Open access Original research

BMJ Open 'Not just a piece of skin in front of you' - a qualitative exploration of the experiences of adolescents with eczema and psoriasis with healthcare professionals

Isabella Joy de Vere Hunt , Abigail McNiven, Amanda Roberts, Himesh Parmar. 4 Tess McPherson 5

To cite: de Vere Hunt IJ. McNiven A, Roberts A, et al. 'Not just a piece of skin in front of you'-a qualitative exploration of the experiences of adolescents with eczema and psoriasis with healthcare professionals. BMJ Open 2021;11:e041108. doi:10.1136/ bmjopen-2020-041108

Prepublication history and additional materials for this paper is available online. To view these files, please visit the journal online (http://dx.doi. org/10.1136/bmjopen-2020-041108).

Received 30 May 2020 Revised 12 December 2020 Accepted 17 December 2020



@ Author(s) (or their employer(s)) 2021. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by

For numbered affiliations see end of article.

Correspondence to

Tess McPherson: Tess.McPherson@ouh.nhs.uk

ABSTRACT

Background There is little qualitative research in the UK focussing on adolescents' experience of their healthcare providers, and inflammatory skin conditions are a common heath problem in adolescence.

Aim To explore the experiences of adolescents with eczema and psoriasis with healthcare professionals, and to distil the participants' key messages for their healthcare

Design This is a secondary thematic analysis of interviews with adolescents with eczema or psoriasis. Participants There were a total of 41 text transcripts of interviews with young people with eczema or psoriasis who had given permission for secondary analysis; 23 of the participants had eczema, and 18 psoriasis. Participants were living in the UK at time of interview, and aged 15-24 vears old.

Results We have distilled the following key messages from young people with eczema and psoriasis for healthcare providers: (1) address the emotional impact; (2) give more information, with the subtheme and (3) appreciate patient research. We identified the following eczema-specific themes: (ECZ-4) 'It's not taken seriously': (ECZ-5) offer choice in treatment and (ECZ-6) lack of structure/conflicting advice. Two psoriasis-specific themes were identified: (PSO-4) feeling dehumanised/treat me as a person; and (PSO-5) think about how treatments will affect daily life.

Conclusion This qualitative data analysis highlights the need for greater recognition of the emotional impact of skin disease in adolescence, and for more comprehensive provision of information about the conditions. We call for greater sensitivity and flexibility in our approach to adolescents with skin disease, with important implications for healthcare delivery to this group.

INTRODUCTION **Background and rationale**

Inflammatory skin conditions represent a common heath problem in adolescence. Atopic dermatitis (AD) affects up to 20% of children, and recurs or continues into

Strengths and limitations of this study

- Our study's qualitative methodology enables the direct utilisation of patients' own opinions recorded in in-depth interviews to help us to improve 'patientcentredness' in our healthcare delivery for adolescents with inflammatory skin conditions.
- Our multidisciplinary team, consisting of two expert patients, an experienced qualitative researcher who conducted the original patient interviews, a clinician with formal training in qualitative research methods and a senior Consultant in Paediatric and Adolescent dermatology enabled a rigorous analysis with a diverse range of perspectives.
- The interviewer was an expert qualitative researcher and not a clinician, which may have enabled participants to give more candid accounts without fear of causing offence or affecting their care.
- There is a potential selection bias since those who agreed to participate are more likely to be actively engaging with their skin condition or more reflective on its emotional impact. The diverse sampling matrix and extensive and varied recruitment strategy helped to mitigate this.
- Limitations of all secondary analyses apply, with no scope to conduct additional interviews to explore arising themes or to probe certain topics further within an interview. However, these interviews provided rich data on participants' experiences of healthcare professionals, with data saturation reached for our themes of interest.

adolescence for a significant proportion of young people. In a large prospective cohort study in Germany, Peters et al found that AD persisted in 47.6% of adolescents (age 16-20 years in their cohort) with AD symptoms at their baseline survey (age 9–11). The UK prevalence of psoriasis is estimated at 1.37% in people aged 10–19 years old, with 30%-50% of adults with psoriasis developing

the condition before the age of 20.⁴ The psychological impact of conspicuous skin conditions on adolescents is well documented.⁵ Higher rates of anxiety and depression are reported in patients with skin conditions, with lifelong cumulative effects more severe in those who develop these in adolescence.⁶ The recent All-Party Parliamentary Group on Skin report addresses the mental health impact of skin disease, and highlights the 'alarming lack of psychological support available to people living with a skin condition', with an urgent call for improvement of psychological services for those living with skin disease.⁷

Historically, adolescents have been largely overlooked by healthcare policy on the assumption that they are a healthy population group who rarely present to medical services. However, data suggest that young people do regularly access healthcare services⁸ and consistently report poorer experiences of NHS care.⁹ The Department of Health and Social Care identified the specialised healthcare needs of adolescents as a key priority.¹⁰ In the context of skin disease, the transitional period of adolescence, during which an individual learns to take responsibility for their medical condition, carries the additional burden of affecting appearance at a time when 'self-image' is already vulnerable.¹¹

Previous qualitative research in Australia exploring the experiences of patients with skin conditions in their relationships with their doctors revealed high levels of dissatisfaction (sample age range 13–73 years). 12 However, there is little qualitative research in the UK focussing on adolescents' experience of their healthcare providers. Furthermore, we advocate identifying the features that adolescents themselves highlight as important, to help improve 'patient-centredness',13 in healthcare delivery. Qualitative interviewing enables the collection of rich data that cannot be captured in surveys or observational work. Secondary analysis of existing qualitative data is an effective and efficient way of maximising knowledge derived from lengthy interview data. 14-16 Secondary analysis in this context is particularly pertinent as adolescents are typically a hard-to-access group in medical research.¹⁷ We carried out a structured secondary analysis of existing high-quality qualitative interview data with adolescents with eczema or psoriasis.

METHODS

Design and data collection

This is a secondary inductive thematic analysis of 41 in-depth semistructured interviews with participants with eczema or psoriasis. The original data were collected by qualitative researchers AMN (40 interviews) from the Medical Sociology and Health Experiences Research Group (MS & HERG) at the University of Oxford, and Ulla Räisänen (one interview) formerly of MS & HERG. The interviews were part of a wider study funded by the National Institute for Health Research (NIHR), Research for Patient Benefit programme (Grant Reference Number: PB-PG-0213-30006). The aim of the original

project was to explore the health experiences of young people with four common skin conditions (acne, eczema, psoriasis and alopecia) to identify their information and support needs. A sampling matrix was devised to facilitate a diverse recruitment sample. 18 Participants were recruited from general practice (GP) surgeries, dermatology departments, social media, dermatology charities' mailing lists, schools and universities. In total, 97 semistructured interviews were conducted by AMN (96 interviews) and Ulla Räisänen (one interview) with young people aged 13-25 years in England between October 2014 and December 2015. Each interview lasted approximately one to 1-2 hours. Twenty four interviews were with young people with eczema, and 18 with young people with psoriasis. All but one interviewee (a participant with eczema) consented to secondary analysis. Interviews were transcribed verbatim and checked by participants for accuracy. The University of Oxford, which holds copyright for the interviews, has given data sharing permission to enable this secondary analysis. All interviews were anonymised by MS & HERG, by removal of identifying names and places, prior to data sharing for the secondary analysis.

Further information about recruitment and data collection can be found in the paper by McNiven. ¹⁸ Video, audio or written extracts from the interviews are available online on Healthtalk.org. ¹⁹

Analysis

There were a total of 41 text transcripts of interviews with young people with eczema or psoriasis who had given permission for secondary analysis; 23 of the participants had eczema, and 18 psoriasis. Author IJdVH. undertook a qualitative thematic analysis on the full interview transcripts, using a constant comparison and mind-mapping approach.²⁰ The qualitative analysis software NVIVO 12 was used to manage and code the interview data. There was no preidentified theoretical framework; all codes were derived directly from the data. The whole interview transcripts were analysed, which included a concluding question asking the participant if they had any messages they would like to give to healthcare professionals. IJdVH. first completed data immersion by reading the full transcripts. The eczema and psoriasis transcripts were separated and each had their own coding framework to prevent projecting experiences of one condition onto the other. A draft coding manual was then developed and discussed with AMN, and modifications made to the coding manual. Once data coding was complete, the analysis team (all authors) discussed the proposed themes from the codes derived from the data. Contradictions and 'negative cases' were actively sought, and data saturation of the principle themes achieved, as demonstrated by increasing overlap and redundancy with issues raised by participants. Triangulation within our multidisciplinary team (two expert patients; an experienced qualitative researcher who conducted the interviews; a clinician with formal training in qualitative research methods and



a senior Consultant Paediatric Dermatologist with qualitative experience) provided different perspectives to expand our understanding of the data. The Standards for Reporting Qualitative Research guideline²¹ was followed in the write-up process.

Patient and public involvement

Two expert patients (HP and AR) are coauthors on this paper; they were keen to be involved because the original project of which they were a part had generated such rich data for service delivery. HP was also a study participant for the original project. They were involved through telephone and email discussions in the planning of the secondary analysis, the analysis process and the critical revision of the piece. The patients' views and experience were taken into account for this secondary analysis as equal members of the multidisciplinary team at all stages. Dissemination plans have been shaped by the patients' knowledge of service delivery, and they intend to actively promote the results to patient organisations via social media.

RESULTS

Of the 23 participants with eczema, 17 were female and 6 male. The mean age was 20.5 years (range 17-24 years old), with a mean of 17 years since diagnosis. Of the 18 participants with psoriasis, 11 were female and 7 male. The mean age was 20 years, with a mean of 8.5 years since diagnosis. See table 1 for further demographic information. There was a range of disease severities across both conditions. Participants sometimes self-identified severity, but this was not clinically assessed as our interest was in the subjective experience of the individual. By analysing the whole interview transcripts, which included a specific question asking the participant if they had any messages for healthcare professionals, the following core themes relating to both conditions were extracted: (1) address the emotional impact; (2) give more information, with the subtheme and (3) appreciate patient research. We identified the following eczema-specific themes: (ECZ-4) 'It's not taken seriously'; (ECZ-5) offer choice in treatment and (ECZ-6) lack of structure/conflicting advice. Two psoriasis-specific themes were identified: (PSO-4) feeling dehumanised/treat me as a person and (PSO-5) think about how treatments will affect daily life. See table 2 for categorisation of themes.

Themes ECZ-1 and PSO-1: address the emotional impact

A dominant theme throughout the participant interviews across both conditions was the importance of the 'emotional side' of their skin condition. There was a considerable spectrum in this, ranging from individuals who would simply like their doctor to 'check in' with them on how they are, to those who felt that the psychological effects were more problematic than the physical symptoms of their skin disease. This was often in conflict with the approaches of healthcare professionals, with

Table 1 Participant demographics	
Variable	Frequency
Condition	
Eczema	23
Psoriasis	18
Sex	
Male	13
Female	28
Age (years)	
15–18	10
19–24	31
Mean (range)	20 (15–24)
Occupation	
School/college student	8
Undergraduate	12
Postgraduate student	2
Full-time employment	19
Ethnicity	
Algerian/White	1
Bangladeshi	2
Black Caribbean/White	1
British Asian	1
British Indian or Indian	3
British Pakistani or Pakistani	4
White British	27
White British (Jewish)	1
White Hungarian	1

a sense that doctors either did not address, or did not even recognise, the emotional impact of their skin condition. Multiple participants with psoriasis explained how at clinic appointments they were asked to fill in tick-box 'quality of life' (QoL) forms, but these were not addressed within the consultation beyond their role in helping to determine treatment thresholds.

Notably, one participant who had seen a counsellor answered 'no', when asked whether they had wanted to talk more about their psoriasis (in addition to other difficulties she had faced in her wider life), saying: 'No, I think talking about it always made it seem more real, and I always quite liked to block it out' (25). However, somewhat contradicting this, when asked what messages she would give to healthcare professionals, she responded, 'I just think that they need to look into how it effects the person in other ways rather than just what is on the outside', and that psoriasis had impacted her 'internally' more than 'physically'. This is demonstrative of a complexity in how young people throughout the interviews discussed their emotional and psychological needs, calling for a dynamic approach within and across individuals. See online supplemental tables 1 and 2 for illustrative quotations.



Table 2 Key theme

Key themes		
Eczema	Psoriasis	
Theme ECZ-1: address the emotional impact	Theme PSO-1: Address the emotional impact	
Theme ECZ-2: give more information	Theme PSO-2: g more information	
Subtheme ECZ-3/PSO-3: appreciate patient research		
Theme ECZ-4: 'It's not taken seriously'	Theme PSO-4: feeling dehumanised/treat me as a person	
Theme ECZ-5: offer choice in treatment	Theme PSO-5: think about how treatments will affect daily life	
Theme ECZ-6: lack of structure/conflicting advice		

Themes ECZ-2 and PSO-2: give more information

Many participants with eczema and psoriasis felt that they never had the condition properly explained to them. One participant (32) did not realise psoriasis was a longterm condition until his mother (a former health centre worker) told him. Another individual (18) believed as a child that he had 'eggsma' from eating too much egg. The barriers to good understanding that can arise when the diagnosis of a chronic skin condition is made in early childhood were raised (10). This participant explained that as a teenager it is assumed that you will understand a condition you have had your whole life. However, if they never actually understood the diagnosis as a child or it was only explained to the parent, this could result it the condition never being understood. The issue of lack of compliance, which can arise from lack of understanding, was described (14) with the participant remembering she was reluctant to have her creams applied because she did not know what they were for. See online supplemental tables 3 and 4 for quotations.

Subtheme ECZ-3/PSO-3: appreciate patient research

There is a problematic interplay with patients feeling that healthcare professionals are dismissive of their online research or experiences with over-the-counter treatments, but that appointments are too rushed for them to ask all their questions, thereby necessitating this research. Interestingly, the majority of participants' reports of using Internet resources were positive. Contrary to medical professionals' fears of a scaremongering 'Dr Google', participants seemed very aware of the dangers of misinformation and discussed seeking reliable and/or NHSbacked resources. Regardless, it is clear throughout that a dismissive approach, for example, 'she just rolled her eyes at me' (41), is damaging to doctor/nurse-patient relationships. Participants recalled feeling too embarrassed or otherwise unable to ask for confirmation or advice on their research, rendering them more vulnerable to the

online misinformation feared by doctors in the first place. See online supplemental table 5 for quotations.

Theme ECZ-4: 'It's not taken seriously'

Beyond a failure to take the emotional impact of eczema seriously, there was a sense from many participants with eczema that the condition as a whole was 'not taken seriously'. One participant had vivid memories of their parents having to demand treatment with the desperate plea, 'Do I have to peel my skin off like to the eighth layer, just be like muscle and bone?' (4). Another participant could only remember being recommended two different creams in their 19 years of living with 'really bad eczema' (2). Being dismissed with 'you'll grow out of it' (11) was another barrier to the condition being addressed in a comprehensive manner. The implications of eczema's unpredictability were described, with the ensuing frustration of a severe flare-up having cleared up by the time of the appointment and being met by the doctor with 'why are you in here?' (13). One participant explained how she kept photo diaries between appointments as 'evidence' for 'how bad it was' (21). Yet another participant described being turned away from an emergency appointment when he tried to see a doctor during a flare-up (17), with ensuing negative psychological consequences. See online supplemental table 6 for quotations.

Theme PSO-4: feeling dehumanised/treat me as a person

Multiple participants with psoriasis emphasised the importance of interactions with healthcare professionals in which they felt treated as an individual: 'Not just a piece of skin' (27). This was related to but distinct from the theme of addressing emotional impact, with this theme focussing on the interpersonal relationships with healthcare providers. This included numerous positive experiences in which participants felt valued when their doctor took an interest in their life more generally (29), or a nurse remembered their name (28) and serves to highlight the significance of these frequently overlooked elements of doctor/nurse-patient relationships. See online supplemental table 7 for quotations.

Theme ECZ-5/PSO-5: offer choice in treatment/ think about how treatments will affect daily life

The variety of treatment options was discussed in interviews with participants with both eczema and psoriasis. Although there was reference to wanting choice from participants with eczema and psoriasis, the emphasis on 'choice' was greater among participants with eczema. In the interviews with individuals with psoriasis, there was an emphasis on participants being prescribed inconvenient, bad-smelling (40) or clothes-staining (29) treatments, and a call for doctors to acknowledge the practical implications of the treatment regimens they prescribe. Participants with eczema also described unpleasant, 'greasy' and 'oily' emollients, with one participant not using their prescribed shampoo because it 'smelt funny' (2), and another participant not using a prescribed cream due



to its inconvenient texture 'almost like pâté' (18). See online supplemental tables 8 and 9 for quotations.

Theme ECZ-6: lack of structure/conflicting advice

Participants with eczema frequently described feeling frustrated, angry or hopeless with aimless treatment plans, in which they were prescribed 'the same thing over and over again' (13) with no effect. Many were frustrated by the perceived reticence of GPs to refer them to secondary care dermatology and the ambiguity regarding when this decision might be made, although others found the referral process straightforward. Several participants found that moving GPs as part of leaving home/going to university exacerbated the problem of lack of structure, or meant they had to 'start over again'. However, for some individuals who had found their 'home' GP unhelpful, moving to a new medical service was a positive experience. For example, one participant explained how a nurse she saw at her university medical centre was the first person who explained to her what eczema was: 'She drew up a diagram and everything and told me and it's the first time I understood' (11). One participant described how her treatment plans were always made on a short-term basis (15), seeing her GP for individual eczema flare-ups but with no clear long-term plan. Conflicting advice—both between different GPs, and between dermatologists and GPs—was a source of confusion and distress, with one participant feeling like she was told off by the dermatologist for following her GP's treatment plan (10). Although an instance of conflicting advice was described by a participant with psoriasis regarding steroid ointments (27), this was a far more dominant issue raised by participants with eczema. See online supplemental table 10 for quotations.

DISCUSSION Summary

Young people with the inflammatory skin conditions eczema and psoriasis reported a diverse range of experiences with healthcare professionals. We have distilled the following key messages from young people with both conditions for their healthcare professionals: (1) address the emotional impact; (2) give more information, with the subtheme and (3) appreciate patient research. We identified the following eczema-specific themes: (ECZ-4) 'It's not taken seriously'; (ECZ-5) offer choice in treatment and (ECZ-6) lack of structure/conflicting advice. Two psoriasis-specific themes were identified: (PSO-4) feeling dehumanised/treat me as a person; and (PSO-5) think about how treatments will affect daily life. These messages call for greater sensitivity and flexibility both between different patients, and as an individual progresses through adolescence.

The apparent conflict in interview 25 regarding emotional support represents a pertinent example of the inner-struggles that adolescents may have when dealing with the emotional impact of skin conditions, often never addressed in a clinical setting. The participant described

how her attitude towards her psoriasis and ability to talk about it changed as she 'grew up', demonstrating the importance of psychological support being continuously available if needed, and not just a one-time offer. We propose that having psychological support embedded within dermatology clinics as demonstrated in a successful clinic model²² is an appropriate method to overcome issues around access of appropriately targeted psychological support, offering both expertise with psychological effects of skin disease, and an 'open-door' policy.

Across both groups, the belief that healthcare professionals did not understand the emotional or psychological impact of their skin condition was a striking finding. This was often a source of frustration, although some participants did not even think their doctors should be expected to understand the emotional aspect of their condition. One likely contributing factor to the failure of many consultations to address emotional aspects of the condition is the problematic time-restraints placed on doctors and nurses. One participant with eczema described his GP consultation as 'just being handed a prescription and sort of shooed out' (5). Thematically, this intersects with the theme 'Give more information'.

Although participants frequently distinguished between care received from their GP versus a dermatologist, they rarely distinguished between different types of healthcare professionals in the 'messages' they wanted to give them. Relationships between participants and their healthcare providers varied considerably, and some participants only had experience of primary care. Some found that their GPs knew them better and took time to explore psychological aspects of their condition, and found their interactions with dermatologists impersonal. Conversely, others experienced considerable delays in diagnosis with GPs who they felt were not interested in their skin condition, and wished they had been referred to dermatology earlier.

Strengths and limitations

Our study's qualitative methodology illuminated the complexity in the relationships between adolescents and their healthcare providers, which often included an understanding of time pressures experienced by their doctors. Open questions enabled participants to use their own words to describe their experiences with healthcare professionals (as opposed to ticking options on a questionnaire).²³ The interviewer was an expert qualitative researcher and not a clinician, which may have enabled participants to give more candid accounts without fear of causing offence or affecting their care.

There is a potential selection bias since those who agreed to participate are more likely to be actively engaging with their skin condition or more reflective on its emotional impact. The diverse sampling matrix and extensive and varied recruitment strategy, which included individuals not currently seeking healthcare for management of their skin disease, helped to mitigate this. There were substantially more female participants than male in

our study. Interesting discussions arose in the interviews about the effect of gender on living with a chronic skin condition, with some female participants feeling that their skin stopped them from conforming to societal beauty standards, or feeling embarrassment over breast or vulval eczema. However, we did not observe a genderinfluence on the overall 'messages' offered by participants for healthcare professionals. Limitations of all secondary analyses apply, with no scope to conduct additional interviews to explore arising themes or to probe certain topics further within an interview. However, these interviews provided rich data on participants' experiences of healthcare professionals, with data saturation reached for our themes of interest. Coauthor AMN was the original researcher who collected 40 of the 41 interviews, thereby retaining this first hand 'bank of knowledge'²⁴ and able to provide further context for making sense of the data.

Comparison with existing literature

The call for greater focus on the emotional and social aspects of skin disease echoes previous qualitative work on adults with psoriasis, ²⁵ and 'provider appreciation for the extent of patient suffering' has been linked to increased confidence in their healthcare provider in adult dermatology patients. ²⁶ The perception expressed by many of the participants that healthcare professionals do not appreciate their emotional needs, is supported, at least historically, by clinician survey data: in an Australian survey conducted in 1995, only 3.4% of dermatologists nominated psychological factors as an important criterion for assessing eczema severity. ²⁷

The failure to use QoL questionnaires as a springboard to discuss psychological issues, as discussed by participants with psoriasis, is demonstrative of the deeprooted nature of the issue. Furthermore, many QoL questionnaires do not adequately screen for emotional or psychological distress, or even sleep disturbance.²⁸ It is possible that some doctors feel they do give patients the opportunity to raise psychological issues. However, we argue that the onus lies with the healthcare provider to ensure that psychological needs are being met, and reticence from adolescents in raising these issues is clearly described throughout the interviews. In a questionnaire study of 300 adults with psoriasis, 38% of patients interviewed were unable to describe their emotional state.²³ Some authors have claimed that a characteristic of patients with psoriasis is their limited ability to express their emotions (alexithymia). 29 30 However, sometimes recognition of emotional distress and offers of support from medical professionals can feel 'scripted' and not genuine to patients, exemplified by the fact that no participants described a positive experience associated with completing QoL questionnaires. Informal discussions need to be carefully managed to avoid feeling like 'tick-box' exercises. Crucially, individuals do not want simply to have their 'mental health problem' (which can often still have stigmatising connotations) passed over to another service, but call for greater understanding and a

holistic approach from their treating doctor. This could of course lead to a formal referral for psychological support.

One participant described her treatments only being planned on a short-term basis, seeing her GP for individual eczema flare-ups but without a long-term plan. Others were frequently told by their GP 'you'll grow out of it' (11). This failure of some GPs to acknowledge eczema as a chronic condition renders the inadequacy of their treatment plans unsurprising. Indeed, in their secondary analysis of the SKINS eczema transcripts exploring young people's perceptions of eczema, Ghio et al concluded that there should be a greater focus on self-care for a long-term condition in the management of young people with eczema.³¹ There was also a complex interplay described by participants with eczema between not seeing the same doctor regularly, feeling that they were not taken seriously and lack of structure to treatment plans. This is arguably a particularly pertinent problem in late adolescence, with many individuals moving to university/away from home.

Noerreslet argues that empowering patients with AD to take greater responsibility for their health and illness implies that they will have to be more in charge of their relationship with physicians—although he stresses that patients are not seeking independence but rather a partnership whereby responsibility for treatment is shared.³² Yet, the majority of participants in our study felt like they had little choice in their treatments or insufficient information to inform these choices. Santer and Roberts discuss the problems that arise from diverging views on eczema treatments and call for promotion of a shared understanding between doctor and patient.³³ They raise the suggestion of health professionals having access to a social media 'digest' to improve understanding of patients' concerns about various treatments, which ties into our theme 'Appreciate patient research'.

Implications for future practice

This qualitative data analysis provides invaluable insight into the experiences of adolescents with eczema and psoriasis with healthcare professionals. Young people voice a need for greater appreciation of the emotional impact of skin disease and more comprehensive provision of information. Importantly, the messages to healthcare professionals offered here are not prescriptive but rather highly nuanced, calling for greater sensitivity and flexibility in approaches to adolescents with skin disease. We believe these are important messages with implications for the delivery of healthcare to adolescents across the health service. In light of the COVID-19 pandemic, many healthcare services are being rapidly redesigned, and this seems an opportune time to include patient voices in this process. Although young people's comfort with technology may well make them ideally placed to embrace a service with a greater emphasis on online support and consults, we must ensure that the emotional impact of skin disease is effectively addressed.



Author affiliations

- ¹Medical Sciences Division, University of Oxford, Oxford, UK
- ²Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, LIK
- ³Centre of Evidence Based Dermatology, School of Medicine, University of Nottingham, Nottingham, UK
- ⁴Aston Business School, Birmingham, UK
- ⁵Department of Dermatology, Oxford University Hospitals NHS Foundation Trust, Oxford, UK

Correction notice This article has been corrected since it first published. The provenance and peer review statement has been included.

Acknowledgements We are grateful to Ulla Räisänen who conducted one of the analysed interviews, the Medical Sociology and Health Experiences Research Group (University of Oxford) for data sharing, and to the young people who took part in the original data collection project.

Contributors AMN, TMP, AR and HP developed the idea for this secondary analysis, with IJdVH subsequently involved in the analysis plan. IJdVH led the thematic analysis supervised by AMN, with all coauthors part of the analysis team to refine initial analysis. IJdVH drafted the report, with all coauthors contributing to multiple critical revisions. TMN is the guarantor and corresponding author who is responsible for overall content. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Funding This study was supported by Oxfordshire Health Services Research Committee (OHSRC) part of Oxford Hospitals Charity. Data collection was funded by National Institute for Health Research under the Research for Patient Benefit programme (PB-PG-0213-30006).

Competing interests All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf. Dr de Vere Hunt reports a grant from Oxfordshire Health Services Research Committee (OHSRC), part of Oxford Hospitals Charity, to support the conduct of the study. Dr McPherson reports personal fees from Sanofi, personal fees from Abbvie and personal fees from Leo pharma outside the submitted work. All authors declare: no other support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Patient consent for publication Not required.

Ethics approval Ethical approval was obtained by Berkshire NRES Committee South Central (Berkshire Ethics Committee REC No 12/SC/0495). All participants gave informed consent before taking part and consent for secondary analysis. The University of Oxford, which holds the copyright for the interviews, has given data sharing permission to enable this secondary analysis of the interview data.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data may be obtained from a third party and are not publicly available. There is an extensive selection of illustrative quotes available in the supplementary files. The University of Oxford holds the copyright for the full interviews and may grant data sharing permission upon request.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

ORCID iD

Isabella Joy de Vere Hunt http://orcid.org/0000-0002-4238-0924

REFERENCES

- Nutten S. Atopic dermatitis: global epidemiology and risk factors.
 Ann Nutr Metab 2015:66:8–16.
- 2 Peters AS, Kellberger J, Vogelberg C, et al. Prediction of the incidence, recurrence, and persistence of atopic dermatitis in adolescence: a prospective cohort study. J Allergy Clin Immunol 2010;126:590–5.
- 3 Gelfand JM, Weinstein R, Porter SB, et al. Prevalence and treatment of psoriasis in the United Kingdom: a population-based study. Arch Dermatol 2005;141:1537–41.
- 4 Bronckers IMGJ, Paller AS, van Geel MJ, et al. Psoriasis in children and adolescents: diagnosis, management and comorbidities. Paediatr Drugs 2015;17:373–84.
- 5 Golics CJ, Basra MKA, Finlay AY, et al. Adolescents with skin disease have specific quality of life issues. *Dermatology* 2009;218:357–66.
- 6 Kimball AB, Wu EQ, Guérin A, et al. Risks of developing psychiatric disorders in pediatric patients with psoriasis. J Am Acad Dermatol 2012;67:651–7.
- 7 British Skin Foundation. All-party parliamentary group on skin report: mental health & skin disease [online]. Available: https://www.britishs kinfoundation.org.uk/news/all-party-parliamentary-group-on-skinreport-mental-health-skin-disease [Accessed 9 Dec 2020].
- 8 Key data on young people 2017: latest information and statistics | BASW Resources [online]. Available: https://www.basw.co.uk/ resource/?id=6944 [Accessed 20 Apr 2018].
- 9 Hargreaves DS, Viner RM. Children's and young people's experience of the National health service in England: a review of national surveys 2001-2011. Arch Dis Child 2012;97:661-6.
- 10 Hargreaves DS. Revised you're welcome criteria and future developments in adolescent healthcare. J Clin Res Pediatr Endocrinol 2011:3:43–50.
- 11 De Vere Hunt IJ, Howard E, McPherson T. The impact of chronic skin disease in adolescence and the need for specialist adolescent services. Clin Exp Dermatol 2020;45:5–9.
- Magin PJ, Adams J, Heading GS, et al. Patients with skin disease and their relationships with their doctors: a qualitative study of patients with acne, psoriasis and eczema. Med J Aust 2009:190:62–4.
- 13 Berwick DM. What 'patient-centered' should mean: confessions of an extremist. *Health Aff* 2009;28:w555–65.
- 14 Ziebland S, Hunt K. Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. J Health Serv Res Policy 2014;19:177–82.
- 15 Ip A, Muller I, Geraghty AWA, et al. Young people's perceptions of acne and acne treatments: secondary analysis of qualitative interview data. Br J Dermatol 2020;183:349–56.
- 16 Heaton J. Reworking qualitative data. London: Sage, 2004.
- 17 Smith KL, Kerr DA, Fenner AA, et al. Adolescents just do not know what they want: a qualitative study to describe obese adolescents' experiences of text messaging to support behavior change maintenance post intervention. J Med Internet Res 2014;16:e103 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4004140/
- 18 McNiven A. 'Disease, illness, affliction? Don't know': Ambivalence and ambiguity in the narratives of young people about having acne. Health 2019;23:273–88.
- 19 Healthtalk [online]. Available: https://healthtalk.org/ [Accessed 18 Mar 2020].
- 20 Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness). *Med Educ* 2006;40:405–14.
- 21 O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014;89:1245.
- 22 Hunt DV I, Chapman K, Wali G. Establishing and developing a teenage and young adult dermatology clinic with embedded specialist psychological support. Clin Exp Dermatol https:// onlinelibrary.wiley.com/doi/abs/10.1111/ced.13950
- 23 Linder D, Dall'olio E, Gisondi P, et al. Perception of disease and doctor-patient relationship experienced by patients with psoriasis: a questionnaire-based study. Am J Clin Dermatol 2009;10:325–30.
- 24 Locock L, Brown JB. 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in motor neurone disease (MND). Soc Sci Med 2010;71:1498–505.
- 25 Nelson PA, Chew-Graham CA, Griffiths CEM, et al. Recognition of need in health care consultations: a qualitative study of people with psoriasis. Br J Dermatol 2013;168:354–61.
- 26 Gibbons C, Singh S, Gibbons B, et al. Using qualitative methods to understand factors contributing to patient satisfaction among dermatology patients: a systematic review. J Dermatolog Treat 2018;29:290–4.



- 27 Stephens RB, Cooper A. The caseload, assessment and treatment of atopic dermatitis: a survey of Australian dermatologists. *Australas J Dermatol* 1999;40:187–9.
- 28 Cardiff University. Dermatology life quality index [online]. Available: https://www.cardiff.ac.uk/medicine/resources/quality-of-lifequestionnaires/dermatology-life-quality-index [Accessed 3 Apr 2020].
- 29 Willemsen R, Roseeuw D, Vanderlinden J. Alexithymia and dermatology: the state of the art. Int J Dermatol 2008;47:903–10.
- 30 Richards HL, Fortune DG, Griffiths CEM, et al. Alexithymia in patients with psoriasis: clinical correlates and psychometric properties of the Toronto Alexithymia scale-20. J Psychosom Res 2005;58:89–96.
- 31 Ghio D, Muller I, Greenwell K. 'It's like the bad guy in a movie who just doesn't die': a qualitative exploration of young people's adaptation to eczema and implications for self-care. *Br J Dermatol* https://onlinelibrary.wiley.com/doi/abs/10.1111/bjd.18046
- 32 Noerreslet M, Jemec GBE, Traulsen JM. Involuntary autonomy: patients' perceptions of physicians, conventional medicines and risks in the management of atopic dermatitis. Soc Sci Med 2009;69:1409–15.
- 33 Santer M, Roberts A. Diverging views on eczema treatments promoting shared understanding between doctors and patients. BMJ 2019 https://blogs.bmj.com/bmj/2019/10/17/diverging-views-on-eczema-treatments-promoting-shared-understanding-between-doctors-and-patients/