the british
psychological society
promoting excellence in psychology

British Journal of Health Psychology (2020)
© 2020 The Authors. British Journal of Health Psychology published by John Wiley & Sons Ltd
on behalf of British Psychological Society
www.wileyonlinelibrary.com

Psychosocial needs of adolescents and young adults with eczema: A secondary analysis of qualitative data to inform a behaviour change intervention

Daniela Ghio*[1], Kate Greenwell[2], Ingrid Muller[1], Amanda Roberts[3], Abigail McNiven[4] and Miriam Santer[1]

[1]Primary Care and Population Sciences and Medical Education, Faculty of Medicine, University of Southampton, UK
[2]Centre for Clinical and Community Applications of Health Psychology, Faculty of Environmental and Life Sciences, University of Southampton, UK
[3]Centre of Evidence Based Dermatology, School of Medicine, University of Nottingham, UK
[4]Nuffield Department of Primary Care Health Sciences, Radcliffe Observatory Quarter, Oxford, UK

Objectives. This study aimed to explore adolescents and young adults' experiences of symptoms related to their eczema in order to determine their psychosocial needs.

Design. A secondary qualitative analysis of two data sources collected through semi-structured interviews for two different projects, SKINS project and Eczema Care Online project.

Methods. In total, there were 28 transcripts with adolescents and young adults with eczema having a mean age of 19.5 years available to analyse. Interview data were collected from face-to-face interviews that were recorded and transcribed. Inductive thematic analysis explored data about symptoms and organized according to psychosocial needs.

Results. Adolescents and young adults with eczema experience both visible symptoms (such as flaky, dry, and inflamed skin) and invisible symptoms (such as itch, pain, exhaustion, and mental distress) that elicit different psychosocial needs. These psychosocial needs are to (i) be understood; (ii) be perceived as normal; and (iii) receive emotional support. Interviewees described a struggle between wanting their peers and family to understand but take their eczema seriously whilst not wanting to stand out and instead to be perceived as 'normal', which they would define as being perceived as other adolescents. This has implications on behaviours, such as seeking support, avoiding going out, hiding their skin, as well as emotional implications, such as social isolation and feeling anxious and low.

Conclusions. Having a better understanding of young people's experiences and psychosocial needs will provide a framework on how best to support adolescents and young adults when managing symptoms related to eczema.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

Correspondence should be addressed to Daniela Ghio, Primary Care and Population Sciences and Medical Education, Faculty of Medicine, University of Southampton, Southampton, UK (e-mail: d.ghio@soton.ac.uk).

DOI:10.1111/bjhp.12467

Statement of contribution

What is already known on this subject?

Eczema has a high impact on children and is considered a burden by children and adults with eczema. However, it is unclear what impact eczema has on adolescents and young adults.

Adolescents and young adults with chronic conditions are known to be vulnerable to negative psychosocial outcomes but psychosocial needs and how to best support this age group with eczema are unknown

What does this add?

Three psychosocial needs were developed from evaluating the impact of visible and invisible symptoms of eczema:

- The need to feel understood (mostly reflective of invisible symptoms such as itch and pain and visible symptoms such as scratching).
- The need to be perceived as 'normal': visible symptoms such as flaky, inflamed skin make them stand out in comparison with their peers and a need emerged to blend in.
- The need for emotional support: adolescents and young adults searched for this from their health care providers, from shared experiences and from online resources.

Adolescents and young adults with eczema appear to feel ambivalent about wishing the impact of the condition to be acknowledged whilst wishing the condition to be invisible to others. This ambivalence had further impact on feeling self-conscious, seeking support, and dealing with unsolicited advice.

Introduction

Eczema, also known as atopic dermatitis, is an inflammatory skin condition that has a lifetime prevalence of 16% to 20% in the UK (Mathiesen & Thomsen, 2019). Eczema is characterized by dry, itchy, and inflamed skin (Chamlin, Frieden, Williams, & Chren, 2004); however, people with eczema also describe eczema as a painful and distressing condition that interferes with sleep and everyday life (Birdi, Cooke, & Knibb, 2020; Chamlin, 2006; Jowett & Ryan, 1985; Ring *et al.*, 2019). Quality of life in children with eczema is comparable to children with cystic fibrosis or cerebral palsy (Beattie & Lewis-Jones, 2006). Eczema has a greater impact on health-related quality of life than asthma and diabetes (Beattie & Lewis-Jones, 2006; Lewis-Jones, 2006). The National Institute for Health and Care Excellence (NICE) guidelines for managing atopic eczema recommends referral to a clinical psychologist if a person has controlled eczema without improvement on quality of life and psychological well-being (NICE, 2007). However, such services are rarely available for adolescents and young adults with skin conditions in the United Kingdom (De Vere Hunt *et al.*, 2019).

A recent large European study of 1189 adults with eczema (18 – 87 years) across nine countries has shown that there is a high burden of eczema, impacting an individual's well-being (Ring *et al.*, 2019). Despite the huge impact eczema can have (Thyssen *et al.*, 2018), especially severe eczema (Ring *et al.*, 2019), parents of children with eczema and adults with eczema often feel that eczema is not taken seriously by health care providers (Gore, Johnson, Caress, Woodcock, & Custovic, 2005; Magin, Adams, Heading, & Pond, 2009; Santer *et al.*, 2012). In the European study, participants desired a better acceptance and understanding in general (Ring *et al.*, 2019). Despite being an important transitional phase between childhood and adulthood in managing a long-term condition (Ghio *et al.*, 2020; Gray, Schaefer, Resmini-Rawlinson, & Wagoner, 2017), little work explores the impact and burden eczema has on adolescents and young adults, and usually this age group is grouped with adults or children. Some of this work has shown that eczema impacts both physical and emotional well-being (Kosse, Bouvy, Daanen, de Vries, & Koster, 2018). Furthermore, the impact of eczema on quality of life and psychosocial factors may change over a young person's developmental trajectory (Lansing & Berg, 2014), so there may be specific needs affecting this population but the specific needs of this age group have not been studied.

Adolescents and young adults with chronic conditions such as eczema are vulnerable to negative psychosocial outcomes (Mizara, Papadopoulos, & McBride, 2012); for example, they are more likely to become victims of bullying (Pittet, Berchtold, Akré, Michaud, & Surís, 2010) and experience higher levels of anxiety, depression, and suicidal ideation in comparison with their peers without a chronic condition (Halvorsen, Lien, Dalgard, Bjertness, & Stern, 2014). Having a better understanding of what would make adolescents and young adults vulnerable to negative psychosocial outcomes and in turn their needs would provide a framework on how best to support adolescents and young adults to manage their condition. Therefore, understanding of the psychosocial context, including issues, needs, and challenges relating to self-management informing development of behavioural interventions (Yardley, Morrison, Bradbury, & Muller, 2015). Previous qualitative research with adolescents and young adults is limited. They mainly sought to understand impact of eczema or experiences of eczema and treatment (Teasdale *et al.*, 2020) without exploring this population's specific psychosocial needs, which a behaviour change intervention could address. The aim of the current study is to explore adolescents and young adults' experiences of their symptoms related to eczema with the purpose of identifying psychosocial needs when dealing with those symptoms.

Methods

Study design and data collection

This phenomenology study involved a secondary analysis (Ziebland & Hunt, 2014) of qualitative interview data from adolescents and young adults with eczema taken from two sources to capture the full age group of both adolescents and young adults. Both data sets were collected by experienced female qualitative researchers. The first data set is from the SKINS project which was approved by Berkshire NRES Committee South Central and the second data set was from the Eczema Care Online project. The secondary analysis of both data sets was approved by Wales REC 7 Ethics Committee (REC 17/WA/0329) as part of the wider project that aims to develop a behaviour change intervention for adolescents and young adults with eczema. Details for how each data set sources collected data are presented below under each project's subheadings.

SKINS project

Qualitative interviews were carried out for the SKINS project by researchers from the Health Experiences Research Group (HERG) at the University of Oxford as part of a wider study funded by National Institute for Health Research (NIHR) for the Research for Patient Benefit programme (Grant Reference Number: PB-PG-0213-30006) that was published on the multimedia website Healthtalk.org. The primary aim of this project was to explore the information and support needs of adolescents and young adults with four common skin conditions (acne, eczema, psoriasis, alopecia). Interviews were conducted with young people aged between 13 and 25 years and published as either written, video, or audio clips. Twenty-four out of the 97 semi-structured interviews were with young people with eczema aged between 17 and 25 years. Participants were recruited from health settings, for example, GP practices or dermatology departments, social media, patient representative groups, universities, colleges, and schools. Recruitment was carried out using a sampling matrix of demographic factors such as age, ethnicity, and geographical location to seek a maximum variation sample (for more information on the SKINS project see McNiven (2018)). AMcN carried out these interviews between October 2014 and December 2015. Interviews were then transcribed verbatim and checked by participants for accuracy. All but one interviewee of this group consented for a secondary analysis, bringing the final sample for this study to 23 adolescents and young adults.

The interview schedule included the following: participants' experience of diagnosis; early knowledge and information; treatment and management; everyday life with a skin condition; sharing information with other young adults with eczema; and changes over time and anticipated future (see Data S1 for an abridged version of the interview schedule). The interview schedule began with an opening question about experiences of having eczema and proceeded with questions and prompts to ensure that it included discussions around areas that would be relevant for publication on the Healthtalk website. Relevance of topic was decided based on the literature and an advisory panel (that included health care providers, researchers and charity representatives), and the final schedule was checked by a patient participant involvement (PPI) representative and other members of the advisory panel. The interviews took place in the participants' preferred settings such as their homes or local community centres and lasted up to two hours.

Eczema care online project

Qualitative interviews were carried out with 19 children and adolescents with eczema. Interviews conducted with adolescents (n = 5) were included in this study to capture the views of 13 to 16 year olds with eczema, which had not been captured in SKINS project. Recruitment for these interviews was through primary care. Potential participants were identified and invited to take part through a GP database search and mail-out to people whose records included a diagnostic code for eczema. Participants who consented to be contacted for an interview were called and interviews were arranged with either the parent or the participant directly. Interviewees were selected based on a sampling matrix of demographic factors including age and gender to ensure quota sampling. The collection of this data was part of a wider project funded by NIHR for Applied Research (PGfAR: RP-PG-0216-20007) and aimed to explore children and adolescents' experiences of eczema and self-management and views about online information and support to inform the development of an online intervention for eczema self-management.

The interview schedule included topics of eczema views and experiences, eczema treatments and self-management, quality of life, online information, and support for eczema (Data S2 for the interview schedule). The interview schedule was developed to be able to address the aims of the wider project of intervention development by identifying views about websites and to match the core questions about experiences similar to the interview schedule of the SKINS project. This interview schedule was checked by the team that included health care providers (HCP) and PPI members. These interviews took place at the young people's homes with some of them attended by their parents. For participants aged under 16, consent was given by the parents and assent was given by the participants. Interviews with the adolescents were carried out between March and May 2018 by DG and lasted between 22 and 50 minutes.

Analysis

All data were transcribed verbatim and coded using latent inductive thematic analysis (Braun & Clarke, 2006) and NVivo software (version 11). Initial coding by author DG was completed after she familiarized herself with the data and the coding manual was developed and discussed with the analysis team (KG, IM, MS). The team (KG, IM, MS) used the manual to code two transcripts and changes were made to the manual following discussions. Definitions of codes were agreed, and the coding manual included examples and description of type of data that were captured under the code. The development of the coding manual and themes were discussed by all authors. Each data set (SKINS and ECO) was coded separately; the process described above was first completed for the SKINS data set first and then subsequently followed for the ECO data set. Both data sets were coded for the wider project. Other codes that were related to different experiences were grouped for separate analyses. The codes taken forward for this current analysis were discussed with the team, and descriptions of the experiences of different symptoms (pain, sleep, itch, skin changes) associated with eczema were generated. Relevant codes related to the aim of the current manuscript (e.g., impact of eczema, self-esteem, relationship with others and stigma) were chosen for further analysis. These codes were further explored in order to identify psychosocial needs arising from invisible and visible symptoms of eczema and participants' experiences of these symptoms. Attention was given to discussions around lessons learnt around coping and changes in self-awareness, which was especially clear in data around feeling self-conscious. This allowed for searching for disconfirming evidence that highlighted a balancing act between the psychosocial needs and the needs that work within the adolescents and young adults' social context. The themes derived from these codes are presented in Figure 1. Psychosocial needs were generated based on how participants coped with either the invisible or visible impact of eczema and through discussions within the team that included HCPs and PPI. Pseudonyms were given to all participants.

Results

This analysis included a total of 28 interviews (5 from ECO and 23 from SKINS) with adolescents and young adults aged between 13 and 25 with the mean age being 19.5 years. The time with eczema ranged from 8 months to all their lives. Of these participants, 20 were women (see Table 1 for the sample demographics from both data sets).

All 28 adolescents and young adults mentioned symptoms related to their eczema. Adolescents and young adults described substantial impact from their eczema as a result of both visible and invisible symptoms. Through this impact, we identified three psychosocial needs: the need to feel understood, the need to feel 'normal', and the need for emotional support. We identified patterns of a struggle between young people wanting their symptoms to be taken seriously, their condition and its impact to be recognized and understood, whilst also wanting to blend in and be perceived as 'normal'.

Visible and invisible symptoms

Adolescents and young adults with eczema described different symptoms associated with their eczema that were categorized during the analysis as visible and invisible symptoms.

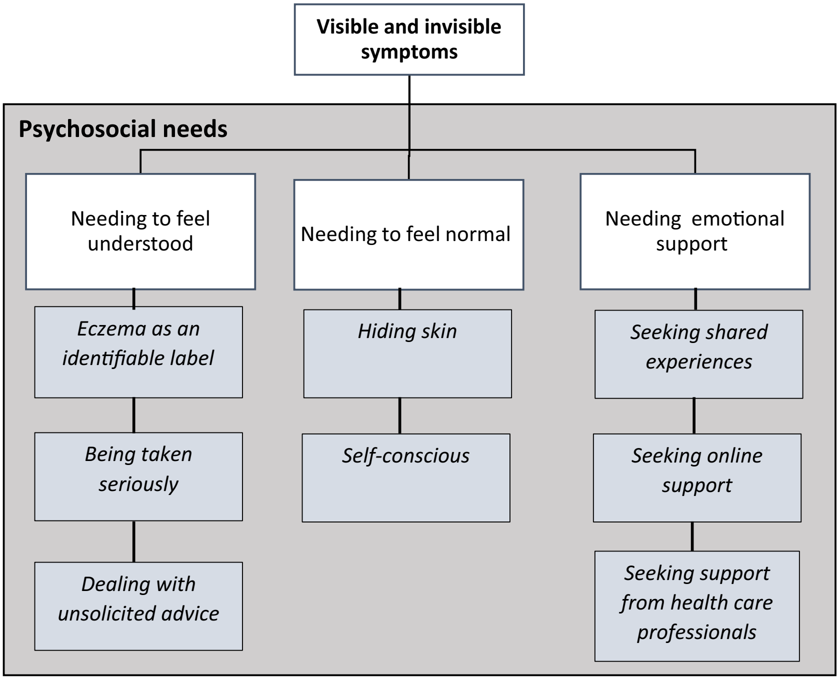

Figure 1. Outline of major themes (psychosocial needs) and related sub-themes identified in the context of visible and invisible symptoms.

The visibility of symptoms had different implications: visible symptoms included skin being inflamed, spotty and flaky, as well as visibly scratching (both the behaviour and the open sores/scratched bloody wounds), whilst invisible symptoms included itch, pain, exhaustion, and mental distress. Interviewees described that eczema could be painful in several ways including stinging when they applied their treatments, open wounds, and sore cracked skin.

Some interviewees recognized that they also experienced cycles in itch, stress, pain, and sleep disturbances. The symptoms of stress and pain got worse when they were not able to sleep but the pain and stress and itch kept them awake. They discussed the impact of this on different aspects of their lives, including their moods and their eczema getting worse.

> I get anxious before I go to sleep because I'm scared I'm going to wake up in the middle of the night and get itchy. And staying asleep is hard because I'll wake up itchy in the middle of the night. And then I'll wake up in the morning and I'll be tired and I'll be itchy because I've not slept properly and because I'm aggravated and irritated. Iris, 20 (SKINS)

Young people recognized cycles in their behaviours such as scratching, where for example the more they scratched the more they would itch despite that initial gratification.

> [You] Kind of learn that scratching, even though it feels very nice, doesn't actually fix it – it actually makes it worse. Hannah, 20 (SKINS)

Table 1. Sample demographics from both data sets

	Frequency	*n* (%)
SKINS project		
Sex		
Male	6	(26)
Female	17	(74)
Age (years)		
16–18	4	(17)
19–21	10	(43)
22–24	9	(39)
Duration of condition (years)		
All life (diagnosis before first birthday)	16	(69)
11 to 21 years (diagnosis in toddler years)	4	(17)
5 to 7 years (diagnosis in adolescence years)	2	(8)
Up to 1 year (diagnosis in young adult years)	1	(4)
Eczema care online project		
Sex		
Male	2	(40)
Female	3	(60)
Age (years)		
13 – 14	2	(40)
15 – 16	3	(60)
Duration of condition (years)		
All life (diagnosis before first birthday)	4	(80)
3 years (diagnosis in adolescence years)	1	(10)

Psychosocial need 1: Needing to feel understood

Eczema as an identifiable label

Some participants found it helpful that people within their social network (peers and extended family) either had eczema or had heard of it. The eczema label normalized their symptoms, enhanced understanding amongst others, and providing reassurance to others that the changes on the skin were not contagious or something to be feared/avoided.

> I would have preferred people knowing I had eczema just so I felt like they would then like chill out, not that anyone was like particularly hecked up about it but like I felt like as soon as they knew that I had eczema, it wasn't being judged – it was kind of like 'Oh, poor thing' then I wouldn't feel like people were questioning or thought I was contagious so many kids at school when I was much younger thought I was contagious and they wouldn't hold my hand or touch me or play with me. Hannah, 20 (SKINS)

Adolescents and young adults felt that the visible aspect of eczema could be understood by providing a label and it was reassuring when others have had eczema themselves or know someone who has eczema. On the other hand, some participants felt the label, and the attached perception of eczema as 'common' also led to their invisible symptoms being minimized and the impact of eczema was not understood.

> They [peers/strangers] just say, 'Ok that's fine. I know people who've got it, so I know it's not a serious condition'. Well, people don't think it is serious but I don't think my eczema's serious, but it does affect my life. Vikki, 20, (SKINS)

Being taken seriously

Participants felt that most people's conception of eczema was that eczema was a mild condition. For some participants, this meant they felt that the extent of their more severe eczema was not taken seriously, and the impact not fully comprehended. Young people reported experiencing a lack of empathy and understanding from others in their social network about how painful their eczema could be.

> Yeh it is just so frustrating. [. . .] you want to be taken seriously and I don't know what is, you just feel like you're not taken seriously. I don't know, I've always felt like that just when it comes to this condition I've never been taken seriously. I don't know what has to happen - do I have to peel my skin off like to the eighth layer, just be like muscle and bone and then just be like, 'Look - I have eczema guys, help me' [laughs]. Dua, 21 (SKINS)
>
> 'You want someone to listen and be like, 'Look it's [eczema] not an irritation. It's not mild. My skin feels like it's actually on fire and it hurts.' But people just are like, "Look it's just like a rash." And it's like, "No, if it was a rash, I would not be complaining"'. Karla, 19 (SKINS)

As in the above quote by Karla, several participants spoke about experiences where they felt that their condition and its related symptoms and impact had been 'minimised' by other people. This meant that the impact of eczema and the related symptoms of pain and itch on their quality of life was not understood and perceived as minor or 'small' condition.

> Having eczema, to some people it seems as though it's something small, but to have it personally it's quite difficult because at the moment, although mine seems very clear and doesn't seem too bad, I do become very insecure about it. Amelia (ECO)

Some adolescents and young adults described feeling understood as synonymous with feeling supported. When they felt that their symptoms and impact of their eczema were understood, they felt they were being supported by those around them and they had people help them cope.

> it's nice to know people care about the pain you're going through, like they kind of they feel so-, awful when you're in such pain. So, you know they've [peers and extended family] just been really supportive about it. Padma, 20 (SKINS)
>
> My brother got used to it [eczema] as well. So, after a while they're [family] not saying anything because they know that I'm in pain but I can't-, I'm just trying to move and I'm sitting and they bring everything for me, so that's a nice part. Charlotte, 22 (SKINS)

Dealing with unsolicited advice

For some participants, the management of eczema was perceived as 'easy' and 'simple' by people around them and this view was not reflective of most of the participants' experiences of managing eczema. The misperception that managing eczema is easy or simple could be interpreted as a consequence of mild eczema being common and recognizable.

> People often say, "You need to put some moisturiser on that." It's like, "Yes I know" [laughs] obviously. [. . .] it's just a bit frustrating with the whole when you try things and they don't work, and yeh, then it's frustrating if people say, "You need to moisturise." You're like, "I've been moisturising," [laughs]. Charlotte, 22 (SKINS)

> I think I'm lucky. I've got friends that don't have eczema and it's really hard when you get people that don't have it and don't understand. So, you know they think, 'Oh why can't you just do this, why can't you do that?' and you just think, 'Oh shut up.' Go and try having skin problems, it's not nice. Gabi, 17 (SKINS)

Simple and sometimes dismissive advice such as 'don't scratch' or 'just put on moisturiser' led to adolescents and young adults feeling that their condition and experiences were not understood. Many young people spoke about being told not to scratch by their families, peers, and health professionals and expressed frustration about the simplicity of this advice. For these participants, such advice demonstrated a lack of understanding around how itchy or painful their eczema was, and the relief and ease scratching could bring to them.

> [her peers say] Stop scratching', I was like 'do you know how horrible and like scratchy it is and how much nicer it feels when it's scratched? Hannah, 20 (SKINS)
>
> I mean the doctor's said that to me "Don't itch it," and I think, other sort of relatives who don't really understand what eczema is -they've said, "Oh don't . . . itch it." Dua, 21, (SKINS)

Psychosocial need 2: Needing to feel 'normal'

Hiding skin

As much as young people wanted their eczema experiences to be 'visible' in order to feel understood by others, they also expressed a need for their eczema to be 'invisible' in order to 'fit in' and feel like a 'normal' young person. Many participants discussed how they are often asked about their skin and, for them, this meant that the difference in their skin was noticeable and that they stood out. To avoid standing out some participants described trying to cover up their skin, either with clothes or by using their treatments (e.g., emollients) more. Participants described how being noticed and being asked about their skin made them feel different and not part of their social network.

> The younger groups [. . .] would probably look at you and you know, whisper to their friends or I don't know say 'eee' or something like that, I know that they don't know what I've got but it kind of makes me feel like if they're seeing it like that what are other people seeing? If that makes sense so I would force myself to cover up, force myself to put more moisturiser I guess just to make sure that my skin is better. Adi, 17 (SKINS)

Many young people described instances in which they avoided taking part in activities (e.g., not staying over at a friend's house) because of their eczema. They changed how they dressed or how they interacted with others to avoid judgement, being noticed, or to avoid dealing with other people's reactions to their treatments or symptoms, such as skin shedding.

> I'm a bit reluctant to stay over at people's houses, mainly because I'm so scared of my skin shedding and their reaction to it. I also get, cos I have to sleep in loose clothing or, or sort of a, like a strappy top, so my arms aren't irritated. I don't like having my arms on show to other people, so I try and cover up when I stay over. Iris, 20 (SKINS)
>
> And you just feel like, oh, you don't wanna see anyone and you don't wanna like bump into anyone if you've gone out the house. Like you're just hoping that no one will see if you, if it's really bad. I remember at uni like everyone goes out clubbing a lot. And then like I'd wear like a

> s-, dress like without sleeves. And you'd be like, have massive like strange red patches along your elbows that people don't really understand what they are. Bridget, 22 (SKINS)

The location of where the eczema may appear had different implications in hiding the skin because the location can make it hard to hide and this could be dependent on the weather/season if it would be easy to use clothes to hide their eczema. For example, one participant described having eczema on her thigh and neck and how difficult it was to hide her eczema in the summer in comparison with winter. Eczema on the face/scalp/hands was harder to hide in comparison with the legs and arms.

> People can see it [eczema on his hands] whereas my knees can have trousers on and they can't see it [eczema]. Simon, 15 (ECO)

Self-conscious

Most of the adolescents and young adults talked about feeling self-conscious and how the impact of having a visible condition extended to their self-esteem. This was found in both male and female interviewees where they felt that their condition made them stand out and felt too self-conscious about their eczema.

> I have this feeling that everybody just keep [sic] on looking at me like I would be Quasimodo or Frankenstein or something. [. . .] I cannot go to a girl like this because I'm just feeling so bad I know that I cannot go there because of my skin and then I'm just sort of being more anxious and it's just getting worse and worse. Tom, 17 (SKINS)

Experiences varied between different age groups and those participants who were older discussed how they found ways to develop their confidence and self-esteem and feel less self-conscious. One young person described how their own awareness of others' eczema made them realize how their own eczema was perhaps not as noticeable as they first thought:

> It's so funny because actually like I talk about it a lot with other people who have it [eczema]. [um] And I talk to like my friends about it and we like discuss and chat it. And they'll be like, "Oh, like I'm feeling like my eczema's so bad today." And then you're like, "I l-, like I hadn't noticed at all." And I'm like quite hot on eczema, so usually I notice. [um] But to them like they feel so self-conscious about it. And so I try and tell myself that when I think that my eczema's bad, like probably no one else like even notices. [um] And if they do notice, they really don't care like [laugh]. Bridget, 22 (SKINS)

Whilst some found being with peers that had shared experiences helped, others embraced situations where they had to be seen by others.

> As a teen I'd probably cover it up more. And so, yeh I was probably a bit like a bit embarrassed about it. But, I don't know, I wouldn't say I'm like not confident now; I think, in a way, as I grew up I kind of found other things that you just have to like find other ways to sort of counter it and become more confident. So, I did a lot, I've done a lot of like teaching and things where you're, you know, face on with people and using your hands all the time and you just, you have to get over it and just sort of find ways to develop your self-esteem and your confidence and things like that so that it doesn't really play a factor anymore. Charlotte, 22 (SKINS)

Psychosocial need 3: Needing emotional support

Seeking shared experiences

Some participants found that as they grew older, they met more people who had eczema and they shared experiences of severe eczema symptoms with them. For these young people, they felt that they had emotional support and understanding in their own community. It seemed that having others in their support system who had the same feelings validated their own and reduced the embarrassment of standing out. Furthermore, by having shared experiences, those experiences became normalized. Shared experiences gave the young people the space to ask for advice and help from those peers who would understand or have their ways of coping.

> Just like knowing that somebody else was, not struggling, but had the same feelings as, "Oh no, like it really hurts to do this; I just don't want to do it," Just having someone to talk to was really nice. Fearne, 21 (SKINS)

Whilst some young people spoke about having supportive peers and families and how this improved their confidence, they also talked about how important it is to have someone with shared experiences to understand what it is like dealing with severe symptoms.

> So having someone there who is also going through the same thing but also discussing things that have happened. [. . .] So it gives you someone to talk to who knows exactly what you're going through. Or if I'm like, "The cream hurts too much. I can't put it on." Then she'll be like, "Look, we'll put it in the fridge or we'll do something and we'll do it together." Karla, 19 (SKINS)

Having others around who have shared experiences, normalizes the condition; amongst peers without eczema, it was easy to compare and feel that they were not normal and an easy target for teasing.

> Well, as a kid emotionally – mm, you'd feel not well as a kid you didn't feel normal, you didn't know it was normal. I was the only person in my class that had eczema, so people really didn't understand it'. Gabi, 17 (SKINS)

Seeking online support

Many of the young people who discussed the value of emotional support also discussed that there is a lack of resources available such as websites with information about eczema and treatment.

> If somebody comes from any sort of situation and they have something that's wrong with them and there's no support out there and they're the odd one out then they're going to kind of feel like, 'What do I do; how do I. where do I go; I need some guidance, I need some help,' so, I think the more support and the more information and education there is about these sort of situations, then the more we can help people. Dua, 21 (SKINS)

Many participants spoke about how there was a lack of credible information online and they resorted to reading blogs and personal experiences. From what the young people said, looking up personal experiences emulated the benefits of having someone in their support system with shared experiences.

> I mean I remember when I was younger, there's a lot of information for parents with children with eczema. But when I got older I found it quite hard to find things for people that were my age. I mean you will h-, find things on the National Eczema Society [UK eczema charity] and things like that, of people that are in their, in their 40s or their 60s with eczema. there isn't anybody say that's a young teenager with it or that's somebody who's in their mid 20s with it that I can relate to with the kind of experiences that they'd be dealing with at that age. But through the online access of blogs I've found a lot more. So there are more people my age blogging. Which I found very helpful at the moment cos you can interact with them as well. Iris, 20 (SKINS)

Seeking support from health care professionals

Young people discussed how they felt that their health care professionals (HCPs) did not recognize the emotional impact that eczema had on them. Some participants wished that their doctors would provide time and support for their emotional needs. They hoped that their struggles were acknowledged by HCPs and that the HCPs could offer referral to psychological services if they were not able to provide the emotional support. Instead, the young people felt that most HCPs only focused on the medical management of their eczema.

> I think they should know that it does affect people not just physically but mentally and sort of, yeh it definitely does affect people in just more than one realm of their life; it's not just a skin condition. It's not like a cut that you can put a plaster over; it's something that needs to be addressed and, you know, looked after and stuff like that. And I would also say for them to not just shove it to the side really. [. . .] I think that point should be a kind of like, you know "maybe we should get you a referral somewhere or, here let's do this or something." Dua, 21 (SKINS)

> It's been hard, it's not easy; really isn't easy to have eczema cos it's a mixture of being physically in pain and emotionally in pain you know? You could have it severely and it not bother you that much; you could have it a teeny bit and it completely destroy the way you think, the way. . .like your life, you might not want to leave the house cos you might have a massive scar on your face cos you've had eczema there or something you know. Gabi, 17 (SKINS)

Some young people talked about feeling down and anxious and avoiding going out because of their skin. A small group of the interviewees talked about accessing mental health services when the impact of their eczema started imposing on their relationship and their quality of life.

> 'I was spending a lot of time inside. I wouldn't go out with my friends. So we, we went to the GP. And she understood that it was having an effect on my life and that I didn't, wasn't enjoying the things that I used to enjoy or enjoy going out with my friends. And she referred me' Iris, 20 (SKINS)

Interrelationships between themes

The three psychosocial needs generated for the current study were presented as independent; however, there seemed to be a balance and interrelationship between the need to be understood and the need to feel normal which in turn called for a need for emotional support. These two interrelated needs could be viewed as a spectrum that is influenced by an individual's context. Contextual factors, including age and eczema severity, may influence a young person's primary drive. As highlighted in Figure 2, as an individual experiences more severe symptoms (e.g., more pain, itch, lack of sleep), the

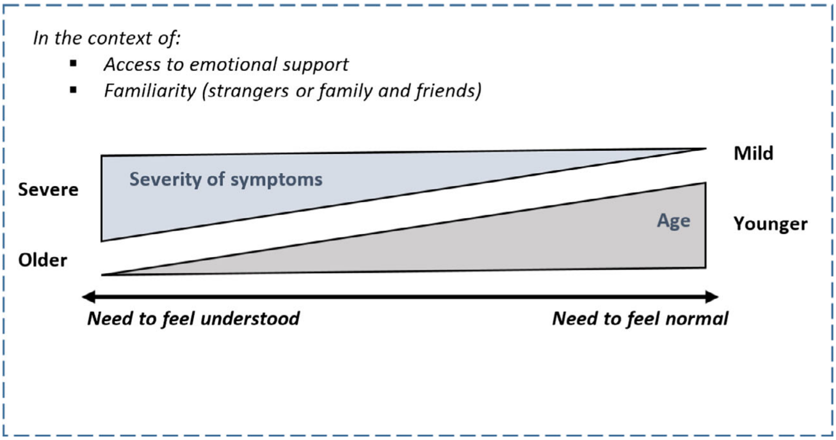

Figure 2. Relationship between the need to feel understood and need to feel normal that is influenced by severity of eczema and age within the context of access to emotional support and familiarity of families and strangers.

need to feel understood seemed stronger than the need to feel normal. In comparison, the adolescents and young adults talking about their younger selves expressed a strong need to feel normal whilst in school and this need had lesser personal importance as they grew up. Furthermore, as the participants grew up, they had more opportunities to meet other young adults with eczema (e.g., at university) which may explain this shift away from feeling the need to feel normal. These psychosocial needs are also influenced by wider contextual factors including an individual's access to emotional support and the familiarity of those in their social circles. The need to feel normal and understood can be addressed when they find others with shared experiences, and when they have emotional support when these two needs are conflicting.

Discussion

The study identified three key psychosocial needs: the need to be understood, the need to be perceived as normal, and the need for emotional support. Adolescents and young adults described their eczema symptoms and how they perceived their self in their social context. Invisible symptoms, such as itch and pain led to the young people wanting to be understood and taken seriously and wanting their self to be visible. At the same time, visible symptoms led young people to wish they were not different to their peers and to have their 'self' be invisible, blending in with their peers.

This struggle between the need to be understood and fit in with their peers has been found in studies of adolescents and young adults with other skin conditions (e.g., psoriasis and epidermolysis bullosa) (Fox, Rumsey, & Morris, 2007; van Scheppingen, Lettinga, Duipmans, Maathuis, & Jonkman, 2008; Williams, Gannon, & Soon, 2011). However, what is unique in eczema is the high prevalence of the condition (which is often mild) as shown in the sub-theme of eczema as an identifiable label, familiar to many. This added a different challenge for young people with eczema that included unsolicited advice about treatment and symptoms and dismissing how serious eczema can be as a condition.

The need to conform is an important developmental step for adolescents and young adults with regard to identity formation, and physical appearance as a self-concept domain is given higher importance especially at early adolescence but this eventually changes and decreases over time (Young & Mroczek, 2003). Body image is perceived as an accumulation of sociocultural factors according to the sociocultural model (Tiggemann, 2002) and although usually applied to research around eating disorders and fitness, the standards and norms can still create pressure for adolescents and young adults with eczema to meet those standards.. There is a strong link between self-esteem and appearance satisfaction (Seidah & Bouffard, 2007). Just like other adolescents, physical appearance was important for those with eczema (Roje et al., 2016), and bullying and teasing was more likely to occur in childhood or adolescence as reported by adults with acne, psoriasis, and eczema (Magin, Adams, Heading, Pond, & Smith, 2008). The findings from the current qualitative study support that a decrease in the importance of conforming occurs over time especially when young people become more exposed to other young people with shared experiences. Shared experiences are an interesting aspect of social support, where young people can switch roles between offering help and needing help. Other patient groups seeking information on online platforms from individuals with shared experiences find it beneficial and a way of validating their own experiences (Wicks *et al*., 2010). Peer support can be a buffer for stress and negative experiences (Cohen et al., 2000) helping a young person build resilience by increasing self-efficacy, aiding self-esteem, promoting social comparisons, and encouraging effective coping (Dennis, 2003).

The findings of this study support that eczema can be burdensome to adolescents and young adults, but importantly it highlights the impact that the trivialization of the condition can have on them. A synthesis of qualitative work with caregivers of children with eczema and adults with eczema also reported experiences of others trivializing eczema, most reported that health care providers perceive eczema as a trivial condition because it was not life-threatening (Teasdale *et al*., 2020). Whilst all those dealing with eczema – children, adolescents, young adults, adults, and caregivers – experience psychosocial impact, the impact is specific to their role or developmental stage; for example, for children and adolescents report an impact on their social relationships, or taking part in activities whilst caregivers and adults also report the impact on routine and family life; however, all ages discuss the impact on emotional well-being (Teasdale *et al*., 2020). This suggests that the need for emotional support may not be age-specific, but the relationship between emotional well-being and the issues arising from experiencing both visible and invisible symptoms leading to the need to be understood and be perceived as normal is a struggle that adolescents and young adults experience.

The struggle between the need for the symptoms and impact to be understood conflicts with their need to blend in and not be noticed or perceived as different from their peers. Goal conflict can lead to emotional distress, as shown by previous qualitative work in adults with psoriasis in which internal goal conflict led to unresolved emotional distress and behaviours that increased non-adherence (Thorneloe, Bundy, Griffiths, Ashcroft, & Cordingley, 2017). Unresolved emotional distress may account for the need for emotional support that we determined from the two data sets in this study. This informed the wider project in developing an intervention that emotional support can be a key aspect for addressing how adolescents and young adults manage their eczema. The current study informed the guiding principles of intervention development (Yardley *et al*, 2015) to ensure the materials acknowledge how painful and disruptive eczema can be, to provide the message that they are not alone and to emulate the social support benefits that are achieved through shared experiences. Self-management of eczema does not occur in a vacuum and advice around behaviour should reflect the psychosocial context. By integrating the social context in the advice, the focus is leading what the adolescents and young adults would define as a 'normal' life. This particular guiding principle is also supported by work exploring caregivers' views about treatment non-adherence in paediatric long-term conditions where caregivers would welcome support and communication about integrating treatments in their everyday routines to continue 'normalcy' in their lives (Santer, Ring, Yardley, Geraghty, & Wyke, 2014).

Strengths and limitations

There are several limitations to this study that need to be considered. As this was a secondary analysis of two different data sets that were collected for different purposes, it was not possible to probe interviewees on topics further or carry out additional interviews to explore further psychosocial needs and how these needs may have changed over time. There are other potential pitfalls in using secondary analysis of data sets that were collected for other aims (Ziebland & Hunt, 2014); however, including both researchers that collected the data allowed a recontextualized analysis that deviated from the original aims from each project but kept an understanding of the origins of the data. Due to the nature of the secondary analysis, information such as current location of eczema was not collected for all interviewees and would have been a useful addition to exploring the visibility of eczema. The data sets were analysed with the goal to understand the specific needs of this age group to inform behavioural interventions for adolescents and young adults with eczema as current qualitative studies have only tried to understand experiences of this age group amongst adults with eczema and other skin conditions. This may have influenced how the data were analysed, identifying tangible findings about psychosocial needs.

Conclusions

Addressing the need for emotional support and validation could address the emerging emotional distress from their conflict elicited from visible and invisible symptoms related to their eczema. Understanding this conflict between wanting to conform to the norm as presented by their peers but also for their condition to not be trivialized is relevant to this age group and may have implications on how they deal with their eczema but also social situations. Providing personalized support considering the needs of this group can lead to adaptive behaviours that can help their social development. Such support can also help adolescents and young adults articulate their treatment goals, thereby improving their self-management of eczema and improving their quality of life.

Acknowledgements

Funding Sources: This publication presents independent research funded by the National Institute for Health Research (NIHR) Programme Grants for Applied Research (RP-PG-0216-20007). Data collection for Healthtalk.org was funded by National Institute for Health Research under its Research for Patient Benefit scheme (PB-PG-0213-30006). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Conflict of interest

All authors declare no conflict of interest

Data availability statement

The data that support the findings of this study are available from Healthtalk SKINS project. Restrictions apply to the availability of these data, which were used under licence for this study. Data are available from Healthtalk SKINS with the permission of Healthtalk SKI:NS.

References

Beattie, P. E., & Lewis-Jones, M. S. (2006). A comparative study of impairment of quality of life in children with skin disease and children with other chronic childhood diseases. *British Journal of Dermatology*, *155*(1), 145–151. https://doi.org/10.1111/j.1365-2133.2006.07185.x

Birdi, G., Cooke, R., & Knibb, R. C. (2020). Impact of atopic dermatitis on quality of life in adults: a systematic review and meta-analysis. *International Journal of Dermatology*, *59*(4), e75–e91. https://doi.org/10.1111/ijd.14763

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Chamlin, S. L. (2006). The psychosocial burden of childhood atopic dermatitis. *Dermatologic Therapy*, *19*, 104–107. https://doi.org/10.1111/j.1529-8019.2006.00060.x

Chamlin, S. L., Frieden, I. J., Williams, M. L., & Chren, M.-M. (2004). Effects of atopic dermatitis on young american children and their families. *Pediatrics*, *114*, 607. https://doi.org/10.1542/peds.2004-0374

Cohen, S., Gottlieb, B., & Underwood, L. G. (2000). Social relationships and health. In S. Cohen, L. G. Underwood & B. Gottlieb (Eds.), *Social support measurement and intervention: a guide for health and social scientist* (3 pp). Toronto: Oxford University Press.

De Vere Hunt, I., Chapman, K., Wali, G., Bullus, S., Fisher, R., Matin, R. N., & McPherson, T. (2019). Establishing and developing a Teenage and Young Adult dermatology clinic with embedded specialist psychological support. *Clinical and Experimental Dermatology*, *44*, 893–896. https://doi.org/10.1111/ced.13950

Dennis, C.-L. (2003). Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies*, *40*(3), 321–332. https://doi.org/10.1016/S0020-7489(02)00092-5

Fox, F. E., Rumsey, N., & Morris, M. (2007). "Ur skin is the thing that everyone sees and you cant change it!": Exploring the appearance-related concerns of young people with psoriasis. *Developmental Neurorehabilitation*, *10*(2), 133–141. https://doi.org/10.1080/13638490701217594

Ghio, D., Muller, I., Greenwell, K., Roberts, A., McNiven, A., Langan, S. M., & Santer, M. (2020). '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. *British Journal of Dermatology*, *182*(1), 112–118. https://doi.org/10.1111/bjd.18046

Gore, C., Johnson, R. J., Caress, A. L., Woodcock, A., & Custovic, A. (2005). The information needs and preferred roles in treatment decision-making of parents caring for infants with atopic dermatitis: a qualitative study. *Allergy*, *60*, 938–943. https://doi.org/10.1111/j.1398-9995.2005.00776.x

Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2017). Barriers to transition from pediatric to adult care: a systematic review. *Journal of Pediatric Psychology*, *43*, 488–502. https://doi.org/10.1093/jpepsy/jsx142

Halvorsen, J. A., Lien, L., Dalgard, F., Bjertness, E., & Stern, R. S. (2014). Suicidal ideation, mental health problems, and social function in adolescents with eczema: a population-based study. *Journal of Investigative Dermatology*, *134*, 1847–1854. https://doi.org/10.1038/jid.2014.70

Jowett, S., & Ryan, T. (1985). Skin disease and handicap: An analysis of the impact of skin conditions. *Social Science & Medicine*, *20*, 425–429. https://doi.org/10.1016/0277-9536(85)90021-8

Kosse, R. C., Bouvy, M. L., Daanen, M., de Vries, T. W., & Koster, E. S. (2018). Adolescents' perspectives on atopic dermatitis treatment—experiences, preferences, and beliefs. *JAMA Dermatology*, *154*, 824–827. https://doi.org/10.1001/jamadermatol.2018.1096

Lansing, A. H., & Berg, C. A. (2014). Topical review: adolescent self-regulation as a foundation for chronic illness self-management. *Journal of Pediatric Psychology*, *39*, 1091–1096. https://doi.org/10.1093/jpepsy/jsu067

Lewis-Jones, S. (2006). Quality of life and childhood atopic dermatitis: the misery of living with childhood eczema. *International Journal of Clinical Practice*, *60*, 984–992. https://doi.org/10.1111/j.1742-1241.2006.01047.x

Magin, P. J., Adams, J., Heading, G. S., & Pond, C. D. (2009). Patients with skin disease and their relationships with their doctors: a qualitative study of patients with acne, psoriasis and eczema. *Medical Journal of Australia*, *190*, 62–64. https://doi.org/10.5694/j.1326-5377.2009.tb02276.x

Magin, P. J., Adams, J., Heading, G., Pond, D., & Smith, W. (2008). Experiences of appearance-related teasing and bullying in skin diseases and their psychological sequelae: results of a qualitative study. *Scandinavian Journal of Caring Sciences*, *22*, 430–436. https://doi.org/10.1111/j.1471-6712.2007.00547.x

Mathiesen, S. M., & Thomsen, S. F. (2019). The prevalence of atopic dermatitis in adults: systematic review on population studies. *Dermatology Online Journal*, *25*(8), 1–9.

McNiven, A. (2018). 'Disease, illness, affliction? Don't know': Ambivalence and ambiguity in the narratives of young people about having acne. *Health*, *23*, 273–288. https://doi.org/10.1177/1363459318762035

Mizara, A., Papadopoulos, L., & McBride, S. R. (2012). Core beliefs and psychological distress in patients with psoriasis and atopic eczema attending secondary care: the role of schemas in chronic skin disease. *British Journal of Dermatology*, *166*, 986–993. https://doi.org/10.1111/j.1365-2133.2011.10799.x

National Institute for Health and Care Excellence (2007). Atopic eczema in under 12s: diagnosis and management. (cg57). Retrieved from https://www.nice.org.uk/guidance/conditions-and-diseases/skin-conditions/eczema.

Pittet, I., Berchtold, A., Akré, C., Michaud, P. A., & Surís, J. C. (2010). Are adolescents with chronic conditions particularly at risk for bullying? *Archives of Disease in Childhood*, *95*, 711. https://doi.org/10.1136/adc.2008.146571

Ring, J., Zink, A., Arents, B. W. M., Seitz, I. A., Mensing, U., Schielein, M. C., . . . Fink-Wagner, A. (2019). Atopic eczema: burden of disease and individual suffering – results from a large EU study in adults. *Journal of the European Academy of Dermatology and Venereology*, *33*, 1331–1340. https://doi.org/10.1111/jdv.15634

Roje, M., Rezo, I., & Buljan Flander, G. (2016). Quality of life and psychosocial needs of children suffering from chronic skin diseases. *Alcoholism and Psychiatry Research*, *52*, 15. https://doi.org/10.20471/apr.2016.52.02.04

Santer, M., Burgess, H., Yardley, L., Ersser, S., Lewis-Jones, S., Muller, I., . . . Little, P. (2012). Experiences of carers managing childhood eczema and their views on its treatment: a qualitative study. *British Journal of General Practice*, *62*(597), e261. https://doi.org/10.3399/bjgp12X636083

Santer, M., Ring, N., Yardley, L., Geraghty, A. W. A., & Wyke, S. (2014). Treatment non-adherence in pediatric long-term medical conditions: systematic review and synthesis of qualitative studies of caregivers' views. *BMC Pediatrics*, *14*(1), 63. https://doi.org/10.1186/1471-2431-14-63

Seidah, A., & Bouffard, T. (2007). Being proud of oneself as a person or being proud of one's physical appearance: what matters for feeling well in adolescence? *Social Behavior and Personality: an international journal*, *35*, 255–268. https://doi.org/10.2224/sbp.2007.35.2.255

Teasdale, E., Muller, I., Sivyer, K., Ghio, D., Greenwell, K., Wilczynska, S., . . . Santer, M. (2020). Views and experiences of managing eczema: systematic review and thematic synthesis of qualitative studies. *British Journal of Dermatology*. https://doi.org/10.1111/bjd.19299

Thorneloe, R. J., Bundy, C., Griffiths, C. E. M., Ashcroft, D. M., & Cordingley, L. (2017). Nonadherence to psoriasis medication as an outcome of limited coping resources and conflicting goals: findings from a qualitative interview study with people with psoriasis. *British Journal of Dermatology*, *176*, 667–676. https://doi.org/10.1111/bjd.15086

Thyssen, J. P., Hamann, C. R., Linneberg, A., Dantoft, T. M., Skov, L., Gislason, G. H., . . . Egeberg, A. (2018). Atopic dermatitis is associated with anxiety, depression, and suicidal ideation, but not with psychiatric hospitalization or suicide. *Allergy*, *73*(1), 214–220. https://doi.org/10.1111/all.13231

Tiggemann, M. (2002). Media influences on body image development. In T. F. C. T. Pruzinsky (Ed.), *Body image: A handbook of theory, research, and clinical practice* (pp. 92–8). New York, NY: Guilford Press.

van Scheppingen, C., Lettinga, A. T., Duipmans, J. C., Maathuis, C. G., & Jonkman, M. F. (2008). Main problems experienced by children with epidermolysis bullosa: a qualitative study with semi-structured interviews. *Acta Dermato Venereologica*, *88*, 143–150. https://doi.org/10.2340/00015555-0376

Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., . . . Heywood, J. (2010). Sharing Health data for better outcomes on patientslikeme. *Journal of Medical Internet Research*, *12*, e19. https://doi.org/10.2196/jmir.1549

Williams, E. F., Gannon, K., & Soon, K. (2011). The experiences of young people with Epidermolysis Bullosa Simplex: A qualitative study. *Journal of Health Psychology*, *16*, 701–10. https://doi.org/10.1177/1359105310387954

Yardley, L., Morrison, L., Bradbury, K., & Muller, I. (2015). The person-based approach to intervention development: application to digital health-related behavior change interventions. *Journal of Medical Internet Research*, *17*(1), e30. https://doi.org/10.2196/jmir.4055

Young, J. F., & Mroczek, D. K. (2003). Predicting intraindividual self-concept trajectories during adolescence. *Journal of Adolescence*, *26*, 586–600. https://doi.org/10.1016/S0140-1971(03)00058-7

Ziebland, S., & Hunt, K. (2014). Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. *Journal of Health Services Research & Policy*, *19*, 177–182. https://doi.org/10.1177/1355819614524187

Received 13 February 2020; revised version received 22 June 2020

Supporting Information

The following supporting information may be found in the online edition of the article:

Data S1 Interview Schedule – Healthtalk SKINS Project.

Data S2 Interview Schedule – Eczema Care Online Project