

ORCA - Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository:https://orca.cardiff.ac.uk/id/eprint/170656/

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Hughes, Olivia, Shelton, Katherine H., Penny, Helen and Thompson, Andrew R. 2024. 'Living in the present' Mindfulness intervention for parents of children with skin conditions: A single group cases series. Behavioural and Cognitive Psychotherapy

Publishers page:

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See http://orca.cf.ac.uk/policies.html for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



'Living in the Present' Mindfulness Intervention for Parents of Children with Skin Conditions: A Single Group Cases Series

Abstract

Background: Parents of children with skin conditions can experience stress from additional responsibilities of care. However, there is a lack of psychological interventions for families affected by a dermatological diagnosis. **Aims:** To investigate (1) whether delivering the Living in the Present mindfulness curriculum to parents of children with skin conditions reduced stress and increased both parental/child quality of life (QoL), and (2) determine intervention acceptability.

Method: Ten parents of children with eczema, ectodermal dysplasia, ichthyosis, and alopecia took part in a mindfulness-based intervention. Using mixed methods, a single-group experimental cases design (SCED) was conducted and supplemented by thematic analysis of exit interviews. Parents completed idiographic measures of parenting stress, standardised measures of QoL, stress, mindfulness, and took part in exit interviews. Children also completed QoL measures.

Results: Tau-U analysis of idiographic measures revealed three parents showed some significant improvements in positive targets, and five parents showed some significant improvements in negative targets. Assessment of reliable change demonstrated that; one parent showed improvement in mindful parenting, three parents showed improvement in parenting stress, seven parents showed improvement in anxiety, three parents showed improvements in depression, six parents showed improvement in QoL, and four children showed improvement in QoL. However, two parents showed increased anxiety. Thematic analysis revealed positive changes to mood following mindfulness, although challenges were highlighted, including sustaining home practice.

Conclusion: Findings suggest this specific form of mindfulness intervention could be effective for parents of children with skin conditions, however, further robust studies are needed.

Key words: mindfulness, childhood skin conditions, parenting stress, single case experimental design.

Main Text

1. Introduction

Parents caring for a child with a skin condition can have demanding routines encompassing a range of additional responsibilities such as administering intensive treatments and attending regular hospital appointments (Hughes et al., 2022; Ablett & Thompson, 2016). Meeting the practical and psychological needs of their child can be time consuming and parents might have to draw upon their levels of resilience and self-compassion at the expense of their own psychological wellbeing or self-care (Cousineau et al., 2019; Hughes et al., 2022). Parents and children affected by skin conditions have expressed a desire for greater access to psychological support and the opportunity to connect with other families with similar experiences (Hughes et al., 2022).

Mindfulness is being increasingly applied across a variety of healthcare settings and involves developing the ability to observe what is happening in the present moment, without judgement (Kabat-Zinn, 1994). The approach has shown promise as an effective intervention for children with physical health conditions, and their parents (Ruskin et al., 2021; Hughes et al., 2023). For example, psychological flexibility and self-compassion could be important mechanisms to target with mindfulness-based approaches. Increasing openness to experience and kindness towards the self could help parents of children with skin conditions manage stress and feelings of uncertainty surrounding treatment and disease progression (e.g., Hughes et al., 2021). Indeed, there has been some evidence to suggest that levels of dispositional mindfulness could be associated with greater wellbeing in parents of children with psoriasis or eczema, and their children (Heapy et al., 2021).

Many inflammatory skin conditions have been associated with increased levels of perceived stress (Balieva et al., 2022). For children with skin conditions, there could be secondary beneficial outcomes from calmer parental interactions. Heapy et al (2022) delivered a mindful parenting intervention to parents of children with eczema and psoriasis and reported reductions in parental stress. However, mindful parenting is a time-intensive intervention, and future research could investigate alternative methods of delivery to reduce the demands placed on parents and limit time spent travelling (Heapy et al., 2022). To increase feasibility and make

mindfulness more achievable for busy parents, there may be value in short, accessible interventions with an online delivery (Hughes et al., 2022). The intensity of mindfulness sessions and amount of formal practice required could also be reduced and replaced with exercises that can fit into pre-existing daily routines (Heapy et al., 2022; Hughes et al., 2022). As such, mindfulness lends itself to a transtheoretical approach to the management of stress (Kabat-Zinn, 1994).

The aims of this pilot study were to: (1) investigate whether delivering the 'Living in the Present' curriculum (The Present Courses, 2022) to a group of parents of children with skin conditions could reduce levels of parental stress and increase parent and child quality of life (QoL); and (2) determine acceptability of a novel mindfulness-based intervention. Participation in the Living in the Present curriculum was hypothesised to reduce levels of parenting stress and improve parent and child quality of life.

2. Method

2.1. Design

Approval was granted from the University departmental ethics committee (EC.22.04.26.6558RA3), and authors abided by the British Psychological Society (BPS, 2013) code of human research ethics. This study used mixed methods, including a single cases experimental design (SCED) and qualitative exit interviews subjected to thematic analysis. SCED was used as the study examined a small group of parents over a set period, and measured target outcomes across each phase (Morley 2018; Krasny-Pacini & Evans, 2018). By gathering and analysing data from a baseline period, SCEDs repeatedly measure behaviour in the presence and absence of an intervention, with each participant acting as their own control (Krasny-Pacini & Evans, 2018). SCEDs make it possible to gather high-quality data with small populations to assess an intervention's effectiveness using patient demographics rather than clinical impressions to guide practise (Morley, 2018; Krasny-Pacini & Evans, 2018). Studies piloting novel interventions with "atypical cases" (i.e., samples who are not the intended targets) can benefit from this (Morley, 2018; Krasny-Pacini & Evans, 2018). SCED have been used previously to investigate mindful parenting for parents of children with skin conditions (Heapy et al., 2022) and MBCT for adults with alopecia (Heapy et al., 2023).

The SCED was an 'A-B-A' design, whereby phase 'A' was a 1-week baseline period, phase 'B' was an 8-session intervention delivered over 10-weeks, and phase 'A' consisted of a 1-week follow-up period (Morley 2018). The main outcome variable was a bespoke measure of parental stress related to parenting a child with a skin condition (Morley, 2017). The criteria used to determine feasibility and acceptability was based on parental measures of stress and quality of life, including the suitability of measures, recruitment strategy, attendance/attrition, combined with qualitative questions surrounding how they interacted with the intervention (Sekhon et al., 2017).

2.2. Participants

An advert was posted on social media. N=10 parents took part in the intervention and completed study measures (Table 1). Of these parents, n=8 of their children (when aged 4 years or over) completed QoL measures. The mindfulness teacher (n=1) also took part in a qualitative exit interview.

[TABLE 1 HERE]

2.3. Inclusion criteria

Parents were required to be over 18 years old and carer to a child (under 16 years), diagnosed with a skin condition. Children were required to be under 16 years old and be diagnosed with diagnosed with a skin condition.

2.4. Measures

2.4.1. Idiographic parental targets or goals

Parents identified one positive target (aspect related to parenting a child with a skin condition they wanted to improve) and one negative target (aspect related to parenting a child with a skin condition they wanted to reduce). Idiographic measures were the primary outcome variable and were collected via text message four times per week. An example text message was as follows:

"Dear *parent's name*,

1. How much success have you had today with feeling calmer about *child's name* playing in sand, water, playing on grass, swimming, or visiting dusty environments?

2. How much stress did you feel today when asking *child's name* to stop scratching?

Please respond to each question on a scale from 0-100, with "0" being "not at all" and "100" being "extremely frequently." When replying please indicate question numbers (e.g., "Q1=75", "Q2=55")."

2.4.2. Standardised measures

Parents provided demographic information including age, gender, ethnicity, geographic location, employment status, the type of skin condition their child had been diagnosed with, and the length of time they had experienced symptoms. Secondary outcomes included self-reported measures of mindfulness, parental stress, parental depression, parental anxiety, parental quality of life, and child quality of life (where the child was old enough) at four time points (baseline, pre-intervention, post-intervention, follow-up). The questionnaires were sent to participants at each time point and took approximately 15 minutes to complete via Qualtrics (Qualtrics, Provo, UT). Intervention acceptability and feasibility was assessed with qualitative exit interviews.

The Interpersonal Mindfulness in Parenting scale (IEM-P; Duncan, 2007) was used to measure levels of parental mindfulness. The IEM-P assesses components of parent and child relationships on a 5-point Likert scale with 10 items across several factors in parenting, including 'present-centered attention', 'present-centered emotional awareness', 'non-reactivity', and 'non-judgment' (Duncan, 2007; Moreira & Canavarro, 2017). The Family Dermatology Life Quality Index (FDLQI: Basra et al, 2007; Basra & Finlay, 2005; 2007) was used to measure parental quality of life on a 4-point Likert scale with 10 items assessing the psychosocial impact and physical impact of a family member's skin condition. The Parenting Stress Index 4 – Short Form (PSI-SF; Abidin, 1995) was used to measure parental stress across 36-items on a 5-point Likert scale (e.g., parental distress, parent-child interactions, child difficulty) (Abidin, 2012). The Patient Health Questionnaire (PHQ-9; Spitzer et al, 1999) was used to measure depression. The PHQ-9 is comprised of 9 items, corresponding with the DSM criteria for depression (Spitzer et al., 1999). The Generalised Anxiety Disorder Questionnaire (GAD-7; Spitzer et al, 2006) is

comprised of 7 items to assess and screen for symptoms related to generalized anxiety disorder and was used to measure levels of anxiety in parents.

Child quality of life was assessed on a 4-point Likert scale using the Children's Dermatology Life Quality Index (CDLQI: Lewis-Jones & Finlay, 1995) (validated for children aged 4-16 years) with 10-items relating to the impact of a child's skin condition on quality of life across several areas (e.g., schooling, holidays, treatment, sleep).

Finally, as one of the aims of this study was to determine acceptability of a novel mindfulness-based intervention, qualitative exit interviews were held with each parent individually after they had completed the Present curriculum. The mindfulness teacher who delivered the Present curriculum was also interviewed separately to allow a richer discussion surrounding their observations as the group facilitator in terms of engagement from parents. The Elliott et al. (2001) Client Change was used to guide conversation towards assessing personal changes, and questions were modified to the context of parenting a child with a skin condition. All exit interviews were held online and lasted one hour. Participants were debriefed at the end of every interview, discussions were recorded, and transcribed verbatim.

2.5. Procedure

2.5.1. Registration

Upon registration, participants were asked to disclose if they had any significant or stressful life events, physical, or mental health conditions that might impact their ability to take part in the exercises. If any concerns were raised, the mindfulness teacher would meet with each parent to discuss their participation.

2.5.2. 'Living in the Present'

The 'Living in the Present' is a novel mindfulness curriculum developed for adults, based on MBSR and MBCT (The Present Courses, 2022; see supplemental files). The Present introduces mindfulness into daily life and allows participants the flexibility to choose how they learn, as opposed to traditional MBIs that demand timed personal practices (The Present Courses, 2022). This curriculum was chosen

to pilot with parents of children with skin conditions, as previous research has highlighted the daily pressures of care, which could make allocating time for personal mindfulness practice difficult and affect engagement (Hughes et al., 2022; Heapy et al., 2022). Therefore, introducing mindfulness through daily activities might make the intervention more achievable.

The course was led by an external, qualified mindfulness practitioner, trained to teach the Present by one of the intervention co-founders. Teaching costs were funded by a skin-related charity to cover delivery and fidelity checks (The Ichthyosis Support Group). The course was delivered online (via Zoom; Zoom Video Communications Inc., 2023) in 8 group sessions over a period of 10-weeks (due to teacher availability), with each session lasting 1.5 hours (Thursday evenings, 7:00 pm – 8:30 pm GMT). Parents were given the option of attending with partners but were free to attend alone if preferred.

2.5.3. Data analysis

Data analysis was led by a White, British Female (O.H) with training from an experienced research team with experience in qualitative research, single case design, and mixed methods (A.R.T, K.S, H.P).

Responses to the idiographic measures gathered on 4 occasions each week were assessed with graphical representations of data from the baseline and intervention phases (Appendix E.8./E.9.). Using Microsoft Excel, the researcher visually assessed parents' data collected with text messages to identify any trends in variation (Morley, 2018). Tau-U is used for single case designs to examine data non-overlap in idiographic measures between intervention phases, with the following online programme (Parker et al., 2011; Vannest et al., 2011):

http://www.singlecaseresearch.org/calculators/tau-u.

Parental stress (PSI-SF), mindful parenting (IEM-P), parental quality of life (FDLQI), child quality of life (CDLQI), anxiety (GAD-7) and depression (PHQ-9) were assessed with standardised measures; and the Jacobson's reliable change index (Jacobson & Traux, 1991; Jacobson et al., 1999) was used to determine if there had been any improvement or deterioration between study phases (baseline, pre-intervention, post-intervention, follow-up). The Jacobson's reliable change index was calculated using the 'Leeds reliable change calculator' (Morley & Dowzer, 2014),

which assesses whether change is reliable or due to the degree of error in the measuring tool.

Qualitative data was analysed using NVivo 12 (released March 2018) and descriptive thematic analysis (Joffe, 2012). The analysis allowed the consideration of existing research investigating the psychological impact of skin conditions, whilst accommodating new insights as to how a novel mindfulness-based intervention could reduce the burden on families (Joffe, 2012). Data was first coded with a line-by-line analysis, followed by complete coding of the entire dataset. Common patterns were identified, compared, and organised into themes.

3. Results

3.1. Attendance

Nine parents attended session one (S1: 90%), eight parents S2 and S3 (80%), nine parents S4 (90%), eight parents S5 (80%), nine parents S6 (90%), six parents S7 (60%), and eight parents attended S8 (80%). One parent could not stay for the duration of every session because of family and treatment responsibilities, but still attended (approx. 30-45 minutes).

3.2. Idiographic measures

3.2.1. Visual analysis

Data from each individual parent's idiographic measure can be seen in Figure 1 and Figure 2. There was variability in positive-framed parent scores across all intervention phases. Six parents (2, 3, 4, 5, 6, 8) showed upward trends in their levels of success related to parenting their child during the intervention period. However, half of the parents (1, 3, 5, 6, 8) showed baseline trends before the intervention phase began. Three parents (1, 7, 9) showed a stable trend across the intervention period. Two parents continued to show an upward trend in improvement at follow-up (5, 6), and five parents remained stable (1, 3, 4, 7, 9). Two parents (2, 8) showed downward trends at follow-up. One parent (10) scored 0 for most of the intervention phases and did not report any improvements, but demonstrated a floor effect across the baseline period, intervention and at follow-up. There was variability in negative-framed parent scores across all intervention phases. One parent (3)

showed an upward trend at baseline. Eight parents (1, 3, 4, 5, 6, 7, 8, 10) showed downward trends for their levels of parenting stress during the intervention phase. One parent (2) remained stable across the intervention phase. However, one parent (9) showed a slight upward trend across the intervention phase. Three parents continued to show downward trends at follow-up (4, 5, 6). Two parents remained stable at follow-up (7, 9). However, four parents (1, 2, 3, 8) showed upward trends at follow-up.

[FIGURE 1 HERE]

3.2.2. Tau-U analysis

After visual analysis, baseline trends were corrected for (Parker et al., 2011; Vannest et al., 2011). Three parents showed significant improvements in positive success-framed (Question 1) measures; one parent (1) showed improvement across all study phases from baseline to intervention, baseline to follow-up, and intervention to follow-up. One parent (6) showed a significant improvement from baseline to intervention, and baseline to follow-up. One parent (9) showed significant improvements from baseline to follow-up, and intervention to follow-up. There were no significant improvements in weighted averages. Half of the parents showed significant improvements in negative stress-framed (Question 2) measures; two parents (6, 7) showed significant improvement from baseline to intervention, and baseline to follow-up. One parent (9) showed a significant improvement from baseline to intervention, and intervention to follow up. Two parents (1, 5) showed significant improvement in stress-framed measures from intervention to follow-up only. Weighted averages showed a significant improvement in stress-framed measures from baseline to intervention, and baseline to follow-up.

[TABLE 2 HERE]

3.3. Standardised measures of QoL, stress, and mindfulness

Using the Leeds reliable change calculator (Morley & Dowzer, 2014), the following scores were used as clinical cut-off points to measure reliable change for standardised measures: IEM-P=9.41; PSI-SF-4=15.00; PHQ-9=6.00; GAD-7=4.00; FDLQI=6.15; CDLQI=5.08 (Heapy et al., 2022) (Table 3). Eight parents (1, 2, 3, 5, 6, 7, 8) showed reliable improvement in at least one of the intervention phases. None of

the parents showed improvement in mindful parenting from baseline to post-intervention, but parent 8 showed improvement at follow-up. Parents 2, 6, and 7 showed reliable improvement in parenting stress from baseline to post-intervention, and parents 2 and 7 maintained to follow-up. Half of the parents (1, 2, 6, 8, 10) showed reliable improvements in anxiety from baseline to post-intervention. However, parent 3 showed a reliable deterioration in anxiety from baseline to post-intervention. Six parents (1, 2, 3, 6, 7, 10) showed reliable improvements in anxiety from baseline to follow-up, and parent 9 showed a reliable deterioration in anxiety from baseline to follow-up. Three parents (1, 6, 7) showed reliable improvements in depression from baseline to post-intervention and maintained from baseline to follow-up. Half of the parents (1, 2, 6, 7, 10) showed reliable improvements in QoL from baseline to post-intervention, and six parents (1, 2, 6, 7, 8, 10) showed reliable improvement from baseline to follow-up. Two parents (4, 9) did not show any improvements across the intervention phases.

Children 2, 5, and 8 showed reliable improvement in QoL from baseline to post-intervention, and children 2, 6, and 8 showed reliable improvement from baseline to follow-up. Children 1, 4, 7, and 9 did not show any reliable improvement across any of the intervention phases. The mean scores (out of a maximum score of 30) on impact of QoL for the entire group of children who completed questionnaires were as follows; baseline m=9.25 (moderate effect), pre-intervention m=8.88 (moderate effect), post-intervention m=5.5 (small effect), and follow-up m=5.62 (small effect).

[TABLE 3 HERE]

3.4. Qualitative feedback

Three themes and seven subthemes were identified as central to describing n=9 parents' experiences (n=1 parent could not attend for personal reasons), and n=1 mindfulness teacher. Each theme will be discussed with supporting quotes, and pseudonyms assigned to protect participant identities. See supplemental files for parental change ratings.

Theme 1: Noticing the benefits of mindfulness

Parents discussed observing positive outcomes in their daily lives following participation in the mindfulness course.

1.1. Shifts in parental mood and attitude

Parents described how mindfulness helped them cope more adaptively with the stresses associated with caring for their child's skin condition:

"I just felt more relaxed, and less stressed, and generally happier and more content." (Parent 3).

The mindfulness teacher also noticed visible differences:

"The participants that attended regularly, you could visibly see less of a frenetic body language..." (Teacher).

However, two parents described being more aware of their thoughts, as "a mixed blessing" (Parent 4):

"You're not always going to notice happy feelings, so some things have made me a little bit down...I've noticed some things that I want to change...and maybe that's a good thing because I'm being more present with myself and how I want to live." (Parent 8).

Two parents also reported noticing interactions with other people changing, which was seen as a positive and negative:

"I started noticing what people were saying to me, it was like, 'oh, this is nice, people are trusting me'...and then it got worse...all sorts of people were telling me all sorts of things...and I don't know why, what changed?" (Parent 4).

1.2. Healthier interactions with child

In some cases, parents noticed improved communication with their children:

"I'm more mindful that I don't want him getting upset...the communication has improved." (Parent 1).

"Me and Charlie used to wind each other up and it would escalate...I can't sit there and listen to him scratch, and he'd just keep scratching...so I've been trying to deal with it differently, rather than getting upset, because that then winds him up." (Parent 6).

Some parents described how interactions surrounding treatment had become more manageable, and they were "dealing with it better." (Parent 3).

"I now put less stress on my relationship with Evie so I don't get as frustrated if she says no to things or she doesn't want her medication, I try to be a bit more calm about it...I'm more mindful about our relationship." (Parent 7).

Theme 2: Acceptability of mindfulness exercises

Parents described how they felt about engaging in mindfulness and provided feedback on the different components of the intervention.

2.1. Bringing mindfulness into daily life

Parents discussed how they had incorporated mindful activities into everyday life, with a willingness to "try anything to help" (Parent 6) their children:

"The breathing techniques when I'm not able to get to sleep at night, because I'm thinking about what's going on." (Parent 7).

"I drive a lot to take the kids different places...so I've tried to just try to focus on the moment and notice what's around me...not let my mind wander too far ahead." (Parent 8).

2.2. Preferences for different course components

However, opinions on mindfulness exercises were mixed; some parents did not respond well to some of the metaphors used for self-compassion:

"There was quite a bit of stuff in there that I was kinda like 'well, why?'...one of the activities was practicing being more kind to more people...why do you think I'm not already kind to lots of people? (Parent 4).

"The theory bit when [teacher] got in detail about the brain, some of the words I could hardly even read...I'm just not sure of the relevance." (Parent 5).

2.3. Suggestions for future interventions

Parents provided some useful suggestions for how mindfulness could be tailored, including reducing intensity:

"What would have been really helpful...to have like two sessions of really quick wins, because finding an hour and a half every week is really tricky." (Parent 9).

Most parents favoured an online format. However, one parent described how they "miss body language" (Parent 5). Importantly, another parent felt they would not have been able to participate in the intervention if it had been in-person:

"I wouldn't have taken part if I had to travel because of the resources, I could not have managed that with children." (Parent 10).

The mindfulness teacher also highlighted the benefits of online delivery:

"We've got to keep it as accessible as possible...online in people's own homes, is going to be more accessible and we couldn't have got all these people together in a room because they're all over the country." (Teacher).

Theme 3: Challenges of taking part in an intervention

Although the mindfulness sessions were generally well-received, parents highlighted barriers to participation:

3.1. Pros and cons of a group format

Most parents appreciated connecting with other parents:

"Sitting there for a couple hours with people that were also going through something similar...because my husband doesn't feel the same way, he doesn't feel the burden and the worry for my son the way that I do, and to be with people that you could see that they were suffering with this, and the helplessness." (Parent 8).

However, some parents discussed finding it "hard to open up sometimes" from feeling "self-conscious" (Parent 6). Of note, one parent of a child with ichthyosis did not want to "burden" other group members:

"The other parents lives are totally different to mine, and I didn't relate to some of them...so I didn't share as much as I could have done, and I think it's a very

niche skin condition that my son has, and not very many people are familiar with [ichthyosis] so some of the struggles other people have are very different to what we go through as a family...you kind of guard and protect." (Parent 1).

3.2. Pressures of time limiting ability to immerse in mindfulness

One of the challenges faced by parents was finding time in their busy schedules to practice mindfulness, which appeared to be related to the significant burden of care: "I couldn't do the full session, and an hour-long time was almost impossible in a busy life where ichthyosis does take over a lot of your time, so that was hard." (Parent 1).

The mindfulness teacher similarly reported one of the "obvious things was the difficulty of committing and attending the sessions regularly" (teacher):

"There was quite a lot of challenge in the lives of the group, there was more than I normally would work with...so I think that perhaps had a bearing then on how much they felt they could take on." (Teacher).

An example of the pressures on parents was provided by one parent (3) who attributed their deterioration in anxiety as being a result of worry about their child with eczema starting nursery at the same time as the intervention:

"We were going through a lot of changes with the nursery, so it's been quite a stressful time for us...that's not a reflection on the course." (Parent 3).

1.1.1. Treatment fidelity

Treatment fidelity was assessed with a modified version of the MBI fidelity checking tool (Kechter et al., 2019) adapted from the Treatment Fidelity Workgroup of the National Institutes of Health Behavior Change Consortium (BCC) guidelines (Bellg et al., 2004; Resnick et al., 2005). Two sessions were audio recorded and reviewed by one of the Present co-founders. Consensus was reached that the curriculum was being delivered as per protocol and met the requirements to confirm fidelity.

4. Discussion

This was a single case series investigation of the 'Living in the Present' mindfulness intervention with parents of children with skin conditions. Analysis of parental bespoke measures revealed three parents showed some significant improvements in positive success-framed measures, and half of the parents showed some significant improvements in negative stress-framed measures. For the standardised measures of QoL, eight parents and four children showed reliable improvements in at least one phase of the intervention. After completing the intervention, there were some improvements to children's dermatology-related quality of life, and several parents reported improved outcomes in their children. For example, many parents found communication had improved, and there was less stress within the family unit from parents responding differently to situations (Portnoy et al., 2022; Ruskin et al., 2018; Albers et al., 2008). For parents who noticed these changes, there was an increased sense of calmness within the parent-child relationship and less distress arising from the pressures of treatment (van Gampelaere et al., 2019; Albers et al., 2008), and a reduction in conflict.

Parents identified positive changes after taking part in the intervention, including feeling calmer in the immediate days following a group session, which was corroborated by the mindfulness teacher. However, several parents described the challenges of having an increased awareness of unpleasant aspects of their lives. There is evidence to suggest that some people might encounter challenges during early attempts of mindfulness and struggle with varying types of discomfort (Lomas et al., 2015; Farias & Wilkholm, 2016). Practicing mindfulness is associated with psychological flexibility (Ruskin et al., 2018), and the ability to separate from negative thoughts rather than being caught up in them. Despite initial difficulties, mindfulness must be practiced over time to change the impact of distressing inner experiences (Lomas et al., 2015). Unexpectedly, parents also reported how more people were conversing with them in public. It could be possible that this was happening previously, but they were noticing it more since developing an attitude shift towards acting with more awareness. Alternatively, it could be that parents began to appear more relaxed and open to new experiences, so might have been more likely to be approached by other people.

Two parents appeared to experience increased anxiety (3, 9). Parent 3 attributed their increased anxiety scores to experiencing stress as a family at the same time as the intervention. However, Parent 9 reportedly had no anxiety at baseline or pre-

intervention, which increased post-intervention and at follow-up. One explanation for this could have been from an attentional focus developing, with parents engaging in more accurate reporting of physiological symptoms (Lomas et al., 2015). Importantly, neither parent spoke of their anxiety because of the intervention.

In terms of acceptability, the group format was generally well-received as has been the case in other studies (Heapy et al., 2022; Hughes et al., 2022). However, one parent of a child with severe ichthyosis felt it was more difficult to connect with other group members as rarer symptoms were involved and found making the time to attend sessions challenging. Most parents favoured an online format for saving on travel expenditures (Heapy et al., 2022), although the disadvantage of missing body language was raised. Most parents successfully incorporated mindfulness into daily routines, however, opinions on certain exercises were mixed (e.g., metaphors vs. theory components). Parents provided suggestions to improve future interventions, including a reduction in the length and number of sessions. Despite previous feedback suggesting the need for less intensive/online sessions for parents of children with skin conditions (Heapy et al., 2022), finding time to attend sessions and carry out practices remained a challenge for some parents. Parents lacking time to practice could explain the variation in psychological outcomes (Hughes et al., 2022; Harris et al., 2021).

4.1. Limitations

The study sample consisting entirely of women limits transferability, and the mothers who volunteered were probably highly motivated to participate. Despite this study being a pilot investigation, the baseline and follow-up periods could have been lengthened to enable greater stability and limit baseline trends, alongside hours of practice and idiographic measures being collected daily. Although this was not possible for this study due recruitment timelines and intervention availability, collecting these additional data would allow mindfulness to be robustly investigated. Future studies might seek to purposively sample fathers, to investigate caregiver roles. Additionally, although the mindfulness teacher was briefed on the nature of typical presenting problems associated with skin conditions by the research team, and this was a pilot study adopting a transtheoretical perspective to mindfulness, there would be merit in exploring adaptation in future interventional studies (e.g., support for skin specific issues and heightened distress).

4.2. Conclusion

The Living in the Present mindfulness curriculum has shown potential as an effective intervention for parents of children with skin conditions and could be feasible for reducing stress and improving QoL. However, it is important to remember the findings represent one curriculum, making it difficult to determine the efficacy of mindfulness for parents of children with skin conditions. MBIs require further intensive research with large sample sizes and control groups to robustly investigate outcomes.

References

- **Abidin R.R.** (2012) *Parenting Stress Index*. Odessa, FL: Psychological Assessment Resources.
- **Abidin, R.R.** (1995). Parenting stress index 3rd edition: Professional Manual. Psychological Assessment Resources, Inc, Odessa, TX.
- **Ablett, K., & Thompson, A.R.** (2016). Parental, child, and adolescent experience of chronic skin conditions: A meta-ethnography and review of the qualitative literature. *Body Image*, *19*, 175-185. https://doi.org/10.1016/j.bodyim.2016.10.001.
- Albers, E.M., Riksen-Walraven, J.M., Sweep, F.C., & de Weerth, C. (2008). Maternal behavior predicts infant cortisol recovery from a mild everyday stressor. *Journal of Child Psychology and Psychiatry*, 49(1), 97–103. https://doi.org/10.1111/j.1469-7610.2007.01818.x.
- Aziah, M.S., Rosnah, T., Mardziah, A. & Norzila, M.Z. (2002). Childhood atopic dermatitis: a measurement of quality of life and family impact. *The Medical Journal of Malaysia*, 57(3):329-339.
- Balieva, F., Schut, C., Kupfer, J., Lien, L., Misery, L., Sampogna, F. von Euler, L. & Dalgard, F.J. (2022). Perceived stress in patients with inflammatory and non-inflammatory skin conditions. An observational controlled study among 255 Norwegian dermatological outpatients. Skin Health and Disease, https://doi.org/10.1002/ski2.162.

- Basra, M.K.A. & Finlay, A.Y. (2005). Family Dermatology Life Quality Index. https://www.cardiff.ac.uk/medicine/resources/quality-of-life-questionnaires/family-dermatology-life-quality-index.
- Basra, M.K.A., Sue-Ho, R. & Finlay, AY. (2007). The Family Dermatology Life Quality index; measuring the secondary impact of skin disease. *British Journal of Dermatology*, *156*(3), 528-538. Erratum: *British Journal of Dermatology*, *156*(3), 791 (Correct FDLQI given here).
- **Basra, M.K., & Finlay, A.Y.** (2007). The Family Impact of Skin Diseases: The Greater Patient Concept. *The British Journal of Dermatology*, *156*(5), 929–937. https://doi.org/10.1111/j.1365-2133.2007.07794.x.
- Bellg, A.J., Borrelli, B., Resnick, B., Hecht, J., Minicucci, D.S., Ory, M., Ogedegbe, G., Orwig, D., Ernst, D., Czajkowski, S., & Treatment Fidelity Workgroup of the NIH Behavior Change Consortium (2004). Enhancing treatment fidelity in health behavior change studies: best practices and recommendations from the NIH Behavior Change Consortium. *Health Psychology*, 23(5). 443–451. https://doi.org/10.1037/0278-6133.23.5.443.
- Cousineau, T.M., Hobbs, L.M., & Arthur, K.C. (2019). The Role of Compassion and Mindfulness in Building Parental Resilience When Caring for Children with Chronic Conditions: A Conceptual Model. *Frontiers in Psychology*, *10*, 1602. https://doi.org/10.3389/fpsyg.2019.01602.
- **Duncan, L.G.** (2007). Assessment of mindful parenting among parents of early adolescents: Development and validation of the Interpersonal Mindfulness in Parenting scale. The Pennsylvania State University.
- Elliott, R., Slatick, E. & Urman, M. (2001). Qualitative change process on psychotherapy: Alternative strategies. In J. Frommer and D.L Rennie (Eds.) *Qualitative psychotherapy research: Methods and Methodology* (pp. 69-111). Lengerich, Germany: Pabst Science.
- **Farias, M. & Wikholm, C.** (2016). Has the science of mindfulness lost its mind? *BJPsychBulletin, 40*(6), 329-332. https://doi.org/10.1192/pb.bp.116.053686.
- Harris, S.A., Harris, P.R., Lenton, J., Warde, C., Gold, E., Gane, T., & Seddon, P. (2021). "Nurturing Parents"—Mindfulness-Based Parent Well-Being Group in Pediatric Cystic Fibrosis. *Clinical Practice in Pediatric Psychology*, *9*(2), 123—134. https://doi.org/10.1037/CPP0000394.

- Heapy, C., Norman, P., Emerson, L.M, Murphy, R., Bögels, S. & Thompson, A.R. (2022). Mindful Parenting intervention for parents of children with skin conditions:
 A single group experimental cases series. *Behavioural and Cognitive Psychotherapy*. 1-19. https://doi.org/10.1017/S1352465822000170.
- Heapy, C., Norman, P., Emerson, L.M., Murphy, R., Bögels, S. & Thompson, A.R. (2021). Is Parental Mindfulness Associated with Quality of Life and Itch Intensity inn Children with Psoriasis and Eczema and Well-Being in Parents? *Mindfulness,* 12. 2707-2717. https://doi.org/10.1007/s12671-021-01733-2.
- Hughes, O., Shelton, K.H., Penny, H. & Thompson, A.R. (2022). Parent and child experience of skin conditions: Relevance for the provision of mindfulness-based interventions. *British Journal of Dermatology*, 188(4). 514-523. https://doi.org/10.1093/bjd/ljac129.
- **Ichthyosis Support Group.** https://www.ichthyosis.org.uk.
- **Jacobson, N.S., & Traux, P.** (1991). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology*, *59*,12.
- Jacobson, N.S., Roberts, L.J., Berns, S.B., & McGlinchey, J.B. (1999). Methods for defining and determining the clinical significance of treatment effects: description, application, and alternatives. *Journal of consulting and clinical psychology*, *67*(3), 300–307. https://doi.org/10.1037//0022-006x.67.3.300.
- **Joffe, H.** (2012). Thematic analysis. In: *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (Harper, D, Thompson, AR, eds). London: Wiley, 209-223.
- **Kabat-Zinn, J.** (1994). Wherever you go, there you are: Mindfulness Meditation in Everyday Life. New York: Hyperion.
- **Kechter, A., Amaro, H., & Black, D. S.** (2019). Reporting of Treatment Fidelity in Mindfulness-Based Intervention Trials: A Review and New Tool using NIH Behavior Change Consortium Guidelines. *Mindfulness*, *10*(2). 215–233. https://doi.org/10.1007/s12671-018-0974-4.
- **Krasny-Pacini**, **A. & Evans**, **J.** (2018). Single-case experimental designs to assess intervention effectiveness in rehabilitation: A practical guide. *Annals of Physical*

- and Rehabilitation Medicine, 61(1), 164-179. https://doi.org/10.1016/j.rehab.2017.12.002.
- Lewis-Jones, M.S. & Finlay, A. Y. (1995). The Children's Dermatology Life Quality Index (CDLQI): initial validation and practical use. *British Journal of Dermatology*, *132*(6), 942-949. https://doi.org/10.1111/j.1365-2133.1995.tb16953.x.
- **Lomas, T., Cartwright, T., Edginton, T. & Ridge, D.** (2015). A Qualitative Analysis of Experiential Challenges Associated with Meditation Practice. *Mindfulness*, *6*(4), 848-860. https://doi.org/10.1007/s12671-014-0329-8.
- Moreira, H., & Canavarro, M.C. (2017). Psychometric Properties of the Interpersonal Mindfulness in Parenting Scale in a Sample of Portuguese Mothers. *Mindfulness*, 8, 691–706. https://doi.org/10.1007/s12671-016-0647-0.
- **Morley, S.** (2018). *Single case methods in clinical psychology: A practical guide*. New York, NY: Routledge.
- **Morley, S. & Dowzer, C.N.** (2014). Manual for the Leeds Reliable Change Indicator: Simple Excel applications for the analysis of individual patient and group data. University of Leeds, Leeds, UK.
- Parker, R.I., Vannest, K.J., Davis, J.L., & Sauber, S. B. (2011). Combining nonoverlap and trend for single-case research: Tau-U. *Behavior Therapy*, *42*(2), 284–299. https://doi.org/10.1016/j.beth.2010.08.006.
- **Portnoy, S., Korchak, G., Foxall, A., & Hurlston, R.** (2023). Are mindfulness groups more mindful face to face or online? A comparison of delivering a mindfulness based well-being group for parents of children with a chronic health condition. *Clinical Child Psychology and Psychiatry*, *28*(1), 56–69. https://doi.org/10.1177/13591045221125617.
- QSR International Pty Ltd. (2018). *NVivo* (*Version 12*), https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home.

- Qualtrics. (2020). Available from https://www.qualtrics.com.
- Resnick, B., Bellg, A. J., Borrelli, B., Defrancesco, C., Breger, R., Hecht, J., Sharp, D. L., Levesque, C., Orwig, D., Ernst, D., Ogedegbe, G., & Czajkowski, S. (2005). Examples of implementation and evaluation of treatment fidelity in the BCC studies: where we are and where we need to go. *Annals of Behavioral*, 29, 46–54. https://doi.org/10.1207/s15324796abm2902s 8.
- Ruskin, D., Campbell, L., Stinson, J., & Ahola Kohut, S. (2018). Changes in Parent Psychological Flexibility after a One-Time Mindfulness-Based Intervention for Parents of Adolescents with Persistent Pain Conditions. *Children*, *5*(9), 121. https://doi.org/10.3390/children5090121.
- Ruskin, D., Young, M., Sugar, C., & Nofech-Mozes, J. (2021). Mindfulness and Acceptance Interventions for Parents of Children and Adolescents Diagnosed with Chronic Medical Conditions: A Systematic Review. *Journal of Alternative and Complementary Medicine*, *27*(2), 120–135. https://doi.org/10.1089/acm.2020.0191.
- **Sekhon, M., Cartwright, M., & Francis, J.J.** (2017). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Services Research*, *17*(1), 88. https://doi.org/10.1186/s12913-017-2031-8.
- Spitzer, R.L., Kroenke, K., Williams, J.B., & Patient Health Questionnaire Primary Care Study Group. (1999). Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. *Jama*, *282*(18), 1737-1744.
- **The Present Courses.** (2022). Living in the Present: 8-Week Online Mindfulness Course. https://www.thepresentcourses.org/living-in-the-present-8-week-mindfulness-course-online/.
- Van Gampelaere, C., Luyckx, K., Van Ryckeghem, D.M.L., Van Der Straaten, S., Laridaen, J., Goethals, E.R., Casteels, K., Vanbesien, J., Den Brinker, M., Cools, M., & Goubert, L. (2019). Mindfulness, Worries, and Parenting in Parents of Children with Type 1 Diabetes. *Journal of Pediatric Psychology*, 44(4), 499–508. https://doi.org/10.1093/jpepsy/jsy094.
- Vannest, K.J., Parker, R.I., Gonen, O., & Adiguzel, T. (2016). Single Case Research: web based calculators for SCR analysis. (Version 2.0) [Web-based

application]. College Station, TX: Texas A&M University. Available from: singlecaseresearch.org.