

Perspective on Living With a Skin Condition and its Psychological Impact: A Survey

Journal of Patient Experience
2019, Vol. 6(1) 68-71
© The Author(s) 2018
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2374373518774397
journals.sagepub.com/home/jpx



A Kanji, MBBS, PhD, MRCP¹

Abstract

Background: Chronic skin conditions can have a profound impact on people's lives, both physically and psychologically, and may predispose to mental health disorders. Providing sufferers with appropriate psychological support is important. **Objective:** In this study, we captured the views of people suffering from a chronic skin condition who were attending the "Skin Matters" conference, held on 20 May 2017, in London. **Methods:** Delegates were provided with a 5-point questionnaire to complete. Questions related to the impact of their chronic skin condition on their life, the nature of any psychological support they had found helpful and whether they felt they could benefit from greater support in managing their condition. **Results:** 59% of the delegates completed the questionnaire. The survey results showed that skin conditions can have an impact of many areas of daily living as well as on mental well-being. The most popular source of psychological support was the Internet. The majority of survey participants felt they would benefit from increased psychological support in managing their condition. **Conclusions:** In the United Kingdom, there is a need to improve the availability of resources for people/patients with skin conditions in order to provide better support.

Keywords

patient perspectives/narratives, patient satisfaction, quality of life, survey data

Introduction

Chronic skin conditions, such as eczema and psoriasis, are common. Since these are not life-threatening, the substantial psychological and social impact of living with a skin condition may be overlooked or underestimated. Up to 85% of dermatology patients report that the psychological aspect of their skin disease is a major component of their illness (1) and suicidal ideation has been reported to be higher amongst those living with a skin disease (2).

In the UK National Health Service, dermatology is a specialty that has been adversely affected by government reforms. There is shortage of dermatologists with only 650 consultants covering the United Kingdom, with long wait times for patients to be seen in dermatology outpatient clinics; up to 5 months in England and 2 years in Wales (3). Providing psychological support is an important component of managing chronic skin disease and providing holistic care to patients. Unfortunately, resources for this are inadequate. The UK All Party Parliamentary Group on Skin published a report in 2003 (2), highlighting the substantial impact of skin diseases on people's lives and the lack of adequate resources to provide appropriate psychological and social support. An updated report, published 10 years after the initial report, highlights

that there has been insufficient progress in improving this in the past 10 years (4).

To our knowledge, the first conference aimed at people (or patients) with chronic skin conditions was held in London in May 2017. We have taken this opportunity to explore the experiences of the delegates, each of whom has a skin condition. In particular, our aim was to better understand the psychological burden associated with their disease and sources which they found helpful in providing psychological support.

Methods

An independently organized 1-day conference titled "Skin Matters" was held at The Wellcome Institute in London, United Kingdom on May 20, 2017. This was advertised on the Internet and on social media sites (Facebook, Twitter, and Meetup) and

¹ Department of Dermatology, The Royal Free Hospital, London, UK

Corresponding Author:

A Kanji, Department of Dermatology, The Royal Free Hospital, Pond Street, London NW3 2QG, United Kingdom.
Email: alpa.kanji@gmail.com



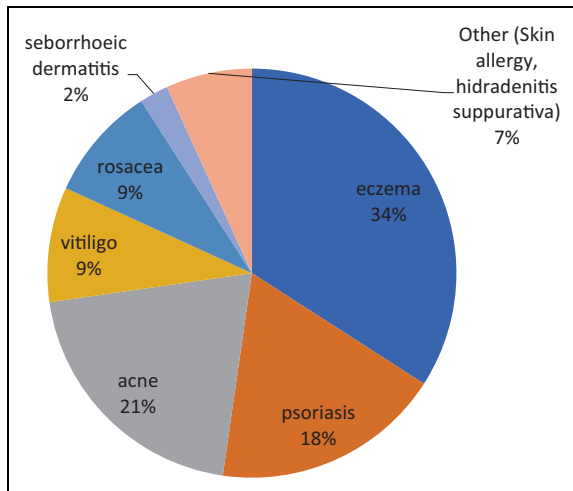


Figure 1. Skin conditions of survey participants.

via the distribution of flyers. The conference consisted of several talks given by a range of speakers such as dermatologists, dermatology nurses, and nutritional therapists. The subjects covered were wide ranging and all concerned with managing a skin condition; from conventional aspects such as emollient use, to more holistic topics such as mindfulness and nutrition. Delegates with a skin condition were issued with a 5-question survey (Supplemental Appendix 1). Those who did not have a skin condition and were not based in the United Kingdom, were excluded. Questions were concerned with how participants felt that their skin condition impacted both their daily activities and emotional state, the types of psychological support they had found to be helpful and whether they felt they would benefit from more psychological support in managing their condition. Answers were in multiple-choice format but included areas where free text could be written. Responses were anonymized.

Results

Of the 75 delegates, 44 completed the questionnaire (59% response rate). The majority of respondents were female (83%) and aged 18 to 30 years old (45%). Collectively, the survey participants reported having a range of skin conditions with over half having psoriasis or eczema (Figure 1). Many aspects of daily life were noted as being affected with the most common being mood (21%) and stress levels (21%), followed by relationships (14%), sleep (13%), hobbies (12%), work (11%), and diet (8%) (Figure 2). Feelings evoked by their condition were: a low or bad mood (31%), embarrassment or self-consciousness (31%), worry/anxiety (19%), social isolation (12%), and that life is not worth living (6%) (Figure 3). Free-text responses were found to have some common themes. Several stated that their confidence was adversely affected and that the skin condition made the sufferer feel less attractive and embarrassed: “affects (my) confidence and ability to reveal affected areas of skin” and “feeling embarrassed as constantly scratching.” A respondent noted that feelings of isolation were evoked: “have found condition very isolating

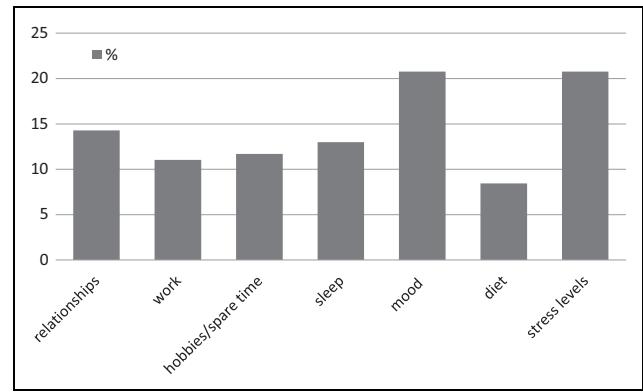


Figure 2. Aspects of life impacted by chronic skin conditions.

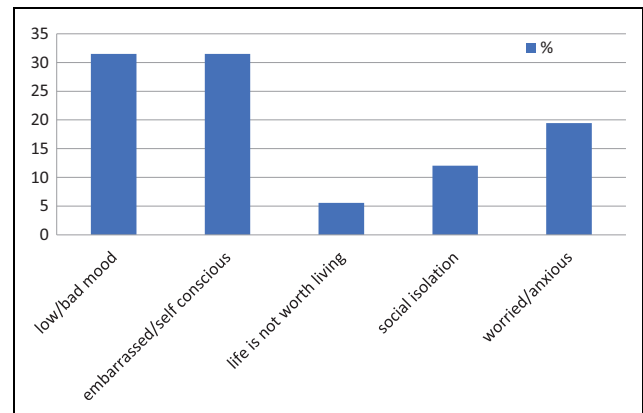


Figure 3. Emotions associated with skin conditions.

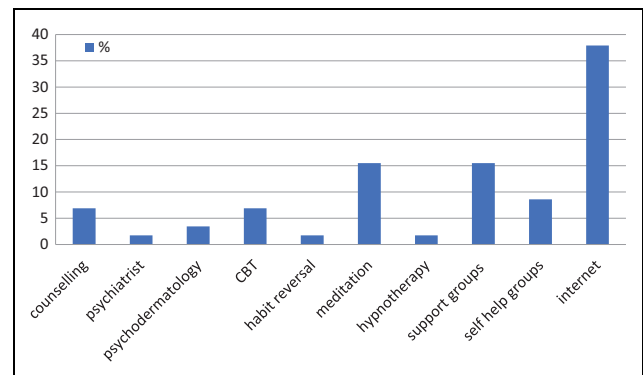


Figure 4. Sources of psychological support.

as don’t know anyone with dark skin with the same skin condition.”

A variety of resources were noted to be helpful in providing psychological support, the most common being the Internet, followed by self-help groups and meditation (Figure 4). The majority of respondents (77%) felt that they would benefit from more psychological support in helping to manage their condition, the nature of which some elaborated on. Access to support groups was desired: “a support group (would be helpful) so that I can meet other people with vitiligo.” Cognitive behavioral therapy (CBT) and habit

reversal were mentioned as therapies patients felt would be useful. A participant noted that help should be more readily available: “psychodermatology, CBT, and counselling should be easier to access for acne sufferers.”

Discussion

This study provides a snapshot of the perspectives of a cohort of people suffering from a range of skin conditions. The survey results show that skin disorders have a profound impact on the sufferer, affecting almost all aspects of daily life. Furthermore, they show that skin conditions can have a serious effect on psychological well-being, to the extent of making the sufferer feel as though life is not worth living. These findings suggest that psychological comorbidity is common and can have serious effects, which is in keeping with previous studies. Furthermore, negative emotions caused by a skin condition can in turn exacerbate skin disease, creating a vicious cycle of positive feedback (5). Dalgard et al. report that a significant number of patients with skin conditions are clinically depressed and anxious and that this burden is grossly underestimated by dermatologists in Europe (6). Providing appropriate psychological support is important given that skin disease can increase the risk of mental health disorders. A substantial majority of survey participants (77%) felt that they would benefit from greater psychological support.

Psychodermatology is considered to be a joint approach of psychologists, psychiatrists, and dermatologists, supporting those with mental health issues secondary to a skin condition, as well as those with a primary psychiatric condition associated with a skin disease (7). Approximately, a third of survey participants had utilized psychiatry, counselling, CBT, and habit reversal, all of which can fall under the broad umbrella of psychodermatology. This multidisciplinary approach is considered to be associated with better outcomes than medical treatment alone and deemed to be more cost-effective (7). Service provision is significantly under resourced, with only 3/127 hospitals reported as having a dedicated psychodermatology service in 2013 (4).

The Internet was reported as the most popular source of psychological support. This may be reflective of the fact that this conference was advertised via the Internet and social media sites and also related to the age of participants, the majority being under 30 years old. The number of dermatology Internet sources has grown exponentially over the years, with more individuals now seeking advice about dermatological issues on the Internet (8). Websites may be readily available and rich in information, which may be used to educate the reader and to share experiences with others. An example of this is the “Skin Support” website, produced by the British Association of Dermatologists (9), which aims to provide emotional support to sufferers of skin conditions by providing useful information such as details of self-help groups. Clinicians may not be aware of this website, and therefore, patients are not routinely referred to it. Social media sites may

connect sufferers to others thus providing emotional support or practical advice, reducing feelings of isolation and enabling experiences to be shared. Indeed, Facebook was noted by one of the survey participants as being helpful.

Self-help groups were another popular source of psychological support. They can provide excellent advice and information, opportunities to contact others with the same condition and therefore alleviate feelings of isolation and embarrassment. Clearly, such groups have an important role to play in supporting those with skin conditions. Interestingly, meditation was noted as being helpful by 16% of respondents. There are studies which suggest that techniques such as mindfulness-based stress reduction meditation can help sufferers cope more effectively with their chronic skin condition (10). Use of mindful meditation was reported to have a positive impact on patients with psoriasis undergoing phototherapy who required substantially less ultraviolet radiation exposure compared to those only receiving phototherapy (11).

Conclusion

This study is limited both in terms of the number of participants and their demographic, given that the conference was advertised mainly on the Internet/social media and was held in London. However, it has provided a brief but useful snapshot on how sufferers live and cope with their skin condition. It is important for all clinicians to be aware of the psychological consequences of living with chronic skin conditions and to be able to assist people in managing these. The responses we have received to our survey demonstrate the profound psychological impact of a chronic skin condition with sufferers experiencing social isolation, embarrassment and a loss in confidence, as well as feeling as though life is not worth living.

There are a number of approaches/tools that participants of this study reported as finding valuable, including the Internet, support groups and meditation. However, there is clearly a need for greater support which suggests that either the existing resources are inadequate; there is a lack of awareness of these or insufficient access to them. Here, participants mentioned several therapies/tools which they would like to have made available to them including support groups, counselling, and CBT. It may be that there is a lack of the available support groups for certain conditions or that patients may be unaware of their existence. CBT and counselling can provide a forum for patients to help them to deal with associated negative emotions, but these are not routinely available. Psychodermatology, specifically targeted at patients with skin conditions, is under resourced in the United Kingdom and therefore may be difficult to access. Further research is needed on the efficacy of tools such as meditation which could be recommended to patients.

In summary, there are a range of methods which could be further developed or made more accessible to help sufferers deal with the immense burden of their chronic skin condition, as there is clearly a need for improved support.

Acknowledgments

Many thanks to Lotte Bateson, organizer of the Skin Matters conference, for her support with this study and to all the participants who completed the survey.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Supplemental Material

Supplemental material for this article is available online.

References

1. Marshall C, Taylor R, Bewley A. Psychodermatology in clinical practice: main principles. *Acta Derm Venereol.* 2016;96:30-34.
2. All Party Parliamentary Group on Skin (APPGS). Enquiry into the Impact of skin diseases on People's lives. 2003. <https://www.appgs.co.uk/publications/>. Accessed April 2018
3. The Guardian. It took my patient six years to see me- a dermatologist. 2015. <https://www.theguardian.com/healthcare-network/views-from-the-nhs-frontline/2015/oct/19/patient-six-years-see-dermatologist-nhs-crisis>. Accessed April 2018.
4. All Party Parliamentary Group on Skin (APPGS). The Psychological and Social Impact of skin diseases on People's lives. 2013. <https://www.appgs.co.uk/publications/>. Accessed April 2018
5. Fried RG, Gupta MA, Gupta AK. Depression and skin disease. *Dermatol Clin.* 2005;23:657-64.
6. Dalgard FJ, Svensspn A, Gieler U, Tomas-Aragones L, Lien L, Poot F, et al. Dermatologists across Europe underestimate depression and anxiety: results from 3635 dermatological consultations. *Br J Dermatol.* 2017;179:464-47.
7. Bewley A. The neglected psychological aspects of skin disease. *BMJ.* 2017;358:j3208
8. George DD, Wainwright BD. Dermatology resources on the internet. *Semin Cutan Med Surg.* 2012;31:183-90.
9. British Association of Dermatologists. Skin support. <http://skin.support.org.uk/>. Accessed April 2018.
10. Niazi AK, Niazi SK. Mindfulness-based stress reduction: a non-pharmacological approach for chronic illnesses. *North Am J Med Sci.* 2011;3:20-23.
11. Kabat-Zinn J, Wheeler E, Light T, et al. Influence of a mindfulness meditation – based stress reduction intervention on rates of skin clearing in patients with moderate to severe psoriasis undergoing phototherapy (UVB) and photochemotherapy (PUVA). *Psychosom Med.* 1998;60:635-32.

Author Biography

A Kanji is a clinical fellow at the Department of Dermatology at The Royal Free Hospital, London, United Kingdom.