School of Psychology
Ysgol Seicoleg

A Systematic Review of the Lived Experience of Alopecia and an Empirical Study Exploring Self-Compassion, Coping, and Sexual Quality of Life in Females with Skin Conditions

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Preface

Skin conditions affect many people worldwide and can have an impact on both physical and psychological wellbeing. In addition, some skin conditions are thought to be exacerbated by stress. Research has shown that individuals with skin conditions may be more likely to experience psychological distress and develop mental health difficulties. The visible nature of skin conditions can result in feelings of shame and people may experience stigmatisation from others. This can result in avoidance of social situations and worries about exposing skin to others, affecting both social and sexual wellbeing. Whilst some individuals with skin conditions may experience significant psychological distress, others cope well with the challenges posed by their condition. It is therefore important to understand both the challenges of living with a skin condition and the factors associated with successful coping, so psychological interventions can be developed for those who need them. The systematic review aimed to understand what it is like to live with alopecia, a skin condition which results in hair loss, from the perspective of people that have experienced it. The empirical study examined the impact of different ways of coping on sexual wellbeing and skin shame in females with skin conditions.

The systematic review examined the experience of living with alopecia. Previous research has highlighted some of the psychological and social challenges that people with alopecia face. To develop interventions, it's important to hear the perspectives and voice of those living with the condition. The review looked at studies that investigated the lived experience of alopecia, 22 studies were identified by searching electronic databases and reference lists. The key themes and findings were examined, and the studies ranged from low to high quality. The words participants used to describe their experiences and author interpretations were coded, then organised into themes. This resulted in five themes related to: the impact of hair loss on changing identity; the difficult journey of learning to live with alopecia; the way social factors both help and hinder people with alopecia; the complexity of concealing hair loss; and the treatment experiences of those living with alopecia. The results highlighted the challenges of living with alopecia, the varied ways in which people cope with the condition and the complexities of this, and the need for the emotional impact of alopecia to be considered in consultations with health professionals. Further research is needed to investigate the effectiveness of psychological interventions for individuals with alopecia on a larger scale.

The empirical study aimed to further our understanding of what factors might be important in maintaining sexual wellbeing in females with skin conditions. Previous research has found that self-compassion is important for reducing psychological distress and increasing sexual quality of life. Self-compassion involves treating oneself with kindness and care in the face of suffering and extending the same compassion that we would show to a friend who is suffering, to ourselves. This research looked at whether self-compassion is related to sexual wellbeing and skin shame in females with skin conditions, and the impact of how people cope. Adult females with skin conditions completed an online survey. The results showed that those higher in self-compassion had better sexual wellbeing and experienced less skin shame. Defeatist coping, such as avoidance, and judgements of how well one is coping, were mediating factors in the relationships between self-compassion and sexual wellbeing and self-compassion and skin shame. The survey also included open-text questions in which participants commented on the impact of their skin condition on sexual wellbeing, how they cope with the challenges posed by skin conditions, and their experiences of seeking support. The results support the use of compassion-focused interventions for females with skin conditions, with the aim to reduce distress related to one's skin and improve sexual quality of life. However, further research is needed to investigate how self-compassion impacts sexual wellbeing and skin shame. Furthermore, the findings from the open-text questions highlight the importance of healthcare professionals acknowledging the potential impact of skin conditions on sexual wellbeing.

Both the systematic review and the empirical paper contribute to our understanding of the experience of living with skin conditions and the psychological factors which may be associated with living well with a skin condition. Our findings highlight the need for evidence-based psychological interventions to be developed and investigated in people with skin conditions and the importance of specialist psychological support being available to those who require it.

Paper 1: Systematic Literature Review

The Lived Experience of Alopecia: A Thematic Synthesis

Running title: Alopecia Thematic Synthesis

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Abstract

Purpose: The aim of this systematic review was to synthesise the qualitative literature investigating the lived experience of alopecia.

Methods: The review was preregistered on PROSPERO. Searches were conducted using the following databases: APA PsycInfo (OVID), Medline (OVID), Embase (OVID), CINAHL (EBSCO), and Scopus. Twenty-two full-text studies were eligible for inclusion in the review. The included studies explored the lived experience of alopecia from the perspectives of adults, adolescents, and parents. The studies were appraised for quality and the extracted data were synthesised and interpreted using thematic analysis.

Results: The synthesis of data extracted from the studies resulted in five themes related to: coming to terms with a changed identity; the journey to acceptance; the complexities of concealing hair loss; the way in which our social world helps and hinders people with alopecia; and treatment experiences highlighting the unmet needs of alopecia patients.

Conclusions: The findings demonstrate that people with alopecia face a range of practical and emotional challenges in adjusting to their condition. The reactions of other people and interpretations of these, appear to play a key role in adjustment. The extant literature showed considerable individual variation in coping, and whilst some participants develop acceptance quickly, others struggle to come to terms with the condition. The findings demonstrate the need for specific support in managing both personal reactions, and the reactions of others, and suggest that greater co-production is needed in the training of healthcare professionals.

Keywords

Alopecia; thematic synthesis; qualitative; lived experience.

Statement of Contribution

What is already known on the subject?

- Alopecia can have a significant impact on an individual's quality of life and emotional wellbeing.
- Historically, there were a lack of long-term effective treatment options, meaning addressing the emotional impact of the condition is important.

What does this study add?

- This is the first review of qualitative evidence investigating the lived experience of alopecia.
- The review shows the complexity of adjusting to alopecia and the varied ways in which people cope.
- The importance of the voice of alopecia patients in psychosocial intervention development is shown.

Introduction

Alopecia is a dermatological condition characterised by hair loss, which can affect the scalp as well as other areas of the body, including eyelashes, eyebrows, and nose hair (Gilhar et al., 2012). Alopecia can impact individuals across the lifespan. There are several different types of alopecia, including, alopecia areata, alopecia totalis, alopecia universalis, and scarring alopecia. In this review, the term alopecia will be used to refer to all conditions. Alopecia can range in severity from patchy hair loss to complete baldness, rate of hair loss can be rapid, and the onset of alopecia and recurrences are unpredictable (Tosti et al., 2006). Some studies suggest that stressful life events can play a triggering role in alopecia, for example, Ferentinos et al. (2022) found that alopecia patients reported more stressful life events, in the year preceding the occurrence of alopecia, than healthy controls, confirming previous findings (Güleç et al., 2004; Picardi & Abeni, 2001). In addition, hair loss itself can be traumatic resulting in further exacerbation of stress and hair loss (Taheri et al., 2012). Whilst there are some physical complications that can occur as a result of alopecia, the psychological and social impacts can be more significant (Cartwright et al., 2009).

The psychological impacts of alopecia have been widely studied. A systematic review of health-related quality of life in individuals with alopecia found significant impairments in the domain of mental health (Rencz et al., 2016). Furthermore, a study comparing children with alopecia to healthy controls found that both children and the parents of children with alopecia had lower health related quality of life ratings (Bilgiç et al., 2014). Despite a small sample size, this finding highlights the wide-ranging impact of the condition (Bilgic et al., 2014). Recently, a meta-analysis of twenty-six studies found that adults with alopecia experience significantly more symptoms of anxiety and depression than healthy controls, with both findings having medium to large effect sizes (van Dalen et al., 2022). In this review, there were mixed findings in relation to symptoms of anxiety and depression for children, with some studies reporting significantly more symptoms in alopecia patients compared to controls, and other studies reporting no significant difference (van Dalen et al., 2022). Overall, reviews of the quantitative evidence demonstrate the psychological impact of the condition, however, they may not capture the breadth of experiences of those living with alopecia.

Social functioning can also be impaired in alopecia patients (Mostaghimi et al., 2021). Alopecia is visible to others which can impact on self-confidence and body image (Tucker, 2009) and social anxiety is not uncommonly reported (Montgomery et al., 2017). Hair can have important symbolic and cultural meanings in society and therefore concealing hair loss, for example by using wigs, is often utilised as a coping strategy (Cash, 2001; Montgomery et al., 2017). In addition to social functioning, there are social risk factors associated with the condition. Higher incidences of alopecia have been associated with urban living and social deprivation, and more deprived individuals are less likely to be referred to specialist dermatology services (Harries et al., 2022). Furthermore, a population-based study of patients with newly diagnosed alopecia has demonstrated the burden of mental health difficulties in alopecia, finding that individuals with alopecia were more likely to be unemployed and issued time off work certificates (Harries et al., 2021; Macbeth et al., 2022).

In addition to the emotional and social impact of alopecia, until recent years there were limited long-term effective treatment options and medications had unpleasant side effects (Delamere et al., 2008). More recently, a systematic review investigating the safety and efficacy of JAK inhibitors in the treatment of alopecia has found that use of JAK inhibitors might lead to safe and effective treatment (Yan et al., 2022). Such treatments are not in common use and may not be suitable for some patients, or patients may not wish to receive this form of treatment. Consequently, given the increased risk of distress and mental health difficulties associated with alopecia, it remains important for psychological interventions to be available (Messenger et al., 2012; van Dalen et al., 2022).

When developing psychological interventions, it is important to understand the factors related to individual differences in adjusting to alopecia. Research shows variability in coping, and this can impact adjustment. For example, research shows alopecia patients using more adaptive coping styles have higher subjective quality of life scores (Schmidt et al., 2001). Furthermore, positive rational acceptance, a strategy associated with greater body image quality of life (Cash et al., 2005), is not associated with time since alopecia diagnosis, indicating that it is not an inevitable outcome of attempting to adjust to hair loss (Veal, 2013). An individual's beliefs about their condition, for example beliefs about controllability, are associated with levels of psychological distress (Chiang et al., 2015) and social support is recognised by professionals as an important factor in facilitating adjustment to alopecia (Prickitt et al.,2004). Intervention studies in dermatology patients can also provide an insight into factors which may be important in adjusting to alopecia. For example, mindfulness-based interventions have shown to improve quality of life in alopecia patients (Gallo et al., 2017), suggesting the potential role of mindfulness in facilitating psychological adjustment to the condition. Whilst the described studies provide an insight into the factors that might be associated with adjustment, they lack an in-depth insight into the perspective of those living with the condition.

When developing acceptable interventions and support systems, it is important to understand what is important to those living with alopecia. Professionals in the field can benefit from understanding the needs of individuals with alopecia including the challenges they face, individual differences in coping, and experiences of treatment. This understanding can aid the development of effective healthcare interventions and qualitative research methods can contribute to answering such questions.

Recently there has been a number of such studies published and despite the increase in qualitative studies investigating the lived experience of alopecia, there is currently no systematic review of this literature. Synthesising qualitative research is widely acknowledged as being able to inform healthcare interventions (Thomas & Harden, 2008) and areas for future research. Consequently, this meta-synthesis seeks to identify, appraise, and summarise the findings from the existing studies that have investigated the lived experience of individuals with alopecia. This synthesis aims to highlight the challenges faced by individuals with alopecia, how individuals cope with alopecia and to provide an insight into the treatment experiences of people living with the condition.

Methods

Review Protocol

A review protocol was developed and registered on PROSPERO (reference: CRD42022352975). Registration was completed prior to searches being conducted. This review follows 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). The thematic synthesis was carried out using the process outlined by Thomas and Harden (2008).

Selection of Studies

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). This was also used to guide the extraction of data from the identified studies.

Table 1

Elements of Research Question Identified Using PICo

Criteria	
Population	Individuals with alopecia or parents of children with alopecia
Phenomena of Interest	Qualitative lived experience of alopecia
Context	Any context

Studies were eligible if they used qualitative methods to collect data on the experience of living with alopecia from the perspectives of both individuals with the condition and parents/carers of children with alopecia. Mixed-methods studies were included where there was extractable qualitative data. No date restriction was applied as there was no prior review of the qualitative literature. Research letters were included where there was sufficient detail on the method of data analysis and extractable qualitative data. Exclusion criteria included studies investigating the lived experience of chemotherapy induced alopecia (a meta synthesis of these studies can be found in Kocan et al., 2023) and where the method of analysis was not sufficiently described to indicate that the study met minimum criteria for qualitative research.

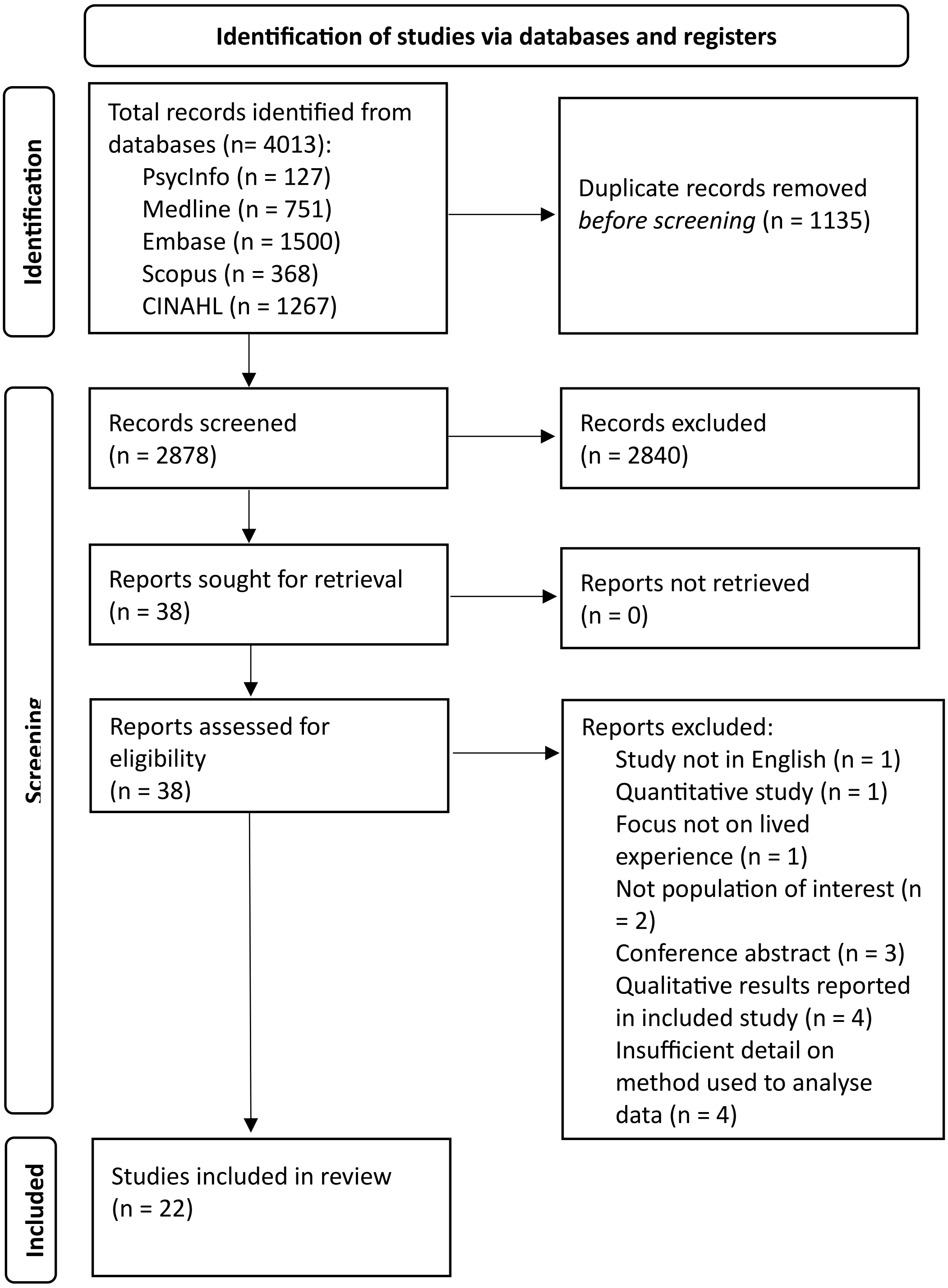
Sources were screened by title and abstract by the primary reviewer according to inclusion and exclusion criteria. The full texts of papers were screened by the primary reviewer and a second reviewer from the study team. To resolve discrepancies, the two reviewers met with the research supervisor and discussed the papers with reference to the inclusion and exclusion criteria until a consensus was reached. Figure 1 displays the PRISMA diagram and outlines the process of study selection. Several studies which used qualitative methods in the development of patient reported outcome measures were identified. In line with the inclusion and exclusion criteria, such studies were included if they also investigated the lived experience of alopecia, and there was sufficient qualitative data to extract.

Information Sources and Search Strategy

A comprehensive search strategy was employed with the aim to identify all relevant primary studies (Tong et al., 2012). An information technology expert was consulted on the search terms and strategy. APA PsycInfo (OVID), Medline (OVID), Embase (OVID), CINAHL (EBSCO) and Scopus databases were searched in September 2022. The databases were chosen 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 phenomenolog*. Two qualitative search filters which included a string of simple free-text terms were used to support finding 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 B.

Figure 1

PRISMA flow diagram



Data Extraction

A data extraction tool was developed using Microsoft Word guided by the ENTREQ guidelines and the PICo (Tong et al., 2012). The primary reviewer extracted data from the studies including title, author, year of publication, country where the study took place, participant characteristics (N, gender, age), recruitment methods, method of data collection, method of analysis and main findings and themes. An example of a completed detailed data extraction table is included in Appendix C.

Quality Appraisal

The Critical Appraisal Skills Programme checklist for qualitative studies (CASP: Critical Appraisal Skills Programme, 2018) was used to assess the studies methodological strengths and limitations (see Appendix D). The CASP checklist was selected as it allowed primary studies using different qualitative methodologies to be assessed using the same tool (Noyes et al., 2018). Prior to conducting the review, it was decided not to exclude any studies based on methodological quality, instead a critical appraisal of the selected studies would be included (Dixon-Woods et al., 2005). Quality appraisal was completed by the primary reviewer, and a random selection of articles (25%, n = 6) were appraised by a second independent reviewer. There were discrepancies on 4 out of 60 checklist items. Where there were discrepancies, the two reviewers met to discuss the papers with reference to the CASP checklist prompts to resolve any remaining ambiguities and reach consensus.

Synthesis of Results

Thematic synthesis was chosen as the review aimed to aggregate findings across the selected studies (Noyes et al., 2018). Files in PDF format for each study were transferred to NVivo 1.7. Line-by-line coding was undertaken on the results and discussion sections of papers and was completed using NVivo to generate a bank of initial codes. Discussion sections were included for line-by-line coding so authors interpretations could be captured (Thomas & Harden, 2008). The initial codes were then organised into descriptive themes. A summary of the descriptive themes can be seen in

Appendix E displayed with illustrative quotes. The next stage of the synthesis involved further interpreting the descriptive themes to develop analytical themes. This process supported the answering of the specified research questions of the review and the identification of patterns and relationships across the studies (Thomas & Harden, 2008). The final list of themes and subthemes was agreed in discussion with the research team. An example of the codes and descriptive themes contributing to an analytical theme can be seen in Appendix F.

Results

Summary of Included Studies

In total, 22 studies were included in the review containing 990 participants, 784 females and 190 males, aged between 12 and 93 years of age. One study did not specify the gender split of the participants, and another used web-based communication as the unit of analysis and so it was not possible to ascertain how many participants were in the study. There were six mixed-methods studies including the studies related to measure 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 that spoke from the perspective of being a parent of a child with alopecia. The majority of studies included participants with alopecia areata, totalis and universalis, although some studies included different types of alopecia. The most common data collection method was interviews, other methods included focus groups, written accounts, video diaries, extracts from online support groups and open-ended survey questions. A range of analysis methods were used including thematic analysis, grounded theory, interpretative phenomenological analysis, and content analysis. Table 2 provides a summary of the main characteristics of each study.

Quality Appraisal Results

The CASP checklist was completed for each of the included studies. A summary of the results from the CASP checklists can be seen in Table 3. 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, although the study was published as a research letter, meaning there was limited opportunity for the authors to provide details of methodology and the process of analysis. The majority of ‘can’t tell’ or ‘no’ answers were related to the question of whether the researchers had adequately considered the relationship between researcher and participants.

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 stigmatisation Psychological and emotional impact of AA Impact on social functioning
Barkauskaite & Serapinas (2020)	Lithuania	N = 6 2 males, 4 females Aged 22-33 AT or AU diagnosis	National alopecia organisation	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

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
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
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 & 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

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
Iliffe & Thompson (2019)	UK	N = 12 12 females Aged 30-59 Individuals with alopecia diagnosis 1 parent of a child with alopecia	Alopecia Facebook support group, individuals 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
Leow & 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 healthcare 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 utilised by participants Stress experiences in the AA journey

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
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
Rafique & 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 & Hlupić (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

Authors (year)	Country	Participant characteristics	Recruitment	Data collection	Method of analysis	Key themes and findings
Welsh & 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
Winnette et al. (2021)	USA	N = 36 10 males, 26 females Aged 12-70 AA diagnosis	Patient databases from research organisations	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

Note. AA = Alopecia Areata; AT = Alopecia Totalis; AU = Alopecia Universalis; FFA = Frontal Fibrosing Alopecia; SA = Scarring Alopecia

Methodological Critique of Included Studies

Whilst some studies in the review published the interview or survey questions, there were several articles that did not, making the data collection process less transparent. 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. 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) did not provide direct quotations in the paper but instead the results and findings section provided a narrative account of the qualitative data. The authors acknowledged limitations in their studies including a lack of diversity in research participants, self-selecting samples, the potential for researcher bias and small sample sizes which could limit the generalisability of the results. The included studies are only capturing a point in time for the perspectives of people living with alopecia, however the extracted data shows that participants often respond based on their lived experience across a lifetime and draw on both past and present experiences. There was a trend towards the more recently published studies being of a higher quality.

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 & Serapinas (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Cook et al. (2022)	✓	✓	✓	✓	?	?	?	?	✓	?
Davey et al. (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
de Vere Hunt et al. (2021)	?	?	?	?	?	?	✓	?	✓	✓
Fox (2003)	✓	✓	✓	✓	✓	✓	?	?	✓	✓
Haskin et al. (2017)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Hunt & McHale (2005)	✓	✓	✓	✓	?	X	X	?	✓	?
Iliffe & Thompson (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

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
Leow & Lee (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Macey et al. (2022)	✓	✓	✓	✓	✓	✓	✓	?	?	✓
Matzer et al. (2011)	✓	✓	✓	✓	✓	X	✓	?	✓	✓
Montgomery et al., (2017)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Rafique & Hunt (2015)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Rajoo et al. (2020)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Razum & Hlupić (2022)	✓	✓	✓	✓	?	X	✓	?	?	✓
Stock et al. (2022)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Welsh & 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 summarise the most prevalent findings. Table 4 displays which studies contributed to each subtheme.

Who am I without hair?

1.1 Hair is important. Participants across the studies discussed the significance of hair loss with some describing losing hair as 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 loss was described as a traumatic experience and many participants remained hopeful for a cure for the condition, highlighting the importance participants placed on hair. The cultural and symbolic meaning of hair was referred to with some individuals associating a full head of hair with youth. There were also comments from participants on the significance of hair loss for women, with hair seen as a sign of femininity and participants talked about the extra pressures on women's appearances.

Table 4

Contribution of Reviewed Studies to Themes

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
Aldhouse et al. (2020)	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓		✓		✓
Barkauskaite & Serapinas (2020)	✓	✓		✓		✓	✓	✓			✓	✓	✓	✓	✓			
Cook et al. (2022)	✓	✓	✓	✓		✓	✓	✓			✓	✓	✓	✓			✓	
Davey et al. (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
de Vere Hunt et al. (2021)	✓	✓			✓	✓	✓			✓		✓			✓	✓	✓	
Fox (2003)	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓		✓	
Haskin et al. (2017)		✓		✓		✓		✓			✓	✓	✓	✓		✓	✓	
Hunt & McHale (2005)	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓		✓	✓	✓
Iliffe & Thompson (2019)	✓				✓	✓	✓	✓	✓					✓				

Leow & Lee (2017)	✓	✓		✓	✓	✓	✓	✓					✓			✓		✓
Macey et al. (2022)	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓			
Matzer et al. (2011)		✓		✓	✓	✓					✓					✓		✓
Montgomery et al. (2017)		✓								✓	✓	✓	✓	✓	✓			
Rafique & Hunt (2015)	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓				✓
Rajoo et al. (2020)	✓			✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓				
Razum & Hlupić (2022)	✓	✓	✓	✓	✓		✓				✓	✓	✓	✓				
Stock et al. (2022)	✓	✓				✓	✓	✓			✓	✓	✓	✓		✓	✓	✓
Welsh & Guy (2009)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
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.

1.2 Loss of, and impact on self. This subtheme refers to the impact of hair loss on an individual's identity and self-confidence. Across the reviewed studies it was evident that hair loss can have a profound impact on an individual's sense of self. Participants reported no longer feeling human without their hair, not feeling confident, having poor body image, and not feeling good enough. Whilst 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. Changes to feelings of both femininity and masculinity were reported. Individual characteristics interacted with hair loss with individuals commenting on race, sexuality, and neurodiversity and how hair loss led to further feelings of being different or of stereotypes being reinforced. 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 commented on the physical changes associated with alopecia and the challenges that comes with this. Where individuals had lost facial hair such as eyelashes and eyebrows, participants reported eye irritation, particularly when sweating:

> *"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).

Some participants commented on how this made it difficult to engage in physical activity. Individuals described the varying rates at which hair was lost, for some it was rapid whereas for others it occurred more gradually. For most, it was unpredictable which further reinforced the feeling of a lack of control and that hair loss had been traumatic.

The (difficult) Journey to Acceptance

2.1 Emotional responses to alopecia. This subtheme refers to the range of emotional reactions described by participants in response to the condition. Participants reported feeling shocked and fearful when first diagnosed with alopecia, for some, this led to feelings of anger and individuals looking for someone to blame: *''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 were reports of individuals wondering if they were to blame themselves and feelings of guilt and shame tied to this. In addition to the strong emotional reactions, there was a sense that individuals 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. A wide range of coping strategies were reported across the studies. Coping styles included active strategies such as seeking support, use of medicines and alternative medicines, and using wigs. Some participants reported using distraction techniques 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 & Hunt., 2015 p. 8).

Participants reported avoidance, for example avoiding looking in the mirror and avoiding public spaces. Other coping strategies included trying to remain positive, use of humour, religious coping, and remaining hopeful for the future. Coping varied from person to person and there was a sense that whilst there were lots of attempts to cope, that they were not always successful. Some differences were reported in the way men and women cope, for example men reported using humour more frequently.

2.3 It is not an easy journey. Participants talked about their struggles of moving towards acceptance. There was a narrative that the journey is not linear and there are numerous factors impacting the process of adjustment. It was important to participants to aim for acceptance, but this didn't feel possible for everyone: *"...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). Participants noted the impact of the unpredictable nature of alopecia and how this made it difficult to adjust to the condition, not knowing whether hair will grow back or if they will lose more hair: *"the uncertainty of not knowing which way it was going to go and why and anticipating that I was going to be completely bald was the most horrific part of the whole experience."* (Aldhouse et al., 2020, p. 5). Some individuals noted that they felt better able to adjust to their condition over time and that coping improved with age.

2.4 Acceptance and the changed self. This subtheme refers to participants experiences of acceptance of their condition and the personal growth that went alongside this. Participants talked about letting go of societies beauty ideals, embracing baldness and placing less importance on what other's think of them. For some, this was associated with a return to work and social activities. Some participants talked about knowing their value as a person is not based on how they look:

> *"[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).

There was a narrative of appreciating life in different ways, being more aware of inner strengths and putting their hair loss into perspective: *"Hair or no hair, we're still fabulous"* (Iliffe & Thompson, 2019, p. 997).

The Ways in Which Society Helps and Hinders

3.1 The role of family, partners, and friends. Participants talked about the way in which support from friends, family, and partners was instrumental in their adjustment. Having supportive partners helped people to feel more confident in their appearance and supportive friends facilitated increased social participation. Participants discussed how the experience of alopecia helped to strengthen some friendships and that going through a challenging time helped them to identify 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 definitely strengthened our relationship"* (Macey et al., 2022, p.S2)

However, this did not reflect all participants experience and some talked about the lack of support from others and the distress this caused: *"my mom is avoiding looking at my bald head, she feels much better seeing me with the wig. It is hurting, because I want time to just be myself…"* (Barkauskaite & Serapinas, 2020, p.4).

3.2 The importance of sharing experiences. As well as support from close others, sharing experiences with others with alopecia was also important. This was particularly true when participants felt that friends and family did not understand what they are going through. Use of support groups and sharing experiences with others was reported to reduce the feelings of isolation and loneliness felt by participants: *"I don't feel shame anymore, not so much like a freak"* (Iliffe & Thompson, 2019, p.996). Being a member of support groups also provided a place for individuals to share tips on coping and practical strategies such as tips for using wigs. Some commented on the positive feelings associated with helping others in the community. There were gender differences reported with some studies highlighting that females were more likely to use support groups, however these findings were mixed, with some male participants reporting finding support groups helpful. It's important to note that not all participants found connecting with others with the condition helpful: *''I tried going to a support group but found it depressing and suppressive…"* (Welsh & Guy, 2009, p.198), however the benefits were more commonly reported.

3.3 Lack of public awareness. The lack of public awareness around alopecia was identified as a factor which could add to feelings of difference and shame. Some participants talked about themselves, and family members, having no idea what alopecia was prior to diagnosis. In addition, participants talked about alopecia not being in mainstream media and how this added to feeling different to others. This was particularly frustrating for men when norms around baldness being acceptable for men invalidated their emotional distress in losing their hair*: "…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). Participants described experiences when they had been mistaken for having cancer and the difficulties with feeling exposed and needing to explain themselves in these situations: *"People assume I have cancer…"* (Montgomery et al., 2017, p.5).

3.4 Fear of, and actual harm from others*.* Across the studies there was a narrative of participants feeling fearful of judgement and rejection from others. However, for many, this was grounded in negative experiences of other's reactions to their hair loss including staring, people making jokes, and for some even being bullied and physically abused: *"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. Overall, these experiences resulted in increased feelings of being othered, feeling unworthy, and shameful:

> *"…I had my jumper set on fire by another student with a cigarette lighter, and I had metal shavings rubbed into my remaining hair on one occasion…I have always felt different, that*

> *there was something wrong with me, that I was ugly and worthless, etc."* (Davey et al., 2019, p.1382).

Some participants even described being turned down for work opportunities as a result of their hair loss.

The Complexity of Concealing Hair loss

4.1 A need to be hidden. Accounts of concealing hair loss were widely reported across the reviewed studies. This subtheme relates to a general narrative throughout participants accounts that their hair loss should not be exposed to others. Participants felt that alopecia was a private issue which led to behavioural changes of avoiding situations or concealment, as being seen with hair loss did not feel acceptable. Reasons for concealing hair loss were not just about avoiding negative reactions and questions from strangers but for some were about concealing hair loss from those close to them including family and partners. Participants described a strong desire not to be seen by others, especially early on in diagnosis, which resulted 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). The desire to hide their hair loss from others also had an impact on adults working lives and younger participants schooling.

4.2 An important tool. Participants recounted the ways in which being able to conceal their hair loss was an important coping mechanism for them. Whilst some participants wore wigs, others used scarves, hats, and used makeup to draw eyebrows. One study recounted the experiences of individual's who had undergone medical tattooing and participants reported on the positive impact of this. 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).

Some participants recounted the practical benefits of concealing hair loss, for example, being able to change their hairstyle more often by trying different wigs and spending less time getting ready in the morning.

4.3 Practical and emotional challenges. Despite it being an important coping mechanism there were reports of the practical and emotional challenges that went alongside concealing hair loss. In terms of the practical challenges, wigs were described as itchy and there were fears of wigs being blown off in the wind. 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).

Some participants had concerns about engaging in physical activity due to fears of sweating off makeup or wigs becoming hot and itchy. These challenges resulted in some individuals feeling more self-conscious that they will be exposed as wearing a wig. In addition, wigs were expensive, often difficult to access, and participants weren't aware whether they were entitled to NHS support for this. There were also concerns that by concealing hair loss, they were being inauthentic, and people were worried about other's reactions to this.

4.4 The unwritten rules. This subtheme refers to the tendency for participants to follow certain rules when it came to concealing hair loss. In terms of wig use, it was important for participants to feel that others 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, and this differed from person to person. Although many had close others they could confide in, 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. There was also some acknowledgement within studies that by concealing hair loss, individuals were conforming to societal beauty ideals and whilst this helped to improve confidence, there were mixed feelings about it.

Unmet Needs

5.1 Professionals should address the emotional impact. Throughout the studies reviewed, participants reflected on their experiences of support seeking. There was a narrative throughout that individuals felt the emotional impact of alopecia was neglected by health professionals, and that given the lack of effective of medical treatments on offer, this should be prioritised. 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. In addition to the emotional impact of alopecia not being addressed, participants across studies described negative experiences with support providers and health professionals. Some participants described feeling let down by health professionals due to long waits to see a specialist and/or get a diagnosis. Participants described not being given sufficient information about alopecia when they were diagnosed and not being properly informed about access to wigs. When participants had managed to access psychological support, there were reports that therapists 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 support providers:

> *"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., 2020, p.558).

5.3 Difficulties with medical treatment. This subtheme described the difficulties with undergoing medical treatment for alopecia. It was noted throughout the studies that individuals had often experienced multiple medical interventions but that these had a short-term impact and 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.

Discussion

This review aimed to systematically appraise and synthesise the qualitative literature relating to the lived experience of alopecia. The meta synthesis resulted in five overarching themes which highlighted the challenges, coping experiences, and views on treatment from the perspective of individuals living with alopecia: *Who am I without hair, The (difficult) journey to acceptance, The ways in which society helps and hinders, The complexity of concealment* and *Unmet needs.*

Throughout the studies, there was a narrative of hair loss resulting in a changed identity. Not only were there physical changes and challenges but a loss to individuals' sense of self and reduced self-esteem. Participants highlighted the significance of hair both personally to them and in society, referring to hair loss as traumatic. This finding complements results from a previous systematic review on the psychological impacts of alopecia which found that hair loss is associated with reduced self-confidence and impaired body image (Tucker, 2009). The impact of hair loss on identity was also found in a qualitative meta-synthesis of studies investigating the lived experience of chemotherapy induced alopecia with patients reporting changes to feelings of femininity and concerns about others' perceptions (Kocan et al., 2023).

There was a sense that participants went on a journey with the aim to accept their new identity. Participants described their varied emotional reactions to hair loss, and this led to a wide variety of coping mechanisms being used by participants. Some participants commented on coping with alopecia improving with age. This may be due to older adults perceiving fewer social pressures in relation to their appearance (Halliwell & Dittmar, 2003). There are mixed findings in the literature in relation to age and psychological adjustment. For example, some research has shown that depression is more likely in those with alopecia under 20 (Chu et al., 2012), however, other research has found that psychological distress, as a result of hair loss, is not related to age (Kranz, 2011). More research is needed, and future studies could utilise longitudinal methods to explore how coping changes over time in this population.

In contrast to those with chemotherapy-induced alopecia who have anticipated losing their hair (Kocan et al., 2023), the unpredictable nature of alopecia was identified as a barrier to acceptance and participants reported feelings of shock. Whilst there were accounts from those who had reached a point of acceptance and stories of personal growth that went alongside this, there was a sense that for many this was a difficult journey, and some struggled to believe that they would be able to feel accepting. For some participants, 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), suggesting that use of this strategy may facilitate adjustment to alopecia. Rajoo et al. (2020) proposed a phased model of adjustment which moved from the onset of alopecia to the initial reactions, then finding support and finally acceptance, which they proposed as a key facilitator to engaging in physical activity. Similar to the findings in the current review, Rajoo et al. suggested that this is not a linear journey and that individuals may move back and forth between different phases of the journey depending on personality, severity and duration of the condition, and social support. The findings of this review support this phased model and suggest the importance of acceptance not just in facilitating engagement in physical activity but for wider social participation and improved self-confidence.

The findings of society both helping and hindering individuals with alopecia could be viewed as social facilitators and barriers to acceptance. In terms of social barriers, participants talked about the lack of public awareness of the condition furthering a sense of difference from others and the fear of and actual harm from others, perpetuating a sense of unsafety in exposing hair loss. Alopecia is associated with increased self-stigmatisation (Temel et al., 2019) and research involving laypersons perceptions of alopecia has revealed that laypeople are likely to stigmatise individuals with alopecia, rating them as less attractive and less likely to hire them for a job (Creadore et al., 2021). In this study, perceptions were influenced by both age and gender with portraits of black women with alopecia less likely to be rated as having a medical condition in comparison to portraits of white men (Creadore et al., 2021). The current review supports these findings as individuals with alopecia commented on experiences of stigmatisation with some participants commenting on the intersecting elements of their identity and how alopecia added to a feeling of difference. The review findings in combination with the previous literature indicates the importance of public education and awareness raising.

Social facilitators included support from family, partners, and friends and opportunities to share experiences with others living with alopecia. These findings mirror quantitative research which has shown that individuals with dermatological conditions with higher perceived social support experience fewer depressive symptoms (Janowski et al., 2012). One of the included studies reported on the beneficial aspects of peer support (Iliffe & Thompson, 2019) and five additional studies contributed to this subtheme. Both young people and their families have reported the importance of meeting others with alopecia (Aschenbeck et al., 2017) and research suggests that this can reduce feelings of social isolation and increase confidence (Fox et al., 2007; Iliffe & Thompson, 2019).

Concealing hair loss, and the complexity that went alongside this, was commonly reported throughout the reviewed studies. Participants described a need to hide their hair loss, which is likely related to the social barriers described above, for example to avoid stigmatisation (Montgomery et al., 2017). There were conflicting reports with some people reporting increased self-confidence and social participation when concealing hair loss, but others reported feeling more self-conscious due to feelings of inauthenticity. In addition, participants highlighted practical challenges around concealing hair loss. Participants tended to follow certain rules regarding concealing and revealing hair loss, such as who can and can't know and what type of concealment was acceptable for whom. Qualitative research investigating participant experiences of disclosing and exposing a visible difference has highlighted a complex decision-making process depending on necessity of exposure and hopes, fears and cost-benefit analysis being considered (Sharratt et al., 2020). The review findings highlight the complexity of hair loss concealment for individuals with alopecia and as a result there is likely to be a complex decision-making process involved in deciding whether, and how to, reveal hair loss to others.

The review found both similarities and differences in men's and women's experience of living with alopecia. There was some evidence in the reviewed studies that men and women use different strategies to cope with their illness, for example, men were more likely to report using humour. The emotional impact of alopecia appeared to be similar, and both men and women commented on the impact of their hair loss on feelings of masculinity and femininity. However, there was a much lower sample of men in the review, limiting the conclusions that can be drawn. There have been mixed findings in the literature in relation to gender differences. Whilst some research has found that the psychosocial effects of alopecia are more severe for women (Russo et al., 2019) other research has found no difference between men and women with skin conditions in levels of social appearance anxiety (Hughes et al., 2021). Further research is needed to better understand how gender impacts adjustment to alopecia.

The final theme relates to participants negative experiences of receiving treatment and the sense that participants felt their needs were not being met. For example, participants talked about the emotional impact of the condition not being addressed. Previous research has found that clinicians may overestimate alopecia patients' quality of life which could be invalidating for patients (Dubois et al., 2010) and the importance of recognising alopecia as more than a cosmetic concern has previously been reported (Marks et al., 2019). It should be noted that some positive experiences with professionals were reported by participants and the findings don't reflect all alopecia patients' experiences. Characteristics of positive experiences included practitioners that listened to concerns, validated emotions, and took time to explain information related to their condition (Davey et al., 2018; Stock et al., 2022).

Clinical Implications

The review findings suggest several clinical implications. Firstly, participants commonly reported on the need for the emotional impact of alopecia to be addressed, indicating the importance of psychological interventions to be offered to those experiencing psychological distress related to their condition. Thompson (2009) (see also Rumsey 2018), suggests the use of a stepped care approach to interventions for individuals with dermatological conditions resulting in visible differences, highlighting that all health professionals should be able to ask individuals about psychosocial concerns and identify when referral to more specialised interventions and services is required.

Further development of specialist psychological interventions in this population is warranted. Harries et al. (2021) suggest that different approaches may be required based on whether individuals are experiencing pervasive or reactive distress to hair loss. Cognitive behavioural therapy is indicated as an intervention for appearance anxiety (Clarke et al., 2013). In addition, mindfulness-based interventions for adults with alopecia have resulted in improvements in quality of life and anxiety (Gallo et al., 2017) and social anxiety (Heapy et al., in press), however these study samples were small. Future research should investigate the effectiveness of psychological interventions in this client group on a larger scale. The findings that highlight the positive experiences of support groups, indicate the potential for the use of group-based psychological interventions.

In addition to the need for the emotional aspects of the condition to be addressed, participants reported difficulties in getting information about alopecia and related medical treatments, therefore highlighting the need for targeted information and time for explanation in consultations. Time to discuss information may support to relieve some of the patient concerns around treatment such as worries about side effects.

Overall, the findings of the review, in line with previous studies, support the development of peer support forums. However, there were some instances in which support groups were experienced as unhelpful. Given the mixed findings around experiences of groups, interventions should be personalised and consider patient preferences, hopes for the intervention and individual differences in coping. Furthermore, the findings in relation to gender highlight the importance of not overlooking the potential impact of alopecia on men. Including those living with alopecia, from diverse backgrounds, in the design of services and interventions can ensure their voice is heard.

Strengths and Limitations

A critique of the included studies can be found in the results section. The current review included a diverse range of studies which looked at a wide range of aspects of the lived experience of alopecia. This fitted with the aims of the current review however, future research may investigate more specific aspects of the lived experience of alopecia which may help to give more insight to some of the complexity that might not have been captured by this review. In addition, a range of types of alopecia were included in the review and it may be that different patterns and severity of hair loss impacts people differently. Although supervision was used to review themes; a second coder could have increased the reliability of findings. In addition, formal interrater reliability for the inclusion of full-text papers was not assessed and inclusion of this could have improved the rigour of the review. Systematic searching was undertaken across a range of databases to provide a comprehensive search strategy and detail is provided for replication of the methods. However, grey literature was not consulted in this review as there were a sufficient number of peer-reviewed studies to include, however, there is likely to be high-quality research in the grey literature that could be consulted in future reviews. To our knowledge, this is the first review of qualitative literature relating to the lived experience of alopecia and the use of thematic synthesis ensured a rigorous process was followed.

Conclusions

The current review aimed to synthesise the qualitative literature on the lived experience of alopecia. There are a variety of both practical and emotional challenges that individuals with alopecia face and a range of coping mechanisms are utilised to try to manage these challenges. Participants described a journey from their initial emotional reactions, finding ways to cope and for some, ultimately accepting their new identity which was talked about in relation to personal growth. The findings highlighted the unmet needs of individuals with alopecia and the importance of access to psychological support and support groups. The findings indicated that individuals have felt invalidated and dismissed by health professionals and so it is important that professionals are supported to acknowledge the emotional impact of the condition and that those living with the condition are involved in the development of interventions. The findings support future research that could lead to the development of psychological interventions for this patient group.

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Paper 2: Empirical Paper

Self-Compassion, Sexual Quality of Life and Skin Shame in Females with Skin Conditions: The Mediating Role of Coping

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This paper was prepared in accordance with the author guidelines for *Body Image* (see Appendix G)

Abstract

Skin conditions can have a negative impact on sexual quality of life, yet little is known about the mechanisms through which psychological variables, such as self-compassion, are associated with sexual wellbeing. The present study examined the relationships between self-compassion, sexual quality of life and skin shame in relation to the role of coping style and coping efficacy as mediators. Two hundred and seventy-seven females aged over 18, with skin conditions such as eczema and acne, completed a cross-sectional online survey. Two parallel mediation models examined the relationships between firstly self-compassion and sexual quality of life, and secondly self-compassion and skin shame. Pearson correlation analyses revealed that self-compassion was positively associated with sexual quality of life and negatively associated with skin shame. Mediation analyses, using the PROCESS macro, revealed an indirect effect of self-compassion on sexual quality of life and skin shame through defeatist coping and coping efficacy. The results suggest that self-compassion may protect against the impact that skin conditions have on sexual quality of life, partially through coping style and appraisals of coping, providing support for the use of compassion-focused interventions. There is a need to develop and test novel self-compassion-based interventions aimed specifically at improving sexual wellbeing.

Keywords

Skin conditions; self-compassion; sexual quality of life; shame; coping.

Introduction

Skin conditions are highly prevalent, affecting between 30% and 70% of the world population, making them a significant contributor to non-fatal disease burden (Bickers et al., 2004; Hay et al., 2014). The impact of skin conditions on health-related quality of life and psychological wellbeing is well documented (Nguynen et al., 2016); Sanclemente et al.,2017) with dermatology patients reporting higher levels of anxiety and depression than controls (Dalgard et al., 2015).

One of the major impacts of skin conditions is on individuals' appearance (Thompson, 2011) which can negatively impact on body related self-esteem, with individuals reporting feelings such as shame and disgust towards their bodies (Wahl et al., 2002). Notably, both the physical and psychological difficulties associated with skin conditions, such as pain and low mood, can affect sexuality and intimate relationships (Alariny et al., 2019; Cuenca-Barrales et al., 2019). For example, some skin conditions, such as psoriasis and lichen sclerosus can cause lesions in genital areas, resulting in pain and itch in intimate areas and impacting on sexual quality of life (Sampogna et al., 2007). Higher levels of itch, a symptom of many skin conditions, is associated with more avoidance of touch, also likely impacting intimacy (Armstrong et al., 2017). This in turn can impact upon sexual wellbeing (Gaikwad et al., 2006). Overall, sexual wellbeing, which examines constructs such as sexual self-esteem and comfort with sexuality, is an important part of an individual's overall physical and psychological wellbeing (Mitchell et al., 2021), however the relationship between skin conditions and its impact on sexual wellbeing has this far received little attention.

The importance of sexual wellbeing and the impact of sexual problems on psychological wellbeing has been demonstrated in individuals with skin conditions. For example, in a study of 3,485 dermatology patients, 21% reported sexual problems and this was associated with depression, anxiety, and suicidal ideation (Sampogna et al., 2017). However, this study used one item on the Dermatology Life Quality Index to measure the impact of skin conditions on participants sex lives, which may not capture the breadth of experiences individuals have. More recently, qualitative studies have added to our understanding of the impact of skin conditions on sexual wellbeing. Qualitative studies are particularly well suited to identifying the psychological processes that might be contributing to the impact of living with a skin condition (Thompson, 2017). A qualitative meta-synthesis of studies investigating sexual wellbeing in skin conditions demonstrated that individuals experience shame and embarrassment in relation to their skin and may feel unattractive and avoid intimacy, overall having a negative impact on their sex lives (Barisone et al., 2020). This review provides a valuable insight into the experience of sexuality and relationships for individuals with skin conditions, however, we are yet to understand what psychological variables are associated with adjustment to the impact of skin conditions on sexual wellbeing. This could provide guidance for health care professionals to identify those who are most likely to be at risk and guide the development of personalised psychological interventions.

Self-compassion is a psychological variable that relates to coping with chronic illness (Sirois et al., 2015). It comprises of three components: self-kindness, common humanity, and mindfulness (Neff, 2003a). Self-kindness refers to being understanding to oneself in times of difficulty rather than being over critical. Common humanity refers to viewing suffering as part of the larger human experience, finally, mindfulness refers to holding negative feelings in balanced awareness (Neff, 2003a) Recently, self-compassion has been investigated in relation to adjustment to skin conditions. For example, self-compassion may protect against depression by reducing one's tendency to feel disgust (Clarke et al., 2020) and mindfulness, an element of self-compassion, has been associated with lower levels of distress in individuals with skin conditions (Montgomery et al., 2016). Furthermore, there is some evidence showing that self-compassion interventions, such as self-help (Hudson et al., 2020) or compassion-based writing interventions (Sherman et al., 2019) can reduce psychological distress in individuals with visible skin conditions.

For sex related wellbeing, emerging evidence indicates that self-compassion might buffer the effects of skin conditions in sexual functioning. For example, in a comparative study, Vasconcelos et al. (2020) found that women experiencing sexual pain had lower levels of self-compassion and more emotion regulation difficulties in comparison to women with no sexual problems. In addition, higher levels of self-compassion have been associated with lower levels of depression, anxiety, and sexual distress in couples managing vulvodynia, however this study had a small sample size (Santerre-Baillargeon et al., 2018). Despite this encouraging evidence, how self-compassion operates in skin conditions and distress, leading to better psychological outcomes or improved sexual quality of life is yet to be explored.

One mechanism through which self-compassion might positively impact upon sexual wellbeing is via a relationship with coping styles. Self-compassion can reduce self-criticism and improve emotional regulation which can facilitate more effective coping (Neff et al., 2018). Research demonstrates that self-compassion is associated with use of more adaptive coping styles, such as positive cognitive restructuring, and less use of avoidant coping (Allen & Leary, 2010). In addition, a cross-sectional study found that individuals higher in self-compassion may be less likely to use shame-focused coping styles such as withdrawal and self-attack (Gu & Hyun., 2021). Coping styles have shown to mediate the relationship between self-compassion and adjustment. For example, research shows that active coping, behavioural disengagement, and self-blame, mediated the relationship between self-compassion and stress in individuals with chronic conditions (Sirois et al., 2015). In the skin condition literature, a cross-sectional study found an indirect effect of attachment orientation on adjustment through use of defeatist coping styles, highlighting the influence of coping style on psychological adjustment in this population (Krasuska et al., 2018). Individuals with skin conditions have reported to use a range of coping styles including task-oriented, emotion-focused, and avoidance-based coping (Hughes et al., 2021) and avoidant coping styles in relation to managing the impact of skin conditions on sexual wellbeing have been reported (Barisone et al., 2020). Overall, the positive effects of self-compassion on adjustment in skin conditions may be further supported through increased adaptive coping responses and less use of shame-based and avoidant coping strategies. These variables are yet to be examined in relation to sexual quality of life in skin conditions.

The effects of self-compassion on adjustment may also be increased through coping efficacy. Coping efficacy refers to appraisals of how an individual feels they are coping with the challenges posed by their illness and has shown to be related to lower emotional reactivity, dependence, and feelings of helplessness (Gignac et al., 2000) and positively associated with self-compassion (Sirois et al., 2015). Coping efficacy has been demonstrated as a mediator in the relationships between self-compassion and stress (Sirois et al., 2015) and is associated with psychological thriving in individuals with chronic health conditions (Sirois & Hirsch, 2013). Coping efficacy has yet to be examined in relation to skin conditions and may also support the effect of self-compassion through more balanced and compassionate appraisals of attempts to cope.

Differences have been found in the way men and women cope with, and experience, the challenges associated with their skin condition. Research has shown differences between genders in how they describe the impact of skin conditions on sex life with men reporting higher levels of sexual dysfunction and females reporting higher levels of sexual distress (Alavi et al., 2018). Differences in coping styles have also been reported between men and women with skin conditions, with women more likely to utilise social support and religious coping strategies (Mazzotti et al., 2012). In qualitative research, females with skin conditions were more likely to describe feelings of shame and embarrassment in relation to sexual wellbeing (Barisone et al., 2020), this may be due to social norms and the internalisation of objectifying and sexualised stereotypes relating to women's bodies (Fredrickson & Roberts, 1997). Women may be more vulnerable to deficits in self-compassion (Neff, 2003b) and research suggests that women may be more likely to experience mental health difficulties associated with their skin condition (Picardi et al., 2000). In addition, research investigating discourses around sexual wellbeing in women highlights the silencing of the importance of sexual satisfaction for women and suggests the need for women's voices to be heard in relation to their sexual experiences (Van Ness et al., 2017). As a result, the present study focuses on examining self-compassion and its relationship to sexual quality of life and skin-related shame in females with skin conditions.

Experiences of shame in relation to one's skin also need to be considered when researching variables that may be important in psychological interventions for sexual wellbeing. Shame is related to a range of psychological difficulties including low self-esteem and psychological distress and body shame has shown to predict levels of psychological distress (Velotti et al., 2017). Furthermore, more self-compassionate individuals experience less body shame (Neff et al., 2018). Feelings of distress, particularly shame and embarrassment, have been noted in the literature in relation to the sexual difficulties experienced by people with skin conditions (Magin et al., 2010). Given the link between shame, sexual quality of life and distress, skin shame was included as an outcome variable to provide an indication of the role of self-compassion and coping styles on skin related distress as well as sexual quality of life.

Overall, research into self-compassion and coping in chronic illness populations provides a basis to explore coping as a potential mediator through which self-compassion impacts on sexual quality of life and skin shame. Understanding the mechanism through which self-compassion effects sexual quality of life and skin related distress can lead to more effective personalised psychological interventions. As an initial exploration of this aim, we conducted an online cross-sectional study, prior to embarking on further complex studies such as longitudinal designs.

Based on the previously discussed literature, the study hypotheses included the following:

1) Self-compassion will be positively correlated with sexual quality of life.
2) Self-compassion will be negatively correlated with skin-related shame.
3) Active coping, defeatist coping and coping efficacy will mediate the relationships between self-compassion and sexual quality of life and self-compassion and skin-related shame.

Method

Participants

Inclusion criteria consisted of participants who identify themselves as females with a skin condition and proficient in the English language. Exclusion criteria included those who identify as male or any individual with a diagnosis of skin cancer or a primary psychiatric diagnosis affecting the skin (e.g., trichotillomania). The study was accessed by 362 participants. Eighty-five were excluded as they had completed less than 93% of the survey or had failed an attention-control check question, resulting in 277 participants being included in further analysis. Demographic and clinical characteristics of participants can be found in Table 1.

Statistical Power and Sample Size

Fritz and MacKinnon (2007) suggest a sample size of at least 162, for .8 power, when *a* and *b* path effect sizes are between small and medium when conducting a percentile bootstrap mediation analysis. In addition, a power calculation was completed using G*Power. To include the outcome variables, predictor variables, mediators, and covariates, the calculation was run with 12 variables. This indicated that for an effect size of 0.15, statistical power level of 0.8 and a *p* value of 0.05 a minimum sample size of 127 is required.

Measures

Demographic Information

Participants were asked to provide demographic information including age group, ethnicity, education level, employment status and marital status.

Skin Condition Information

Participants were asked to indicate the type of skin condition, whether they have received a formal diagnosis, duration of condition and which part of their body is affected. Participants were also asked to rate the visibility, severity, level of pain and itch intensity related to their skin condition on a Likert scale from 0-10. This method of measuring itch has been recommended by the special interest group for scoring itch in clinical trials (Ständer et al., 2013).

Sexual Quality of Life

Sexual Quality of Life was measured using the Sexual Quality of Life – Female questionnaire (SQOL-F; Symonds et al., 2005). The questionnaire consists of 18 items on a 6-point Likert scale from 1 (*completely agree*) to 6 (*completely disagree*). Items assess the impact of sexual difficulties on self-esteem, emotional issues, and relationship issues. Factor analysis revealed that these items are interrelated and should be assessed as an overall total score (Symonds et al., 2005). A total score can be calculated, and higher scores indicate a better sexual quality of life. The measure indicates good internal consistency (0.95) and test-retest reliability (0.85). Cronbach's alpha in this sample was 0.95, which also indicates excellent reliability.

Skin Shame

The Skin Shame Scale (SSS; Scott, 2004) was used to measure levels of skin related shame. It contains 24 items, which are rated on a scale from 1 (*never*) to 5 (*always*) and measures an individual's level of skin distress using items such as 'I am ashamed of my skin'. A total score can be calculated, by summing all items, and a higher score indicates higher skin shame. The SSS shows to have good internal consistency (0.92) and construct validity, as assessed with theoretically related scales (Scott, 2004; Montgomery et al., 2016). Cronbach's alpha in this sample was 0.84, which indicates a good reliability.

Self-Compassion

Self-compassion was measured with the Self-Compassion Scale (SCS; Neff, 2003b). This questionnaire consists of 26 items asking participants how they typically act towards themselves in times of difficulty. Participants rate items from 1 (*almost never*) to 5 (*almost always*). Items assess the three main components of self-compassion: self-kindness, common humanity, and mindfulness. The 26 items reflect the six subscales of the scale, namely self-kindness, self-judgement, common humanity, isolation, mindfulness, and over-identified. Each component has its negative counterpart (e.g., self-kindness - self-judgment). In the current study, an overall score was calculated by reverse scoring items on the negative subscales (self-judgement, isolation and over-identified) then calculating a mean of all six subscales. The measure shows a good internal consistency (0.92) and construct validity (Neff, 2003b), as assessed with theoretically related scales. Cronbach's alpha in this sample was 0.93, indicating an excellent reliability.

Coping Style

Coping style was measured using the Brief COPE which contains 28 items designed to measure use of a range of coping styles (Carver, 1997). Items are scored from 1 (*I haven't been doing this at all*) to 4 (*I've been doing this a lot*). For the aims of this study, we divided the COPE into two subscales 'activity – passivity' and 'defeatism – resilience'. The active coping subscale measures strategies such as support seeking and positive reframing and refers to items such as 'I've been taking action to try to make the situation better'. The defeatist coping subscale measures strategies such as avoidance and behavioural disengagement and refers to items such as 'I've been giving up trying to deal with it'. The items for each subscale are averaged to get a total score for each scale. These scales were chosen as they encompass a range of strategies individuals with skin conditions employ (for example Hughes et al., 2021) and they have been previously used within the skin condition literature (Krasuska et al., 2018). Relevant research indicates this division of the COPE's items has good validity and reliability (Mohr et al., 2014). Cronbach's alpha in this sample were α = 0.88 for the activity coping scale and α = 0.85 for the defeatist coping scale, indicating good reliability.

Coping Efficacy

The three-item coping efficacy scale, which was developed by Gignac et al. (2000) to assess appraisals of coping in chronic illness, was used and adapted by changing the word "arthritis" to "skin condition". The three items were "I am successfully coping with the symptoms of my condition", "I am successfully coping with the day-to-day problems living with my condition creates" and "I am successfully coping with the emotional aspects of my condition". Participants indicated their response on a 5-point Likert scale, 1 (*strongly disagree*) – 5 (*strongly agree*). An average of the three items can be calculated to get a total score. These items have shown good internal reliability (Gignac et al., 2000), Cronbach's alpha in this sample was 0.81.

Additional Participant Comments

To further explore participants' views on the impact of skin conditions on sexual quality of life and how they cope with this, the study also included some open text responses. There were two prompts examining: (a) further details on the impact of their skin condition on sexual quality of life and (b) how they cope with it. Also, there was an open-ended item where participants could make any further comments.

Procedure

Ethical approval was gained from Cardiff University School of Psychology Ethics Committee (Appendix H). Recruitment took place between August 2022 and January 2023. Participants were recruited online through social media sites such as Facebook, Twitter and Instagram and the study was advertised on a health-related website (talkhealth: www.talkhealthpartnership.com). Participants had to first access the survey link, then read the information sheet, provide electronic informed consent, and finally, fill out the series of self-report measures. Participants were then directed to a debrief sheet, which included details of organisations they could find support from, if required. Due to the study being advertised online, skin condition information was based on self-report. Participants spent approximately 20 minutes to complete the survey. All survey responses were completed through the Qualtrics platform, and no individuals IP addresses were retained. At the end of the survey, participants had the choice to enter a prize draw for a £50 shopping voucher.

Analyses

Statistical analyses were carried out using IBM SPSS Statistics (version 27). The initial step included data cleaning and the testing of assumptions of normality, linearity, multicollinearity, and homoscedasticity. Preliminary analysis determined associations between demographic variables (age, relationship status), clinical variables (subjective pain, itch, severity and visibility, area of body affected) and the key predictor (self-compassion) and outcome variables (sexual quality of life and skin shame) using correlations, t-tests, and ANOVAs as appropriate. For the t-tests, a Bonferroni adjusted α level of 0.0167 was used due to multiple tests of difference being carried out. Secondly, Pearson's correlation coefficients were calculated to explore the relationships between self-compassion, sexual quality of life, skin shame, coping style, and coping efficacy. Next, two parallel mediation models were tested. Model 1 included sexual quality of life as the outcome variable and Model 2 with skin-related shame as the outcome variable. In both models, self-compassion was the independent variable and coping efficacy, active coping and defeatist coping were assessed as mediators. The proposed models (Figure 1) were tested using the PROCESS macro version 4.2, (model 4) following the procedure outlined by Hayes (2017). 95% percentile bootstrap confidence intervals, based on 5000 bootstrap resamples, were used to test for an indirect effect via active coping, defeatist coping, and coping efficacy. Mediation was deemed to be significant if the 95% confidence intervals did not include zero (Hayes, 2017).

Content analysis was employed to analyse the qualitative data from the open-text responses (Mayring, 2004). The additional participant comments were imported to NVivo 1.7 where each response was coded. An inductive approach to analysis was taken in which participants language used to describe their experiences were coded, then organised into higher level themes. For example, comments about a 'non-existent sex life' due to 'splitting and soreness' were coded into the themes 'Impact on sexual activity' and 'Physical Factors'. Frequency of the occurrence of the themes were reported.

Table 1

Demographic characteristics of participants

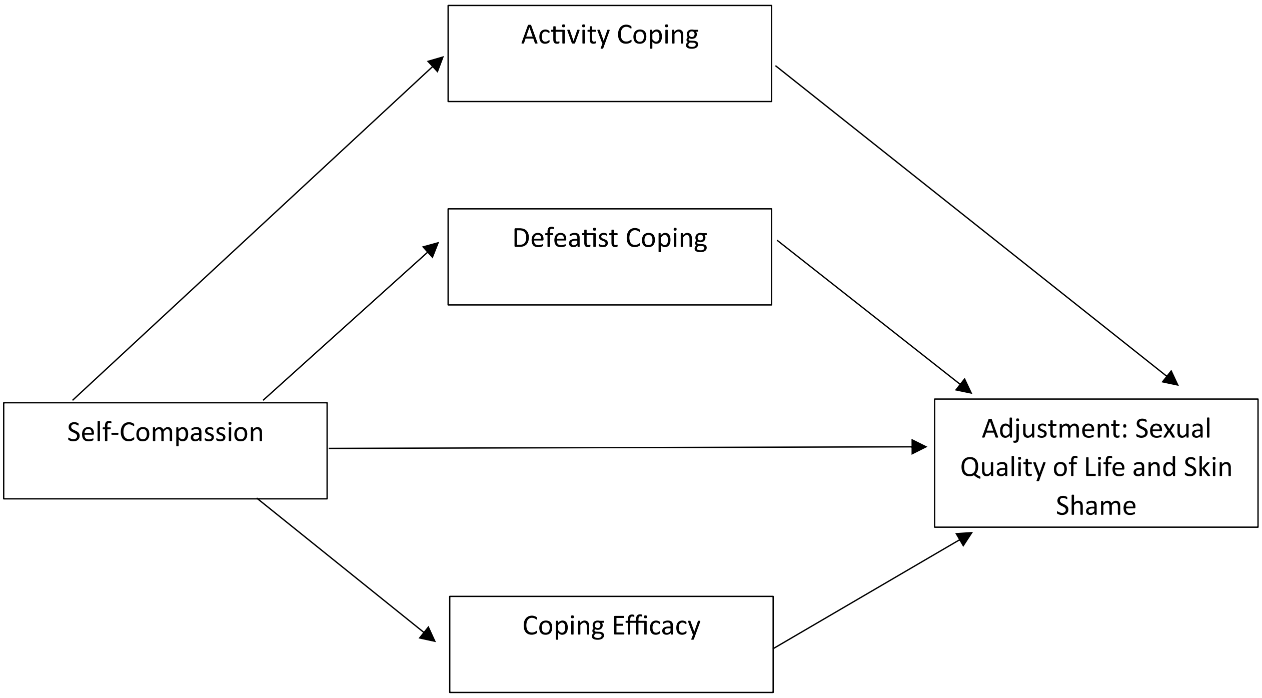
Characteristic		n (%)	Characteristic		n (%)
Age	18 - 24	21 (7.6%)	Highest qualification level	< 5 GCSE’s or equivalent	40 (14.4%)
	25 - 34	102 (36.8%)		5+ GCSE’s or equivalent	63 (22.7%)
	35 - 44	62 (22.4%)		A-level or equivalent	58 (20.9%)
	45 - 54	45 (16.2%)		Degree or above	93 (33.6%)
	Over 55 years	47 (17%)		No formal qualifications	7 (2.5%)
Gender	Female	275 (99.3%)		Other	12 (4.3%)
	Non-binary	1 (0.3%)		Prefer not to say	4 (1.4%)
	Prefer not to say	1 (0.3%)	Employment Status	Full-time employment	144 (52%)
Ethnicity	Asian other	3 (1.1%)		Part-time employment	64 (23.1%)
	Black other	1 (0.4%)		Full-time education	12 (4.3%)
	Other Ethnic Group	1 (0.4%)		Prefer not to say	7 (2.5%)
	White Other	22 (7.9%)		Retired	23 (8.3%)
	Bangladeshi	1 (0.4%)		Unemployed	27 (9.7%)
	Chinese	3 (1.1%)	Marital status	Cohabiting	54 (19.5%)
	Indian	1 (0.4%)		Divorced/separated	18 (6.5%)
	Pakistani	1 (0.4%)		Married	139 (50.2%)
	Black Caribbean	4 (1.4%)		Prefer not to say	5 (1.8%)
	Black African	7 (2.5%)		Single	61 (22%)

Characteristic		n (%)	Characteristic		n (%)
Ethnicity (cont.)	Mixed Other	2 (0.7%)	Formal Diagnosis	No	32 (11.6%)
	White and Asian	1 (0.4%)		Not sure	13 (4.7%)
	White and Black African	2 (0.7%)		Yes	232 (83.8%)
	White and Black Caribbean	1 (0.4%	Length of time with skin condition	< 1 year	47 (17%)
	Prefer not to say	4 (1.4%)		1 - 3 years	45 (16.2%)
	White British	177 (63.9%)		3 - 5 years	51 (18.4%)
	White Gypsy or Irish Traveller	13 (4.7%)		5 - 10 years	42 (15.2%)
	White Irish	33 (11.9%)		10 - 20 years	41 (14.8%)
				> 20 years	51 (18.4%)
Skin condition (s)	Acne	61 (22%)	Site(s) of skin condition	Head/scalp	119 (43%)
	Alopecia	16 (5.8%)		Arms	82 (29.6%)
	Darier disease	9 (3.2%)		Legs	91 (32.9%)
	Hidradenitis suppurativa	23 (8.3%)		Torso	96 (34.7%)
	Ichthyosis	15 (5.4%)		Genitals	104 (37.5%)
	Lichen Sclerosus	51 (18.4%)		Hands	63 (22.7%)
	Psoriasis	37 (13.4%)		Feet	48 (17.3%)
	Eczema	87 (31.4%)			
	Rosacea	33 (11.9%)			
	Vitiligo	24 (8.7%)			
	Other	16 (5.8%)			

Note: For skin condition and site(s) of skin condition n = > 277 as participants were asked to select all options that applied to them.

Figure 1

Proposed Mediation Model



Note. The figure illustrates the proposed models testing two different outcomes: sexual quality of life and skin shame, respectively.

Results

Assumptions and Descriptives

Initially, the data were screened and assumptions for statistical tests were explored. Univariate outlier analysis using boxplots indicated a small number of outliers on the self-compassion scale and the skin shame scale. None of these were extreme outliers and were not removed. No multivariate outliers were identified as assessed by Mahalanobis distance. Normality was explored by producing histograms, examining values for skewness and kurtosis, and the Kolmogorov-Smirnov test. Kolmogorov-Smirnov was significant in all variables suggesting that the data were not normally distributed. The data were not transformed as it was felt some skewness would be expected when looking at the selected psychological variables in the skin condition population and the Kolmogorov-Smirnov test can be considered sensitive in large data sets (Drezner et al., 2010). Scatterplots were inspected for key variables, and these indicated the assumption of linearity was met. Additional assumptions for mediation analysis were explored; there were no multicollinearity issues that needed attention and the assumption for homoscedasticity was met. Descriptive statistics were calculated for each variable and are presented in Table 2.

Table 2

Means and Standard Deviations

Variable	***M (SD)***	**Range**
Self-Compassion Scale	2.83 (0.63)	1-4.83
Sexual Quality of Life	59.11 (20.81)	18-108
Skin Shame Scale	75.46 (12.40)	39-107
Active Coping	2.68 (0.61)	1.06-4
Defeatist Coping	2.40 (0.70)	1-4
Coping Efficacy	3.00 (0.85)	1-5

Note. Range represents findings in the current sample.

Demographic Variables

Preliminary analyses revealed significant differences between age groups in sexual quality of life *F*(4, 193.46) = 9.44, *p*<.001*)* and skin shame *F*(4, 89.27) = 3.87, *p* = .006)[1]. For sexual quality of life, those between 18–24-years and 25–34-years reported higher sexual quality life than those aged 45-54 and over 55 years of age (all *p*'s <.001). Those in the 35–44-year-old group did not differ significantly to the other groups. For skin shame, those aged 45-54 had significantly higher skin shame scores than all other age groups (all *p*'s <.05). Age groups did not differ significantly on the self-compassion scale (*F*(4, 88.69) = 1.97, *p* =.11) [2]. There were no significant differences in sexual quality of life (*F*(4, 272) = 1.14, *p* = .34), skin shame (*F*(4, 272) = 1.81, *p* = .13) or self-compassion (*F*(4, 272) = 1.58, *p* = .18) based on relationship status.

Area of Body Affected

Individuals with genital regions affected had lower sexual quality of life scores (*t*(189.58 = 5.08, p<.001)[3] than those without genital regions affected. No other significant differences were found based on area of body affected.

Subjective Ratings of Physical Variables

Correlation analyses revealed significant negative correlations between self-compassion and subjective ratings of pain (*r* = -.164, *n* = 277, *p* = .006), itch (*r* = -.162, *n* = 277, *p* = .007), and severity (*r* = -.263, *n* = 277, *p*<.001). Skin shame and subjective ratings of ratings of visibility (*r* = .321, *n* = 277, *p*<.001), pain (*r* = .383, *n* = 277, *p*<.001), itch (*r* = .269, *n* = 277, *p*<.001) and severity (*r* = .409, *n* = 277, *p*<.001) were positively correlated. When examining sexual quality of life, significant negative associations between sexual quality of life and pain (*r* = -.189, *n* = 277, *p* = .002), itch (*r* = -.172, *n* = 277, *p* = .004) and severity (*r* = -.218, *n* = 277, *p* < .001) were found.

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[1] The Welch test was used with the Games-Howell post-hoc on both ANOVAs due to the violation of the assumption of equal variances between groups.

[2] The Welch test was used with the Games-Howell post-hoc on the ANOVA due to the violation of the assumption of equal variances between groups.

[3] The Welch test was used due to the violation of the assumption of equal variances between groups.

Correlations Between Measures

Table 3 displays the correlation coefficients for the psychological variables of interest. Self-compassion scores were significantly and positively associated with sexual quality of life and negatively associated with skin-shame. Self-compassion was positively associated with active coping and coping efficacy, and negatively associated with defeatist coping. Active coping and coping efficacy were positively associated with sexual quality of life scores. Skin shame was positively associated with use of defeatist coping styles and negatively associated with use of active coping styles and coping efficacy.

Table 3

Pearson's Correlations for all variables

Variable	SCS	SQOL	SSS	AC	DC
SQOL-F	.436**	—			
SSS	-.562**	-.428**	—		
AC	.362**	.292**	-.161**	—	
DC	-.123*	-.014	.268**	.412**	—
CE	.473**	.410**	-.491**	.230**	-.108

Note. SCS = Self-Compassion Scale. SQOL-F = Sexual Quality of Life-Female Scale. SSS = Skin Shame Scale. AC = Active Coping. DC = Defeatist Coping. CE = Coping Efficacy. **p*<.05; ***p*<.01.

Mediation Analyses

Two parallel mediation analyses examined whether the relationships between self-compassion and sexual quality of life and self-compassion and skin shame, were mediated by active coping, defeatist coping, and coping efficacy, as illustrated in the proposed mediation model (Figure 1). Age, area of skin affected, pain, itch, visibility, and severity were included as covariates in the models.

Model 1 –The mediating role of active coping, defeatist coping, and coping efficacy in the relationship between self-compassion and sexual quality of life.

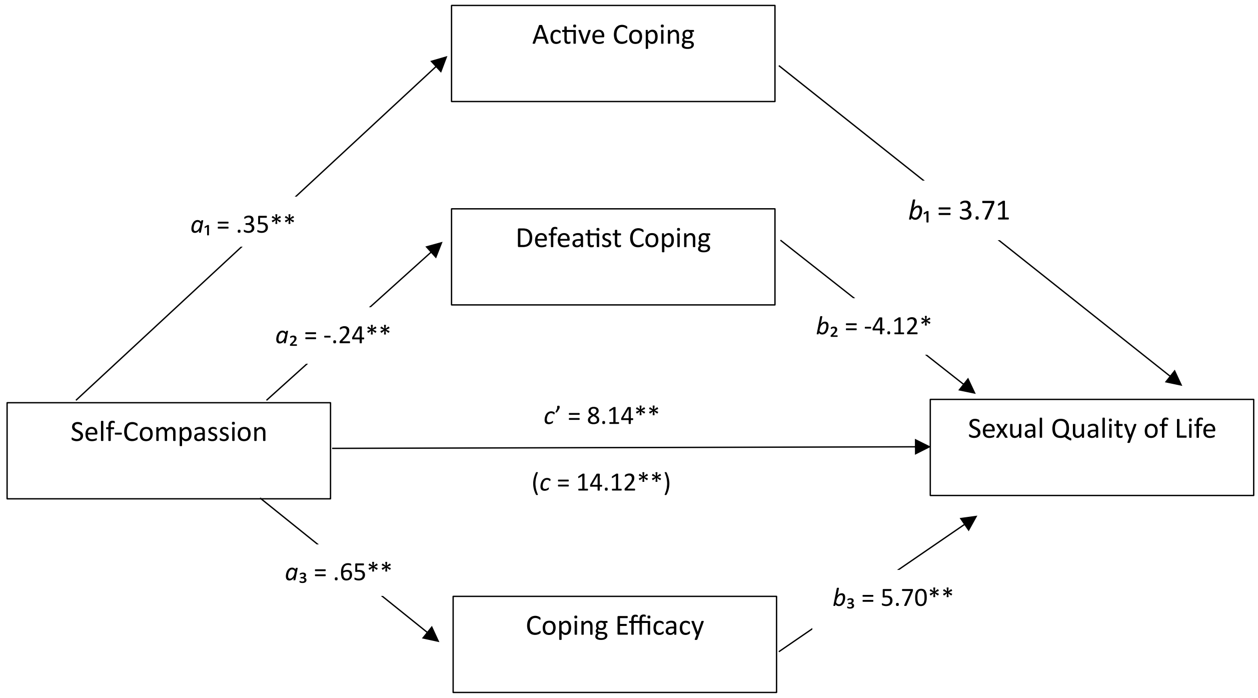
Parallel mediation analysis found a positive total effect of self-compassion on sexual quality of life (c = 14.12, p<.001). Figure 2 displays the total and direct effects. Higher self-compassion scores were associated with a higher degree of coping efficacy (a_3 = .65, p<.001) and participants with higher coping efficacy scores reported increased sexual quality of life (b_3 = 5.70, p<.001). Higher self-compassion scores were associated with less use of defeatist coping styles (a_2 = -.24, p<.001) and those using less defeatist coping styles reported increased sexual quality of life (b_2 = -4.12, p = .025).

Parallel mediation analysis found self-compassion indirectly influenced sexual quality of life through its effect on both coping efficacy and defeatist coping. No indirect effect was found for active coping. Table 4 displays the indirect effects and confidence intervals for all mediator variables.

The overall mediation model was statistically significant (p<.001) and explained 34% of the variance in sexual quality of life. However, self-compassion was found to influence sexual quality of life independent of the indirect effects via the mediator variables examined (c' = 8.14, p<.001)

Figure 2

Result of Parallel Mediation Model 1



Note. Figure shows direct effects of self-compassion on mediator variables (a_{1-3}), mediator variables on sexual quality of life (b_{1-3}) and self-compassion on sexual quality of life (c'), as well as the total effect of self-compassion on sexual quality of life (c); *=p<.05; **=p<.01

Table 4

Indirect Effects and Confidence Intervals

		Indirect Effects†	**95% Percentile Bootstrap Confidence Intervals** (Based on 5000 bootstrap samples)	
Sexual Quality of Life	Active Coping	1.281	-.216	3.221
	Defeatist Coping	.984	.055	2.254
	Coping Efficacy	3.715	1.705	5.806
Skin Shame	Active Coping	-.430	-1.350	.297
	Defeatist coping	-1.062	-1.815	-4.82
	Coping Efficacy	-2.477	-3.838	-1.354

Note † Unstandardised indirect effects.

Model 2 – The mediating role of active coping, defeatist coping, and coping efficacy on the relationship between self-compassion and skin-shame.

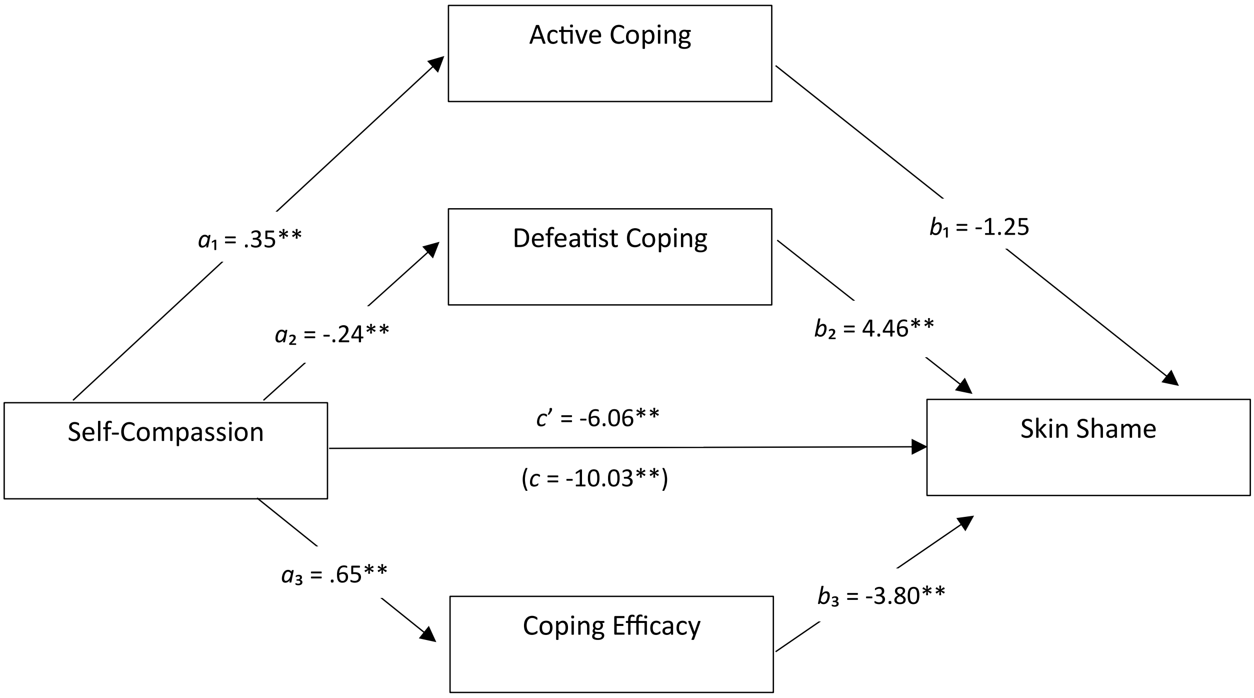
Parallel mediation analysis found a negative total effect of self-compassion on skin shame (c= -10.03, p<.001). Figure 3 displays the total and indirect effects. Higher self-compassion scores were associated with a lower degree of defeatist coping (a_2 = -.24, p<.001) and those using less defeatist coping styles reported lower levels of skin shame (b_2 = 4.46, p<.001). Higher self-compassion scores were associated with a higher degree of coping efficacy (a_3 = .65, p<.001) and participants with higher coping efficacy reported lower skin shame scores (b_3 = -3.80, p<.001).

Parallel mediation analysis found that self-compassion indirectly influenced skin shame through its effect on both coping efficacy and defeatist coping. No indirect effect was found for active coping. Table 4 displays the indirect effects and confidence intervals for all mediator variables.

The overall mediation model was statistically significant (p<.001) and explained 45% of the variance in skin shame. However, self-compassion was found to influence skin shame independent of the indirect effects via the mediator variables examined (c' = -6.06, p<.001).

Figure 3

Results of Parallel Mediation Model 2



Note. Figure shows direct effects of self-compassion on mediator variables ($a_{1\text{-}3}$), mediator variables on skin shame ($b_{1\text{-}3}$) and self-compassion on skin shame (c'), as well as the total effect of self-compassion on skin shame (c); *p<.05; **p<.01.

Additional Participant Comments

Of 277 participants, 172 (62%) provided a response to at least one of the open text questions in the survey. Table 5 illustrates the codes with supporting quotations. A description of the themes is provided below.

Impact on Sex Life and Intimacy

Participants were offered a space to provide any further details on how their skin condition affects their sex lives. The impact of skin conditions on the amount of sexual activity engaged in was commented on by 52.33% of respondents. Whilst some described a non-existent sex life (23.33%), others described a minimal impact on their sexual activity (24.44%). Some individuals described aspects of intimacy that were now different, such as a lack of spontaneity. Physical aspects of skin conditions were described to have an impact on intimacy by 44.19% of respondents. Individuals commented on pain and itch making it difficult to maintain a sexual relationship. Some individuals commented changes to their genitals as a result of their skin condition and described that sex can make their symptoms worse. Psychological factors were commented on by 43.6% of participants. Individuals commented on the impact of their skin condition on feelings of self-confidence and femininity and the effect of this on their sex lives. Participants described feeling embarrassed, self-conscious, and anxious about being intimate and some felt hopeless about the future of their sex lives. 13.95% of respondents commented on aspects of their relationship in relation to their sex lives. Whilst some described supportive partners, others described negative experiences within relationships, or reported avoiding seeking out relationships. Some individuals (7.56%) commented on how their skin condition impacts a wide range of activities, as well as their sex life.

Coping

Participants were offered a space to provide any more detail on how they cope with their skin condition. Avoidant coping was reported by 23.26% of respondents. This included concealing their skin condition, avoiding thinking about it, and avoiding socialising with others. Active coping strategies were reported by 70.93% of respondents. For example, participants reporting using medicine, seeking therapy, being part of support groups and trying different skincare routines. Remaining hopeful and trying to accept the reality of their skin condition was reported by 14.53% of participants. A number of participants (15.70%) discussed the challenges of managing their skin condition. Individuals described the long process of using multiple creams, the side effects of medication, and listed things they need to avoid to manage their skin condition.

Experiences of Support Seeking

Participants were given an opportunity to provide any additional comments on their experience. Many responses related to either the impact of skin conditions on sex or coping and these responses were coded accordingly. Several participants described their experiences of support seeking in this section. Some individuals commented on their negative experiences of seeking support (6.98%) including waiting a long time for specialist support and misdiagnosis. Respondents also commented on the need for increased awareness, training, and research for support providers (11.01%).

Table 5

Codes and Example Quotes from Qualitative Responses

Code		Example Free Text Comments	(%)
Impact on Sex Life and Intimacy	Impact on sexual activity	*'My sex life is non-existent - it's too embarrassing.'* *'I don't feel it impacts my sex life at this stage.'* *'Sex isn't spontaneous as I have to wash creams off first.'*	52.33%
	Physical Factors	*'The splitting of skin and soreness makes intercourse simply not worth the pain.'* *'It is often painful to be touched and often the heat of someone close to me makes the itchiness unbearable.'*	44.19%
	Psychological Factors	*'It gets me very down. I feel less of a woman and not very attractive.'* *'Difficult to get undressed at the start of a relationship. Feel ugly and ashamed of my heavily scarred skin. Don't like showing it to my partner.'*	43.60%
	Relationship Factors	*'My partner is understanding so that does make things easier, but my own thoughts tend to drown out his comments.'* *'It kept me from seeking out a relationship for a long time, until I was 25 and I realized it was a waste of time. But then I sought only casual sexual partners because I thought I was hideous.'*	13.95%
	It's one of many challenges	*'My life has been blighted by my skin for as long as I can remember - I would not wish it on another living soul. It affects what I eat, my sleep, how I dress and my self- esteem. In the overall scheme of things, my sex life is just "one more thing".'*	7.56%
Coping	Avoidant Coping	*'I just try to hide it as much as possible, from everybody.'*	23.26%
	Active Coping	*'I use my steroid and moisturiser regularly, follow my GP and consultant's advice and belong to a very good support group.'*	70.93%
	Hope and Acceptance	*'Now I can look at myself as uniquely beautiful. My spots are a testimony to my story, and I love them for that reason.'*	14.53%
	Cost of Coping	*'Often it is seen as just 'eczema' but it dictates your whole life. Everyday there has to be a strict routine of moisturising and steroid/tacrolimus-based treatments. They damage your clothes and bedding. Then due to treatments being used my skin is sun sensitive so sunscreen has to be worn most of the year even though that causes additional skin problems'.*	15.70%
Experiences of Support Seeking	Negative Experiences	*'I wish I could have been diagnosed sooner. My GP didn't refer me for 2 years and this impacted my quality of life.'*	6.98%
	The Need for Increased Awareness, Training and Research	*'More awareness of how tough this condition is would be good. Also, general awareness with GPs and doctors would be great - it took me 4 years to be diagnosed and the stress of that was really hard. I went to numerous skin specialists and gynaecologists too.'*	11.01%

Discussion

The present study aimed to examine the relationships between self-compassion and sexual quality of life and self-compassion and skin shame. Coping style (active and defeatist coping) and coping efficacy were investigated as potential mediators in these relationships. Correlation analyses demonstrated that self-compassion was positively associated with sexual quality of life and negatively associated with skin shame. Furthermore, mediation analyses revealed a direct effect of self-compassion on sexual quality of life and skin shame. This supports previous findings, indicating that self-compassion is associated with better adjustment in chronic health conditions (Sirois et al., 2015) and skin conditions (Clarke et al., 2020). The relationships between self-compassion and skin-shame and self-compassion and sexual quality of life were mediated by defeatist coping and coping efficacy. Our results contribute to previous research indicating how defeatist coping is associated with poorer adjustment (Krasuska et al., 2018; Mazzotti et al., 2012) by demonstrating the role of coping efficacy, as well as defeatist coping, in the relationships between self-compassion and the outcomes of sexual quality of life and skin shame.

Coping efficacy explained more of the variance in both sexual quality of life and skin shame, than defeatist coping, suggesting the potential role of appraisals in coping with a skin condition. Those with previous successful attempts to cope are likely to have higher appraisals of their coping efficacy and therefore feel less distressed by the challenges their conditions pose. This indicates that previous appraisals of successful attempts to cope can boost a sense of coping efficacy (Gignac et al., 2000). Research indicates that coping efficacy is associated with lower ratings of pain severity (Sirois & Gick, 2016), highlighting that boosting self-efficacy can lead to better adjustment. Coping efficacy had not been previously investigated in the skin condition literature and the current findings provide tentative support as for the benefits of coping efficacy in females with skin conditions.

Overall, our models showed that self-compassion was associated with higher coping efficacy and less defeatist coping which were associated with lower skin shame and increased sexual quality of life. The results from our hypothesised mediation models may indicate that individuals higher in self-compassion may be more likely to appraise their attempts to cope more successfully by talking to themselves with self-kindness, boosting one's sense of self-efficacy, and using less defeatist coping styles such as self-blame and denial. On the other hand, those lower in self-compassion may be more likely to use more defeatist coping styles and negatively appraise their attempts to cope. This may occur, by talking to themselves with more self-judgment resulting in a lower sense of self-efficacy.

Contrary to our hypothesis, active coping was not a significant mediator in either model suggesting that, as far as the tested models are concerned, use of active coping styles may have less of a role in how self-compassion influences adjustment to skin conditions. Some potential explanations for this finding are discussed below. First, the active coping scale measures a range of coping strategies, including problem focused coping strategies such as instrumental support seeking, cognitive restructuring strategies such as positive reframing, and emotion focused coping styles such as acceptance. However, it may be that some strategies that were measured are more important than others in the relationships between self-compassion, sexual quality of life and skin shame. A meta-analysis of self-compassion and coping styles found that self-compassion was more strongly associated with emotion-focused coping styles than problem-focused coping styles (Ewert et al., 2021). In addition, a recent study in patients with psoriasis found that whilst emotion-focused coping was associated with a higher quality of life, problem-focused coping was associated with a lower quality of life (Shaukat et al., 2023). It may be that for individuals managing a skin condition where there is no cure, such as lichen sclerosus, that continued use of problem-focused coping which attempts to change or solve the problem may be less helpful (Krasuska et al., 2018), perhaps similar to the way in which experiential avoidance is not wholly negative when using it to cope for a stressor that cannot be changed (Karademas et al., 2017). Instead, use of strategies that change the way an individual appraises or feels about the challenges posed by their skin condition, such as positive reframing, may be more beneficial at supporting the effects of self-compassion on adjustment. Indeed, relevant research highlight the role some coping responses have in supporting individuals to lessen the impact of symptoms on an individual's life, rather than attempting to change them, such as self-compassion and psychological flexibility (Vasiliou et al., 2023; Woodruff et al., 2014). Future research could investigate specific active coping styles, perhaps differentiating between problem-focused and emotion-focused coping, to ascertain if some are more instrumental in the relationship between self-compassion and adjustment in this population.

Another potential explanation as for the non-mediating effect of active coping may be the presence of practical barriers in implementing active coping strategies such as support seeking. Previous research suggests that health professionals struggle to acknowledge and talk about the impact of skin conditions on sexual wellbeing (Barisone et al., 2020; Gott et al., 2004). If individual's feel they are not listened to, or health care professionals are reluctant to discuss these issues in consultations, then support seeking is unlikely to be effective. Participant responses to the open-text questions highlighted other potential barriers to successful active coping. In terms of support seeking, individuals commented on being put on waiting lists or struggling to get a diagnosis, highlighting how this coping strategy may not be instantly successful and therefore might be less likely to result in positive adjustment. Relevant research indicates the potential negative effects of waitlists on lowering engagement and treatment motivation (McDonnell et al., 2022). The burden of continued use of active coping was commented on by some participants such as using long hygiene routines, managing diet, and avoiding triggers such as sun exposure, which could add to the sense of their skin condition limiting their life.

Clinical Implications

The findings that higher self-compassion is associated with increased sexual quality of life and reduced skin shame supports the emerging evidence base for the use of compassion-focused interventions for individuals with skin conditions (Hudson et al., 2020; Sherman et al., 2019). Our study expands previous findings by highlighting the potential benefits of fostering self-compassion to improve the sexual quality of life of individuals with skin conditions. Fostering self-compassion, could promote more compassionate appraisals of challenges, further supporting the impact of self-compassion by increasing coping efficacy. By enhancing a positive appraisal of coping efficacy, previous successful uses of self-compassion may be repeated, improving adjustment to the challenges posed by skin conditions. Furthermore, increasing self-compassion, may reduce use of defeatist coping strategies, such as avoidance, as the mindfulness element of self-compassion involves acknowledging one's difficult emotions without trying to repress them. The current study highlights the importance of further research in the development and testing of compassion-focused interventions aimed at improving sexual wellbeing.

The findings in relation to age and physical variables may also have clinical implications by providing some insight into who may be most in need of psychological interventions. In our sample, older participants reported a lower sexual quality of life. This may be explained by hormonal changes in the menopause which can have an impact on both sexual functioning and skin conditions. However, findings in the literature are mixed in relation to age and sexual wellbeing, with one study reporting sexual wellbeing reducing as women age (Lindau & Gavrilova, 2010) whilst another study reported older people feeling satisfied with their sex lives (Heywood et al., 2018). In addition, Harlow et al. (2000) found no association between age and quality of life in individuals with skin conditions however, another study reported higher levels of stress in young people (Niemeier et al., 2002).

In terms of physical variables, those with genital regions affected had significantly lower sexual quality of life scores than those without genital regions affected. This supports previous findings showing that impairments to sexual wellbeing and quality of life are more likely in those with genital regions affected (Sampogna et al., 2007; Yang et al., 2018). Given the association between psychological distress and poor sexual quality of life (Sampogna et al., 2017), those with genital regions affected may be more in need of intervention. All skin condition variables (pain, itch, severity, and visibility) were associated with skin-related shame, highlighting the impact of physical variables on how people think and feel about their skin. This supports previous findings associating skin shame with poorer physical quality of life (Homayoon et al., 2020). Finally, not all individuals with skin conditions will experience an impact on their sexual quality of life as indicated by the range of responses to the open-text questions and the range of scores on the SQOL-F. Age, subjective ratings of skin condition variables, and area of skin affected may provide some indication as to who may be more likely to require intervention.

Overall, it's important that health professionals consider the impact of skin conditions on sexual quality of life. Patients with chronic health conditions have reported that even when conversations about their sex life did happen, that this was done poorly (Fourie et al., 2021), indicating that health professionals may need to be supported to talk about sexual wellbeing. Health professionals that come into contact with dermatological problems may benefit from further training to support them to discuss sexual quality of life with patients. In addition, feelings of embarrassment or shame might prevent patients from initiating conversations about sexual wellbeing with health professionals (Fourie et al., 2021). Health professionals may consider giving written information to all patients on sexual wellbeing and skin conditions as part of a stepped-care approach, which has been suggested for use when providing psychologically informed interventions to dermatology patients (Thompson, 2009). Information could include signposting to further support and suggestions for self-help such as compassion-focused self-help which has shown to reduce distress in individuals with skin conditions (Hudson et al., 2020). Supporting health professionals to have conversations around sexual wellbeing and the psychological impact of skin conditions will support services to identify those in need of psychological intervention and the level of intervention needed.

Limitations and Future Directions

It's important to consider the limitations of this research. The cross-sectional design of the study limits the conclusions that can be drawn, as causality cannot be inferred. Future research could use longitudinal methods or experimental methods to foster self-compassion. For example, asking participants to talk, or write, about their sex lives in a self-compassionate way could confirm the direction of effects found. The study used online recruitment via social media, therefore the sample was self-selecting and individuals undertaking the research might have been more likely to experience difficulties with their sexual quality of life, however our findings demonstrated a varied impact on sexual wellbeing. For the qualitative content analysis, a second coder and a calculation of inter-rater reliability was not assessed which would have improved the rigour of the analysis. However, the process of content analysis was discussed in supervision. The active and defeatist coping scales were chosen to measure the scope of coping styles that have shown to be used in individuals with skin conditions (Barisone et al., 2020; Hughes et al., 2021; Krasuska et al., 2018). However, measures of specific coping strategies could enhance the clinical implications of the findings by specifying which strategies are most important for adjustment.

The significance of the direct effect of self-compassion on sexual quality of life and skin shame indicates the potential for there to be other mechanisms through which self-compassion impacts adjustment. Relevant research shows that mindfulness, an element of self-compassion, can predict distress and itch catastrophising in individuals with skin conditions (Lüßmann et al., 2021; Montgomery et al., 2016). In particular, present moment awareness and non-judgement of inner experience are associated with less social anxiety (Montgomery et al., 2016). Furthermore, self-disgust has been associated with self-compassion and adjustment to skin conditions (Clarke et al., 2020; Schienle & Wabnegger, 2022) highlighting another potential area for investigation, as feeling disgusted with one’s skin may mean they are less comfortable with intimacy (Magin et al., 2010). Mindfulness and self-disgust may be variables warranting further investigation in relation to self-compassion and sexual quality of life in skin conditions. Finally, the responses to the open-text questions provided rich data and a further insight into the way sexual quality of life is impacted by skin conditions and the challenges that come with managing a chronic illness. Using a more in-depth analysis such as interpretative phenomenological analysis could provide a deeper understanding of the experience of individuals with skin conditions and their attitudes about the impact their conditions can have on their sexual quality of life. Gaining a male perspective on this would be particularly interesting.

Conclusions

This study builds on previous findings on the impact of skin conditions on sexual quality of life by examining the role of self-compassion and coping responses. Our findings showed that more self-compassionate individuals experience a better sexual quality of life and lower skin shame. Mediation analysis revealed that self-compassion impacts sexual quality of life and skin shame indirectly through defeatist coping and coping efficacy. Our study supports the use of interventions to increase self-compassion to improve adjustment in females with skin conditions and indicates the importance of healthcare professionals considering the impact of skin conditions on sexual wellbeing.

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Appendix A: British Journal of Health Psychology Author Guidelines

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

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2. AIMS AND SCOPE

The British Journal of Health Psychology publishes original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan including:

- experimental and clinical research on aetiology
- management of acute and chronic illness
- responses to ill-health
- health-related behaviour change and maintenance
- screening and medical procedures

- psychosocial mediators and moderators of health-related behaviours
- influence of emotion on health and health-related behaviours
- psychosocial processes relevant to disease outcomes
- psychological interventions in health and disease
- emotional and behavioural responses to ill health, screening and medical procedures
- psychological aspects of prevention

Papers must make a clear potential contribution to health psychology theory, knowledge and/or practice and employ rvigorous research design and methodology..

We do not typically publish cross-sectional studies or those using only student populations unless there is a strong rationale for doing so.

Papers describing intervention development (without also presenting an analysis of the outcomes of the intervention) will usually only be considered if they make a contribution to health psychology theory, knowledge and/or practice beyond the specific intervention context.

3. MANUSCRIPT CATEGORIES

The types of paper invited are:

- papers reporting original empirical investigations, using quantitative, qualitative or mixed methods;
- theoretical papers which report analyses of theories in health psychology;
- review papers, which should provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses);
- methodological papers dealing with methodological issues of particular relevance to health psychology;
- we particularly welcome papers reporting effectiveness (for example, Randomised Controlled Trials) and process evaluations of interventions in clinical and non-clinical populations.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

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Acknowledgements

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The journal offers rapid publication via Wiley's Early View service. **Early View** (Online Version of Record) articles are published on Wiley Online Library before inclusion in an issue. Before we can publish an article, we require a signed license (authors should login or register with **Wiley Author Services**). Once the article is published on Early View, no further changes to the article are possible. The Early View article is fully citable and carries an online publication date and DOI for citations.

8. POST PUBLICATION

Access and Sharing

When the article is published online:

- The author receives an email alert (if requested).
- The link to the published article can be shared through social media.
- The author will have free access to the paper (after accepting the Terms & Conditions of use, they can view the article).
- For non-open access articles, the corresponding author and co-authors can nominate up to ten colleagues to receivea publication alert and free online access to the article.

Promoting the Article

To find out how to best promote an article, click **here**.

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Wiley also helps authors measure the impact of their research through specialist partnerships with **Kudos** and **Altmetric**.

9. EDITORIAL OFFICE CONTACT DETAILS

For help with submissions, please contact: Jeyashree Ramamoorthy, Editorial Assistant, **bjhp@wiley.com** or phone +44 (0) 116 252 9504.

Appendix B: Search Terms

PsycInfo

Alopecia/ OR Alopecia AND qualitative methods OR interview* OR thematic* or thematic analysis/ OR grounded theory OR focus group OR template* OR interpretative phenmomenolog* OR framework analysis OR attitude* OR coping style/ or coping or coping behaviour OR life experiences/ or life experience* OR perspective* OR discourse analysis or discourse analysis/ OR perspective* OR ((semi structured or semistructured or unstructured or informal or in depth or indepth or face-to-face or structured or guide) adj3 (interview* or discussion* or questionnaire*)) OR (focus group* or qualitative or ethnograph* or ethnology or phenomenology or discourse analysis).mp.

Medline

Alopecia/ OR Alopecia AND qualitative research OR interview* OR thematic* or thematic analysis/ OR grounded theory OR focus group OR template* OR interpretative phenmomenolog* OR framework analysis OR attitude* OR coping style/ or coping or coping behaviour OR life experiences/ or life experience* OR perspective* OR discourse analysis or discourse analysis/ OR perspective* OR discourse analysis OR ((semi structured or semistructured or unstructured or informal or in depth or indepth or face-to-face or structured or guide) adj3 (interview* or discussion* or questionnaire*)) OR (focus group* or qualitative or ethnograph* or ethnology or phenomenology or discourse analysis).mp.

Embase

Alopecia/ OR Alopecia AND qualitative research OR interview* OR thematic* or thematic analysis/ OR grounded theory OR focus group OR template* OR interpretative phenmomenolog* OR framework analysis OR attitude* OR coping style/ or coping or coping behaviour OR life experiences/ or life experience* OR perspective* OR discourse analysis or discourse analysis/ OR perspective* OR discourse analysis OR ((semi structured or semistructured or unstructured or informal or in depth or indepth or face-to-face or structured or guide) adj3 (interview* or discussion* or questionnaire*)) OR (focus group* or qualitative or ethnograph* or ethnology or phenomenology or discourse analysis).mp.

CINAHL

TX alopecia AND

TX qualitative* OR interview* OR thematic* OR "grounded theory" OR "focus group" OR template* OR "interpretative phenomenolog*" OR "framework analysis" OR attitude* OR coping* OR "life experience*" OR perspective OR "discourse analysis" OR TI ((((“semi-structured” or semistructured or unstructured or informal or “in-depth” or indepth or “face-to-face” or structured or guide) N3 (interview* or discussion* or questionnaire*))) OR AB ((((“semi-structured” or semistructured or unstructured or informal or “in-depth” or indepth or “face-to-face” or structured or guide) N3 (interview* or discussion* or questionnaire*)))

Scopus

(TITLE-ABS-KEY (alopecia)) AND (TITLE-ABS-KEY (qualitative* OR interview* OR thematic* OR "grounded theory" OR "focus group" OR template* OR "interpretative phenomenolog*" OR "framework analysis" OR coping OR attitude OR "life experience*" OR perspective OR "discourse analysis" OR (semi AND structured OR semistructured OR unstructured OR informal OR in AND depth OR indepth OR structured OR guide) W/3 (interview* OR discussion* OR questionnaire*) OR (focus AND group* OR qualitative OR ethnograph* OR ethnology OR phenomenology OR discourse AND analysis)))

Appendix C: Detailed Data Extraction Example

Extraction Field	Data Extracted
Authors (year)	Iliffe and Thompson (2019)
Country	UK
Participants (number, age, gender) and recruitment	Purposive sampling in which twelve participants from Alopecia UK Facebook peer support group were recruited. The study recruited those who felt they had benefitted from the group. Females aged between 30 and 59 years of age. Eleven diagnosed with alopecia, and one family member of those diagnosed with alopecia. Only one participant was currently undergoing treatment for alopecia.
Study design, data collection and methodology	Semi-structured interviews over Facebook messenger. Open-ended questions and prompts about joining the group, experiences since joining the group, changes in how the individual is managing with alopecia, and changes in coping since joining the group. Interviews lasted approximately one hour. Participants asked to send a screenshot of a critical incident, in this context, a time the use of the group had been helpful. There were questions included about this specific experience. Data were analysed using interpretative phenomenological analysis.
Key themes and findings	Four overarching themes were found. 1: Gradual healing, included the use of the group for expressing emotions. 2: Image concern, included use of the group for practical support e.g., wig use and makeup and tips on coping within the group. 3: Belonging, the importance of connecting reduces loneliness and shared experiences creates feeling of normality. 4: New identify and self-acceptance including internal changes e.g., compassion and social life and openness e.g., better coping and returning to work, hobbies and talking to others.
Limitations	This study did not address negative experiences of support groups. Generalisability of findings may be limited due to small and specific sample. Reliance on interviews on messenger could have lost sense of rapport with participants.

Appendix D: Quality Appraisal Tool

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research

HINT: Consider

- what was the goal of the research
- why it was thought important
- its relevance

Yes	
Can’t tell	
No	

2. Is a qualitative methodology appropriate?

HINT: Consider

- if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- is qualitative research the right methodology for addressing the research goal

Yes	
Can’t tell	
No	

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

HINT: Consider

- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Yes	
Can’t tell	
No	

4. Was the recruitment strategy appropriate to the aims of the research?

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Yes	
Can’t tell	
No	

5. Was the data collected in a way that addressed the research issue?

HINT: Consider

- If the setting for the data collection was justified

- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic
- guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the researcher has discussed saturation of data

Yes	
Can't tell	
No	

6. Has the relationship between researcher and participants been adequately considered?

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Yes	
Can't tell	
No	

Section B: What are the results?

7. Have ethical issues been taken into consideration?

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Yes	
Can't tell	
No	

8. Was the data analysis sufficiently rigorous?

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings

- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Yes	
Can’t tell	
No	

9. Is there a clear statement of findings?

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher’s arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Yes	
Can’t tell	
No	

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Yes	
Can’t tell	
No	

Appendix E: Summary of Descriptive Themes

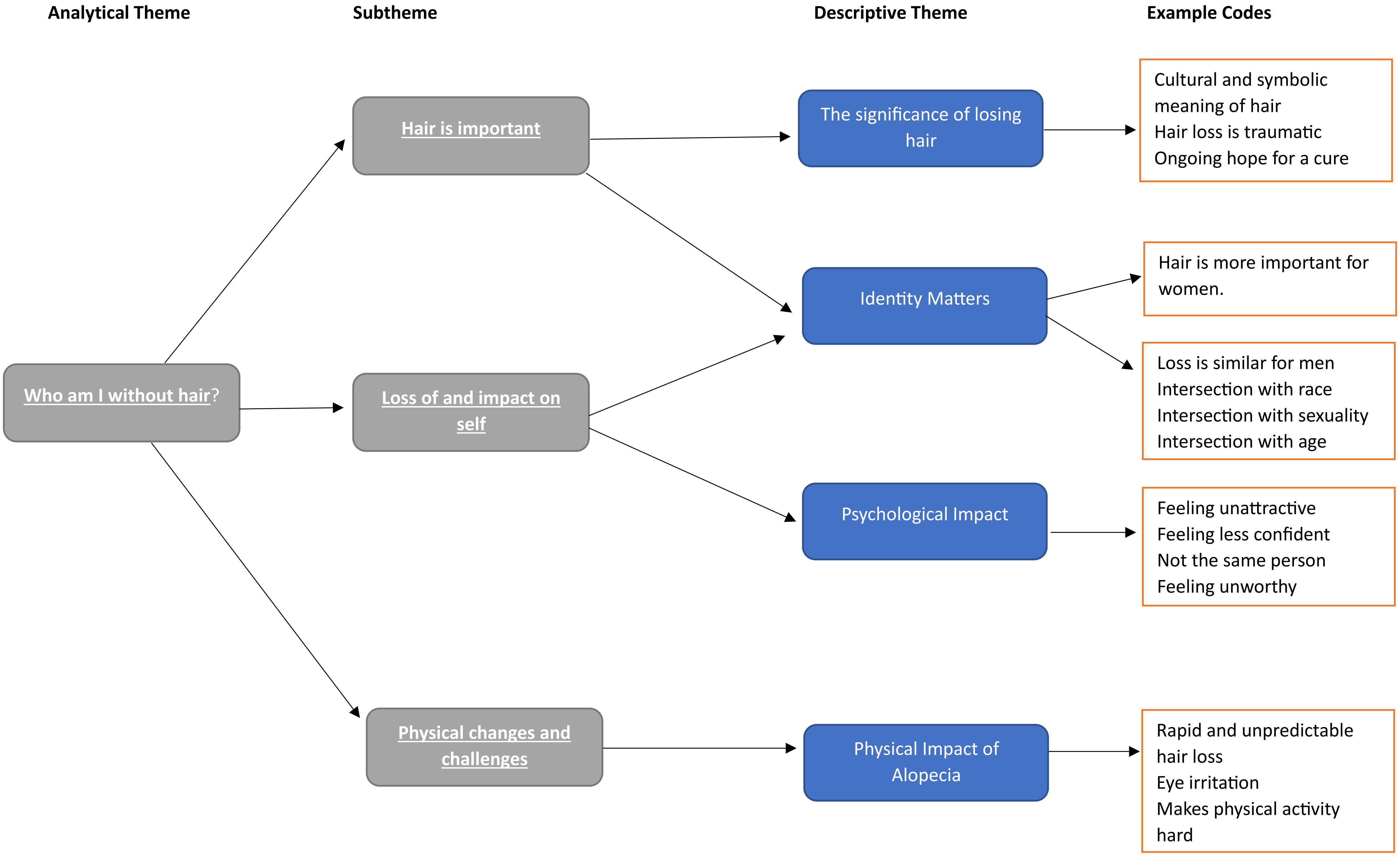
Descriptive Theme	Description	Contributing Studies	Illustrative Quotes
Treatment experiences	Codes related to both positive and negative experiences of support, emotional impact of alopecia not being addressed, concerns about medical treatments, lack of effective medical treatment, difficulty accessing psychological support, suggestions for improved treatment.	21	*"I have visited many dermatologists, doctors and naturopaths to help with my condition. Each has given me hope in a new treatment that could cure my hair loss. None have worked."* (Davey et al., 2018, p.1385) *"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) *"I was bullied for having alopecia so it's like I now will look at it every day and like I will see oh is it [the trial treatment] working, is it working and like I just get more excited every day because I see growth."* (Macey et al., 2022, p.S2).
The wide range of ways in which people cope	Codes included a range of different coping styles e.g., religious coping, humour, getting on with it. Coping is personal and differs from person to person.	19	*''My daily routine changed. I started offering all the five prayers. My daily routine revolved around prayers and reciting Holy Quran, all this relaxed me''* (Rafique & Hunt, 2015, p.8). *"It's a highly personal journey which has to be taken at an individual pace."* (Davey et al., 2018, p.1386).
The importance of social support	Codes related to support from family, friends, partners and the benefits of this. The use of support groups and online support communities.	16	*"Yes my wife is my strongest pillar. First and foremost, she doesn't talk about it. She just takes it as though I have full hair because this is a crowning glory of a man. My condition does not change the love or feeling that she has."* (Leow & Lee, 2017, p.54) *''I find the support group much more helpful than any treatment I could have''*. (Welsh & Guy, 2009, p.198)

Descriptive Theme	Description	Contributing Studies	Illustrative Quotes
The process of adjustment	Codes related to the process of adjusting to the condition, including acceptance, personal growth, looking for meaning, factors impacting adjustment.	20	*"Alopecia made me compassionate and able to understand others suffering – it also made me develop a sense of who I was inside. I feel that my physical body is not who I am deep down... . so I have grown confident and self-accepting from inside out."* (Davey et al., 2018, p.1387) *"Hair or no hair, we're still fabulous"* (Iliffe & Thompson, 2019, p.997) *"...some days I do believe that its true that I am beginning to accept this and adjust to my change in life and self but on others I know that its a con because I am not"* (Fox, 2003, p.555)
Physical impact	Codes included physical factors such as itch, eye irritation and nose irritation, descriptions of the pattern and unpredictability of hair loss.	19	*"Its the unpredictability that's hard to deal with a bit of growth then you lose it again that the bit that's difficult, the roller coaster"* (Fox, 2003, -.556) *"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)
The psychological impact	Codes related to the impact on self-confidence, identity, mental health and a range of emotional responses to alopecia.	22	*"The most important thing that affected me was how I felt about myself. […] I felt like I was not, like, worth loving."* (Aldhouse et al., 2020, p.5) *"It must be treated like grief. The psychological impact is all encompassing and never seems to diminish. It is extremely lonely and isolating."* (Davey et al., 2018, p.1381) *"When I first discovered my alopecia, I decided that I would not want to live if I lost all my hair. I seriously considered suicide that night."* (Hunt & McHale, 2005, p.39)

Descriptive Theme	Description	Contributing Studies	Illustrative Quotes
The social challenges	Codes related to the harmful reactions of others, lack of public awareness, alopecia as exposing, changes to social behaviour, fear of rejection from others.	22	*"I was a teacher. And right before I retired, one student started making jokes about me and my hair loss. And I had a coteacher, a male, who also had hair loss and he made up funny names for the two of us. And at the time it did make me laugh, and I blew it off. But I was happy to get out of teaching. I felt like "you know, I think I'm done with this and working with kids". And that's one thing where I feel like, yes, it [FFA] did affect my choice. It expedited my retirement."* (Cook et al., 2022, p.1014) *''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)
The significance of losing hair	The symbolic and cultural meanings of hair, hair loss as traumatic, not feeling human without hair.	19	*"…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., 2018, p.1381) *"look at this egghead.. I feel like an alien, a stranger"* (Barkauskaite & Serapinas 2020, p.4) *"I think when you first see someone it's their hair, at least for me, like the hair is everything."* (Aldhouse et al., 2020, p.4)
Concealing hair loss	Codes related to the benefits of concealing hair loss, the burden of concealing, feelings of inauthenticity, noticeability, impact of concealment on physical activity and practical challenges of concealment.	21	*"No matter how attractive I look in a wig I feel like a sham."* (Montgomery et al., 2017, p.4) *"I'm real self-conscious over it. Even with me brushing back with a ponytail, I'm looking in the mirror to make sure that that spot is not seen."* (Winnette et al., 2021, p.608) *"Trying to disguise it. Trying to make it where nobody else can see it, that you just know it's there but nobody else does"* (Cook et al., 2022, p.1014)

Descriptive Theme	Description	Contributing Studies	Illustrative Quotes
Identity matters	Codes related to aspects of identity and the interaction of these with alopecia, for example, hair loss is worse for women, intersection of hair loss with sexuality, age, and race.	11	*“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) *“before the hair loss it was the colour of my… skin… that I was angry with, because of what I was going through... I’d had a lot of race stuff–crap, so it’s been like a life of being angry at my own appearance and the psychology effect was really, really big”* (Zucchelli et al., 2022, p.7) “There is a perceived difference between men and women being seen in public without hair: *‘I have never seen a bald woman out and about in Sainsbury’s doing her shopping.’”* (Hunt & McHale., 2005, p.42). *‘‘I think I do cope better now the older I’ve got. It’s not as important, if you’ve got children and you get to your thirties and think, its nothing really, I think I have got better with it, definitely’’* (Welsh & Guy, 2009, p.198)

Appendix F: Analytical Theme Example



Appendix G: Body Image Author Guidelines

GUIDE FOR AUTHORS

Types of Papers
The journal publishes

1. Full-length articles of the following types:

- **Original research articles** (studies that do not fit one of the other types listed below)
- **Systematic reviews / meta-analyses** (please follow PRISMA checklist: http://www.prisma-statement.org/
- **Methodological / protocol articles** (articles that explicate an innovative research study design in which data are currently being collected)
- **Unexpected / null results articles** (articles grounded in extant theory that have a sound methodological design and adequate statistical power and are analyzed appropriately, but primary hypotheses were not supported)
- **Scale development / adaptation articles** (multi-study/sample articles that investigate the psychometric properties of a newly developed or existing scale relevant to body image; scale translations and applications to different samples are welcome)
- **Replication studies** (consistent with Open Science initiatives, we encourage articles that replicate--or fail to replicate--existing body image research)
- **Theoretical review articles** (typically invited; however, if you have an idea, propose it to the Editor-in-Chief)

Please choose the article type that is the best fit for your article (we realize that some articles may fit into more than one type).

While full-length articles have no explicit limits in terms of numbers of words, tables/figures, and references, an article's length must be justified by its empirical strength and the significance of its contribution to the literature.

2. Shorter communications of the following types:

- **Brief research reports** (articles with a more defined and/or limited focus than original research articles)
- **Ideas worth researching** (articles that propose a novel idea for advancing research on body image)
- **Methodological innovations** (articles that discuss the application of a novel statistical approach to the study of body image)

Guidelines for short communications are <= 3000 words from Introduction through Discussion and <= 30 references. There are no limits on tables and figures

3. Themed special issues

- **Theoretical special issue** (a collection of review articles from experts in the body image field that focus on a relevant body image topic)

- **Empirical special issue** (a collection of empirical articles that offer novel insights into a relevant body image topic)
- **Data set special issue** (a collection of empirical articles that emerge from the same, large data set; each article within the issue must be incremental and overlapping data between articles must be minimal)

We especially encourage special issues that bridge body image theory and research with other disciplines and social science constructs.
Please contact Editor-in-Chief to propose your idea for a special issue.

If you are proposing a theoretical or empirical special issue and it is accepted, you will be the Guest Editor(s) and work with the Editor-in-Chief (or an Associate Editor) and our Special Issue Journal Manager to develop and prepare your special issue.

If you are proposing a data set special issue, then Guest Editors will be appointed that manage your issue and they will work with the Editor-in-Chief (or an Associate Editor) and our Special Issue Journal Manager.

For each paper type, we would like authors to know that we are impartial regarding the source of citations and we recommend against excessive string citations.

Impartiality statement regarding citations. We, the editorial team, strongly encourage authors to cite the highest quality work believed to be most relevant to their article; we are impartial to the use of citations from Body Image versus other journals. We review and accept articles based on their scientific rationale, merits, design, analysis, and interpretation rather than the source of their citations.

Note regarding string citations. We encourage authors to avoid excessive string citations, whereby multiple citations support a single statement, finding, or proposition, when such citations would be superfluous. In many cases, one citation will suffice, and this citation should be the best supporting reference for that statement, finding, or proposition. All important previous work can be included, and if a cite is important, there often will be additional text that accompanies it. Please note that we are okay with the overall number of references.

Of note, the recommendation to avoid string citations does not apply to:

1. Statements that include more than one finding. For example, "Over the past 10 years, researchers in a number of countries have begun to explore the relationship between positive body image and psychological well-being" needs multiple citations because authors are referring to researchers and countries (both plural. However, reference to all work that has explored this relationship is probably not needed.
   As another example, "research shows that body dissatisfaction is correlated with disordered eating, anxiety, and depression" may include multiple citations, with different citations supporting different aspects of this statement.
2. Systematic reviews and meta-analyses whereby the citations are linked to relevant themes/data that are included in the analysis.

The presence of string citations alone is not a reason to reject an article. If submitted articles contain string citations, the editorial team will simply note this, and it will be up to the author to decide whether to retain or remove citations if asked to revise and resubmit their article.

The Seymour Fisher Outstanding Body Image Dissertation Annual Award

The journal gives an annual award for the best doctoral dissertation in this field. Click here for more information.

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:
- E-mail address
- Full postal address

All necessary files have been uploaded:
Manuscript:
- Include keywords
- All figures (include relevant captions)
- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided
- Indicate clearly if color should be used for any figures in print

Graphical Abstracts / Highlights files (where applicable)
Supplemental files (where applicable)

Further considerations
- Manuscript has been 'spell checked' and 'grammar checked'
- All references mentioned in the Reference List are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet)
- A competing interests statement is provided, even if the authors have no competing interests to declare
- Journal policies detailed in this guide have been reviewed
- Referee suggestions and contact details provided, based on journal requirements

For further information, visit our Support Center.

Before You Begin

Ethics in publishing

Please see our information on Ethics in publishing.

Studies in humans and animals

If the work involves the use of human subjects, the author should ensure that the work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. The manuscript should be in line with the Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly

Work in Medical Journals and aim for the inclusion of representative human populations (sex, age and ethnicity) as per those recommendations. The terms sex and gender should be used correctly.

Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed.

All animal experiments should comply with the ARRIVE guidelines and should be carried out in accordance with the U.K. Animals (Scientific Procedures) Act, 1986 and associated guidelines, EU Directive 2010/63/EU for animal experiments, or the National Research Council's Guide for the Care and Use of Laboratory Animals and the authors should clearly indicate in the manuscript that such guidelines have been followed. The sex of animals must be indicated, and where appropriate, the influence (or association) of sex on the results of the study.

Declaration of interest

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential competing interests include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. Authors must disclose any interests in two places: 1. A summary declaration of interest statement in the title page file (if double anonymized) or the manuscript file (if single anonymized). If there are no interests to declare then please state this: 'Declarations of interest: none'. 2. Detailed disclosures as part of a separate Declaration of Interest form, which forms part of the journal's official records. It is important for potential interests to be declared in both places and that the information matches. More information.

Declaration of generative AI in scientific writing

The below guidance only refers to the writing process, and not to the use of AI tools to analyse and draw insights from data as part of the research process.

Where authors use generative artificial intelligence (AI) and AI-assisted technologies in the writing process, authors should only use these technologies to improve readability and language. Applying the technology should be done with human oversight and control, and authors should carefully review and edit the result, as AI can generate authoritative-sounding output that can be incorrect, incomplete or biased. AI and AI-assisted technologies should not be listed as an author or co-author, or be cited as an author. Authorship implies responsibilities and tasks that can only be attributed to and performed by humans, as outlined in Elsevier’s AI policy for authors.

Authors should disclose in their manuscript the use of AI and AI-assisted technologies in the writing process by following the instructions below. A statement will appear in the published work. Please note that authors are ultimately responsible and accountable for the contents of the work.

Disclosure instructions

Authors must disclose the use of generative AI and AI-assisted technologies in the writing process by adding a statement at the end of their manuscript in the core manuscript file, before the References list. The statement should be placed in a new section entitled ‘Declaration of Generative AI and AI-assisted technologies in the writing process’.

Statement: During the preparation of this work the author(s) used [NAME TOOL / SERVICE] in order to [REASON]. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

This declaration does not apply to the use of basic tools for checking grammar, spelling, references etc. If there is nothing to disclose, there is no need to add a statement.

Submission declaration and verification

Submission of an article implies that the work described has not been published previously (except in the form of an abstract, a published lecture or academic thesis, see 'Multiple, redundant or concurrent publication' for more information), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder. To verify compliance, your article may be checked by Crossref Similarity Check and other originality or duplicate checking software.

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Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Content should make no assumptions about the beliefs or commitments of any reader; contain nothing which might imply that one individual is superior to another on the grounds of age, gender, race, ethnicity, culture, sexual orientation, disability or health condition; and use inclusive language throughout. Authors should ensure that writing is free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions. We advise to seek gender neutrality by using plural nouns ("clinicians, patients/clients") as default/wherever possible to avoid using "he, she," or "he/she." We recommend avoiding the use of descriptors that refer to personal attributes such as age, gender, race, ethnicity, culture, sexual orientation, disability or health condition unless they are relevant and valid. When coding terminology is used, we recommend to avoid offensive or exclusionary terms such as "master", "slave", "blacklist" and "whitelist". We suggest using alternatives that are more appropriate and (self-) explanatory such as "primary", "secondary", "blocklist" and "allowlist". These guidelines are meant as a point of reference to help identify appropriate language but are by no means exhaustive or definitive.

Reporting sex- and gender-based analyses

Reporting guidance

For research involving or pertaining to humans, animals or eukaryotic cells, investigators should integrate sex and gender-based analyses (SGBA) into their research design according to funder/sponsor requirements and best practices within a field. Authors should address the sex and/or gender dimensions of their research in their article. In cases where they cannot, they should discuss this as a limitation to their research's generalizability. Importantly, authors should explicitly state what definitions of sex and/or gender they are applying to enhance the precision, rigor and reproducibility of their research and to avoid ambiguity or conflation of terms and the constructs to which they refer (see Definitions section below). Authors can refer to the Sex and Gender Equity in Research (SAGER) guidelines and the SAGER guidelines checklist. These offer systematic approaches to the use and editorial review of sex and gender information in study design, data analysis, outcome reporting and research interpretation - however, please note there is no single, universally agreed-upon set of guidelines for defining sex and gender.

Definitions

Sex generally refers to a set of biological attributes that are associated with physical and physiological features (e.g., chromosomal genotype, hormonal levels, internal and external anatomy). A binary sex categorization (male/female) is usually designated at birth ("sex assigned at birth"), most often based solely on the visible external anatomy of a newborn. Gender generally refers to socially constructed roles, behaviors, and identities of women, men and gender-diverse people that occur in a historical and cultural context and may vary across societies and over time. Gender influences how people view themselves and each other, how they behave and interact and how power is distributed in society. Sex and gender are often incorrectly portrayed as binary (female/male or woman/man) and unchanging whereas these constructs actually exist along a spectrum and include additional sex categorizations and gender identities such as people who are intersex/have differences of sex development (DSD) or identify as non-binary. Moreover, the terms "sex" and "gender" can be ambiguous—thus it is important for authors to define the manner in which they are used. In addition to this definition guidance and the SAGER guidelines, the resources on this page offer further insight around sex and gender in research studies.

Author contributions

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Appendix H: Ethical Approval for Paper 2

Dear Andrew,

The Ethics Committee has considered your revised PG project proposal: Sexual Quality of Life in Skin Conditions (EC.22.04.26.6554R).

Your project proposal has received a **Favourable Opinion** based on the information described in the proforma and supporting documentation.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to psychethics@cardiff.ac.uk within three months of research project completion.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

Kind regards,
Deborah

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Appendix I: Information Sheet

School of Psychology, Cardiff University

Study: Sexual Quality of Life in Females with Skin Conditions

You are being invited to take part in a research project that is being undertaken as part of a Doctorate in Clinical Psychology. Please read the information below carefully before deciding whether to take part. If you have any questions, please contact the researcher.

Why is this study being done?

This study aims to find out about sexual quality of life in skin conditions and what people do to cope with their skin condition. We are interested in females as some research shows that females may be more vulnerable to deficits in some ways of coping. The findings of this study will help to further our understanding of sexual quality of life in skin conditions and may help to inform future psychological interventions.

Do I have to take part?

No, it is your choice whether to participate or not. You are able to change your mind and withdraw from the study at any time.

Am I eligible to take part?

You are eligible to take part if you identify as female, are aged 18 or over, are in a sexual relationship, have a skin condition and are proficient at reading the English language.

What will happen if I decide to take part?

Once you have read this information and decided that you would like to take part, click on the arrow below to find the consent form. Please read the information carefully and tick the box to confirm that you would like to take part.

You will then be asked to complete several questionnaires about your skin condition, sexual quality of life and coping. The study will take approximately 20 minutes to complete.

What are the possible disadvantages to taking part?

There are minimal anticipated disadvantages to taking part in the study. The study will take 20 minutes of your time. There is a possibility that it will be distressing to answer the questions. You are free to withdraw from the study at any time and details of organisations that can provide support will be provided at the end of the study.

What are the possible advantages to taking part?

You will have the opportunity to enter a prize draw for a £50 Love2shop voucher at the end of the study. Your participation will contribute to our knowledge of sexual wellbeing in skin conditions. To enter the raffle, you will be invited to complete a second, unrelated survey to enter your email address so that you can be contacted if you win. Your email address will be stored separately to your study data, and it will not be possible to link your email address to the information you provided. The raffle will be drawn once data collection is complete and the winner will be notified by email.

What will happen to the information that I provide?

All information that you provide will be anonymous and your data will not be able to be traced back to you.

The email address that you provide as part of the prize draw will be stored separately to the other information provided and will not be linked to your responses to the questionnaires. Once the prize draw is complete, your email data will be deleted. Personal data will be processed in accordance with GDPR regulations.

What will happen when the study ends?

The results of the study will be written up and submitted to Cardiff University in order to fulfil the requirements for a Doctorate in Clinical Psychology. A report may also be sent to a peer-reviewed journal for publication. You will not be identified in any publication or report that follows this study.

Who has reviewed the study?

This research study has been reviewed and approved by the School of Psychology Research Ethics Committee at Cardiff University.

If you have any concerns or complaints about the research, you can contact the School of Psychology Research Ethics Committee in writing at:
Secretary to the Research Ethics Committee
School of Psychology, Tower Building
70 Park Place, Cardiff, CF10 3AT
psychethics@cardiff.ac.uk

Contact Details

If you require any further information or have any questions, please contact:

Researcher	**Supervisor**
Zoe Hurrell Trainee Clinical Psychologist Email: hurrellz1@cardiff.ac.uk	Prof. Andrew Thompson Course Director, South Wales Doctoral Programme in Clinical Psychology Email: ThompsonA18@cardiff.ac.uk

South Wales Doctoral Programme in Clinical Psychology,
11th Floor, School of Psychology, Tower Building,
70 Park Place, Cardiff, CF10 3AT

Thank you for taking the time to read this information.

Appendix J: Consent Form

Cardiff University, School of Psychology

Study: Sexual Quality of Life in Females with Skin Conditions

This research study has been reviewed and approved by the School of Psychology Research Ethics Committee at Cardiff University.

If you have any concerns or complaints about the research, you can contact the School of Psychology Research Ethics Committee in writing at:
Secretary to the Research Ethics Committee
School of Psychology, Tower Building
70 Park Place, Cardiff, CF10 3AT
psychethics@cardiff.ac.uk

Please read the following statements. To complete the consent form, tick the box at the bottom of the page.

- I can confirm that I have read and understood the information sheet.
- I understand that participation in this study is voluntary and that I am free to withdraw from the study at any time without giving reason.
- I understand that I am free to ask questions at any time. I am free to discuss my concerns with the researcher (Zoe Hurrell hurrellz1@cardiff.ac.uk) and research supervisor (Prof. Andrew Thompson ThompsonA18@cardiff.ac.uk).
- I understand that my participation will involve answering questions about my skin condition, self-compassion, sexual quality of life, skin-related shame and coping styles and it will take approximately 20 minutes of my time.
- I understand that my participation is anonymous and no identifiable information will be collected.
- I understand that there is an opportunity to take part in a prize draw at the end of the study, the email address I provide will not be linked to my responses to the questionnaires and will be deleted once the prize draw is complete.
- I can confirm that I am over the age of 18.
- I agree to take part in the above study.

Please tick this box to confirm that you have read the above information and consent to taking part: ☐

Appendix K: Debrief Form

Cardiff University, School of Psychology

Study: Sexual Quality of Life in Females with Skin Conditions

Thank you very much for your participation in this study.

What was this study about?

The aim of this study is to investigate the relationships between sexual quality of life and the way people cope with their skin condition. We are interested in finding out how different ways of coping may impact quality of life. We hope that the results of this study will contribute to the knowledge around sexual wellbeing in skin conditions and inform the future development of psychological interventions for individuals with skin conditions.

What will happen to the data?

All the data you have provided is anonymous and cannot be linked back to you. The email address that you provide as part of the prize draw will be stored separately to the other information provided and will not be linked to your responses to the questionnaires. Once the prize draw is complete, your email data will be deleted. Personal data will be processed in accordance with GDPR regulations.

If you have any concerns or complaints about the research, you can contact the School of Psychology Research Ethics Committee in writing at:
Secretary to the Research Ethics Committee
School of Psychology, Tower Building
70 Park Place, Cardiff, CF10 3AT
psychethics@cardiff.ac.uk

Below are some organisations that may be able to offer support:

The Samaritans (www.samaritans.org)
The Samaritans is a national charity and the co-ordinating body for the 201 Samaritans branches across the UK. The Samaritans aims to help alleviate emotional distress and has a helpline which is open 24 hours a day for anyone in need.
Telephone: 08457 909090.

Skin Support – www.skinsupport.org.uk
Skin Support provides information on skin conditions and details of condition specific support groups can be found on the website.

If you have any further questions in relation to this study, please see below contact details:

Researcher	**Supervisor**
Zoe Hurrell Trainee Clinical Psychologist Email: hurrellz1@cardiff.ac.uk	Prof. Andrew Thompson Course Director, South Wales Doctoral Programme in Clinical Psychology Email: ThompsonA18@cardiff.ac.uk

South Wales Doctoral Programme in Clinical Psychology,
11th Floor, School of Psychology, Tower Building,
70 Park Place, Cardiff, CF10 3AT

Appendix L: Self-Compassion Scale

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never				**Almost always**
1	**2**	**3**	**4**	**5**

______ 1. I’m disapproving and judgmental about my own flaws and inadequacies.
______ 2. When I’m feeling down I tend to obsess and fixate on everything that’s wrong.
______ 3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.
______ 4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.
______ 5. I try to be loving towards myself when I’m feeling emotional pain.
______ 6. When I fail at something important to me I become consumed by feelings of inadequacy.
______ 7. When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.
______ 8. When times are really difficult, I tend to be tough on myself.
______ 9. When something upsets me I try to keep my emotions in balance.
______ 10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.
______ 11. I’m intolerant and impatient towards those aspects of my personality I don't like.
______ 12. When I’m going through a very hard time, I give myself the caring and tenderness I need.
______ 13. When I’m feeling down, I tend to feel like most other people are probably happier than I am.
______ 14. When something painful happens I try to take a balanced view of the situation.
______ 15. I try to see my failings as part of the human condition.
______ 16. When I see aspects of myself that I don’t like, I get down on myself.
______ 17. When I fail at something important to me I try to keep things in perspective.
______ 18. When I’m really struggling, I tend to feel like other people must be having an easier time of it.
______ 19. I’m kind to myself when I’m experiencing suffering.
______ 20. When something upsets me I get carried away with my feelings.
______ 21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.
______ 22. When I'm feeling down I try to approach my feelings with curiosity and openness.
______ 23. I’m tolerant of my own flaws and inadequacies.
______ 24. When something painful happens I tend to blow the incident out of proportion.
______ 25. When I fail at something that's important to me, I tend to feel alone in my failure.
______ 26. I try to be understanding and patient towards those aspects of my personality I don't like.

Appendix M: Sexual Quality of Life – Female Scale – REMOVED BY THE AUTHOR FOR COPYRIGHT REASONS

Appendix N: Skin Shame Scale

Here is a list of statements describing feelings and experiences about your skin that you may or may not have. Many people have had these feelings at some time while others will rarely or never have had these feelings. Please try to be as honest as you can in responding to each statement.

Please read each statement carefully and circle the number on the right that best describes how often it has applied to you over the last week.

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

1. I've learnt to live with my skin condition

2. I avoid looking at my skin the mirror

3. My skin looks unattractive

4. I avoid undressing in front of people

5. My skin condition rules my life

6. Others stare at my skin

7. My skin makes me different

8. My skin is beautiful

9. I avoid getting treatment for my skin

10. I am ashamed of my skin

II. I avoid socialising because of my skin

12. Hiding my skin makes me feel better

13. I worry how my skin looks to others

14. I find myself thinking about my skin

15. I am proud of my skin

16. I avoid discussing my skin

17. I believe that people accept my skin

18. I avoid intimate contact because of my skin

19. My skin is as attractive as other people

20. I avoid touching my skin

21. I can control my skin condition

22. I feel despondent about my skin

23. I feel good when people touch my skin

24. My skin condition is only one aspect of me

Appendix O: Brief COPE

The following questions ask how you have sought to cope with a hardship in your life. Read the statements and indicate how much you have been using each coping style.

I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1	**2**	**3**	**4**

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real.".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.

28. I've been making fun of the situation.

Appendix P: Coping Efficacy Scale

Please indicate how well you feel you have been dealing with the different aspects of your health condition in general by checking a box for each question.

	Strongly Disagree 1	**Disagree 2**	**Neither Agree nor Disagree 3**	**Agree 4**	**Strongly Agree 5**
a) I am successfully coping with the symptoms of my condition					
b) I am successfully coping with the day to day problems that living with my condition creates					
c) I am successfully coping with the emotional aspects of my condition					