

Parent and child experience of skin conditions: Relevance for the provision of mindfulness-based interventions

Running head: Parent and Child Experiences of Skin Conditions

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Bulleted Statements

What's already known about this topic?

- Having a skin condition can be associated with significant psychosocial impacts for children.
- Parents and families may also experience impacts on quality of life and stress associated with caring for a child with a skin condition.
- There remains a lack of evidenced based psychological interventions available to support children and families.

What does this study add?

- This study highlights how parents and children encounter a wide range of challenges associated with living with a skin condition.
- This study is the first to investigate the relevance of offering mindfulness-based interventions, and the findings suggest that such interventions are relevant and desirable.
- However, the findings also indicate that a number of misconceptions exist about the fundamental nature and aims of mindfulness.

What are the clinical implications of this work?

- Parent and child narratives highlight the gap in current services, placing emphasis on the need for dermatological treatment to embed psychological assessment and intervention into existing treatment pathways.
- Psychological approaches that utilise mindfulness based techniques were seen as likely to be acceptable, feasible, and have the potential to be effective.
- The misconceptions that may exist about the nature and aims of mindfulness need to be considered when planning future studies and service delivery.

Summary

Background: Managing a skin condition can be difficult, and there is a lack of psychological support for children and their families.

Objectives: The objectives of this study were to identify issues surrounding caring for a child with a skin condition, investigate experiences of current psychological support to gain a sense of what is needed, and determine the relevance of offering mindfulness-based interventions for children and families.

Design: This study employed a mixed inductive and deductive form of qualitative inquiry to understand children and families experiences and needs.

Methods: Twenty-three participants (n=12 parents/carers, n=11 female, n=1 male), (n=11 children, n=6 female, n=5 male, aged 8-11 years) were recruited with an advert posted on social media. In-depth data was collected from semi-structured interviews. Interviews were recorded, transcribed, and analysed with a descriptive form of thematic analysis.

Results: Systematic analysis of the data led to five themes being developed: (1) Caregiver burden of childhood skin conditions; (2) Skin condition overshadowing childhood; (3) Battling for recognition and lack of support; (4) Naturalistic use and understanding of mindfulness in everyday coping; and (5) Openness and relevance of offering a mindfulness-based interventions.

Conclusions: Living with a skin condition was reported as being associated with mood disturbance, with impacts on schooling, sleep, and daily life. Parents and children expressed a desire for short/accessible interventions that could fit with daily routines and might provide the opportunity to connect with other families. The findings indicate that mindfulness-based interventions may be likely to be accepted, as many participants had experience of using mindful techniques in school, and described that they were naturalistically using 'mindfulness' to manage itch and stress. However, the findings indicate that a number of misconceptions exist about the fundamental nature and aims of mindfulness. Addressing misconceptions related to mindfulness need to be considered when planning both future studies and service delivery.

1. Introduction

Having a condition affecting appearance as well as functioning during childhood and early adolescence could have a lasting impact on social development and adult personality.¹⁻³ Childhood skin conditions have potential to create a psychological burden at a time when identity is developing and may affect individuals equally, regardless of gender.⁴ There might also be implications for the family, specifically for the child's main caregiver's psychological wellbeing⁵ and sleep.^{6,7} Parents may share the burden of their child's skin condition from the demands of attending appointments, and increased housework from shedding skin and unpleasant treatments.⁸⁻¹³ Meeting care needs could undermine self-care and result in parents encountering their own health problems. For example, emotional disturbances have been found in mothers of children with skin conditions^{14,15} and impairments to quality of life in parents of children with vitiligo, and alopecia.¹⁶⁻¹⁹ The associated stresses might affect the child's skin itself, as many inflammatory skin conditions involve interactions between the environment, the immune system, and the central nervous system.²⁰

Despite the challenges associated with skin conditions, the psychological burden for children remains under researched.²¹ As such, there is a lack of psychosocial interventions for children/parents, and those that do exist are mostly educational or target adults.²²⁻²⁴ This is problematic for two reasons: 1) service developments are currently unable to draw on evidence from interventions with solid theoretical underpinnings, and 2) existing evidence is limited in the extent to which it is child centred. A theoretical approach increasingly being integrated into psychotherapeutic interventions, is mindfulness. Mindfulness involves "paying attention to the present moment, non-judgmentally and on purpose" (p.4).²⁵ Holding and developing a sense of non-judgemental acceptance has been reported to be linked to reducing stress and interrupting negative ruminative cycles associated with maintaining distress.²⁶

Mindfulness, and the related concept of self-compassion have previously shown success for improving the quality of life of adults with skin conditions.²⁷⁻³² Self-compassion involves three factors including self-kindness to instances of pain and failure as opposed to self-judgement; understanding to suffering as a shared human experience as opposed to feeling separated by such suffering; and an ability to be mindful of distressing thoughts and feelings as opposed to being fixated with them.^{33,34} There may be an association between mindfulness and distress, with the approach reducing negative illness-related outcomes from

regulating the stress response and changing how stressors are appraised.^{26,27-32,35} Altering the perception of skin-related phenomena could lessen stress from decreasing rumination about symptoms, or worry about adverse reactions from other people.²⁶ Further, enhancing self-compassion as part of mindfulness-based interventions could bring additional benefits via facilitating an attitude of kindness towards the self.²⁷ Indeed there is evidence for the use of mindfulness based parenting interventions in targeting parental stress associated with parenting a child with a long-term condition.³⁶⁻³⁸ Specifically, mindful parenting has been evaluated as an intervention with parents of children with psoriasis and eczema and was found to reduce parental stress.³⁹

Further dyadic research is needed to explore the impact of childhood illness on families and to investigate which types of psychosocial intervention might be most appropriate to develop and test.^{5,40} Consequently, the present study was guided by the Medical Research Council framework⁴¹ for using qualitative data to understand phenomena with participant accounts of needs/barriers to interventions.⁴¹⁻⁴³ A dual deductive and inductive interpretative thematic analytic approach was adopted.^{44,45} This enables consideration of existing knowledge, whilst at the same time enabling space for pertinent issues important to the participants to be identified. Thus, the aims of this study were to: (1) identify issues surrounding caring for a child with a skin condition, and current support resources, (2) gain feedback on what is needed from future interventions, and (3) specifically explore the relevance of offering mindfulness-based interventions.

1. Materials and methods

1.1. Design

This study employed qualitative inquiry with dyadic semi-structured interviews to investigate parent and child experiences of skin conditions.

1.2. Participants

Using purposive sampling, 23 participants were recruited (see Table 1 for parent demographics, and Table 2 for child demographics).

[TABLE 1 HERE]

[TABLE 2 HERE]

1.3. Recruitment

This study was approved by Cardiff University ethics committee (EC.21.04.20.6335R2A4). Participants were recruited via social media (Facebook, Twitter, Instagram, LinkedIn, Yammer). The study was also advertised in school and community magazines, and through internal University and charity email lists. Eligible children were a) 8-11 years, b) diagnosed with any skin condition, and c) English language speakers. Eligible parents were a) 18 years or over, b) the child's main caregiver(s), and c) English language speakers. Families volunteered by email and confirmed their eligibility. No participants were excluded based on the inclusion criteria, and there were no drop-outs.

According to Braun and Clarke,^{46,47} meaning in qualitative research is established from subjective interpretations, making data collection iterative and sample sizes undeterminable from data saturation alone. Therefore, based on the theoretical basis showing a gap in support, combined with the strength of interview dialogue, the data was regularly assessed by researchers until consensus was reached regarding the study having gained sufficient information to address the aims.⁴⁵⁻⁴⁸

1.4. Semi-structured interviews

All interviews were held online for convenience and flexibility (following COVID-19 restrictions). The interviews lasted approximately one hour, and participants were given the choice of being audio or video recorded. Parents and children were interviewed separately, with two flexible schedules to guide discussions (see Table 3 for parent questions, and Table 4 for child questions).

[TABLE 3 HERE]

[TABLE 4 HERE]

1.5. Measures

1.5.1. Demographics

Parents provided information on age, gender, ethnicity, geographic location, employment status, skin condition, and length of time since diagnosis.

1.5.2. Family Dermatology Life Quality Index (FDLQI)

To provide additional contextual information, the Family Dermatology Life Quality Index (FDLQI)⁴⁹ was used to measure parent/carer quality of life. The FDLQI is a self-report questionnaire consisting of 10-items assessing how the family member's skin condition has affected quality of life, with two factors (psychosocial/physical impact).

1.5.3. Children's Dermatology Life Quality Index (CDLQI)

To gather further contextual information on the participating sample the Children's quality of life was measured with the Cartoon version of the Children's Dermatology Life Quality Index (CDLQI).⁵⁰ The CDLQI is a self-report questionnaire presenting 10-items assessing quality of life in six areas (symptoms/feelings, leisure, school/holidays, relationships, sleep, treatment).

1.6. Thematic Analysis

Data was analysed with thematic analysis.⁴⁵⁻⁴⁷ This method was appropriate for the study objectives as it produces novel insights into health-related phenomenon, and has previously been applied to burn injuries,⁵¹ visible difference,⁵² and skin conditions.⁵³ O.H led the data analysis, and began by transcribing interview recordings verbatim and assigning pseudonyms to protect identities. To generate themes, participant comments were highlighted to form preliminary codes, followed by systematic coding across datasets. Themes and subthemes were developed from shared meanings, and cross-referenced with raw data. To maintain rigour, O.H, K.H.S and A.R.T conducted appraisals of information power⁴⁸ by frequently assessing data to confirm it was of high relevance.⁴⁶⁻⁴⁸ An audit process was conducted by the research team (K.H.S and A.R.T), who looked at data during each stage of analysis to corroborate the process had been adhered to.

2. Results

Child quality of life measures showed a range of levels of impact from 'no effect' (n=1 vitiligo) to 'small effect' (n=3 eczema), 'moderate effect' (n=2 eczema, n=2 ichthyosis, n=1 vitiligo, n=1 psoriasis), and 'extremely large effect' (n=1 psoriasis). Whilst quality of life scores also ranged for parents, with the highest percentage of impairment being 70.00% (n=1 psoriasis), followed by 53.33% (n=2 ichthyosis), 46.76% (n=1 eczema), 23.33% (n=1 psoriasis, n=1 ichthyosis), 16.67% (n=2 eczema), 13.33% (n=2 vitiligo, n=1 eczema), and last, 6.76% (n=1 eczema). Despite the variation in scores, the collected qualitative data nearly

all spoke of some degree of significant psychological impact, and one child with severe psoriasis and their parent equally showed the greatest impairment. Two children with eczema and vitiligo reported the least impairment to quality of life, but their parents scores were higher, perhaps evidencing a caregiver burden. From thematic analysis, five themes and seventeen subthemes were developed (Table 5) and will be discussed with supporting quotes (P; for ‘parent’, and C; for ‘child’).

[TABLE 5 HERE]

2.1. Caregiver burden of childhood skin conditions

Parents described the burden of providing care for a child with a skin condition, including managing treatment regimens and coping with fluctuations in disease severity.

2.1.1. Living with uncertainty: The unknowns of treatment decisions and condition progression

Parents discussed the difficulties of being in a situation with uncertainty surrounding whether the appropriate treatment had been decided, and worries about their child’s skin condition worsening:

“This internal voice inside me going ‘am I doing the right thing?’...that’s pretty much a constant voice...it’s affected my quality of life” (P5).

“It’s a rare disease and you don’t know what’s going to happen...we’ve got a lot better at living in the moment...because there is so much uncertainty” (P11).

2.1.2. Impact on mood

The psychological impact of providing care for a child with a skin condition on was discussed, with some parents experiencing a “rollercoaster of emotions” (P11):

“It is a form of stress...a small dark cloud...just a thought, and sometimes that thought floats into my head, stays there for a while, and then floats out” (P5).

In some cases, parents blamed themselves for passing on a hereditary condition, and reported feeling ‘guilt’ from not being able to ease painful symptoms:

“It is hard, because you feel guilty...it’s hereditary” (P6).

In some cases, parents described how conflict arose with their child, over how to administer creams:

“She’ll say, ‘why are my legs still dry after I’ve had a bath?’ and I’ll say, ‘it’s because you’ve rubbed your cream off’...and that’ll cause conflict because she has a different opinion” (P10).

2.1.3. “Extra leg work” of additional considerations, housework, and costs.

Parents reported having increased duties of care, including blood-stained bedding, which added to the strain of coping:

“There’s so many extra things to think about, you can’t just get up and go” (P11).

“There’s blood all over the bed...you’re like ‘has something serious happened?’...you have a momentary panic” (P1).

Additional household costs were mentioned by parents, from using more water to bath eczema:

“We’re sticking him in the bath pretty much every day...it does add up” (P8).

2.1.4. Being more prepared: Parent and family as experts by experience

Many of the skin conditions had genetic links, and parents described how knowing the condition was hereditary made them more prepared to care for their child with the same condition, from their own experience:

“It was helpful that my husband has psoriasis...it was something relatable” (P9).

“We knew what to do...because [ichthyosis] runs in the family we know that although it’s an inconvenience, it hasn’t ever stopped anybody” (P10).

2.2. Skin condition overshadowing childhood

Skin conditions were described as having a profound impact on the child’s daily life, influencing mood, school, clothing, and confidence.

2.2.1. Skin influencing mood and flaring from emotion

Children described how itch was an intense and defining feature, and in many cases, the physical sensation of itching, and the desire to scratch influenced affect:

“The itching doesn’t go away, the itch is always there” (C11).

“It pricks and it really just annoys me...it’s the beginning of anger...because it’s not allowing me to put my full concentration on doing something” (C7).

Children described noticing a relationship between their thoughts and the physical feelings in their skin:

“When I’m nervous it gets really flaky...when I’m happy it’ll go down and it’ll be red but without the little white bits...but when I’m annoyed and fed up, that causes the flakiness” (C6).

“If it’s really bad I get really sad...it starts to feel a bit prickly when I’m sad” (C1).

2.2.2. Low confidence and shame: Negative appraisals from other people

Parents felt their child had “no confidence” (P6) and had become “shy and withdrawn” (P11). This was supported by children, who described feeling different to peers, reflecting a desire to ‘fit in’, and in some cases, they had experienced intrusive comments from others:

“I’m kind to other people but to myself it’s hard...I feel different to other people” (C1).

“People asked me like ‘eww what’s that, is it contagious?’...and that just broke me for the rest of my life and still to this day I still think about some of the things they said” (C6).

2.2.3. Impeding daily life: Sleep, school, and clothing choices

Participants described the shared impact the skin conditions had on their daily life, including disruptions to sleep from intense itching at night:

“When you’re itching, and you can feel the pain and how it hurts you can’t really fall to sleep because it’s irritating you” (C2).

Children reported how their skin irritated them at school, and interrupted their work from becoming distracted by the physical discomfort and itch:

“It’s itchy and I keep getting the thought in my head to scratch it while I’m in the middle of doing my work and I can’t think of the sum in maths” (C8).

Some children described dressing differently to their peers, and adapting their clothing choices to conceal their skin condition:

“I don’t think I’ve ever taken my blazer off in school” (C6).

2.2.4. Better with older age: Challenges of caring for a younger child

However, parents discussed how caring for their child with a skin condition had become easier with increasing age, as they were more capable of taking responsibility for treatment:

“When she was a small baby...it was extremely intensive...but as she’s gotten older...she’s taken more of a hand in doing that herself” (P11).

2.3. Battling for recognition and lack of support

Parents described the “fight” for a diagnosis, and the “battle to try and explain” (P3) their child’s symptoms. Participants often felt they had not been fully acknowledged by

medical professionals.

2.3.1. Not offered psychological support

Of the eleven families, ten had not been offered specialised psychological support for living with a skin condition:

“There’s nothing available to help...it’s seen as cosmetic...but it affects them mentally and their mental health more than everything else” (P6).

“I’ve not had any support from a doctor” (C1).

2.3.2. Feeling dismissed and marginalised as a parent carer

Parents often felt marginalised from having a child with a skin condition, which was perpetuated by a lack of resources tailored for children:

“Everything was for adults, not children...even the print outs of the leaflets and information we’ve had, they’re not child friendly” (P9).

2.4. Naturalistic use and understanding of mindfulness in everyday coping

When discussing coping on a daily basis, participants described using strategies overlapping with mindfulness-based concepts such as acceptance, self-compassion, and use of focused attention.

2.4.1. Feeling safe and accepted with friends

Children described how having supportive friends provided comfort and acceptance during periods of skin-related distress:

“I can’t do anything on my own...I always need someone there just in case someone does stare at me” (C6).

“I feel okay about it because I know that my friends make me happy when I’m sad” (C10).

2.4.2. Breathing through the stress

Several participants used breathing techniques to manage the stress associated with the skin condition. One child described a direct relationship between slow breathing, and the physical sensation of itch intensity:

“I breathe in and out...my breathing slowly makes the itch go away...it like calms my skin down...it slowly washes the eczema away... out of my body” (C7).

2.4.3. Self-compassion with affirmations and a positive mindset

Children described the significance of other people’s judgements, which many managed by rehearsing positive affirmations:

“It doesn’t matter if you have things going on with your skin, you’re just like other people” (C3).

“If I was thinking about being so different from everybody else, then I would probably think something like ‘we are all humans’ and ‘we are all the same’ and ‘it doesn’t matter what we look like’, it matters what we feel like and if we’re kind” (C5).

In addition, some parents adopted a positive mindset to cope during times of stress when their child had been unwell:

“We were doing what we could to keep ourselves focused on the positive things in a very unsettling and uncertain environment” (P11).

2.4.4. Focused attention and mental imagery

Children discussed controlling itch by tuning in to physical sensations in the body. This strategy involved moving attention to the itch with mental imagery, and appeared to change the physical experience of the skin condition itself:

“I use my concentration to fight [the itch]...I have this method of imagining what it’s like and moving your energy to different parts of your body...the energy burns out the eczema and the itch” (C7).

“When I focus on the itchiness, I feel it more” (C11).

2.5. Openness and relevance of offering a mindfulness-based intervention

Some children practiced mindfulness in school which meant the approach was familiar to them, and they were able to make connections with managing their skin.

2.5.1. Familiarity with the concept of mindfulness

Children described how mindfulness had been beneficial, and noticed the feelings they had in their body when practicing. Nevertheless, some of these descriptions highlighted a degree of misunderstanding of the theoretical concept of mindfulness:

“That helped me...I just wasn’t in the mood for thinking about things, I just kind of was focused on being calm” (C4).

“It really helps keep my brain quiet and nice and empty...because I’m focusing on colouring, I don’t feel [the eczema]...it helps me take my mind off it” (C7).

2.5.2. Thoughts on trying a mindfulness-based intervention

Participants described the relevance of mindfulness to their skin conditions, and how they thought practicing the technique could promote adaptive coping. Although, these quotes demonstrate some fundamental misunderstandings about the concept of mindfulness:

“If you have a way to send happy thoughts then you would think those happy thoughts and then know that they’re happy, and you would feel happy” (C5).

“If she’s feeling in a better emotional state...[it will] help her manage stress and anxiety on a day-to-day basis and she can use those tools...to help with flare ups” (P9).

2.5.3. Dyadic needs and expert recommendations for a useful resource

Children provided suggestions as experts by experience regarding their views on the delivery of a mindfulness-based intervention:

“I’m a big fan of technology, if I’m doing something on a computer, I just completely forget about all of my thoughts” (C1).

When asked if there were any barriers, parents described how finding the time to commit to a time-consuming intervention would be challenging, and expressed a preference expressed for short exercises:

“Something that can fit into routine...if you think about moisturization, you put loads on, and then you’re like ‘what am I supposed to do now?’...but maybe you put your creams on, and then ‘you do this’, and by the time it’s finished your creams have dried” (P1).

In some cases, participants described living with the skin condition as “quite isolating” (A1), which led to the suggestion of connecting with other families:

“It would be cool if I had a club where I could talk about how you’re feeling.” (C2).

3. Discussion

Our findings support existing literature indicating that skin conditions can have a significant psychological impact on families.²¹ Parents described a range of challenges connected to caring for their child^{11,12} including extra considerations when leaving the house, managing uncertainty surrounding disease progression, upkeeping treatment, additional housework,^{9,10} and increased financial expenditure. These challenges reduced quality of life by adding to the pressures of parenting, influenced mood, and perpetuated stress.¹⁴⁻¹⁹ Parents reported feeling ‘guilt’ from passing on a hereditary condition, which has been previously found in chronic skin conditions,²¹ and other physical illnesses such as lymphedema.⁵⁴ Parents also questioned whether they were doing enough, supporting findings from parents of children with eczema feeling like they are ‘failing.’^{55,56}

For children, skin conditions caused a significant amount of pain from scratching itchy skin.⁵⁷⁻⁵⁹ In this study, itch was described by the majority of children as the defining feature of their skin condition, suggesting intense itch is one of the main symptoms children need support to manage.⁶⁰ The physical discomfort was described by children as precipitating a feeling of difference from their peers, which was exacerbated by the struggle of dressing differently in comfortable clothing.⁵⁹ Children reported being distracted by the symptoms of their skin condition at school, and described how their mood was affected^{13,61} from feelings of anger⁶² at their concentration being interrupted, to sadness when they experienced a flare-up, and distress from intrusive comments.¹⁷

This is the first study to investigate the relevance of mindfulness-based interventions for families affected by skin conditions. Of the eleven families interviewed, only one parent-child dyad had been offered a specialised psychological intervention, with the remaining ten dyads describing a lack of support.⁶³ Parents expressed a desire for dermatological care to integrate greater psychological awareness into treatment, which might be achieved using mindfulness as many children were familiar with the approach from school. Unexpectedly, some children were naturalistically practicing strategies overlapping with mindfulness concepts such as positive affirmations building self-compassion,^{33,34} a facet of mindfulness that has been found to reduce shame and improve quality of life in adults with skin conditions.^{64,65} In addition, the children living well with their skin conditions could be explained by (self-)acceptance from peers reducing reactivity to negative affect.⁶⁶

Children described how itch increased when they thought about their skin, and caused them to worry.²⁶ This cycle could be targeted with mindfulness, as previous research into worry about itch in atopic dermatitis suggests a relationship between the mindfulness facet “acting with awareness” and itch catastrophizing.⁶⁷ A mindful approach to itch could involve noticing the itch and the related impulse (e.g., scratching the itch), but not acting on that impulse. Children also described moving their attention away from their skin condition by engaging in activities such as playing with friends, watching videos, reading, and drawing. Although these activities could promote positive affect and acceptance, there could be overlap with previous findings distinct from mindfulness facets, such as using distraction to reduce itchy skin in atopic dermatitis and psoriasis with audio-visual distraction techniques.⁶⁸

Suggestions for future interventions included short exercises that fit into daily ‘routine’,

the incorporation of skin-specific, and dyadic exercises. There was a desire for interventions to be quickly accessible, using an online format^{69,70} and parents felt it would be helpful to connect with other families. Although children provided useful insights of how mindfulness could be used to manage their skin condition (e.g., with awareness of itch, instead of avoidance), there were also misconceptions of the concept evident in the data. For example, some participants incorrectly spoke of ‘mindfulness’ in relation to trying to avoid unpleasant thoughts or change present experience, and such misinterpretations of mindfulness have been reported elsewhere in the literature.^{71,72} It was difficult to ascertain the overall understanding of mindfulness, and future studies are needed to investigate this issue further.

The study does have several limitations. Whilst the study deliberately sought in-depth data from a small sample, the findings may only be reflective of this particular group of participants, and generalisability to other conditions might be limited. Further, the diversity of the sample also limits transferability. There was an underrepresentation of fathers in our study, focused entirely with a British sample. Therefore, the conclusions drawn about mindfulness may not be shared across groups. Although the interview questions were asked in an open way regarding future psychological support, asking specifically about ‘mindfulness’ may have led to demand characteristics and reduced the likelihood of negative views being elicited. Further investigations are required to explore the needs of families affected by skin conditions, and there is a need to purposively sample to ensure research is inclusive of fathers and people from a wider range of ethnic backgrounds. Our findings also demonstrate that future research in this area needs to be sensitive to considering how to manage the potential for misconceptions about mindfulness.⁷³

Overall, skin conditions have the potential to negatively impact children and their families. There is a lack of psychological support for children with skin conditions, which must be considered in the dermatological stepped care pathway. Herein, mindfulness might be appropriate, as children in this study often practiced the approach in school and in some cases, adopted a mindfulness mindset to manage symptoms.

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Table 1. Participant demographics: parents (n=12)

Characteristic	Number
Gender	
Female	11
Male	1
Relationship to child	
Mother	11
Father	1
Age (years)	
35-40	2
40-45	9
45-50	1
Ethnicity	
White British	9
White Scottish	1
White Irish	1
Mixed British	1
Employment status	
Full-time work	5
Part-time work	4
Volunteer/unpaid care work	2
Homemaker	1
Geographic location	
Wales, UK	3
England, UK	6
Scotland, UK	1
Europe	2
FDLQI scores: impact of condition 0-30 (% out of total score of 30)	
2 (6.76%)	1
4 (13.33%)	3
5 (16.67%)	2
7 (23.33%)	2
14 (46.76%)	1
16 (53.33%)	2
21 (70.00%)	1

Note: FDLQI: Family Dermatology Life Quality Index.

Table 2. Participant demographics: children (n=11)

Characteristic	Number
Gender	
Female	6
Male	5
Age (years)	
8-9	6
10-11	5
Skin condition	
Eczema	5
Psoriasis	2
Vitiligo	2
Ichthyosis	2
Age of diagnosis	
0-8 months	4
1-2 years	1
3-4 years	3
5-6 years	2
7-8 years	1
Ethnicity	
White British	6
White Welsh	1
White Scottish	1
Mixed British	2
Mixed British Asian	1
Geographic location	
Wales, UK	3
England, UK	6
Scotland, UK	1
Europe	1
CDLQI scores: effect of condition (0-30)	
No effect on child's life (0-1)	1
Small effect (2-6)	3
Moderate effect (7-12)	6
Extremely large effect (19-30)	1

Note: CDLQI: Child Dermatology Life Quality Index

Table 3: Example parent/carer interview questions

Question
<ul style="list-style-type: none">• From your experience, what do you think are the issues surrounding current available support options for children with skin conditions and their families?• What do you think would be the most helpful aspect to include in future support or psychological support?• What are your thoughts on trying some mindfulness exercises such as slow breathing, meditation, or focussing your attention on one thing in your mind, to help you relax?

Table 4: Example child interview questions

Question
<ul style="list-style-type: none">• Your mum/dad/carer told me you've got <i>*skin condition*</i>, can you tell me a little bit about your <i>*skin condition*</i>?• Some children say that having a skin condition can affect their hobbies, and other children say it doesn't. What is it like for you?• We might make some activities like slow breathing or focussing on one thing in your mind to help you relax; how would you feel about that?

Table 5: Themes and subthemes

Theme	Subtheme
1. Caregiver burden of childhood skin conditions	1.1. Living with uncertainty: The unknowns of treatment decisions and condition progression 1.2. Impact on mood 1.3. “Extra leg work” of additional considerations, housework, and costs 1.4. Being more prepared: Parents as experts by experience
2. Skin condition overshadowing childhood	2.1. Skin influencing mood and flaring from emotion 2.2. Low confidence and shame: Negative appraisals from other people 2.3. Impeding daily life: Sleep, school, and clothing choices 2.4. Better with older age: Challenges of caring for a younger child
3. Battling for recognition and lack of support	3.1. Not offered psychological support 3.2. Feeling dismissed and marginalised as a parent carer
4. Naturalistic use and understanding of mindfulness in everyday coping	4.1. Feeling safe and accepted with friends 4.2. Breathing through the stress 4.3. Self-compassion with affirmations and a positive mindset 4.4. Focused attention and mental imagery
5. Openness and relevance of offering a mindfulness-based intervention	5.1. Familiarity with the concept of mindfulness 5.2. Thoughts on trying a mindfulness-based intervention 5.3. Dyadic needs and expert recommendations for a useful resource