

An analysis of qualitative responses from a UK survey of the psychosocial wellbeing of people with skin conditions and their experiences of accessing psychological support

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Summary

Background. Skin conditions have a large emotional, psychological and psychiatric impact on the individual. The All-Party Parliamentary Group on Skin (APPGS) commissioned a qualitative survey to further explore this relationship alongside the experiences of those accessing services in relation to these difficulties in the UK.

Aim. To examine the experiences of UK individuals living with a skin condition, and their views of seeking and receiving psychological treatment. This survey formed part of the evidence collected in the preparation of the APPGS Mental Health and Skin Disease report.

Methods. A free-text electronic survey was widely distributed by professional bodies and skin-related charities. Responses were analysed using descriptive thematic analysis and descriptive statistics. Data for each question were classified and labelled, leading to the development of a coding frame. Inter-rater reliability was assessed using Cohen kappa statistic.

Results. In total, 544 participants (84% female) completed the survey. The majority of respondents had inflammatory skin diseases such as eczema (43%) or psoriasis (33%). The thematic analysis revealed five key themes associated with impact on mood; impact of intimacy; impact on activities of daily living; lack of recognition from others of the impact; and lack of accessible services.

Conclusion. The survey demonstrates that there is an urgent need to improve both awareness of the impact that skin conditions can have, and for the provision of psychological services to address this impact.

Introduction

Living with a dermatological condition is associated with increased risk of experiencing psychological distress,¹ including increased levels of anxiety and depression,² which can adversely affect quality of life.³

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Studies have demonstrated that psychological distress can affect the perceived physical severity of a variety of skin disorders.¹ Cumulatively, these phenomena highlight the adverse and cyclical effect that living with a skin condition can have on an individual's mood and physiological wellbeing.⁴ Furthermore, these experiences often result in individuals adapting their behaviours and lifestyle, such as deploying avoidance-based coping, which can further perpetuate mental health difficulties.⁵

Currently there are only a small number of in-depth large-scale qualitative studies that have sought to describe the range of psychosocial experiences of those

living in the UK with skin conditions. There is also relatively little information on people's experience of seeking support for the treatment of such psychological impacts, which is an area of need as psychological interventions have shown to be beneficial in improving psychological outcomes for those with dermatological disorders.⁶

This project was commissioned by the All-Party Parliamentary Group on Skin (APPGS) to analyse data collected by the group's mental health committee, which elicited the views of members of the public living with skin disorders in the UK. The aim of this study was to analyse the data to explore the psychosocial impacts associated with skin conditions and to report respondents' accounts of seeking support.

Methods

Ethical approval for the study was obtained via Cardiff University's School of Psychology Ethics committee.

Study design

Cross-sectional survey methods were used, and the data were analysed using a descriptive version of thematic analysis.⁷ This specific form of inductive thematic analysis was selected because it best suited the aim of summarizing the qualitative responses and experiences, and thus is grounded in a critical realist approach.

Participants

The APPGS recruited respondents from the UK population via outreach to all relevant patient support groups (PSGs) and professional bodies that were known to the APPGS secretariat. The PSGs and professional bodies (including but not limited to the Psoriasis Association, National Eczema Society, Vitiligo Society, Ichthyosis Support Group, British Association of Dermatologists, British Skin Foundation, British Dermatological Nursing Group, and Primary Care Dermatology Society) circulated the questionnaire on their social media profiles.

The survey was open to individuals of any age. Participation was open only to respondents certifying that they lived within the UK, and all participants had to self-certify that they had been diagnosed with a skin condition at some time (even if the condition had been successfully treated or was in remission).

Survey

The survey was open between January and March 2020. The survey content was assembled by the

APPGS secretariat with the support of the group's Mental Health Committee and led by two of the authors (APB, ART). The survey included questions relating to: demographic information (sex, age, location); requests for information about the psychological, emotional and social experiences of living with a skin condition; feedback on the individual's knowledge of the services available offering psychological support; and feedback on their experiences of engaging in such psychological services. Further detail of the questions used within the survey can be found in Table S1.

Procedure

Invitations to participate in the survey were disseminated by the professional bodies and PSGs, via social media and the APPGS website. People viewing the survey were provided with additional information before choosing to give consent and complete the questions. Participants were provided with a debrief statement after completing the survey and were given information on sources of support should these be required.

Data analysis

Thematic analysis⁷ was used to identify themes within the data, and data analysis was completed via the process described in Table S2. Data were primarily analysed by one author (MJW) with additional analysis carried out by a second (SG) so as to examine inter-rater reliability. The analytical process was guided by another author (ART).

Results

This study extracted and analysed responses from 544 individuals; demographic characteristics are described in Tables S3 and S4. Inter-rater reliability of the codes was calculated using Cohen kappa (κ) statistic,⁸ and All questions were found to have adequate rates of inter-rater reliability ($\kappa > 0.6$) in relation to the developed codes. The coding process generated 5 superordinate themes and 12 subthemes (Table S5). Each theme was supported by illustrative quotes.

Theme 1: The adverse psychological impact of skin conditions

This theme encapsulated the psychosocial impact associated with skin conditions. When asked, 97.61% of respondents ($n = 530$) reported that their skin condition had affected their emotional wellbeing. Responses

indicated that this psychological impact was extremely significant:

It's honestly soul destroying, it destroys every part of you physically and mentally

[respondent with atopic dermatitis (AD)]

The chronic nature of many of the respondents' skin conditions appeared to exacerbate the impact.

I do not go a day without thinking or worrying about my skin conditions.

(respondent with eczema, hidradenitis suppurativa and seborrheic dermatitis)

Others reflected on their view of themselves and how living with a condition affected their self-worth and body image.

I feel so embarrassed to even go out, I feel I'm the ugliest.

(respondent with psoriasis)

This small box cannot begin to describe the sheer living hell of attempting to tear your own skin off.

(respondent with AD)

Theme 2: An obstacle to social and romantic intimacy

This theme captured the reported impact on both intimate and social relationships. Cumulatively, 72.88% of respondents ($n = 395$) reported that their condition had negatively affected intimate relationships.

There were two main subthemes noted within this higher order theme, (i) respondents actively avoiding relationships themselves, and (ii) respondents feeling that others avoided interaction and intimacy with them as a result of their condition.

I don't like to be touched as I feel they will be grossed out.

(respondent with psoriasis)

It's hard to let anyone love you, look at you, kiss you, etc when you feel and look disgusting.

(respondent with acne and rosacea)

Just the look of my skin is repulsive. I have been single for 5 years.

(respondent with cutaneous and systemic mastocytosis)

Indeed, some respondents described having had experience of being rejected when they had attempted to pursue intimate relationships.

...saying they wouldn't want children with me because they might have it.

(respondent with AD)

...felt unsure if I'd ever meet a man who would accept me, love me.

(respondent with psoriasis)

Some respondents reported having supportive relationships, nevertheless there was a sense of the fragility of this support for some or a sense that they were 'lucky'.

I'm lucky now that I have a supportive and accepting partner.

(respondent with psoriasis)

Theme 3: A barrier to everyday living and work

Perhaps in part due the psychological impact of the skin conditions, 87.48% of respondents ($n = 475$) reported that their condition had directly affected their social life and leisure activities, while 69.24% ($n = 376$) reported that it had affected work or education. In addition, 82.50% of respondents ($n = 448$) stated that it had affected their sleep.

The impact on quality of life was via avoidant coping, discrimination or direct physical limitation.

When it's bad [I] just want to hide as I feel everyone's staring.

(respondent with AD)

Constant fatigue makes productivity difficult, being unable to stop scratching long enough to actually perform a task.

(respondent with AD)

These barriers were reported as preventing some respondents from achieving their full educational potential or adversely affecting their career opportunities or options.

I was always in hospital as a child and missed a lot of school. I'm now in work but was unable to make grades to go to university.

(respondent with AD)

I have been laid off work due to health issues and do not have the confidence to discuss issues in interviews as it results in discrimination.

(respondent with psoriasis and urticaria)

In response to these barriers, respondents had changed their lifestyle and developed 'self-management strategies' to try and mitigate these difficulties.

Changes what you do, who you meet, opportunities you take, clothes you wear, you can never do anything spontaneously.

(respondent with psoriasis)

Theme 4: A lack of recognition, understanding and acceptance

A notable theme throughout was respondents' experiences of rejection from others, including a lack of understanding in relation to both the physical and psychological impact associated with living with a skin condition. 'Judgement from others' was often hypothesized by respondents to be a result of the lack of education about skin conditions.

The misinformation that acne is caused by being dirty fuelled the unsolicited advice I received that implied I had acne due to poor hygiene... fuelled the 'blame' culture of acne further and made me feel like it was my fault.

(respondent with acne)

Even when others were noted as being accepting of the respondent's skin condition, people were usually described as failing to fully empathize with the depth of the impact:

Other people say "it's not that bad, nobody will notice."
[However] People do notice and stare

(respondent with cutaneous mastocytosis)

although people want to be sympathetic, they really don't understand the impact

(respondent with AD, contact dermatitis and psoriasis)

This lack of understanding was not only reflected on in terms of peers and members of the public, but was also frequently reported during encounters with medical professionals.

Theme 5: A demand for the clinical recognition of the psychological impact and the lack of available and appropriate psychological support

A lack of understanding and recognition from medical professionals, particularly in relation to the severity of psychological impacts were frequently referenced.

I've never felt properly supported by dermatologists, as they're only interested in treating physical symptoms, and not the emotional difficulties attached.

(respondent with psoriasis)

Very little support in my area for psychological services. All they offer is anti-depressants.

(respondent with AD and contact dermatitis)

When asked if they were aware of the availability of specialist psychological services within the NHS in the UK, 86.48% ($n = 467$) responded reported they were not.

I spoke to my GP about this about 12 months ago and asked for psychologist support. But have had no support and there is no record of me asking in my medical records.

(respondent with AD, contact dermatitis and psoriasis)

I have not been made aware of any psychological support by the NHS. I have broken down in tears at so many of my appointments. Why are they not offering this support?

(respondent with psoriasis)

Even though I (a man in his fifties) [have] burst into tears several times, I've never been offered the support I need.

(respondent with Gorlin syndrome and nonmelanoma skin cancer)

I wasn't offered any other route. When I asked my dermatology nurse for help, she was rude and dismissive.

(respondent with psoriasis)

Many that had received support emphasized that the service they received was not helpful, appropriate or relevant to their needs:

[I received] two sessions then was told nothing could be done. Told me to find a non-sexual relationship.

(respondent with lichen sclerosus)

My GP referred me to my local NHS well-being service; however, this was very generic and did not specialise in skin so it was mostly irrelevant and did not help me.

(respondent with AD)

[I was] only seen once, it seemed they were just ticking a box, this is not good enough

(respondent with AD and psoriasis)

Cumulatively, respondents felt that there needed to be more recognition and formal psychological support available.

We need more information about the help that is available, and greater understanding from GPs and not just another tub of cream to try and send you away.

(respondent with psoriasis and rosacea)

Take these comments seriously. Do not dismiss as a small patch [of] dry skin, many conditions can be all over debilitating both physically and emotionally.

(respondent with ichthyosis)

When empathic and person-centred support was available (6.99% of the entire respondents, $n = 38$), the psychological effects were reported to be minimized.

My psychologist was amazingly understanding, where I felt I was drowning she offered me a window of hope, a small solution to each aspect that was affecting me, and showed me a way out.

(respondent with psoriasis)

Discussion

This study highlights the adverse effect that living with a skin condition can have on an individual's psychological wellbeing and social interactions, which is often perpetuated by the experience of stigmatization and judgement from others. Cumulatively, these experiences reportedly result in changes to views of self, as well as adaptations being made to behaviours and/or lifestyle. These findings align with the findings of existing research.¹

A notable finding of this study was the prevalence of the number of respondents (5.33%, $n = 29$) who either referenced suicidal ideation directly or alluded to desires to end their life as a result of their experience of living with a skin condition. This finding is significant as none of the questions specifically asked about suicidal tendencies, and therefore these reports

were raised by respondents independently without prompting.

Another key issue highlighted within the responses to the survey was a general sense that the respondents felt that their needs and issues were not well understood from either other members of society or by healthcare professionals (HCPs). Furthermore, respondents reported that there was a lack of appropriate psychological support available, and they emphasized how progress needs to be made to develop such services and the awareness of medical professionals in relation to the psychological impact associated with skin conditions. These findings indicate that despite the growth in general psychological services within National Health Service provision,^{9,10} significant gaps remain for people experiencing distress associated with skin disease. Within the findings it was positive to note that there were a small number of respondents who reported having had positive experience of receiving support. This finding is supportive of previous research,⁶ giving evidence that when available and appropriately delivered, psychological support for skin conditions can be beneficial in improving such outcomes.

This study has a number of limitations. The survey specifically sought views on psychological distress and service use, and thus may have attracted participation from people experiencing particularly high levels of psychological distress. Further, as 84% of the respondents were women, the findings may not be applicable to men. This is not untypical of psychological studies that tend to struggle to recruit men, and this may in part be reflective of cultural barriers to expressing distress or/and seeking assistance. Clearly, future surveys need to purposively seek to capture and understand the barriers faced by men in both accessing mental health services and participating in research. In addition, 46% of the respondents were in the age group 25–44 years, with 43% and 32% of respondents having AD and psoriasis, respectively; as a consequence, our findings have greater relevance to this age group of adults with inflammatory skin disease, and may be less applicable to other conditions and age groups. Finally, the themes highlighted in this review are based on the APPGS initial questions and our interpretation of the responses received. Therefore, there is the potential for subjective bias in interpreting the responses. However, this risk was reduced by the use of dual coders and the calculation of inter-rater reliability. In addition, our aim was not to quantify the level of psychological distress present but rather to

provide affected individuals with the opportunity to describe the impact.⁸

Conclusions

Psychosocial comorbidities for skin disease are common. Our study has shown that patients with psychosocial comorbidities may express their concerns to HCPs, but HCPs are usually not proactive in enquiring about psychosocial comorbidities during consultations. Where access to psychodermatological interventions is facilitated, patients report benefit in their physical and psychological well-being. More often, patients are either unaware or are not engaged in psychological co-management of their skin disease and its psychosocial comorbidities. HCPs need to become better at assessing, sign-posting and managing the psychosocial comorbidities of skin disease.

What's already known about this topic?

- It is well established from qualitative studies and questionnaire-based surveys that skin conditions can have an impact on psychosocial functioning.
- Previous reports and surveys indicate that there is potentially a high level of unmet need.

What does this study add?

- This is the first large free text qualitative survey of people with skin conditions examining their psychosocial concerns and experience of seeking support in the UK.
- The survey identified five main themes associated with impact on mood; impact of intimacy; impact on activities of daily living; lack of recognition from others of the impact; and lack of accessible services.

Conflict of interest

SG is employed as a Secretariat of the APPG on Skin; ART is an unpaid psychological advisor to the APPG on Skin and APB is an unpaid psychological advisor to the APPG on Skin.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Survey questions.

Table S2. Process of completion for the discussed thematic analysis.

Table S3. Participant demographics (gender, age and area of residency) ($n = 544$).

Table S4. Frequency of different skin disorders within the sample ($n = 544$).

Table S5. Survey themes.