

# A Qualitative Exploration of the Impact, Management, and Existing Psychological Support Available for Adults Living with Skin Conditions

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**Skin conditions carry a significant physical, psychological, and social burden. People with skin conditions often engage in health-threatening behaviours that can worsen symptoms and increase cardiovascular disease risk. However, access to dedicated psychological and behaviour-change support is limited. The impact, management, and existing psychological support available to adults living with skin conditions was qualitatively explored to inform the development of a psychologically supportive digital intervention. Qualitative research involving a hybrid inductive-deductive approach was performed. Data collection and analysis were theoretically informed by the Common-Sense Model of Self-Regulation. Eight synchronous online group interviews with 43 English-speaking adults (≥18 years) with a range of skin conditions were conducted. Data were analysed using Reflexive Thematic Analysis. Three superordinate themes are outlined: (i) visibility underpinning life course impairment, (ii) seeking control amid uncertainty, and (iii) existing support for people with skin conditions. Skin conditions carry a substantial psychological burden, yet dermatology service provision is sub-optimal and patients often resort to seeking support from unreliable sources. Psychological support can have benefits, but barriers exist. This study reinforces the need for high-quality psychological support, and that patients wanted digital means to support effective self-management.**

*Key words:* psychodermatology; qualitative research; self-management.

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**S**kin conditions carry a substantial burden for patients and their families, health services, and societies worldwide (1, 2). Physical, psychological, social, financial, and daily consequences are ubiquitous across common and rare skin conditions, yet the psychological consequences are most profound (3). Cumulative life course impairment (CLCI) describes the burden of health

## SIGNIFICANCE

This research investigated the impact of skin conditions, and what support is currently available. Online group interviews with adults who lived with a range of skin conditions revealed that skin conditions impacted all aspects of life, particularly for children and young people, and adults with late-onset conditions. Medical, psychological, and social support was limited. The few adults who had received psychological support explained its benefits. Most adults found patient organizations and online peer support helpful but were concerned about information quality. This study showed that adults need additional support to be able to live well with a skin condition.

conditions over time reported by dermatology patients (3–5). Despite this evidence of impact, there is a widespread and persisting lack of integrated, dedicated, psychological support within dermatology (6, 7). In addition, patients commonly report engaging in health-threatening behaviours, such as smoking and drinking alcohol (8, 9). These behaviours can trigger and worsen skin conditions (10, 11) and increase cardiovascular disease (CVD) risk (12). Behaviour change is important for managing skin conditions, but patients generally receive generic, often ineffective, lifestyle advice (13) and specialist support is limited (7). A new approach is needed to improve patient self-management.

Digital approaches are convenient for supporting people to self-manage their health (14, 15) and can improve health behaviours and quality of life (QoL) in people with CVD (16), diabetes, and asthma (17). Our systematic review found digital interventions in dermatology were mostly web-based and educational (18). They targeted specific conditions and treatment-related behaviours and improved some clinical and health outcomes (18). Other studies (19–22) also indicate the potential effectiveness of digital interventions in dermatology, but were not applied across skin conditions or to target health behaviour change. Whilst digital interventions may be acceptable to patients, barriers exist (18). New digital interventions targeting psychological processes, especially modifiable health behaviours, are needed in dermatology.

We are developing a complex behaviour change intervention for adults with skin conditions to be delivered via a new smartphone application (app) called MiDerm. As

qualitative research should inform intervention development (23, 24), we conducted this qualitative study aiming to: (i) understand the impact of skin conditions and their management; (ii) understand how adults currently self-manage skin condition(s); (iii) identify existing types of support currently available to adults with skin conditions beyond standard medical care.

## MATERIALS AND METHODS

### Design

Synchronous, online, semi-structured group interviews. Ethical approval was obtained (CU SREC: REC807).

### Participants

English-speaking adults ( $\geq 18$  years) living with a skin condition(s) with access to the internet.

### Recruitment

We advertised the study on social media (Twitter, Facebook, and Instagram) and through 5 patient organizations:

- International Alliance of Dermatology Patient Organizations (aka Global Skin).
- British Skin Foundation.
- Skin Care Cymru.
- Psoriasis Association UK.
- Eczema Outreach Support.

Participants were enrolled after completing registration and consent procedures online. To diversify the sample, we used demographic information to sample purposively thereafter. Recruitment ceased when no new information was emerging from the data.

### Materials

*Online registration form:* An online registration form was created using the Jisc Online Survey platform (see Appendix S1).

### Topic guide

A semi-structured topic guide explored the (i) impact and (ii) self-management of skin conditions, and (iii) existing types of support. Items were based on the study aims, the clinical and academic expertise of the research team, and the Common Sense Model of Self-Regulation (CSM) (25) to explore cognitive, emotional, and behavioural responses to skin conditions. The guide was reviewed by Patient and Public Involvement (PPI) contributors.

### Analytical framework of impact

Data were coded deductively using an existing analytical framework of condition impact, based on the CSM (25) and developed by 3 authors (RP, RH, CB). Two authors (RH and RP) piloted the analytical framework on 1 transcript initially. Discrepancies were resolved through discussion. The process was repeated on other transcripts until they were confident the framework was comprehensive and applied consistently.

### Procedure

Eligible participants were recruited between February 2022 and June 2022 and agreed a time and date for their group interview, plus joining instructions, via email. RH conducted and audio recorded

interviews via Zoom. Use of the 'raise hand' function and chat box were encouraged. Audio recordings were transcribed verbatim by an external transcription service.

### Analysis

Data collection and analysis were concurrent; emerging topics not covered in the original topic guide were incorporated and probed in later interviews. Anonymized transcripts were imported to NVivo 12 Pro (<https://lumivero.com/resources/free-trial/nvivo/>). Qualitative data were analysed using Reflexive Thematic Analysis (26) at the latent level from an essentialist/realist perspective to capture, contextualize, and critically interpret the participants' personal views, experiences, and ideas.

The lead author (RH) completed data familiarization and coding. One co-author (RP) independently coded a selection of transcripts and codes were compared to check for accuracy and consistency. Data were coded deductively to identify supporting concepts within the existing framework and inductively to capture other relevant information. Themes were derived and agreed by the research team.

Quantitative data from the online registration forms were imported to IBM SPSS Statistics 27 (IBM Corp, Armonk, NY, USA) and descriptive statistics were calculated describe the sample.

## RESULTS

A total of 43 people participated across 8 group (G) interviews. Most participants identified as female (69.8%), Caucasian (83.7%), and lived in England, UK (67.4%). The average age was 44.63 (SD=3.02). Common conditions included vitiligo (27.9%), psoriasis (25.6%), and types of ichthyoses (20.9%). Most participants were not affiliated with a patient organization (67.4%). The mean number of years lived with a skin condition was 28.02 (SD=15.92). Sample characteristics are presented in **Table I**.

Three themes were derived (see Table I, Table SI) and the relationships between these are depicted in Fig. S1:

1. Visibility underpinning CLCI.
2. Seeking control amid uncertainty.
3. Existing support for people with skin conditions.

### *Theme 1: Visibility underpinning CLCI*

Physical symptoms impacted sleep, mobility, and well-being. Participants reported that skin conditions challenged their self-image and led to feeling different from others, which was linked to social anxiety. Some described their appearance as "disgusting" (G7, ichthyosis, England) or "repulsive" (G8, vitiligo, England), illustrating low self-esteem.

... it had such great negative connotations for me and my self-image and my body image, which has led on to eating disorders, depression, PTSD ... It's a lot to do with wanting to disappear, not be seen, not wanting to be seen with the skin that I had. (G2, psoriasis, England)

Psychological impact was exacerbated by expressions of persistent public stigma, for example:

I literally saw the dermatologist this afternoon and he

**Table I. Sample characteristics of the sample**

Categorical demographic variable	
Gender, <i>n</i> (%)	
Male	13 (30.2)
Female	30 (69.8)
Ethnicity, <i>n</i> (%)	
White	36 (83.7)
South Asian	2 (4.7)
Other	5 (11.6)
New Zealand European/Pacific Islander	1 (2.3)
White and Southeast Asian	1 (2.3)
Anglo Caribbean	1 (2.3)
Mixed heritage	1 (2.3)
Indian	1 (2.3)
Skin condition, <i>n</i> (%)	
Psoriasis	11 (25.6)
Eczema	4 (9.3)
Vitiligo	12 (27.9)
Hidradenitis suppurativa	1 (2.3)
Pachyonychia congenita	1 (2.3)
Hyperpigmentation	1 (2.3)
Ichthyosis	9 (20.9)
Netherton syndrome	2 (4.7)
Ichthyosis vulgaris	2 (4.7)
Llamellar ichthyosis	2 (4.7)
Epidermolytic hyperkeratosis	1 (2.3)
Type not specified	2 (4.7)
Multiple skin conditions	4 (9.3)
Post-hypertrophic cystic acne scarring, hyperpigmentation	1 (2.3)
Seborrheic dermatitis, psoriasis	1 (2.3)
Seborrheic dermatitis, vitiligo, eczema	1 (2.3)
Acne, rosacea, hidradenitis	1 (2.3)
Country, <i>n</i> (%)	
England	29 (67.4)
Wales	9 (20.9)
Scotland	1 (2.3)
Ireland	1 (2.3)
USA	1 (2.3)
Denmark	1 (2.3)
Sweden	1 (2.3)
Patient organization member	
Yes	14 (32.6)
No	29 (67.4)
Continuous demographic variables, mean $\pm$ SD, range	
Age, years, mean $\pm$ SD, range	44.63 $\pm$ 13.02, 25–69
Years lived with condition	28.02 $\pm$ 15.92, 4–68

SD: standard deviation

called it [psoriasis] like asbestos on my scalp.... (G2, psoriasis, England)

Avoidant coping methods, including social withdrawal and covering and concealing the skin, were reported.

Persistent stigma led to consequences that continued throughout an individual's life. For example, some participants reported choosing not to pursue their preferred career because of their skin:

Um, I actually chose a job which was fully remote working, um because I felt like I couldn't cope with going into an office. (G5, psoriasis, England)

*Sub-theme 1.1: CLCI and vulnerable patient sub-groups.* For some, impact was more significant as a young person and lessened with time and acceptance, suggesting that young people may be more vulnerable to the impact of skin conditions.

I've had my skin condition for 20 years, give or take, and I would say now it doesn't affect me whatsoever. (G1, vitiligo, England)

Almost all the supporting quotes categorized under this sub-theme came from women, indicating female gender may be a risk factor for CLCI.

### *Theme 2: Seeking control amid uncertainty*

*Sub-theme 2.1: Limitations to people's understanding of causal factors.* Flares of psoriasis, ichthyosis, and eczema were attributed to stress, hormonal changes, chlorinated/salt water, and health behaviours. Whilst there is some evidence to support these triggers, there were also gaps in participants' understanding.

... looking at what makes it worse, or aggravates it. For me, those examples would be sort of stress.... I live with anxiety and certainly the two things completely go hand in hand. (G6, eczema, England)

... but up until this day, I don't know what the root cause is. (G1, eczema, Wales)

Symptoms were unpredictable. Female participants, for example, reported symptom changes during pregnancy and when using some types of contraception. This was linked to anxiety and sometimes influenced family planning decisions, demonstrating CLCI.

*Sub-theme 2.2: Regaining control through understanding, self-management and acceptance.* Unpredictability influenced self-management; participants described comprehensive skincare routines, gathering knowledge of self-management practices and engaging in health behaviours to exert personal control over symptoms.

I love to work out ... so getting in like my thirty minutes of working out or yoga and eating all the proper things that make me feel good, like inside of my body – and I also do feel like I help my skin somewhat. So, that's one. And then two is, managing my skin.... Um, if I didn't do those things [bathing and ear irrigation], if I didn't take care of my skin ... then I just ... I, I hurt. Like my skin doesn't feel great. (G3, lamellar ichthyosis, USA)

"Trial and error" (G7, ichthyosis vulgaris & psoriasis, England) approaches were common. Desperation drove some participants to try treatments and lifestyle changes, such as elimination diets, against official guidance.

Participants deemed self-acceptance necessary for living well with skin conditions and to interrupt the CLCI, but recognized that acceptance took time.

... I had to accept because I know that otherwise it ends up in a spiralling level of lack of confidence and low self-esteem and it is something that obviously I have to live with every single waking hour of my life.... (G8, vitiligo, England)

### *Theme 3: Existing support for people with skin conditions*

*Sub-theme 3.1: Provision and delivery of dermatology care.* Poor communication from healthcare professionals (HCPs) was a source of disappointment. Participants



reported that descriptions of incurability lacked sensitivity, and treatment decisions lacked the shared decision-making that they desired:

... it was the hardest thing hearing it from dermatologists, like there's nothing we can do... it was like just having a door close in your face, like there's no hope. (G1, vitiligo, England)

These experiences, combined with repeated treatment failures, eroded trust in the healthcare system resulting in individuals self-managing their skin conditions with little or no support:

I self-manage my condition completely ... which is because no one else can really do anything about it. (G7, pachyonychia congenita, Wales)

Perceived inequities in treatments and healthcare systems presented challenges in accessing effective treatments. Geographic constraints and long waiting lists reportedly limited access to health services. Participants were dissatisfied with dominance of the biomedical model and stepped-care approach:

... we know that GPs have to kind of go through first line, second line treatment, they have to kind of prove you failed them [laughs] you have to prove that you failed the previous treatments in order for them to consider referral.... So you have to faff around [laughs] for months and then they eventually say, "oh okay, I'll refer you to secondary care" ... he said it's almost no point referring because the waiting list is 12 months for my local dermatology service, so I just thought I'm going just, er, have to go privately unfortunately. (G8, multiple skin conditions, England)

*Sub-theme 3.2: Barriers to provision of psychological support.* Those who had accessed psychological support (including cognitive behavioural therapy, counselling, psychotherapy, and hypnotherapy) reported benefits, including changed perspective, improved emotional regulation, and practical coping techniques. One participant reported reduced disease activity following hypnotherapy.

However, despite the evident need, access to psychological support was limited:

Interviewer: just to clarify, so you've gone to your GP and Dermatologist, saying that you would like some support with your mental health, psychological health. Participant: Yeah.... No, it's very much "Oh why don't you try this cream?" or you know, like it's, it's a kind of, it goes down a medication route.... (G6, psoriasis, England)

Barriers to psychological support included inaccurate or stigmatizing beliefs around skin conditions or mental health, avoidant coping mechanisms, cost, and biomedical models of patient care:

It's never offered, because it's ... I think it comes under the lines of mental health.... But I don't think it's something that I would reach out to a doctor for, because if I can fix.... If my feet aren't bleeding, then I'm not in

that state of mind.... For me, if I was offered the support, I wouldn't take it anyway – mental support.... (G7, ichthyosis vulgaris & psoriasis, England)

*Sub-theme 3.3: Social support is important but limited.* Advantages and disadvantages of social support were discussed. Despite participants mentioning benefits including feeling known and understood, assistance with treatment, and creation of a safe space, they found social support from family and friends was limited by poor understanding of skin conditions:

... they say, oh no, what's wrong, what have you done to yourself? And all of a sudden you feel like you did when you were ten years old and you're different from everybody else (G5, psoriasis, England)

*Sub-theme 3.4: Poor awareness and understanding.* Skin conditions, and their psychological impact, were perceived to be poorly understood by both HCPs and the public. Common misconceptions caused distress (e.g., mistaking skin conditions for other illnesses, the perception that skin conditions are a result of poor hygiene).

Some participants saw themselves as experts in managing their skin condition, but not all shared this confidence. Poor understanding of skin conditions, comorbidities (including CVD), and triggers sometimes led to extensive online research. There were calls for more research and resources as well as public campaigns to increase understanding:

... I've had this [psoriasis] since I was seven, but I've only just realized that psoriasis has got a connection to people having heart attacks and problems with the heart – and it's like: "How has no-one ever told me?" (G1, psoriasis, England)

*Sub-theme 3.5: Peer support: a double-edged sword.* Peer support and patient organizations were valued for emotional and informational support. Many accessed peer support through social media platforms, mainly Facebook™:

I think the first time I spoke to someone, er, was in my thirties, who had vitiligo, I'd never seen anyone with vitiligo, so, it, it did a lot to boost my confidence, that this person, who had it much worse than I did, was coping. (G4, vitiligo, England)

However, poor regulation of information and lack of evidence-based guidance led some to be more sceptical:

So, yeah, just need to be aware, it just needs to be monitored, the people only share factual information and information that can't, wouldn't make somebody do it to burn their face and things like that, or skin, or anything. (G6, hyperpigmentation, Wales)

## DISCUSSION

Several aspects of current provision of dermatological care are problematic. Despite reporting difficulties with managing the psychological impact and asking for sup-

port, most participants reported not receiving psychological support. Poor awareness of available services, including NHS psychodermatology services, was a barrier to access. The few who had received psychological support reported benefits, but highlighted a lack of tailoring of the support to skin conditions.

Social support was also valued but often limited. Patient organizations and online patient groups were potential sources of support, but there were concerns over the quality, safety, and credibility of information shared.

#### *What this study adds*

These findings support research showing CLCI across dermatological conditions (3), highlighting vulnerable sub-groups who may have greater need of psychological support, including adults with late condition onset, children, and young people and females (4).

We found current care provision continues to follow the biomedical model (13) and dedicated and integrated psychological support in dermatology is still widely lacking (6, 7). Participants wanted to collaborate with HCPs (27) to identify suitable management approaches, but rarely had the opportunity to do so (28).

This study highlights the pros and cons of support from patient organizations and groups online. Whilst these may be helpful for self-management, online platforms need to be better regulated to protect patients from harmful practices (29).

Health-threatening behaviours can increase CVD risk in mainly inflammatory skin conditions (10, 11), yet qualitative exploration of patient understanding is limited. People with psoriasis (13) and parents of children with eczema (30) have reported low levels of knowledge and competence regarding the links between their condition, lifestyle, and comorbidity risk. Recent evidence shows digital psychological interventions can increase condition-specific knowledge in people with eczema (31). These data suggest that providing evidence-based information may motivate health behaviour change.

#### *Strengths and limitations*

Qualitative research is limited in dermatology intervention development (18, 23, 32). This study builds upon our previous research (18) and shows how using theory-informed qualitative methods can aid intervention development (33).

Six PPI contributors with eczema, rosacea, psoriasis, and X-linked ichthyosis supported recruitment and material design, ensuring relevance, appropriateness, and comprehensibility for the target population.

Use of online recruitment methods was cost-effective and increased global reach (34), although several suspicious requests for participation were received and identity validation was challenging, highlighting the need for better safeguarding (35). Use of non-probability

sampling may have introduced self-selection bias, with these participants being highly motivated to share their opinions (34). Over-representation of participants with vitiligo and psoriasis in the UK limited the transferability of these findings.

#### *Implications for research*

Female participants reported dermatology symptom changes during pregnancy and when using some types of contraception. More research is needed to produce evidence-based guidance on the relationship between female reproductive health and skin conditions, as this is currently limited to eczema (36) and epidermolysis bullosa (37).

Young people and adults with late condition onset may be in greater need of additional support. Research with these groups should inform dedicated interventions to support adjustment.

Despite the high prevalence of acne worldwide (38), recruiting from this population was challenging. Research involving people with acne is needed to ensure MiDerm is relevant to them.

#### *Practical implications*

These findings support the development of a new digital intervention for adults with skin conditions that includes behaviour change (6). The valued, and arguably under-recognized, role of dermatology patient organizations is highlighted. Increasing awareness of the benefits of psychological support could reduce stigma and improve patient engagement. Furthermore, this study emphasizes the almost complete lack of support for adults with skin conditions and strengthens existing calls for increasing psychology provision within dermatology (6).

It seems HCPs could benefit from additional training to address the psychological impact of skin conditions. The PsoWell™ training programme (39, 40) could increase clinical competency for breaking bad news, shared decision-making and addressing behaviour change.

#### *Conclusion*

Skin conditions carry a substantial psychological burden, yet current dermatology service provision does not address this. Psychological support can be beneficial, but barriers exist. Dedicated support delivered by qualified experts in psychology and dermatology is needed, as are tighter controls to regulate information online. New interventions are required to support effective self-management and these data support the development of MiDerm as a new digital tool.

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