (2014)	●	●						●			●	●	●	●	●			
Winnette et al. (2021)	●		●	●			●				●	●		●				
Wyrwich et al. (2020)	●		●				●				●	●						
Zucchelli et al. (2022)	●	●	●	●	●	●	●		●	●	●	●	●	●		●		

Note: 1.1 = hair is important, 1.2 = loss of, and impact on self, 1.3 = physical changes and challenges. 2.1 = emotional responses to alopecia, 2.3 = people cope in varied ways, 2.3 = it is not an easy journey, 2.4 = acceptance and the changed self. 3.1 = the role of family, partners and friends, 3.2 = the importance of sharing experiences, 3.3 = lack of public awareness, 3.4 = fear of, and actual harm from others. 4.1 = a need to be hidden, 4.2 = an important tool, 4.3 = practical and emotional challenges, 4.4 = the unwritten rules. 5.1 = professionals should address the emotional impact, 5.2 = negative experiences with support providers, 5.3 = difficulties with medical treatment.

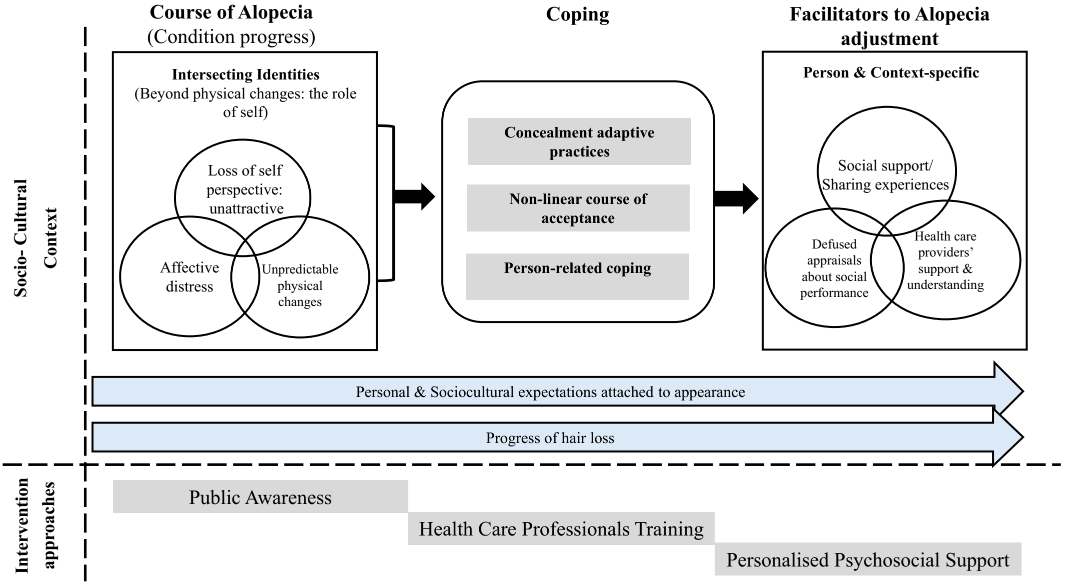

FIGURE 2 Conceptual model of the analytic themes and subthemes.

Hunt, 2015 p. 8), while others avoided mirrors or public spaces. Remaining positive, using humour (more common among men), religious coping and remaining hopeful were also employed. Coping varied from person to person and was not always effective, with individuals reporting continued distress despite use of varied coping mechanisms.

2.3**It is not an easy journey.** Acceptance was described as non-linear, influenced by factors such as time and the unpredictability of alopecia: *"…some days I do believe that it's true that I am beginning to' accept this and adjust to my change in life and self but on others I know that it's a con because I am not'* (Fox, 2003, p. 555). Some people noted that over time, coping improved, especially with age.

2.4**Acceptance and the changed self.** Some participants' experiences of acceptance seemed to come along with a sense of personal growth. Participants talked about letting go of societal beauty ideals, embracing baldness and placing less importance on what others think of them. For some, this led to re-engagement with work and social life: *'[AA] really has just made me appreciate things a lot more. It's just really opened my mind to people that stick around you and so on. They don't stick around because of the way you look or anything, it's all to do with how you are as a person'* (Zucchelli et al., 2022, p. 9). Many expressed gratitude for life, awareness of their strengths and putting their hair into a new perspective.

Overarching theme 3: The ways in which society helps and hinders

3.1**The role of family, partners and friends.** Support from loved ones was crucial for some participants in adjusting to alopecia. Having supportive partners helped people to feel more confident in their appearance and supportive friends facilitated increased social participation. Participants discussed how going through challenging times with alopecia helped them to strengthen genuine friendships: *'I feel like you definitely realize, 'specially with friends, who your real friends are when you go through something that's tough, who abandons you and who sticks with you and wants to help you. So, I feel like with the real friends that I've gotten through this experience it's strengthened our relationship'* (Macey et al., 2022, p. S2).

3.2 **The importance of sharing experiences.** When family or friends lacked understanding, support groups offered a sense of belonging, reducing isolation and loneliness. Participants found value in sharing tips on coping and practical strategies, such as using wigs or helping others in the community. Women were more likely to engage in support groups; however, these findings were mixed, with some male participants reporting not feeling engaging in supporting groups helpful: *'I tried going to a support group but found it depressing and suppressive…'* (Welsh & Guy, 2009, p. 198). Overall, the benefits were more commonly reported.

3.3 **Lack of public awareness.** Many participants and their families were initially unfamiliar with the condition. The lack of public awareness around alopecia was identified as a factor contributing to feelings of shame and alienation. Likewise, a lack of media representation compounded feelings of being different. This was frustrating for mostly males who expressed frustration over societal expectations that downplay male concerns about their appearance: '*…what society kind of projects onto us, or expectations for men. So, one of the things that I think's pretty unfair is that, because you're a man you shouldn't really care so much about your appearance*' (Zucchelli et al., 2022, p. 7). Some participants were misinterpreted as having cancer, leading to difficulties with feeling exposed and the need to explain their condition: '*People assume I have cancer…*' (Montgomery et al., 2017, p. 5).

3.4 **Fear of, and actual harm from others.** Across the studies participants feared judgement, rejection and experienced negative reactions, including staring, jokes, bullying and even physical abuse for some: *'I've lost my hair at various life stages. Initially as a teen I was bullied at school and stared at and shouted at in the street by strangers'* (Davey et al., 2019, p. 1382). Some participants described negative experiences when dating as well as fear of exposing themselves to potential partners due to fear of rejection. Others described being turned down for work opportunities because of their hair loss. Overall, these experiences resulted in increased feelings of being 'othered', feeling unworthy and shameful.

Overarching theme 4: The complexity of concealing hair loss

4.1 **A need to be hidden.** Participants described alopecia as a private issue that they felt compelled to conceal, not only to avoid negative reactions from strangers but also to escape questions from family and partners. Participants described a strong desire not to be seen by others, especially early on in diagnosis, resulting in missing out on important social events: *'Shortly after the hair loss I was asked to be an usher at a good friend's wedding, I felt I had to turn it down because I wasn't ready to be seen in public'* (Welsh & Guy, 2009, p. 197). Concealing hair loss also affected work and school participation for many individuals.

4.2 **Concealment: An important tool.** Concealing hair loss was an essential coping mechanism for participants. Whilst some participants wore wigs, others used scarves, hats and used makeup to draw eyebrows. Some mentioned the practical benefits, like trying different hairstyles with wigs or reducing grooming time. Likewise, medical tattooing was also cited by one study as having a positive impact. Participants talked about feeling more self-confident and more likely to participate in social activities when their hair loss had been concealed. For example, when talking about wearing a wig, one participant said: *'It's improved my confidence as I avoided harsh overhead lights in retail stores as it emphasised my thinning hair, particularly distressing when I saw my reflection in a mirror. Now I can walk past a mirror with harsh lighting overhead and check my hair and smile!'* (Montgomery et al., 2017, p. 4).

4.3 **Practical and emotional challenges.** In terms of the practical challenges, wigs were described as itchy, and there were fears of wigs being blown off in the wind or becoming hot during physical activity. In addition, the burden of having to use makeup to draw on eyebrows was discussed: *'The other thing is just kind of making sure that you always look the same every day because if there's a big difference in what you look like, what your wig looks like, how you do your eyebrows, how you do everything, it also makes you a bit insecure'* (Macey et al., 2022, p. S2). Cost and accessibility of wigs were significant barriers, with some unaware of financial support options. Concealing hair loss also triggered emotional conflicts, as participants worried about inauthenticity and how others might react if their concealment was discovered.

4.4 **The unwritten rules.** In many studies there was a narrative about people following social rules to gain approval rather than being directly benefited. Many participants described feeling societal pressure to conceal their hair loss, to conform to beauty ideals. Others reported that it was important for them to feel that people would not be able to notice that they are wearing a wig. Participants talked about navigating who they could and couldn't tell that they were wearing a wig. Some had close others they could confide in while others did not want anyone to know about their use of wigs: *'I wear a wig every day and do not tell anyone about the fact that I wear a wig. Even my closest friend doesn't know'* (Davey et al., 2019, p. 1383). For men, it was felt that wearing wigs was not acceptable and they looked to other ways of concealing hair loss, such as wearing hats. Overall, whether following 'unwritten rules' is a behaviour that helps improve confidence appeared to be related to socio-interpersonal factors and individuals' appraisals and expectancies regarding social performance (e.g. the degree to which hair loss deviates from social conformity).

Overarching theme 5: Unmet needs

5.1 **Professionals should address the emotional impact.** Participants felt that health care providers prioritized medical treatment over addressing the emotional toll of alopecia. Some participants recalled specific incidences where they felt that their emotional responses had been invalidated by health professionals: *'Some doctors showed a lack of empathy or interest in the outcomes for the patient: I was just told to wear a wig. 'After all it's only your pride that's hurt' said one doctor'* (Hunt & McHale, 2005 p. 46). Participants also reported struggling to access psychological support.

5.2 **Negative experiences with support providers.** Across studies participants described negative experiences with health professionals. Delays in seeing specialists or receiving a diagnosis were common frustrations. Many felt they were not provided with sufficient information about alopecia, treatment options, or access to wigs. *'Have you Googled alopecia?' and I said 'Yeah', he said 'Well that will tell you all you need to know.' That's just what he said to me…if he'd have maybe just spent an extra five minutes with me explaining why'* (de Vere Hunt et al., 2021, p. 558). When participants had managed to access psychological support, there were reports that the mental health professional did not have sufficient understanding of alopecia and at times these sessions were damaging. Overall, there was a narrative across studies that people felt dismissed and let down by health care providers.

5.3 **Difficulties with medical treatment.** Participants frequently noted the short-lived effects of treatments and their unpleasant side effects. *'I had various dermatology appointments where we tried lots of different treatments…but they hardly ever work…Even when I did have some regrowth you can't have those treatments forever, so once you stop it just falls out again, which can be more traumatic than losing it in the first place'* (Stock et al., 2022 p. 1435). Some participants talked about some of the concerns of undertaking treatments, for example needing to have injections. Participants were also concerned about the practical implications of treatment; for example, the cost of clinic visits and lengthy treatment regimes. The impact of these difficulties led to increased feelings of hopelessness around treatment options. These challenges left participants feeling hopeless about their treatment options.

Figure 2 presents a data-driven conceptual model of alopecia experiences, illustrating how individuals navigate identity and appearance changes through three interconnected pillars. The *course of alopecia* involves not only the unpredictable progression of hair loss but also profound emotional and social impacts, with participants describing feelings of dehumanization, unattractiveness and marginalization—especially when intersecting with personal characteristics such as race, sexuality and neurodivergence. The *coping pillar* reflects a wide range of strategies, from active approaches, like medical treatments and wig use, to emotional tactics such as humour, religious faith and distraction. Acceptance was often nonlinear, shaped by time and personal growth, with some individuals embracing baldness and rejecting societal beauty norms. Finally, the *facilitators to adjustment* highlight the importance of supportive relationships and the challenges posed by societal expectations and health care systems. While loved ones could bolster confidence and social engagement, many participants faced rejection and felt pressured to conceal their hair loss. Negative experiences with health care professionals—such as emotional invalidation and lack of information—further underscored the need for more empathetic, holistic support.

DISCUSSION

This systematic review is the first to conduct a meta-synthesis of qualitative findings on the lived experience of alopecia. Five overarching themes emerged, underscoring the profound impact of hair loss across individuals and the socio-contextual parameters involved. These themes include the critical role of intersecting identities during the progression of the condition, the ongoing struggle people face towards acceptance, the function of coping and concealing practices in daily life, and the widespread dissatisfaction with health care providers and the available medical treatments. Overall, the findings align with the phased model of adjustment in alopecia, proposed by Rajoo et al. (2020), which posits that individuals navigate non-linear phases, influenced by personality, the severity, duration of the condition and the availability of social support. The discussion integrates these themes with existing literature, highlighting the need for personalized non-pharmacological interventions.

The synthesis identified that hair loss profoundly impacts on identity. Participants described a range of changes to their sense of self, including impact on gender affirmation and reduced self-esteem, often describing hair loss as recurrently stressful or to a sense 'traumatic' due to both societal and personal significance attached to hair. These findings complement research linking alopecia to impaired self-confidence and body image (Tucker, 2009). Likewise, a qualitative meta-synthesis on chemotherapy-induced alopecia found that hair loss alters feelings of femininity and raises concerns about others' perceptions (Kocan et al., 2023). This synthesis further highlighted that the unpredictability of hair loss intensifies feelings of stress and loss of control in social contexts.

Participants' narratives described a journey towards accepting a new identity after hair loss, followed by fluctuating periods of emotional responses, including shock, grief, the unpredictable progression of the condition and the experimentation with problem-focused and emotion-focused coping responses. For some, there was a narrative of not being defined by their hair, indicating the use of positive rational acceptance, as described by Cash et al. (2005). However, longitudinal research is needed now to examine how acceptance is shaped by significant events in the course of the condition and is influenced by both contextual factors and individual psychosocial variables (Veal, 2013). Coping appeared to improve with age, potentially due to reduced social pressures on appearance among older adults (Halliwell & Dittmar, 2003). However, age alone appears unlikely to determine psychological adjustment. Instead, it clearly interacts with sociocultural factors, such as gender, social class, ethnicity (Adler, 2013; Chu et al., 2012; Kranz, 2011).

Another contributor to adjustment is the context in which social support is available/occurs. The findings demonstrate that social support is critical for emotional processing, practical assistance and fostering a sense of belonging. Support from family, friends and peers aligns with research showing that higher social support reduces depressive symptoms (Janowski et al., 2012) and promotes self-efficacy (Fox et al., 2007; Iliffe & Thompson, 2019; Helgeson et al., 2018; Hofmann & Hayes, 2019; Zhang, 2024). On the darker side of the social context, our synthesis found that the lack of public awareness and professional understanding of the psychosocial implications of alopecia contributes to stigma (Hughes et al., 2021), self-stigmatization (Temel et al., 2019) and feelings of exclusion (Creadore et al., 2021); similarly to other conditions, such as chronic pain (Scott et al., 2024). Socially derived misconceptions from health care providers and the public, such as viewing alopecia as merely cosmetic or perceiving individuals with hair loss as less attractive or employable, amplified the intersecting elements of changes in identity.

Concealing hair loss was a common coping strategy that was associated with both practical and emotional difficulties across the reviewed studies. Similar to previous findings, participants in the current study described hiding their hair loss to align with societal beauty standards, avoid stigma (Montgomery et al., 2017), or escape feelings of shame (Rafique et al., 2024). Decisions around concealment varied based on the extent of visible hair loss and its perceived fit with societal expectations. While some people reported increased self-confidence and social participation when concealing hair loss, others felt self-conscious due to feelings of inauthenticity. Others tended to follow '*specific*' rules for concealment, such as deciding who could know about their hair loss and what types of concealments were acceptable for whom. The current synthesis extends previous findings (Sharratt et al., 2020), indicating the complex and multifaceted decision-making involved in concealment. Cosmetic concealment, such as wearing a wig or concealing eyebrow/eyelash loss, can have a positive impact on people's quality of life (Rencz et al., 2016). Yet, its effectiveness as a coping mechanism depends on intrapersonal factors, such as level of acceptance of the condition (Aldhouse et al., 2020), affective status, such as anxiety or fears of concealment (Barkauskaite & Serapinas, 2020), and socially derived contextual factors, including stigma and other intersectional factors, such as societal expectations and marginalization.

Participants frequently reported negative experiences within health care, citing unmet needs and having feelings unidentified or even invalidated. Clinicians may minimize the impact and overestimate the quality of life of people with alopecia, which can be invalidating and prevent access to appropriate support (Dubois et al., 2010). Clearly, it remains important to challenge remaining naivety that alopecia is largely a cosmetic issue (Marks et al., 2019). However, some positive health care experiences have also been reported in the literature, and these are often associated with participants reporting that professionals listened to concerns, validated emotions and took time to explain the condition (Davey et al., 2019; Stock et al., 2022).

The findings from the current review have significant clinical implications. Participants often expressed a need for professionals to be able to address both the emotional impact of alopecia and the psychological distress that may be present during different phases of the condition. Thompson (2009) and Rumsey (2018) propose a stepped care approach, where professionals devote time to process emotional-related issues pertaining to alopecia, during consultations. This time should also be used to screen for psychosocial concerns, provide basic psychoeducation and refer when appropriate. To implement this, professionals require training on the psychosocial implications of alopecia and strategies to validate emotions, normalize experiences, support self-management, coping and access to peer support. It should be noted that even with training, professionals who work in systems with limited resources and a high volume of service receivers may struggle to have sufficient time to cover such issues within allotted consultation times.

Further development of psychological interventions in this population is warranted. Harries et al. (2021) suggest that personalized approaches may be required based on whether people experience pervasive or reactive distress from hair loss. Research evaluating psychological interventions for individuals with skin conditions tends to focus on cognitive–behavioural (Lavda et al., 2012) and third-wave informed interventions (Gallo et al., 2017; Heapy et al., 2023; Powell et al., 2023). Cognitive–behavioural therapy is likely to be effective for appearance anxiety (Clarke et al., 2013), while third-wave mindfulness and acceptance-based interventions are also likely to improve quality of life, reduce distress (Gallo et al., 2017; Heapy et al., 2023; Powell et al., 2023), and may help manage stigma (Vasiliou et al., 2023). Further research examining personalized approaches with the use of new AI technologies and meta-models is now the next step. For example, when psychological therapy became personalized to individuals' needs, the personalized therapy showed better mental health outcomes from the standardized CBT treatment (Nye et al., 2023).

Notably, this meta-synthesis underscored the importance of addressing '*contextual threats*', including stigmatization, socially compliant behaviours and intersectionality in psychological interventions. Thus, future research should leverage more dynamic approaches to study the bi-directional and complex relationships that differ between people. Such relationships should be better studied using idiographic methods, intensive longitudinal designs and ecological momentary assessment (EMA), using within-person and personalized network analyses (Hofmann et al., 2020), if we ought to make progress in the psychosocial support for dermatology conditions. Further, approaches such as process-based interventions (Hayes & Hofmann, 2020; Hayes et al., 2019, 2022) could optimize efforts towards evidence-based personalized support. Further, there is a need for greater involvement of experts-by-experience from diverse backgrounds to help shape up services and interventions (Srikanthan & Ngo, 2024).

The findings were not without limitations. To align with the aims of the review, we included a diverse range of studies and looked at a wide range of aspects of the lived experience of alopecia. However, future research should focus on specific areas like intersectionality and stigma, to better understand social threats and how they interact with interpersonal and contextual factors. The review included different types of alopecia, but the differences in patterns and severity of hair loss may affect individuals differently, warranting further investigation. A methodological limitation was the absence of formal interrater reliability testing with regards to the inclusion of full-text papers, which could have strengthened the review's rigor. Additionally, we did not include grey literature where professionals often share their perspectives, which might have provided additional insights. Further, while we considered all the available data present when conducting our synthesis, we were not able to verify whether there was any data collected within each individual study that might present an alternative or outlying perspective to our findings. Finally, despite a rigorous approach in identifying, appraising and synthesizing the selected studies, and the consideration of reflexivity, as with all meta-syntheses the influence of the authors is the final set of themes requires acknowledgment.

In sum, this review synthesized qualitative literature on the lived experience of alopecia, highlighting various practical and emotional challenges faced by individuals. Participants described a journey that often starts with intense emotional reactions, followed by efforts to adapt, and for some, eventual acceptance of a new identity with elements of personal growth. The findings highlighted the unmet needs of people with alopecia and the importance of psychological and peer support. Many individuals reported feeling invalidated or dismissed by health care professionals, underscoring the need for professional training to provide basic support, validation and screening, and to refer those most severely affected to specialized psychology or psycho-dermatology services. These findings also indicate a need for further research on the role social threats and intersectionality play, and the need for personalizing psychological approaches that account for the nuanced sociocultural parameters shaping the experiences of those living with alopecia.

AUTHOR CONTRIBUTIONS

Zoe Hurrell: Data curation; formal analysis; writing – review and editing. **Vasilis S. Vasiliou:** Writing – review and editing; visualization; resources. **Fuschia M. Sirois:** Supervision; writing – review and editing. **Andrew R. Thompson:** Supervision; writing – review and editing; project administration.

CONFLICT OF INTEREST STATEMENT

Vasilis Vasiliou reports a relationship with Wanax Health Care Solutions Ltd. that includes ad hoc health psychology consulting or advisory roles.

DATA AVAILABILITY STATEMENT

Data are available upon request from the corresponding author.

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