



# **Mindfulness-Based Online Support for Children and Families Affected by Skin Conditions**

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the degree of Doctor of Philosophy*

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## Summary

The research presented in this thesis concerns the psychosocial impact of skin conditions for children and parents, with a specific focus on understanding their needs, and determining the potential role that mindfulness might have in alleviating stress. A mixed methods approach was used, broadly following a participatory person based approach and ultimately led to the testing of a novel intervention. Mindfulness involves acting with awareness, focusing attention on the present, and responding in a non-judgemental manner to experiences. A systematic review of mindfulness for children with physical health conditions suggested there is a gap in research employing interventions with families and indicated the approach could reduce anxiety, depression and caregiver stress. To understand the issues faced by children affected by skin conditions, there is a need to investigate the experiences of people with lived expertise. Study 1 employed qualitative enquiry with dyadic interviews with families (n=23) to identify issues surrounding care/current psychological support, gain feedback on what is needed from future interventions, and investigate the relevance of mindfulness. Findings suggested that mindfulness might be well-accepted by children and their parents, and desires were expressed for exercises to reduce daily stress, that could: (1) fit into everyday routines, (2) be delivered online, and (3) include group support. Study 2 was a qualitative investigation of (n=15) dermatology/psychology healthcare professionals' (HCPs) experiences of providing care for children with skin conditions and their views on psychological support. Findings supported existing evidence for the burden experienced by families, and suggested that parents might benefit as the therapeutic target. HCPs acknowledged the need for further support for children and their families. Therefore, Study 3 used single-case methods to investigate the effectiveness of a mindfulness-based intervention for n=10 parents of children with common and rare skin conditions. The 'Living in the Present' intervention was an eight-week facilitated psychoeducational group. The findings suggested mindfulness could reduce parental stress and improve quality of life. Overall, the body of work within this thesis demonstrates that mindfulness could be an effective intervention for families affected by skin conditions.

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## List of Acronyms

ACT	Acceptance and Commitment Therapy
AD	Atopic Dermatitis
ADHD	Attention Deficit Hyperactivity Disorder
AIDS	Acquired Immunodeficiency Syndrome
APPGS	All Party Parliamentary Group on Skin
BADBIR	British Association of Dermatologists Biologics and Immunomodulators Register
BDD	Body Dysmorphic Disorder
BJD	British Journal of Dermatology
BPS	British Psychological Society
CBT	Cognitive Behavioural Therapy
CDLQI	Children's Dermatology Life Quality Index
CFT	Compassion-Focussed Therapy
CI	Confidence Interval
CONSORT	Consolidated Standards of Reporting Trials
EB	Epidermolysis Bullosa
FDLQI	Family Dermatology Life Quality Index
GAD-7	Generalised Anxiety Disorder Questionnaire
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HCP	Healthcare Professional
HIV	Human Immunodeficiency Virus
HPA Axis	Hypothalamo-pituitary-adrenal Axis
HS	Hidradenitis Suppurativa
IBD	Inflammatory Bowel Disease
ICBT	Internet-Delivered Cognitive Behavioural Therapy
ICF	International Classification of Functioning, Disability and Health
IEM-P	Interpersonal Mindfulness in Parenting Scale
MARS-A	Mindful Awareness and Resilience Skills for Adolescents
MBCT	Mindfulness-Based Cognitive Therapy
MBCT-C	Mindfulness-Based Cognitive Therapy for Children

MBI	Mindfulness-Based Intervention
MBSR	Mindfulness-Based Stress Reduction
MBTSC	Mindfulness-Based Training for Chronic Skin Conditions
MBVR	Mindfulness-Based Virtual Reality
MiSP	Mindfulness in Schools Project
MRC	Medical Research Council
MSC	Mindful Self-Compassion
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PBA	Person Based Approach
PCOS	Polycystic Ovary Syndrome
PHQ-9	Patient Health Questionnaire
PO-SCORAD	The Patient-Oriented SCORing Atopic Dermatitis
POEM	The Patient Oriented Eczema Measure
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PSI-SF	Parenting Stress Index - Short Form
PUVA	Psoralen and Ultraviolet Light A
QoL	Quality of Life
RCADS	The Revised Child Anxiety and Depression Scale
RCT	Randomized Controlled Trial
RoB 2	The Cochrane Risk of Bias—second edition
ROBINS-I	The Cochrane Risk of Bias in Nonrandomized Studies-of Interventions
SAM Axis	Sympathetic Adrenal-medullary Axis
SCED	Single-Cases Experimental Design
SRED	Society for Research in Child Development
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TAU	Treatment as Usual
UNICEF	United Nations International Children’s Emergency Fund
UVB	Ultraviolet Light B
WHO	World Health Organisation

## Preface

### Publications

Below is a list authored and co-authored papers published by the researcher (including articles in-press) over the course of this doctoral studentship, with note of how they relate to the research presented in this thesis, and the wider literature surrounding the psychological impact of skin conditions. Papers marked with an asterisk indicate work directly carried out as part of the PhD.

Arents, B.W.M., van Zuuren, E.J., **Hughes, O.**, Fedorowicz, Z. & Flohr, C. The future is now: the Global Atlas on Atopic Dermatitis. *British Journal of Dermatology*. <https://doi.org/10.1093/bjd/ljad286> *Note:* I am a co-author on this perspectives article and worked as part of an international writing team for this global project on atopic dermatitis.

Guckian, J., **Hughes, O.**, Nikookam, Y. Nair, R., Brown, J., Bewley, A. & Latheef, F. (2023). PS03 Dermatologist perspectives on topical steroid withdrawal: distrust, disinformation and distance? *British Journal of Dermatology*, 188(4). <https://doi.org/10.1093/bjd/ljad113.355>. *Note:* I worked on this group project investigating the impact of topical steroid withdrawal on dermatology patients.

Hewitt, R.M., Ploszajski, M., Purcell, C., Pattinson, R., Jones, B., Wren, G.H., **Hughes, O.**, Ridd, M.J., Thompson, A.R. & Bundy, C. (2022). A mixed methods systematic review of digital interventions to support the psychological health and well-being of people living with dermatological conditions. *Frontiers in Medicine*, 9. 1024879. <https://doi.org/10.3389/fmed.2022.1024879>. *Note:* I am a co-author and worked on this group systematic review examining digital interventions for people with skin conditions.

**Hughes, O.** (2022). The need for psychological support in routine dermatological care across the UK. *British Journal of Dermatology*, 187(5). 778-779. <https://doi.org/10.1111/bjd.21720>. *Note:* I authored this perspectives article highlighting from my own experience, the importance of psychological support for people with skin conditions.

**Hughes, O.** & Bewley, A. (2023). 'Is it really ever 'just acne'? - considering the psychodermatology of acne'. *British Journal of Dermatology*. (In-press). *Note:* I was invited to co-author this supplement article highlighting the psychological impact of acne and the importance of psychodermatology.

**Hughes, O.**, Prescott., L. & Arents, B.W.M. (2022). Patient engagement with the BJD: encouraging the patient voice and readership. *British Journal of Dermatology*, 187(6). 835-836. <https://doi.org/10.1111/bjd.21812>. *Note:* I co-authored this article highlighting the importance of involving dermatology patients in medical journal publication processes.

\***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>. *Note:* This publication is based on the research presented in Chapter 3 of this thesis.

\*Author video: **O. Hughes et al.** (2022). Parent and child experience of skin conditions: relevance for the provision of mindfulness-based interventions. *British Journal of Dermatology*. <https://www.youtube.com/watch?v=kwmXxEDWZ8>.

\***Hughes, O.**, Shelton, K.H., Penny, H. & Thompson, A.R. (2023). Living with Physical Health Conditions: A Systematic Review of Mindfulness-based Interventions for Children, Adolescents, and their Parents. *Journal of Pediatric Psychology*, 48(4), 396–413. <https://doi.org/10.1093/jpepsy/jsad003>. *Note:* This publication is based on the research presented in Chapter 2 of this thesis.

International League of Dermatological Societies: Arents B.W.M., van Zuuren, E.J., **Hughes, O.**, Fedorowicz, F., Flohr, C. (2022). *Global Report on Atopic Dermatitis*. <https://www.atopicdermatitisatlas.org/en/explore-data/reports>. *Note:* I worked as part of an international writing team for this global project on atopic dermatitis.

McGrath, B.M. & **Hughes, O.** (2023). The dermatology patient journey from initial consultation to diagnosis. *JEADV*. (In-press). *Note:* I co-authored this

commentary article, highlighting the challenges faced by dermatology patients in getting a first diagnosis from healthcare professionals.

**Hughes, O.** & Thompson, A.R. (2023). "*Mindfulness based approaches for supporting people living with a skin condition*" in F Sirois (Ed.) *Handbook of Positive Psychology and Health*, Palgrave Macmillan. (In-press). *Note*: I co-authored this book chapter, providing an overview of mindfulness-based approaches for people with skin conditions.

Watkins, H., **Hughes, O.**, Jones, L., Tate, L., Mouris Khela, M. & Hurrell, C. (2022). The use of inpatient goal planning in a regional burns centre: A thematic analysis of staff and patient experiences. *Burns*, *49*(1). 100-109. <https://doi.org/10.1016/j.burns.2022.02.013>. *Note*: I co-authored this study investigating the use of goal planning in a clinical setting, for the rehabilitation of people with burns and related injuries.

## Conference Presentations

Below is a list of conference presentations delivered over the course of this doctoral studentship, with note of how they related to the research presented in this thesis, and the wider literature surrounding the psychological impact of skin conditions (presenting author in bold).

Watkins, H., **Hughes, O.**, Jones, L., Tate, L., Mouris Khela, M. & Hurrell, C. (2021, June 14-17). *'The Use of Inpatient Goal Planning in a Regional Burns Centre, A Thematic Analysis of Staff and Patient Experiences.'* [Conference session]. The 20th Congress of the International Society for Burn Injuries. *Note:* This presentation was based on a group project investigating the use of goal planning in a clinical setting, for the rehabilitation of people with burns and related injuries.

\***Hughes, O.**, Shelton, K.H., Penny, H. & Thompson, A.R. (2021, July 14). *'Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families.'* [Poster presentation]. Cardiff University, School of Psychology Annual PhD Student Conference. Cardiff, United Kingdom. *Note:* This presentation was based on the research presented in Chapter 3 of this thesis.

\***Hughes, O.**, Shelton, K.H., Penny, H. & Thompson, A.R. (2022, June 28-29). *'Parent and Child Experiences of Skin Conditions: Towards Offering a Mindfulness-Based Support Intervention.'* [Poster presentation]. British Psychological Society Division of Health Psychology Conference. Bristol, United Kingdom. *Note:* This presentation was based on the research presented in Chapter 3 of this thesis.

Arents, B.W.M., Abuabara, K., Aoki, V., Austin, J., Barbarot, S., Bissonnette, R., Delleuran, M., Dhar, S., Fedorowicz, Z., French, L., Griffiths, C., Hughes, O., Irvine, A., Kabashima, K., Schmid Grendelmeier, P., Shipowick, T., Taieb, A., Thyssen, J., Todd, G., van Zuuren, E., Wollenberg, A., & **Flohr, C.** (2022,

October 17-19) '*The Global Atopic Dermatitis Atlas: Mapping the global burden of AD and more. Filling the gaps in epidemiological data on atopic dermatitis.*' [Poster presentation]. Symposium of the International Society of Atopic Dermatitis. Montreal, Canada. *Note:* This presentation was based on a global report for atopic dermatitis.

**\*Hughes, O.,** Shelton, K.H., Thompson, A.R. (2023, June 21-25). '*UK Healthcare Professionals Views on Psychological Support for Children and Families Affected by Skin Conditions: A Qualitative Study.*' [Oral presentation]. 20th Congress of the European Society for Dermatology and Psychiatry (ESDaP). Rotterdam, The Netherlands. *Note:* This presentation was based on the research presented in Chapter 3 of this thesis.

**Guckian, J.,** Hughes, O., Nair, R., Nikookam, Y., Brown, J., Bewley, A. & Latheef, F. (2023, June 27-29). '*Dermatologist Perspectives on Topical Steroid Withdrawal: Distrust, Disinformation and Distance?*' [Oral presentation]. British Association of Dermatologists 103<sup>rd</sup> Annual Meeting, Liverpool, UK. *Note:* This presentation was based on a group project investigating the impact of topical steroid withdrawal on dermatology patients.

**\*Hughes, O.,** Shelton, K.H., Thompson, A.R. (2023, July 11-13). '*Mindfulness for Parents of Children with Skin Conditions: A Single Group Cases Series.*' [Poster presentation]. The 51<sup>st</sup> BABCP Annual Conference. Cardiff, Wales, UK. *Note:* This presentation was based on the research presented in Chapter 4 of this thesis.

## **Professional Activity**

Below is a list of professional roles the researcher has been fulfilling over the course of this doctoral studentship, with description of how they relate to the research presented in this thesis, and the wider literature surrounding the psychological impact of skin conditions.

### **Trustee to Skin Care Cymru (January 2018 - present)**

I volunteer as a trustee to Skin Care Cymru - a charity providing guidance for people with skin conditions in Wales. The committee regularly meets to address issues arising from health-board provisions in Wales, and we work collaboratively towards enhancing dermatological care and awareness of skin conditions. For example, I was part of the cross party group on skin in the Welsh Assembly, working with the Welsh Government to address issues related to skin care in Wales. I have also assisted with the delivery of the 'Don't Be a Lobster' sun safety campaign, helped with organising fundraisers, and given a media interview as a charity representative. As part of my role with Skin Care Cymru, I am responsible for managing the website and keeping it up to date with the latest research on skin conditions.

### **Honorary Assistant Psychologist, Welsh Centre for Burns and Plastic Surgery, Morriston Hospital, Swansea (February 2020 - December 2020)**

I completed a clinical placement in the Welsh Centre for Burns and Plastic Surgery, as an honorary assistant psychologist (as part of my MSc studies). During this placement, I took part in clinical observations of burn-injured adults and children through shadowing, and participated in multidisciplinary team meetings. The clinical placement ran through the coronavirus outbreak, and I helped create videos of narrated mindfulness exercises for frontline National Health Service (NHS) staff. I also worked on a research report of a study carried out in the unit, qualitatively investigating staff and patient experiences of goal planning (Watkins et al., 2022; see publications).



**Patient Associate Editor for the British Journal of Dermatology (November 2021 – present)**

I am a Patient Associate Editor for the British Journal of Dermatology (BJD). As part of this role, I assist with the publication process by editing plain language summaries of empirical research articles submitted to the journal. This work is highlighted in an editorial article we published in the BJD (Hughes et al., 2022; see publications), describing the importance of involving patients in medical journals. I also work to encourage patients to submit pieces to the perspectives section of the journal, to inform clinicians about novel issues related to living with a skin condition (e.g., Hughes, 2022; see publications).

**Patient Representative on the British Association of Dermatologist Biologics and Immunomodulators Register (BADBIR) steering committee (August 2022 – present)**

I am a patient representative on the British Association of Dermatologists Biologics and Immunomodulators Register (BADBIR) steering committee. As part of this role, I work alongside dermatologists and healthcare professionals to provide insights into the needs of psoriasis patients/carers to ensure these are considered in relation to the aims, objectives and delivery of BADBIR, including assisting with reviewing patient newsletters.

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# Chapter 1

## Introduction to Childhood Skin Conditions and the Role of Mindfulness

In this first chapter, the context and rationale for the research is outlined, including consideration of the theoretical principles that underlie the programme of work, a discussion of the relevance of psychological perspectives to an understanding of the experiences of children with skin conditions and an overview of mindfulness as an intervention to support families affected by skin conditions. Children's emotional and cognitive development and attachments are discussed, along with an overview of research into childhood skin conditions, and the role mindfulness may play in therapeutically targeting the psychological sequelae of dermatological symptoms.

### 1.1. Childhood Skin Conditions

#### 1.1.1. Definition and prevalence

The skin is the largest organ in the human body and acts as a physical barrier between us and the outside world (Gawkrodger & Ardern-Jones, 2021; Weller et al., 2015). Our skin is essential to our body functioning by protecting us from irritants, retaining water and nutrients, and regulating our temperature (Gawkrodger & Ardern-Jones, 2021; Weller et al., 2015). Most people will experience a problem with their skin at some point in their lifetime, and there can be many different types of 'disruption' to the skin barrier, including sunburn, irritation, warts, and skin conditions (Weller et al., 2015).

Skin conditions are common, diagnosable medical conditions affecting the skin, and include physical symptoms such as dryness, scaling, flaking, rashes, pustules, blisters, moles, redness and inflammation, or lesions on any part of the body (Gawkrodger & Ardern-Jones, 2021; Weller et al., 2015). Examples of the most

prevalent types of skin conditions in the United Kingdom (UK) include “*skin cancers (e.g., premalignant disorders, basal cell carcinoma, squamous cell carcinoma, malignant melanoma), acne, atopic dermatitis (AD)/eczema, psoriasis, viral warts, infective skin conditions (e.g., fungal and viral), benign tumours, vascular lesions, leg ulcers, contact dermatitis, and other eczemas*” (Weller et al., 2015, pg.2). Other examples of skin conditions include alopecia, vitiligo, rosacea, and hidradenitis suppurativa (HS). There are also rarer skin conditions which are less commonly diagnosed in dermatology, such as Epidermolysis bullosa (EB), Ectodermal dysplasia, and certain forms of ichthyosis (e.g., Harlequin ichthyosis, and Netherton syndrome) (Gawkrodger & Ardern-Jones, 2021).

Skin conditions can be caused by range of internal and external factors, including food or environmental allergens, exposure to irritants/chemicals, drugs, trauma, sunshine, genetic expressions, infections (e.g., necrotising fasciitis, staphylococcus, syphilis), certain cancers, autoimmune conditions (e.g., lupus), diabetes, liver and kidney problems, or high cholesterol (National institute of Arthritis and Musculoskeletal and Skin Diseases, 2022; Weller et al., 2015). Being diagnosed with certain skin conditions can lead to the onset of a range of comorbidities. For example, ichthyosis has been associated with cardiac arrhythmias, neurodevelopmental conditions, haemorrhages, cancer, and corneal opacities (Wren & Davies, 2022). As well as this, psoriasis is linked to the development of arthritis (psoriatic arthritis), cardiovascular disease, and diabetes (Thomas et al., 2021). For these reasons, people with conditions such as ichthyosis and psoriasis may be at an increased risk of developing affective disorders (Wren et al., 2022).

Skin conditions can also develop as a result of immune system dysregulation. For example, psoriasis, eczema, and acne, are classed as inflammatory skin conditions, and involve an ‘immunological geneses’ between environmental experiences, biological factors and the immune system and central nervous system (Latheef, 2016; Farber et al., 1986, in Harth et al., 2009; Millard, 2005, in Walker & Papadopoulos, 2005). When exposed to stress, the hypothalamo-pituitary-adrenal (HPA) and the sympathetic adrenal-medullary (SAM) axes are activated (Watkins, 1997; Bewley et al., 2014; Latheef, 2016), but in some skin conditions, stress lowers the HPA and heightens the SAM response, and produces stress hormones (e.g.,

cortisol) (Rohleder, 2019; Watkins, 1997; Latheef, 2016; Millard, 2005, in Walker & Papadopoulos, 2005). This hormonal fluctuation creates an upsurge of mast cells and pro-inflammatory cytokines, which can impede functioning of the skin barrier (Rohleder, 2019; Latheef, 2016; Taieb, 2012). In a similar way, negative experiences or perceived environmental threats can activate the HPA axis and trigger the body's stress response and production of cytokines (Black, 2002; Rohleder, 2019).

### **1.1.2. The psychological impact of skin conditions on children**

Skin conditions commonly emerge during childhood years, and diseases such as AD globally peak in approximately 15-20% of children (Nutten, 2015; Flohr & Hay, 2021). In the UK, acne is the most common reason for children aged ten and eighteen years to seek National Health Service (NHS) treatment (All Party Parliamentary Group on Skin; APPGS, 2020). Whilst less common childhood conditions, such as psoriasis, is diagnosed in 0.71% of children (National Institute for Health and Care Excellence; NICE, 2017) and affects approximately 40,000 children under the age of ten (Gelfand et al., 2005). Based on the high prevalence, skin conditions can result in profound social and emotional consequences for children, who may have to manage the burden of disease from a young age.

There are certain skin conditions that can influence a child's development from birth. For example, a rare type of ichthyosis (Sjögren-Larsson's syndrome) has been associated with neurocutaneous manifestations in children, including quadriplegia, neurodevelopmental conditions, and conduction aphasia (Gupta et al., 2011). Moreover, one third to half of children with EB may experience delays in pubertal development, especially for those diagnosed with severe forms (Rodari et al., 2022). However, the relationship between genetics, development, and childhood health is not fully understood. There is likely to be a complex multifactorial relationship between congenital conditions primarily influencing development, and secondary implications from the skin condition impeding developmental milestones (e.g., interruptions to schooling, early socialisation, or attention).

Any consideration of the lived experience of skin conditions in childhood requires recognition of the developmental context in which this occurs. One way in which skin conditions may affect a developing child is in relation to their first social

interactions. Developing a secure bond with a primary caregiver could be challenging or even interrupted when the age of onset and severity of a childhood skin condition is considered, and there is some evidence to suggest that skin-to-skin contact with caregivers during early years could have implications for adult mental health (Norholt, 2020). For example, skin conditions arising in the first weeks and months of life could affect bonding behaviour (e.g., co-sleeping, or level of contact), as if medical advice is to keep the skin uncovered/cool and moisturized, mothers may struggle to balance this against advice on forming a bond with a new-born. As well as this, skin conditions can be hereditary, and many parents may have the same condition as their infant. This could make providing care painful, as conditions such as nipple dermatitis affect 11-23% of people with AD, and could be exacerbated from the demands of breastfeeding (Raimondo & Lembo, 2021).

The development of children's internal working models could be influenced from interruptions to early parent and child bonding. Attachment theory was first proposed by Bowlby (1969) and suggests that a developing child's experiences during infancy of forming close bonds with their primary caregiver are internalized and determines their ability to regulate emotion. This working model is theorised to influence the quality and expectations of relationships in later life (known as attachment styles). For example, a child who has had a responsive caregiver will develop a secure attachment and feel worthy of receiving love (Siegler et al., 2020; Bowlby, 1969). In contrast, a child who has had an inconsistent or insensitive caregiver is more likely to develop negative perceptions of themselves and others (Siegler et al., 2020; Bowlby, 1969). Thus, there could be implications for a child's later psychological adjustment to illness, social behaviour, and self-esteem (Siegler et al., 2020).

Evidence suggests an association between dermatological conditions and attachment orientation (Tomas-Aragones, 2018; Demirci et al., 2020) with insecure attachments persisting into adult years with potential to affect quality of life including adjustment to skin conditions and levels of distress (Krasuska et al., 2018). The relationship between skin conditions and attachment styles could be bidirectional. According to a study by Demirci et al. (2020), insecure attachment styles could be associated with affective disorders and reduced quality of life in people with

psoriasis, and alter the body's response to stress. Similarly, a study involving 3,000 people with skin conditions in Europe (Szabó et al., 2017) found that there was a greater percentage of non-stressed people with secure attachments compared to those with insecure attachments, and attachment styles could be linked to levels of stress.

The role of attachment might be particularly important for adjustment to a skin condition as there could be physiological consequences from developing insecure attachments. Robles et al. (2013) investigated the relationship between the skin barrier and attachment styles in adults, and found that individual differences in attachment and stress were related to skin healing, from the cortisol response to social interactions slowing recovery. Thus, the style of attachment developed during childhood could influence resilience to stress via dysregulation of the HPA axis (Pietromonaco & Powers, 2014), and play a significant role in the propagation of a skin condition affected by emotions. Thus, people with skin conditions who develop insecure attachments during childhood might be more likely to experience higher levels of stress later in life. This could ultimately result in increases instances of mood disorders and reduced quality of life in people with conditions such as psoriasis (Demirci et al., 2020).

When addressing childhood illnesses and, specifically, the impact of living with a skin condition, it is also important to consider how developmental stages may be disrupted by a dermatological diagnosis. According to early research by Erikson (1950), as children progress through the developmental stages of childhood and early adolescence, they will begin to develop a sense of identity and establish their sense of self (e.g., "identity vs. role confusion"). Identity formation could be impacted by the existence of a long-term condition disrupting emotional/cognitive maturation as well as functioning, and there could be a lasting impact on social development and adult personality (De Vere Hunt et al., 2020; Linthorst Homan, 2008; Erikson, 1950; Krasuska et al., 2018). Although many children do appear to cope well (Moss et al., 2020), some young people may develop body image concerns (De Vere Hunt et al., 2020), experience mood changes, (Cheung & Lee, 2012; Kemp, 2003) or even clinical levels of depression (Rønnstad et al., 2018).



The impact of a skin condition could depend on age and where a child is with their developmental milestones. For example, as proposed in the Piagetian model, a child may not notice their skin condition at a younger age, when they are progressing through the earlier sensorimotor and pre-operational stages of development (Piaget, 1962, in Slater & Bremner, 2017). However, as a child cognitively develops and starts to question their environment, they could become more inquisitive about their health as they enter the 'concrete' (7-11 years) and 'formal operations' (11 years onwards) stages (Piaget, 1962, in Slater & Bremner, 2017) and may ruminate on the reasons for their visibly different appearance (e.g., 'why me?').

As well as the stresses associated with having a visibly different appearance, the physical symptoms can be equally as disruptive. Painful symptoms may inhibit children from taking part in regular childhood activities (including hobbies and exercise) or could even alter their life goals and shift the trajectory of self-perceptions. If negative appraisals of the self are experienced, they might ultimately lead to feelings of unworthiness, and adversely affect a child's response to chronic illness (McPherson, 2021). Consequentially, a child with a skin condition may not feel good about themselves in the developmental domains for self-esteem outlined by Harter (1983, 1999, in Slater & Bremner, 2017). For example, the development of self-worth could be affected from having a visibly different appearance, missing education to attend dermatologic appointments, and from being unable to participate in physical activities (e.g., swimming).

For adolescents, there will be fluctuations in pubertal hormones that can cause strong emotions and increase vulnerability to criticism (Leman et al., 2019) and contribute to flare-ups in severity of skin conditions such as psoriasis (Ceovic et al., 2013). Adolescents will begin to engage in social evaluations and might start to compare themselves to their peers. Engaging in social comparisons at a sensitive time of development, and not 'fitting in' could result in negative body image and self-evaluations. It is perhaps for these reasons, a study conducted across Europe by Schut et al. (2022) suggested that people with skin conditions are five times more likely to develop symptoms of body dysmorphic disorder (BDD), particularly for females, and those of a younger age.

Living with a childhood condition could therefore have a profound effect on a child's emotional and cognitive development (McPherson, 2021). Experiencing interruptions during an important time for psychosexual maturation could have implications for mental health, as the APPGS (2020) reported out of twenty-seven paediatric participants, all felt their skin condition had negatively impacted on their wellbeing and ability to relate to peers. Indeed, other people may play a role in how a child makes sense of their illness and their secondary emotions (Leman et al., 2019). Herein, the experience of stigmatisation could be significant, and children may face negative reactions from others, including disgust or staring, particularly from other children, who may still be learning about social norms (Titman, 2005). The development of children's responses and stigma towards other children with visible difference has long been evidenced, with early research by Sigelman et al. (1986) reporting over thirty years ago that children of varied ages and sexes show a preference for children who look 'normal.' In some cases, it could be that children's reactions to visible difference might simply be explained by curiosity as they are still learning about how their behaviour affects others, but this could escalate to bullying and have serious implications for mental health (Titman, 2005; Papadopoulos & Walker, 2003).

The bias towards unblemished skin could be challenging for a child with a visible condition, as their appearance may not align with other people's image standards. Society attaches value to having perfect skin and emphasises the importance of conforming to idealised images of 'beauty' (Trekels & Eggermont, 2017). With the rise in social media, children and young people are constantly exposed to flawless body image standards, which creates pressure for young people to strive towards attaining an idealised image to be considered 'attractive' (Tiggeman & McGill, 2004; Clark & Tiggeman, 2007). The desire to look a certain way could be damaging for the self-esteem of children with visible skin conditions, as they may not be able to achieve such unrealistic standards of physical attractiveness (Harter 2012, in Siegler et al., 2020). For instance, Adkins et al. (2023) examined how adults with acne used social media and discovered a link between Facebook photo activity (time spent engaging with images on Facebook) and stigmatisation. This relationship was impacted by "upward" comparisons to those who were considered "superior", but it

was not the same on all platforms and more research is needed (Adkins et al., 2023).

Attempting to meet widespread idealised image standards could support self-objectification theory, as from an image-conscious culture, 'third-person perspectives' on the self are developed instead of 'first-person perspectives,' with young girls and children perhaps placing greater value on their appearance rather than other life skills (Calogero, 2012). Indeed, it is argued that from viewing the self as a sexual object, women become their own 'critic' in anticipation of negative judgement from other people, which might be heightened from having broken skin and result in body dissatisfaction, depression, or feelings of shame and 'failure' (Calogero, 2012; Tiggeman & Slater, 2015). However, there is research to suggest that the psychological burden of living with a skin condition is significant and may negatively affect men and women equally (Hughes et al., 2021).

Experiencing intense emotions from a young age could precipitate maladaptive emotional development from a disproportionate level of negative secondary emotion (Leman et al., 2019). For example, the development of primary emotions does not require self-reflection (e.g., "fear, joy, disgust, surprise, sadness, interest") but secondary emotions are classed as 'self-conscious emotion' (e.g., "pride, shame, embarrassment, guilt, jealousy") and often emerge later from interactions with other people (Lewis, 1998; Saarni et al., 2006, in Leman et al., 2019). Indeed, a cross-sectional analysis of 1,162 children and adolescents with HS revealed they had 1.42 times the odds of developing a mood disorder, and there was a prevalence of 11.7% for depression compared to 4.1% in healthy controls (Wright et al., 2022).

Perhaps perpetuating the psychological burden, are the immediate and painful physical symptoms of skin conditions that can alter physical functionality. Indeed, levels of itch and pain could have an equivalent negative impact and contribute to lowered affect. Childhood psoriasis and AD have been found to impair health-related quality of life in a similar way, at least equal to children experiencing other chronic childhood illnesses (e.g., 'cerebral palsy, renal disease, epilepsy, diabetes') (Beattie & Lewis-Jones, 2006). Children with itchy skin conditions may find controlling their urge to scratch difficult, with scratching worsening the skin, causing bleeding, and increasing chances of infection (known as an "itch-scratch cycle") (Reid & Lewis-

Jones, 1994; Lewis-Jones, 2006; Papadopoulos & Walker, 2003). This could have implications for children's pattern of rest, as significant itch can keep a child awake at night and cause tiredness or problems with concentration during the day (Reid & Lewis-Jones, 1994; Lewis-Jones, 2006; Fennessy et al., 2000; Papadopoulos & Walker, 2003).

### **1.1.3. Treatment and prognosis**

The field of dermatology is concerned with the treatment and management of skin and hair conditions by a specialist clinician (dermatologist) who will oversee treatment and monitor progression. In the UK, dermatology patients progress through a pathway of recommended treatments (NICE, 2017). Diagnosis will normally begin with a patient seeking advice from their primary care General Practitioner (GP), who will refer for assessment by a dermatologist depending on clinical severity, age, and health of the patient. In the first instance, treatment begins with the use of topical steroid creams and ointments (NICE, 2017). When topical therapies are unsuccessful in controlling the skin condition, or if the patient's quality of life is significantly affected, they will often commence treatment with ultraviolet light phototherapies (e.g., UVB, or PUVA; Psoralen and ultraviolet light A), systemic non-biological drugs (oral suspensions, tablets, capsules and injections), or biological and small molecule therapies (injections and infusions) (NICE, 2017).

Depending on the age of a child, compliance might be an issue when applying topical treatments (moisturizers, lotions, and sticky creams or ointments) which can be messy and unpleasant. Although older children can take responsibility for their treatment, younger children's parents may be responsible for cream application (Papadopoulos & Walker, 2003), which could result in stress from trying to foster cooperation (Santer et al., 2012). It could be that children resist treating their skin, as in a study of families affected by EB, it was estimated that wound care could take several hours, with 12.7% of patients and 9.7% of caregivers dedicating over four hours per day (Bruckner et al., 2020). For a younger child, staying engaged and committed to intensive daily routines could be challenging. Previous research has recommended that clinicians consider the impact on the family when deciding treatment plans, as for many, systemic treatments might be more appropriate if a topical treatment is becoming a burden to a family (Snyder et al., 2022). As well as

applying topical treatments, some skin conditions (such as HS) may require surgery/de-roofing procedures to remove recurrent or treatment-resistant lesions (Leszczynska et al., 2022).

Determining the prognosis of skin conditions is difficult, and they may affect children in different ways. Importantly, this means that the severity of a skin condition may not be a straightforward predictor of how a child adjusts. For example, a child with mild acne could be more psychosocially impaired than a child with severe psoriasis, depending on how they make sense of their condition, and how they view their diagnosis (Titman, 2005). How a child copes could depend on a range of factors, including environment, age at onset, family beliefs and attitudes (Hughes et al., 2022) and their level of psychological resilience (Titman, 2005).

The impact of a skin condition can be bidirectional, as elevated stress can affect the skin itself. If a child does not healthily develop emotionally, and does not learn to regulate their emotion, there could be negative consequences for the propagation of a skin condition via the stress-inflammation pathway and result in lasting psychological and biological effects across the lifespan (Rohleder, 2019). Experiencing chronic stress during childhood years can alter brain functioning from increased levels of stress hormones influencing healthy cognitive development (Lupien et al., 2009; Siegler et al., 2020). However, the association between levels of perceived stress and skin conditions is complex, as there have been findings to suggest that patients with inflammatory skin conditions have a 'tripled risk' of experiencing stress (Balieva et al., 2022).

Although developing healthy and secure attachments are critical for all children, there could be additional importance for a child managing a chronic illness, to have the sufficient psychological resilience to buffer against negative psychological sequela. Particularly when considering the complex relationship between stress, chronic inflammation, and the trajectory of several autoimmune conditions including cancer, diabetes, obesity (Couzin-Frankel, 2010) and multiple sclerosis (Hunter, 2020). For example, skin conditions such as psoriasis (Afonina et al., 2021; Schabitz et al., 2021), acne (Roman et al., 2016), AD/eczema (Peate, 2011; Schabitz et al., 2021), and vitiligo (Taieb, 2011) are inflammatory conditions, caused by a dysregulation in the body's immune system. The inflammation from chronic health

conditions (such as skin conditions) may even play a role in depression (Maes et al., 1993; Bullmore, 2018), as elevated levels of inflammatory cytokines reportedly occur alongside major depression and could decrease serotonin in the brain (Maes et al., 1993; Bullmore, 2018).

Indeed, there is a high prevalence of depression experienced in both adults and children with skin conditions (Rønstad et al., 2018; Thompson & Kent, 2001; Jensen et al., 2016; Bahmer et al., 2007). In terms of a physical explanation, experiencing pain and itch from a skin condition could alter nerve signals to the brain, and precipitate affective fluctuations (Shenefelt, 2018). The relationship between inflammation and mental health has been previously investigated in a longitudinal survey of 15,000 children from 9-18 years of age, and those who had high blood cytokine levels were one and a half times more likely to be depressed at the age of 18 years, than children with lower inflammation during childhood (Khandaker et al., 2014, in Bullmore, 2018). However, there was a considerable time gap between the children being inflamed and experiencing depression, so it is difficult to determine whether inflammation may have directly influenced later mental health (Khandaker et al., 2014, in Bullmore, 2018). It is also important to remember that not every person who experiences depression, will have systemic inflammation (Bullmore, 2018). Indeed, a recent investigation into the serotonin theory of depression concluded there is no longer adequate nor empirically robust evidence to support the long-standing belief that lower levels of serotonin play a role in depression (Moncrieff et al., 2022).

Despite the gaps in understanding, pro-inflammatory cytokines might play a role in many skin conditions and could be increased in childhood for conditions such as acne, HS (Di Caprio et al., 2017), psoriasis (Brembilla et al., 2018) and eczema (Wittmann et al., 2014). This could be exacerbated, as there is evidence to suggest that having low self-esteem could mediate inflammatory responses to acute stress (O'Donnell et al., 2008), as lower stress ratings have been found in individuals with greater dispositional self-resources (e.g., trait self-esteem, optimism) and from affirmed personal values (Creswell et al., 2005). This could be significant, as a survey of children with skin conditions has shown 85% have low self-esteem (APPGS, 2020), suggesting that living with an inflammatory illness perpetuated by

social strain and anxious arousal, could result in poorer health over time (Guevara & Murdock, 2019).

#### **1.1.4. The nature of existing psychological support for people with skin conditions**

Psychodermatology is a subspeciality of dermatology delivering specialist services for people experiencing two types of clinical presentations: (1) a primary psychiatric diagnosis resulting in skin-related symptoms (e.g., skin picking disorder) and (2) primary skin disease resulting in psychological distress (e.g., psoriasis, acne, eczema) (Bewley, 2014; Hughes & Bewley, 2023). Currently, psychological assistance for the treatment of skin conditions across the UK and access to specialised services are inconsistently spread across regions. The APPGS (2020) investigated level of service provision and reported there are a total of 10 specialist psychodermatology clinics in England, and three across the devolved nations (i.e., 'two in Scotland, one in Northern Ireland, none in Wales'). As well as these specialist services being unequal, some are for specific skin conditions (such as psoriasis) and not broader psychodermatology services (APPGS, 2020). The APPGS (2020) report also found that despite 98% of people surveyed reporting their skin condition had affected their emotional and psychological wellbeing negatively, only 18% had sought psychological assistance.

The gap in psychological support for people with skin conditions could be due to a lack of awareness/recognition of the associated psychological sequelae, and a lack of training and funds (Blackstone et al., 2022). For example, a qualitative investigation of patients experiences of accessing psychological support for skin conditions revealed that respondents felt their needs and issues were not always understood by healthcare professionals, and they had not had access to the appropriate support (Wheeler et al., 2022). However, it could also be that patients with dermatological disease self-stigmatise, and do not actively seek help themselves as they view their condition as 'trivial' or non-life threatening (Blackstone et al., 2022).

The integration of trained psychologists into the pathway of care for patients living with skin conditions has long been called for in previous literature from

clinicians and patients alike (Manolache & Finlay, 2022; Hughes, 2022; Wheeler et al., 2022), supported by an audit of support services for psoriasis (Smith et al., 2020) showing a lack of psychological consideration when approaching skin management. Additional support might be needed for this patient demographic more than ever, with consideration of the psychological repercussions of the COVID-19 pandemic, as many patients on immunosuppressant medication had to shield or might have experience serious illness as a result of their drug treatments dampening their immune system's ability to fight infection (Blackstone et al., 2022). The appropriate resources, training, and support is required in order to provide a service to best support the needs of people diagnosed with skin conditions (Blackstone et al., 2022), with particular attention to the overlooked area of children and families.

In lieu of standardised commissioning for specialist psychological services across the UK, there is an urgent need to minimise the burden of skin conditions, reduce parental stress, and assist families in healthily coping with the demands of treatment, with targeted psychosocial interventions (De Maeseneer et al., 2019; Walsh et al., 2022). In an attempt to fill the gaps of service availability, online and self-help interventions could be the most feasible form of intervention to reach people experiencing distress from living with skin conditions. There are many benefits of delivering psychological interventions online, including increasing availability, and allowing participants the flexibility of access. The mode of delivery of interventions has been investigated with people with skin conditions, and some web-based digital interventions have shown promise for people with psoriasis and eczema (Hewitt et al., 2022). For example, an online CBT intervention 'Face IT' was developed for adults with a range of conditions affecting appearance, including skin conditions (Williamson et al., 2015; Norman et al., 2022) and has also been tested with adolescents (Zelihić et al., 2022; Millgård et al., 2022).

Studies investigating the use of online-based support for skin conditions have included a randomized controlled trial (RCT) of internet-delivered cognitive behavioural therapy (ICBT) (van Beugen et al., 2016). ICBT has been examined in patients with psoriasis, with reported improvements to physical functioning and levels of fatigue, but no significant differences in psychological functioning (van Beugen et al., 2016). It could be that an online format might be suitable for this patient



demographic, as there has been research to suggest the benefits for people with dermatological disease having the opportunity to connect with other people online, using techniques such as blogging to promote positive adjustment, although the mechanism for change could have been support and the benefits of expressive writing (Tour et al., 2022). Further, another RCT examining ICBT for adults with AD reported improvements in skin condition symptoms, including itch, level of stress, sleep disruptions, and depression (Hedman-Lagerlöf et al., 2021). As well as this, the digital delivery of unguided mindfulness ('Headspace') has previously been found to reduce healthcare workers stress and could be a viable mode of delivery (Taylor et al., 2022).

To date, most psychosocial interventions for people with skin conditions reported in the literature are defined as educational, rather than drawing on psychological theory (Ersser et al., 2014; Pickett et al., 2015; Pickett et al., 2016; Zhao et al., 2020). For example, there have been recent education-based interventions created, such as 'Eczema Care Online' which has shown promise for supporting young people with AD via a website platform (Greenwell et al., 2022). Indeed, a systematic review by Jenkinson et al. (2015) reported that the long and short term effectiveness of interventions for adolescents experiencing appearance-related distress is 'inconclusive' from current research. This was further highlighted in another systematic review by Costa et al. (2021) investigating the effectiveness of psychosocial interventions for parents of children with visible difference (including AD/eczema), which found strong to moderate evidence in a sample of studies mostly consisting of educational/training interventions.

Along with a lack of clear psychological theory, most existing studies employing digital interventions with people with skin conditions have recruited adult samples. Importantly, in addressing this gap in specificity to children and families, there is a need for interventions to address the needs of families affected by skin conditions. For example, although an RCT of the 'Young Persons Face IT' intervention showed the curriculum was effective for reducing social anxiety in adolescents affected by visible difference (Zelihić et al., 2022), further investigation with qualitative interviews revealed that despite the intervention being self-help to strengthen young people's ability to build connections outside of the family context, some adolescents desired

greater parental support, and parents missed being more involved (Millgård et al., 2022).

The value of ensuring an intervention is designed around the target user has been evidenced in research into a web-based platform for dermatological patients, where perceived patient relevance was low as a result of a lack of consideration of individual needs (Van Cranenburgh et al., 2015). In line with this, online resources could be enhanced with patient accounts of individual experiences, to help people feel supported with a health condition (Ziebland & Wyke, 2012; Iliffe & Thompson, 2019). As such, HealthTalk.org (2019) collected footage of young patients describing their hair loss and the consequential impact on their daily lives, which were incorporated into a support resource to increase relevance to real-life patients.

Indeed, developing interventions that are accessible for patients and their families is vital to their success in real-life, and with society being technologically orientated, digital interventions may be appropriate (Iliffe & Thompson, 2019). Supportive of this, investigations have been carried out with smartphone apps, and some success has been shown for improving treatment adherence (Svendsen et al., 2018), therapy compliance (Balato et al., 2012) moisturizer application (with text messages) (Erdil et al., 2020), and for increasing knowledge (Hawkins et al., 2017), and improving mental health (Domogalla et al., 2021). Thus, online delivery might be effective for this specific group of people, as supported by feedback from a web-based psychosocial support resource for adults (Heapy et al., 2020). In order to develop such interventions, findings from a systematic review by Hewitt et al. (2022) has shown that a multidisciplinary approach is needed to work towards developing digital psychological interventions for people living with skin conditions.

## 1.2. The Role of Mindfulness

### 1.2.1. Definition

Mindfulness is an approach based on Buddhist principles, involving developing an open and non-judgmental awareness of what is happening in the moment (Bishop et al., 2004; Schindler & Friese, 2022; Kabat-Zinn, 1994; Phan-Le et al., 2022). The definition of mindfulness that guided the research presented in this thesis was based on Jon Kabat-Zinn's (1994, pg.4) well-known description of "*paying attention on purpose, in the present moment, non-judgementally*". By allowing thoughts to come and go, attention can be focused on the present moment by simply observing emotions (Bishop et al., 2004; Schindler & Friese, 2022). Practicing mindfulness is the antithesis of acting without awareness or being on 'autopilot' (Schindler & Friese, 2022). There are differences in the stability of mindfulness as a 'trait' between people depending on the situation, and also as a 'state' across time periods (Schindler & Friese, 2022). These varying levels of mindfulness and the association with psychological wellbeing has been the subject of much research, investigating both trait and state mindfulness (Schindler & Friese, 2022).

The practice of exercises to build behaviours such as observing and non-judgement of inner experiences are part of structured programmes (Kabat-Zinn, 1994). A wide range of psychological interventions have encompassed mindfulness-based practices to facilitative emotional regulation (Bishop et al., 2004; Shapero et al., 2018). In manualised formats, mindfulness-based curriculums consist of group-based interventions to target conditions including anxiety and depression (Shapero et al., 2018). Mindfulness-based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT) are two of the most commonly used models to increase adaptive thought patterns and promote psychological well-being (Shapero et al., 2018; Kabat-Zinn, 1994). As a result, group mindfulness and meditation (MBCT) has recently been recommended in NICE guidelines as a treatment for less severe depression in adults (e.g., subthreshold/mild symptoms, scoring less than 16 on Patient Health Questionnaire [PHQ-9]) (NICE, 2022). Other interventions based on related facets of mindfulness include acceptance and commitment therapy (ACT) teaching acceptance towards uncontrollable experiences, mindful self-compassion

(MSC) aiming to build kindness towards the self, as well as a range of smartphone applications, such as Headspace, delivering short, digitalised mindfulness exercises (Allen et al., 2021).

The goal of traditional MBSR is to raise body awareness and reduce levels of stress, whereas MBCT integrates with cognitive behavioural theory to help people manage negative thinking by noticing thought patterns and viewing them as temporary experiences (Shapiro et al., 2018). Usually, these interventions last for eight weeks, and often build in a one-day 'mindfulness retreat' to reflect on learning (Shapiro et al., 2018). In these mindfulness based interventions (MBIs), people engage in a range of formal practices, including meditation and the 'body scan'. These practices have the aim of teaching people to focus their attention on their bodily sensations while maintaining an accepting attitude towards any feelings that emerge (Shapiro et al., 2018). MBIs frequently involve homework exercises to be completed regularly, for example, by carrying out daily activities in a mindful way (e.g., mindful eating) (Shapiro et al., 2018).

Practicing mindfulness has been associated with structural changes in the brain. A systematic review by Melis et al., (2022) of brain outcomes after participating in MBIs found that in some cases, there was occasionally a change in the functional connectivity between networks related to attention, executive function, emotional reactivity, and mind wandering. Engaging in mindfulness has also been associated with a range of positive mental health outcomes for varying psychological conditions, such as obsessive-compulsive disorder (Strauss et al., 2018), anxiety and depression (Hofmann et al., 2010), and bipolar (Burgos-Julián et al., 2022). There have also been promising results for physical health conditions (Hughes et al., 2023), with reductions in levels of pain and fatigue in people with multiple sclerosis (Han, 2021), and increased post-traumatic growth and resilience for people with cancer (Faghani et al., 2022).

For children, mindfulness has been increasingly applied in school-based settings (Zenner et al., 2014). Mindfulness in Schools Project (MiSP) is a well-established charity initiative delivering mindfulness-based activities and teachings to classrooms, to reduce conflict, lessen impulsivity, assist in coping with stressful

exams, and teach efficacy (MiSP, 2021). However, there has been less research focusing on families. A systematic review of MBIs for children in early childhood settings by Bockmann and Yu (2022) found that from a sample of 19 included articles, only one involved a training component for parents to practice at home (Jackman et al., 2019). A lack of parental involvement in MBIs with children could limit how successful MBIs are outside of the school environment, when the influential role of the family is considered (Bockmann & Yu, 2022). The absence of family components in MBIs may reduce the ability of children to transfer mindfulness training from school to the home (Bockmann & Yu, 2022). By extending mindfulness training to include parents, there may be added therapeutic outcomes in strengthening informal practices from the family environment, and the inclusion of parents in future MBI has been suggested as necessary (Bockmann & Yu, 2022; Crooks et al., 2020; Jackman et al., 2019).

Perhaps further evidencing the need for family-targeted MBIs, and in contrast to previous findings, the effectiveness of mindfulness in its application to children was recently investigated with a large-scale cluster RCT of universal school-based mindfulness programmes for early adolescence investigating outcomes for mental health and well-being outcomes. There was “no evidence for the superior effectiveness of mindfulness compared with usual social-emotional learning provisions” (Kuyken et al., 2022). Although this finding is important, it could be that the successful application of mindfulness in schools is dependent on personal levels of practice, that are important to generating meaningful behavioural change. This could be relevant to children with skin conditions as school-based activities might be challenging for those with visible differences, perhaps not engaging fully, or being influenced by social embarrassment. Thus, it could be necessary to consider context when delivering MBIs in order to facilitate the appropriate depth of concentration and awareness to achieve optimum outcomes.

Whilst evidence from cross-sectional studies such as Montgomery et al., (2016) has suggested there may be an association between mindfulness and distress in adults with skin conditions, and the technique could lessen negative illness-related outcomes. For example, by paying attention to the experience of what is going on in the immediate environment, mindfulness could alter cognitive appraisals of events as

either positive or negative with acceptance of what is happening (Montgomery & Thompson, 2018). Therefore, through practicing non-judgement, the experience of negative events in daily life could be reduced, and pleasurable experiences could be increased (Hunter, 2020; Creswell et al., 2012). Mindfulness could be particularly relevant for children with skin conditions and their families, as awareness of the mind and body could improve resilience to illness, quality of life, and alter responses to stress (Hunter, 2020; Pascoe et al., 2017).

### **1.2.2. Self-compassion**

A related facet of mindfulness is being kind to the self. The role of self-compassion could be an integral part of mindfulness and its potential therapeutic application to children with skin conditions. Self-compassion involves being open to suffering instead of avoiding it and alleviating negative experiences with kindness to the self (Neff, 2003; Neff, 2007). By practicing self-compassion, a non-judgmental understanding to pain, inadequacies, and failures can be cultivated and applied to everyday life (Neff, 2003; Neff, 2007).

There is increasing evidence for the role of self-compassion with people living with skin conditions (Clarke et al., 2022). For example, Clarke et al. (2020) conducted a cross-sectional survey investigating the role of disgust traits in depression in people with skin conditions, and found that being self-compassionate could be a protective factor against depression. Further, a systematic review indicated that mindfulness-based third wave therapies might have value in addressing feelings of self-stigma and shame (Stynes et al., 2022).

Learning to be kinder to the self could be relevant for people with skin conditions, as Almeida et al., (2020) investigated the relationship between skin condition severity and self-compassion, and found the dimension of 'self-kindness' showed a significant correlation with disease severity perception. These findings could suggest that a higher level of self-kindness could be associated with lower disease severity (Almeida et al., 2020). However, this was an initial exploratory study, so there is a need for longitudinal investigations to strengthen understanding of how self-compassion may be associated with psoriasis symptoms (Almeida et al., 2020).

### **1.2.3. Mindfulness for therapeutically targeting the psychological sequelae of dermatological symptoms**

One of the first studies investigating mindfulness with people with skin conditions was carried out by John Kabat-Zinn et al. (1998) with 37 patients undergoing light therapy (UVB and PUVA) for psoriasis. In this study, patients were randomised to receive treatment as usual (TAU), or with guided meditation, and those who participated in mindfulness achieved skin clearance faster than those who did not (Kabat-Zinn et al., 1998). Since then, there has been increasing evidence for the use of a range of MBIs with people with skin conditions. Zangi et al., (2012) carried out a study and randomised 73 patients with joint conditions (including psoriatic arthritis) to receive a 10-week mindfulness meditation intervention, and although there were no significant differences in level of pain, disease activity or emotional expression, there were significant differences in levels of fatigue and stress. Further, Fordham et al. (2015) carried out a pilot study and delivered a group-based mindfulness-based cognitive therapy to 29 patients with psoriasis as an adjunct to their usual therapy, and found there were improvements in patient-reported psoriasis severity and dermatology-related quality of life, but did not find any improvements in depression and anxiety.

When considering the current literature base, a recent systematic review of MBIs for people with skin conditions (Meneo et al., 2022) concluded that most available MBIs used with dermatological conditions consist of MBCT (D'Alton et al., 2019; Fordham et al., 2015; Gojani et al., 2017; Maddock et al., 2019; Maddock et al., 2020a; Maddock et al., 2020b). MBCT has received attention from researchers, such as D'Alton et al (2019) who compared the use of MBCT, mindfulness-based self-compassion therapy (MBSCT), and self-help (MBSCT-SH) with TAU in ninety-four adults affected by psoriasis. It was reported that although participants found the interventions useful, there were no significant differences in measures of psychological wellbeing, psoriasis symptoms, or quality of life (D'Alton et al., 2019). The authors speculated this could be a result of the study sample being deemed as having mild to moderate psoriasis (D'Alton et al., 2019). Whilst another study by Maddock et al., (2019) investigated MBCT in 101 patients diagnosed with psoriasis and reported significant effects for psoriasis symptoms and psychological wellbeing

following participation in the intervention. The differences in results from this study compared to previous findings by D'Alton (2019) and Fordham et al., (2015) has been explained as potentially a result of the differences in skin severity of participants, and levels of psychological distress at baseline potentially resulting in a floor effect (Maddock et al., 2019).

To understand individual differences in people with psoriasis and their response to mindfulness, research has investigated the underlying mechanisms of change involved in MBIs (Maddock et al., 2020a). Using a clinically modified Buddhist psychological model, patients with psoriasis were assessed for psychological variables, and it was reported that “aversion, acceptance, non-attachment, and self-compassion” could have a direct impact on wellbeing and anxiety and depression in adults with psoriasis, and indirectly through reduced worry (Maddock et al., 2020a). To examine mindfulness further, Maddock et al., (2020b) carried out qualitative interviews with ten patients with psoriasis who had attended MBCT sessions, and participants described how the consistent practice of mindfulness had helped to reduce their patterns of rumination and negative thinking, and had led to improved coping from changing maladaptive thought processes.

Indeed, Rafidi et al. (2022) suggested that both psychological and mind–body interventions could be efficient for improving psychological outcomes in people with skin conditions, with therapies such as cognitive behavioural therapy and mindfulness showing success for psoriasis, and habit reversal for AD. Similar findings were reported in a systematic review by Qureshi et al (2022), suggesting the most promising methods of psychological intervention for people with psoriasis included cognitive behavioural therapy, MBIs, motivational interviewing, and educational and interdisciplinary interventions.

There have also been promising research findings for mindfulness improving skin severity and quality of life in the short term (Bartholomew et al., 2022). As well as this, when compared to other therapies, Gojani et al. (2017) found a significant increase in general health of people with psoriasis after participating in mindfulness (including anxiety, social function, and depression) when compared to a control group receiving Schema Therapy for improving maladaptive cognitive schemas



related to their skin condition. Despite this, the study involved a small sample of patients so generalisations must remain cautious (Gojani et al., 2017).

Mindfulness could have some benefits for physical functioning (Bartholomew et al., 2022), as shown in one of the earlier studies by Kabat-Zinn (1998) with the combination of mindful meditation tapes with ultraviolet light therapy reportedly reducing self-perceived severity of psoriasis lesions, but not psychological outcomes. Similar findings were reported by Fordham et al., (2015) who found a significant improvement in participants' self-reported psoriasis severity and a 39% decrease in symptoms, but not for affect. Of note, severity of skin conditions could be an issue when assessing the effectiveness of MBIs, as although people with skin conditions experience a similar psychological burden despite level of visibility, there can be variations across conditions (Meneo et al., 2022; Thompson & Kent, 2001). For example, psoriasis has been associated with greater impairments to psychological wellbeing and quality of life (Meneo et al., 2022).

Currently, there appears to be an unequal focus of existing literature investigating mindfulness being mostly conducted with people with psoriasis (Bartholomew et al., 2022; Almeida et al., 2020; Maddock et al., 2020a) and less focus on other skin conditions, (Clarke et al., 2020; Montgomery et al., 2016; Gallo, 2017). However, there appears to be increasing evidence for the use of mindfulness with AD, and findings have included the feasibility and efficacy of an MBI with a psychoeducational component on eczema and itch, or 'mindfulness-based training for chronic skin conditions' (MBTSC). For example, MBTSC was investigated by Harfensteller (2022) for promoting emotional self-regulation and coping with itch, and findings showed a small improvement in eczema severity, and a decrease in itch perception post-intervention (Harfensteller, 2022). However, the study relied on subjective self-report measures, and a small sample size which makes generalising findings problematic. Most recently, an RCT by Kishimoto et al. (2023) investigated the efficacy of an online-based mindfulness and self-compassion intervention for adults with AD with an RCT of 107 adults, and found that disease-specific quality of life, patient-reported disease severity, and all secondary outcomes improved (e.g., itch, eczema severity, mindfulness, self-compassion). However, the study sample was self-selecting, highly-motivated Japanese participants, so further investigations

are warranted to determine if the findings are generalisable across different populations.

There is some limited support surrounding the use of mindfulness with people with alopecia areata. Gallo et al., (2017) conducted a pilot study delivering a group MBSR intervention to eight outpatients with alopecia as an adjunct to their usual treatment, and found that there was a significant improvement in quality of life. The study however, relied on a small sample size of patients with worse baseline scores on psychometric measures than controls, which could have influenced the size of improvements recorded (Gallo et al., 2017). Most recently, Heapy et al. (2023) delivered an MBCT intervention to a group five adults with alopecia to target clinical levels of anxiety, and found significant reductions in social anxiety from baseline to follow-up. Mindfulness has also been investigated in an online format with a sample of sixty-nine patients diagnosed with melanoma, and was found helpful by 72% of the respondents who took part in the intervention, for reducing fear surrounding cancer recurrence (Russell et al., 2019). The intervention was well accepted, with a completion rate of 80%, however, the researchers relied on participants tracking their own progress rather than with digital tracking, so there may have been bias in reporting rates of completion (Russell et al., 2019).

When considering how effective mindfulness could be for the management of a range of different skin conditions, there could be biological explanations for therapeutic outcomes. Some evidence has suggested that MBSR could reduce protein biomarkers of systemic inflammation in chronic illness (Carlson et al., 2007; González-Moret et al., 2020; Black & Slavich, 2016), and could reduce inflammatory interleukins in caregivers (Lengacher et al., 2012). Indeed, participation in mindfulness could improve immune function, and consequently have a therapeutic effect in somatic disorders and conditions involving dysregulation of the immune system (Dunn & Dimolareva, 2022). There has been recent evidence to suggest mindfulness retreats could even improve biomarkers of inflammation, although it is unclear if practicing mindfulness or brief relaxation was the underlying mechanism of change (Gardi et al. 2022). Although there is emerging research suggesting a link between mindfulness and reductions in the inflammation pathway, further

investigations are required to understand the processes involved, as the interactions between emotion and psychological reactivity are complex (Lindsay, 2021).

In terms of stress, mindfulness could lessen the lasting impact of early life experiences on the body by teaching healthy emotional management of biological pathways that might have become dysregulated during childhood (Lindsay, 2021). Indeed, mindfulness could play a role in reducing reactivity, experiential avoidance, and consequently, cumulative stress and allostatic load (Hunter, 2020; Montgomery & Thompson, 2018). For skin conditions, mindfulness could improve control of the stress response and alter how stressors are experienced, which might ultimately reduce psychological arousal and the impact on the skin barrier (Montgomery & Thompson, 2018). For example, children's experience of dermatological symptoms could support Lethem's theory of exaggerated pain perception (Lethem, 1983; Montgomery & Thompson, 2016; Hughes & Bewley, 2023) and the fear-avoidance model of psychological difficulty following disfigurement (Newell 1991; 1999). Indeed, a child's personality, experiences, and fear related to having visibly different skin (e.g., being bullied or receiving negative comments) could influence how a child interprets and responds to an event with avoidance or confrontation (Newell 1991; 1999; Hughes & Bewley, 2023).

Mindfulness training could shift how skin-related phenomena are viewed (e.g., the associated physical sensations) which might be perpetuated by psychological stress (Verhoeven et al., 2008). In accordance with previous research (Lethem et al., 1983; Newell 1991;1999), mindfulness has been found to reduce reactivity in the amygdala in response to threat stimuli (Dutcher et al., 2021), which may be effective for children experiencing a fear or 'threat' of adverse reactions from other people (Newell, 2991;1999; Montgomery et al., 2016; Hughes & Bewley, 2023). Thus, child coping strategies could be enhanced from reducing negative cognitions in daily life. For instance, qualitative interviews following attention-based training for chronic spontaneous urticaria with mantra meditation revealed that levels of stress, anxiety, and depression may decrease (Ridge et al., 2021). Although this was not a traditional MBI, it did contain some components of mindfulness, which may demonstrate the relevance of shifting attention to regulate affect.

Moreover, mindfulness could assist in fostering healthier, more secure styles of attachment during childhood. Resilience has been positively associated with mindfulness, whilst attachment avoidance and attachment anxiety have been negatively associated with both mindfulness and resilience (Yang & Oka, 2022). By engaging in mindfulness, people can become more aware of their automatic patterns of reaction (e.g., internal working models of attachment) and they can learn to pause before acting, which could build more adaptive behavioural responses (Yang & Oka, 2022). Thus, mindful attention could lessen attachment avoidance and attachment anxiety from practicing and cultivating a non-judgmental attitude to improve levels of psychological resilience (Yang & Oka, 2022). However, findings on mindfulness and attachment styles are limited and mixed in their findings, as attachment avoidance could mediate responsiveness to mindfulness (Stevenson et al., 2021). Indeed, it has been suggested that attachment orientation may influence a person's capacity for mindfulness (Stevenson et al., 2021).

In terms of the related facet of self-compassion, practicing being kinder to the self could be relevant to children living with skin conditions. Children might experience body dissatisfaction, feelings of shame, or depressive symptoms from having a visibly different appearance (e.g., self-objectification theory; Calogero, 2012; Trekels & Eggermont, 2017; Tiggeman & McGill, 2004; Clark & Tiggeman, 2007; Tiggeman & Slater, 2015). In these cases, if children act with more compassion towards the self and their altered appearance instead of striving to meet unrealistic body image standards, mood and affect could be improved and healthy coping could be promoted (Neff, 2007; Trekels & Eggermont, 2017).

There has been overlap between mindfulness and self-compassion and the use of self-help interventions, as opposed to more rigorous psychotherapy orientated group interventions (e.g., MBCT). The effectiveness of self-compassion was investigated by Sherman et al. (2019) with an online self-compassion focussed writing intervention 'My Changed Body' for adults with skin conditions, and found that taking part in the web-based therapeutic approach reduced levels of negative affect. Similarly, Hudson et al., (2020) tested a self-help intervention based on compassion-focused therapy (CFT) with 176 adults living with skin conditions, and found increases in psychological wellbeing and quality of life. However, the duration of

treatment effects could not be calculated, so it may be necessary for further research to test the intervention further with a follow-up period to see if positive outcomes are maintained (Hudson et al., 2020).

More recently, Muftin et al. (2022) carried out a randomized controlled feasibility trial in which people with psoriasis completed online self-help, based on either self-compassion or mindfulness. Both were found to be well-received as over 70% of people reported the psychological materials were helpful, and outcomes demonstrated a decrease in shame, and improvement to quality of life (Muftin et al., 2022). However, although the study yielded encouraging findings, there is still a need for further research with diverse samples of participants, as the study groups were primarily comprised of younger females (Muftin et al., 2022).

For parents, 'mindful parenting' is a structured 8-week programme that has been applied to help parents manage stresses associated with childhood illness (Bögels & Restifo, 2014). Mindful parenting is described by Jon Kabat-Zinn (1997, in Bögels et al., 2010) as "*paying attention to your child and your parenting in a particular way: intentionally, here and now, and non-judgementally.*" Having a mindful awareness of parent-child interactions aims to foster a non-judgemental attitude in parenting and reduce over reactivity to child behaviour (Bögels et al., 2008; Bögels et al., 2010; Bögels, 2020; Bögels & Restifo, 2014; Kabat-Zinn & Kabat-Zinn, 2021, pg. 1). Levels of dispositional mindful parenting could reduce psychologically controlling parenting and increase responsiveness in parents of children with cerebral palsy (Dieleman et al., 2021), and has been associated with healthy hemoglobin/glycaemic control and less hospitalization for ketoacidosis in diabetes (Serkel-Schrama et al., 2016). Mindful parenting has also been delivered using an online format to mothers of toddlers and appeared to be effective in targeting affective symptoms and levels of over-reactivity (Boekhorst et al., 2020). In reducing parental over-reactivity, conflict could be limited, and intense negative emotions could be reduced (e.g., anger or aggression), with positive implications for parenting cognitions (i.e., a parent's sense of 'competence', and 'parent-centred attributes') (Lippold et al., 2021; Bögels et al., 2013; Bögels & Restifo, 2014).

#### **1.2.4. Conclusion**

MBIs could be an effective approach for improving the psychological wellbeing of people with skin conditions. However, there are gaps in the literature; most research has focussed on MBCT, and patients with psoriasis. Although there have been useful suggestions from correlational and cross-sectional studies, robust evidence from intervention studies are in their infancy (Meneo et al., 2022). There is a need for further research to robustly examine psychological interventions for people with skin conditions, in order to allow concrete conclusions to be made. Indeed, the majority of existing studies investigating psychological interventions for the management of skin conditions are limited by small sample sizes and heterogeneity of methodologies and outcome measures (Rafidi et al., 2022; Qureshi et al., 2022). Importantly, there is also a dearth of intervention studies investigating the use of mindfulness with children and families affected by skin conditions, which needs to be addressed if paediatric patient outcomes are to be optimised with mindfulness-based approaches.

## **1.3. Research Aims of the Thesis**

The research presented in this thesis had a broad aim of investigating the needs and experience of families affected by skin conditions, with a particular focus on informing the development of a mindfulness-based online intervention. In order to determine the potential utility of offering mindfulness to children and their parents, this research sought to:

1. Establish a rationale for a mindfulness-based online support intervention for children affected by skin conditions, and their families.
2. Incorporate participant feedback into the delivery of a mindfulness-based support intervention.
3. Test whether a modified form of mindfulness has the potential to establish change in specific targets relevant to children or/and parents.

### **1.3.1. Overview**

Chapter 1 presents an introduction to the impact of childhood skin conditions (including definition and prevalence, the psychological impact of skin conditions on children, treatment and prognosis). The role of mindfulness is discussed with supporting evidence for therapeutically targeting the psychological sequelae of dermatological symptoms of skin conditions, related facets of self-compassion, and the relevance of online interventions.

Chapter 2 presents a systematic review of MBIs for children and adolescents and their parents, to provide context and summarize recent research investigating the use of the approach within the field of physical health conditions. Importantly, this Chapter focuses on which health conditions mindfulness has been previously investigated with, outcomes for caregiver stress, symptoms of depression and anxiety, and the level of involvement of parents in interventions to determine the acceptability of including families in psychological support.

Chapter 3 (Study 1) consists of a qualitative investigation, interviewing parent and child dyads to assess their experience of managing a skin condition, and identify

their needs from an intervention, including mindfulness. This study used a dual deductive and inductive interpretative thematic analytic approach to consider existing knowledge in terms of the psychological burden, whilst at the same time enabling space for pertinent issues important to each family dyad to be identified.

Chapter 4 (Study 2) consists of a qualitative investigation interviewing healthcare professionals regarding their views on psychosocial support for families affected by skin conditions. This study used a dual deductive and inductive interpretative thematic analytic approach to consider important issues to dermatology and psychology healthcare professionals to be identified, whilst acknowledging the well-evidenced service gaps in psychological support provision.

Chapter 5 (Study 3) reports the findings of a pilot study of a mindfulness-based intervention for parents of children with skin conditions. A mixed methods approach was adopted using a single cases experimental design to investigate the effectiveness of mindfulness, and allow the comparison of data from standardised measures with qualitative feedback collected from exit interviews. Collecting in-depth qualitative data enabled parent preferences to be considered, and useful recommendations for future interventions to be suggested.

Chapter 6 presents a general discussion of the conclusions that can be drawn from the research, including the relevance of mindfulness for families affected by skin conditions, the implications for clinical practice, strengths and limitations, future directions, and researcher reflections.



## 1.4. Epistemological Position of the Thesis

This chapter briefly outlines the underlying philosophical position guiding the empirical work contained within this thesis. All research is built on philosophical assumptions relating to people's views surrounding how the world operates, including what knowledge is, known as ontology, and how knowledge is acquired and understood, known as epistemology (Harper, 2012). Transparency of these assumptions is useful in ensuring that there is an appropriate match between aims and methods used.

In general, quantitative research comes from a critical realist position asserting that fixed psychological processes and variables can be identified and generalised to specified populations and/or situations. This is generally achieved by testing variables and using statistical methods to quantify hypothesis, evidence correlations, and investigate the potential for causation via sophisticated longitudinal designs. However, whilst qualitative research can also adopt the same sort of 'essentialist' or 'realist' stance to investigate people's experiences, it can also come from a range of other more relativist positions (such as 'constructionist') that places focus on psychological phenomenon being context based. Qualitative methodologies can vary dramatically with regard to the extent to which they are either relativist or realist (Harper, 2012; Willig, 1999; Braun & Clarke, 2006).

This thesis is concerned with understanding the experience of children with skin conditions, their parents, and their healthcare professionals and accepts that there are both fixed variables and contextual factors likely to be involved. As the aim of this research is to work towards providing interventions to support children and families, the epistemological position of the questions being investigated sit within a critical realist stance. Further, given the aims of the thesis, the broad methodological approach taken has been guided by the Medical Research Council (MRC: Skivington et al., 2021) and 'Person Based Approach' (PBA; Life Guide, 2019; Yardley et al., 2015a; Yardley et al., 2015b) as well-established frameworks for the development of health interventions using qualitative data to inform early stages of design.

When planning and designing health interventions, the MRC and PBA frameworks state that stakeholders should be involved during early stages of

intervention development to improve the usability of a resource (Skivington et al., 2021; Bobrow et al., 2018; Life Guide, 2019). The involvement of 'experts-by-experience' or people with lived experiences of the health condition being targeted by an intervention can enhance understanding through in-depth accounts of participants' needs/barriers to participation, and produce valuable information regarding intervention functioning (Moore et al., 2015; Skivington et al., 2021; Campbell et al., 2000). This has led to a welcome shift in power dynamics over recent years, with service users enlisted as co-designers instead of traditionally being seen as the 'subjects' of studies (Faulkner, 2012). There are different roles experts-by-experience can have in research, ranging from 'consultation' (e.g., when the research questions are being drafted) to 'collaboration'/'user-controlled research' (Faulkner, 2012). The research presented in this thesis sought to involve experts-by-experience with a consultative approach (Faulkner, 2012), and the exact steps taken to involve service users in study designs will be described in each chapter.

Analytic approaches can be used to reflect people's reality and unpick the surface of that reality (Braun & Clarke, 2006). Thematic analysis can be located within a critical realist paradigm. The approach is a widely used method of qualitative data analysis in health psychology (Watkins et al., 2022; Hughes & Hunter, 2022a) and can be used to rigorously identify themes, patterns and shared meanings (Braun & Clarke, 2021). Although thematic analysis has the aim of identifying salient lived experiences, the data collected often requires some interpretation (Joffe & Yardley, 2004, in Joffe, 2012). There can be pre-conceived theoretical assumptions brought to analysis by the researcher (known as inductive) or from the raw data (known as deductive) (Joffe, 2012). Theoretical assumptions are generated from empirical literature and can be used to refute and critically compare data with existing evidence. However, with the collection of detailed qualitative data, new insights can be gathered that shed light on the phenomenon being investigated (Joffe, 2012). Therefore, a dual deductive-inductive and latent-manifest set of themes can usefully be used when conducting thematic analysis (Joffe, 2012).

When conducting research, there can be strengths and weaknesses to following a single method. For this reason, mixed methods can be used to yield additional data on the subject under investigation (Harper, 2012). Combining

qualitative and quantitative data to address a research question can arguably strengthen findings from complimenting personal narratives with statistical analysis of psychometric measures, and can work towards persuading a broader audience (Harper, 2012).

Herein, Studies 1, 2 and 3, of this PhD project employed a dual deductive and inductive interpretative thematic analytic approach (Joffe, 2012) (combined with mixed methods in Study 3). These studies were informed by the MRC (Skivington et al., 2021) and PBA frameworks (Life Guide, 2019) using consultation from experts-by-experience to investigate the parent and child experience of skin conditions, and determine the acceptability of a mindfulness-based support intervention for families.

#### **1.4.1. Researcher characteristics**

Considering researcher characteristics and reflecting on experience is a central part of interpretative methodologies (Findlay & Gough, 2003). This was relevant for this doctoral research, as I am a White British woman in my twenties, and a so-called 'insider researcher' (Braun & Clarke, 2019) because of my lived experience of having a skin condition. When discussing these dual roles as an expert-by-experience researcher, I will switch to writing in the first person at specific points to consider my own insights in relation to the research.

In understanding participant realities, I will be drawing on my own experience of having psoriasis since the age of seven (see Hughes, 2022). I have been prescribed many medications, including ciclosporin, acitretin, methotrexate, and apremilast. I have received several rounds of ultraviolet light B (UVB) therapy, and dithranol. At my worst, I was admitted to hospital with erythroderma. As a result of these intensive treatments, I missed a significant period of secondary school, and my psoriasis impacted every part of my life. My parents' well-being was also affected, and we shared the burden as a family unit. In 2016, my psoriasis was no longer controllable with systemic drugs, and I was experiencing unpleasant side effects, including topical steroid withdrawal, vomiting, and hair loss. It was after a second severe flare of my psoriasis where I had to reduce my employment hours to avoid a second hospitalisation, that I started a biologic drug (Ustekinumab) which cleared my psoriasis and allowed me to apply to university. However, the challenges of

immunosuppressive treatment continued, and in 2019 I was diagnosed with suspected lymphoma. Eleven days before my undergraduate dissertation was due, I underwent surgery to remove a lymph node. I still submitted my work on time, and thankfully it was later found to be a reactive lymph node and negative for malignancy. Appropriately, my dissertation was on the subject of coping with skin conditions, and I went on to graduate with first-class honours. My experiences living with psoriasis has made me passionate about researching the impact of skin conditions, and I hope this is reflected in this thesis. Neither myself nor my parents ever received psychological support. I aim to make a meaningful contribution to improving services.

Adopting a realist approach has enabled myself as the researcher, to theorize and inform novel participant data from my lived assumptions (Braun & Clarke, 2006; Joffe, 2012). In order to ensure my experiences did not unconsciously influence results, regular supervision meetings were held to discuss the research progress and provide support throughout the entirety of the doctoral studentship. The supervisory team also carried out an audit (Chapter 3), and incorporated a member validation procedure (Chapter 4), which are described in more detail later in this thesis.

In addition to this, it is important to acknowledge the scope of this doctoral research and the focus on mindfulness from conceptualisation to completion. Although the broad body of work was concerned with investigating the relevance of mindfulness-based interventions, I have remained open to other psychotherapeutic approaches throughout the entirety of carrying out this PhD. By considering the relevance of alternative approaches (e.g., cognitive behavioural therapy, acceptance and commitment therapy etc) I have endeavoured to limit potential bias and gather balanced insights from participants.

## Chapter 2

# Living with Physical Health Conditions: A Systematic Review of Mindfulness-based Interventions for Children, Adolescents, and their Parents

As outlined in Chapter 1, childhood skin conditions have potential to create a significant psychological burden for children and their families. The psychological sequela associated with living with a chronic skin condition could be targeted with mindfulness. This next chapter presents a systematic review of the existing literature employing mindfulness-based interventions for children and adolescents with physical health conditions, and their parents, to investigate where the approach has been previously applied, for which health conditions, and if it could be an effective strategy for reducing child anxiety and depression. The review will also examine levels of parental involvement in existing studies, and whether including families could lessen levels of caregiver stress.

### 2.1. Introduction

Physical health conditions (such as skin conditions) often require ongoing management with medication and other therapies, over a period of years or decades, and often cannot be cured (NHS, 2021). This applies to a range of health conditions including non-communicable diseases (e.g., cancer and cardiovascular disease), communicable diseases (e.g., human immunodeficiency virus; HIV, and acquired immunodeficiency syndrome; AIDS), or impairments in structure (e.g., joint conditions). Many physical health conditions are long-term, such as diabetes, cardiovascular conditions, chronic respiratory conditions (e.g., asthma), neurological conditions (e.g., multiple sclerosis), chronic pain (e.g., arthritis), and inflammatory bowel disease (IBD) (NHS, 2021). During childhood, non-communicable diseases are globally responsible for over half of disability-affected life years (United Nations International Children's Emergency Fund; UNICEF, 2019). Some of the most common physical health conditions affecting children include skin diseases (e.g.,

AD), migraine, and congenital abnormalities (UNICEF 2019). In the UK, asthma is the most prevalent childhood illness affecting 1.1 million children, epilepsy is diagnosed in 112,000 children, diabetes affects 36,000 children, and 1 in 5 children develop eczema (Royal College of Paediatrics and Child Health, 2020; Great Ormond Street Hospital for Children, 2020).

Physical health conditions are classified by the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF) as a dynamic interaction between a person's health condition, environment, and personal factors (WHO, 2001), suggesting that physical health conditions could have an impact across several domains of life (McDougall et al., 2008). Indeed, children diagnosed with physical illnesses during childhood have been found to have a disproportionate level of mental health conditions by the age of ten (Brady et al., 2020). Children with physical illnesses may experience adverse educational outcomes from poor school attendance (Emerson et al., 2016) and attending medical appointments/undergoing treatment, or from deliberate avoidance (Sentenac et al., 2013). Although the psychological burden may depend on age (Ablett & Thompson, 2016), feeling 'different' could alter identity during an important time for development. Childhood illnesses also have the potential to dramatically affect family functioning, with parents experiencing stress (Cohn et al., 2020), as a result of adapting daily life and assuming the dual role of parent/caregiver without formal training (Ong et al., 2021). More psychological support is needed for children and their families living with physical health conditions.

Over recent years, mindfulness has been investigated as an approach to develop positive ways of healthily managing emotion and regulating affect (Zoogman et al., 2015). MBIs have shown promise with parents of children with mental health conditions, including obsessive compulsive disorder (Belschner et al., 2020), attention deficit hyperactivity disorder (Behbahani et al., 2018), and autism (Dykens et al., 2014). Similarly, MBIs involving the child and their parents have been investigated with children with mental health conditions and developmental disorders (Bögels et al., 2008; Ridderinkhof et al., 2018). Mindfulness has been investigated for children with obesity (Cotter et al., 2020; Emmanouil et al., 2018) and their families (Jastreboff et al., 2018) and has shown promising health outcomes for

weight and blood pressure. Thus, mindfulness could improve quality of life by increasing effective management of symptoms and promote healthy regulation in other areas of life (e.g., lifestyle) that have a secondary impact on illness.

Mindfulness could decrease stress in parents of children with chronic pain (Anclair et al., 2018; Seidman et al., 2019), reduce depression in parents of children with cancer (Mehranfar et al., 2012), and improve quality of life in parents of children with cerebral palsy (Mak et al., 2019). Similarly, mindful parenting could increase parental responsiveness to children with cerebral palsy (Dieleman et al., 2021) and improve stress in caregivers of children with psoriasis and eczema (Heapy et al., 2022) perhaps from shifting focus from future worries, to accepting problems as they arise. Acceptance could therefore mediate parental distress (López et al., 2021), as experiential avoidance and cognitive defusion predicts negative outcomes in parents of children with chronic health conditions (e.g., burnout, stress, anxiety, depression) (Sairanen et al., 2018). Indeed, mindfulness concepts promoting present moment awareness and psychological flexibility could equip families to cope adaptively with childhood illness (Cousineau et al., 2019).

There could be relevance in implementing MBIs with families affected by physical health conditions, as an alternative to more traditional CBT approaches. Specifically, practicing mindfulness could promote acceptance and healthy coping with the permanency of body symptoms or intense emotions related to long-term illness, instead of endeavouring to change maladaptive patterns of thinking. Importantly, the use of MBIs with children and their parents is under-researched, and there is a need for research to examine the impact of physical illness on families in more depth. There have been calls for research to adopt a dyadic focus with wider investigations into the family unit to focus on the impact of being an informal caregiver (Moons et al., 2020). Although there have been studies investigating mindfulness with caregivers of children diagnosed with physical health conditions (Ruskin et al., 2021), study samples are often treated as separate groups, instead of acknowledging the shared burden to parent and child.

This systematic review aims to address several gaps in the literature. This review will examine the involvement of parents/relevance of the inclusion of families in MBIs, which has not been previously investigated (Ahola Kohut et al., 2017;

Abujaradeh et al., 2018). Previous systematic reviews by Abujaradeh et al. (2018) and Ahola Kohut et al. (2017) investigated MBIs in clinical samples of children and adolescents, whereas the current review will examine all samples (clinical and non-clinical). Previous reviews have examined samples of children (from 12 years of age) with chronic illnesses including mental health conditions (Abujaradeh et al., 2018), whilst the present review has a focus on MBIs for physical health conditions only, in samples <18 years. Since previous investigations (Ahola Kohut et al., 2017), the use of online delivery for psychological interventions has increased with advancing digital technology, which could have implications for feasibility and acceptability of mindfulness.

The objectives of this narrative systematic review are twofold: (1) to identify and synthesise the most recent literature, since previous systematic reviews have been published (Ahola Kohut et al., 2017; Abujaradeh et al., 2018) and (2) to employ a narrative synthesis to address a gap in knowledge in an understudied area and investigate the feasibility, acceptability and efficacy of MBIs for improving depression, anxiety and parental stress in families affected by childhood illness. This review will appraise existing evidence for MBIs with focus on psychological outcomes in children, and parental stress in their caregivers, to determine how well including parents in MBIs has been received, or if it might be practical to involve the family unit. Ahola Kohut et al. (2017) suggests there is a need for further studies to focus on measures of emotional distress (e.g., anxiety and depression). This is an important area to investigate, as a synthesis of findings related to the potential role of mindfulness for promoting the psychological wellbeing of children, adolescents and families affected by childhood illnesses, could have value for the development of dyadic interventions.

## **2.2. Method**

### **2.2.1. Registration and protocol**

This systematic review protocol was pre-registered: Olivia Hughes, Andrew Thompson, Katherine Shelton, Helen Penny. A Systematic Review of Mindfulness-based Interventions for Children and Adolescents Living with Physical Health Conditions and their Families. PROSPERO 2021: CRD42021234011. Available from: [https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD4202123401](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD4202123401)



1. An amendment was made to the title to reflect the design of the review, comparators were updated to include studies not using control groups, and the database list was refined.

### **2.2.2. Eligibility criteria**

Studies were eligible for inclusion if they: (1) included a sample of children and adolescents with a physical health condition (e.g., diabetes, heart conditions, or cancer); (2) included an entire sample (<18 years old) of children or adolescents as the target population, and their parents or caregivers (e.g., involved in the MBI, provided support/assessment outcomes, or received MBI in parallel); (3) included an intervention based on a structured mindfulness programme (e.g., MBSR or MBCT), and had been peer-reviewed and reported in English.

Studies were excluded if they investigated single components of mindfulness (e.g., meditation, mindful eating, yoga, transcendental meditation) and trait/dispositional mindfulness in the absence of intervention. Qualitative studies, case studies and single cases were excluded unless they included an experimental design enabling assessment of efficacy. Children 'at risk' (not clinically diagnosed) of physical disease were excluded. Additionally, developmental and mental health conditions, and obesity were not included (Cotter et al., 2020; Emmanouil et al., 2018), and have similarly been excluded from previous systematic reviews as there exists a substantial literature base elsewhere (Abujaradeh et al., 2018). Dissertations and grey literature, protocols, conference abstracts, review, theory, and commentary papers were excluded.

### **2.2.3. Information sources and search strategy**

The searching and screening process was carried out between the 2<sup>nd</sup> and 17<sup>th</sup> of February 2021. A total of 5 databases were searched, including Embase, PsycINFO, Scopus, Medline, and PubMed. On the 17<sup>th</sup> of February 2021 a snowball search was also carried out to identify additional eligible articles, with Google Scholar and a citation search by hand on relevant papers (references cited in articles included in this review, and references cited in systematic reviews on similar topics).

Finally, the search was updated on 5<sup>th</sup> August 2022, using the same search method, but the results were filtered from 2021 onwards (See Appendix A.1.).

#### **2.2.4. Selection process**

The search results from each database were exported into Microsoft Excel and duplicates were removed. Studies were first screened for eligibility by title, followed by abstract. All studies conducting a MBI with the target population were subjected to full-text scrutiny, and studies not meeting eligibility criteria were excluded with reasons noted. The screened studies were independently corroborated by the supervisory team, to ensure there was agreement between researchers on included articles, and reasons for exclusion were discussed.

#### **2.2.5. Data collection process and data items**

The data collection process followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; 2020) statement (Page et al., 2021) (See Appendix A.2.), and focused on extracting information for tabulation on several outcome domains of interest including presenting a summary of psychological measures of quality of life, depression, anxiety, or parental stress, and feasibility and acceptability of mindfulness across the timeframe of intervention.

Data was extracted from each report, including information on authors, geographical location, study sample (e.g., age, gender, race/ethnicity), involvement of parents, health condition and recruitment, study design, type of MBI/delivery, drop-outs, control groups, outcome measures/frequency, and effect sizes/95% Confidence Intervals (where reported). Information on the structure of MBI was also extracted, including session content, facilitator, homework requirements and fidelity checks (see Appendix A.3.). Feasibility was operationalised as being investigated by reporting information on recruitment and retention (Eldridge et al., 2016) and acceptability was determined from the perspective of the participant (e.g., from intervention feedback).

### **2.2.6. Certainty of evidence assessment**

The certainty of evidence of each of the included articles was assessed with either the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for cohort, case-control, and cross-sectional studies (combined) (Von Elm et al., 2007), the Consolidated Standards of Reporting Trials (CONSORT) checklist for parallel group randomized trials (Schulz et al., 2010), or the CONSORT extension for randomised pilot and feasibility trials (Eldridge et al., 2016). These checklists were used to determine the quality of studies included in this review, and to assess study designs.

### **2.2.7. Study risk of bias assessment**

Based on PRISMA (2020; Page et al., 2021) guidelines, risk of bias assessments were conducted for each individual study included in this review. To maintain rigour and corroborate risk of bias assessments, discrepancy checks were carried out by the supervisory team, and differences were resolved with discussion. The Cochrane Risk of Bias—second edition (RoB 2) was used to assess risk of bias for randomised studies (Sterne et al., 2019; Higgins et al., 2011), whereas the Risk of Bias in Nonrandomized Studies-of Interventions (ROBINS-I) Assessment Tool was used to assess risk of bias for all nonrandomised studies included in this review (Sterne et al., 2016).

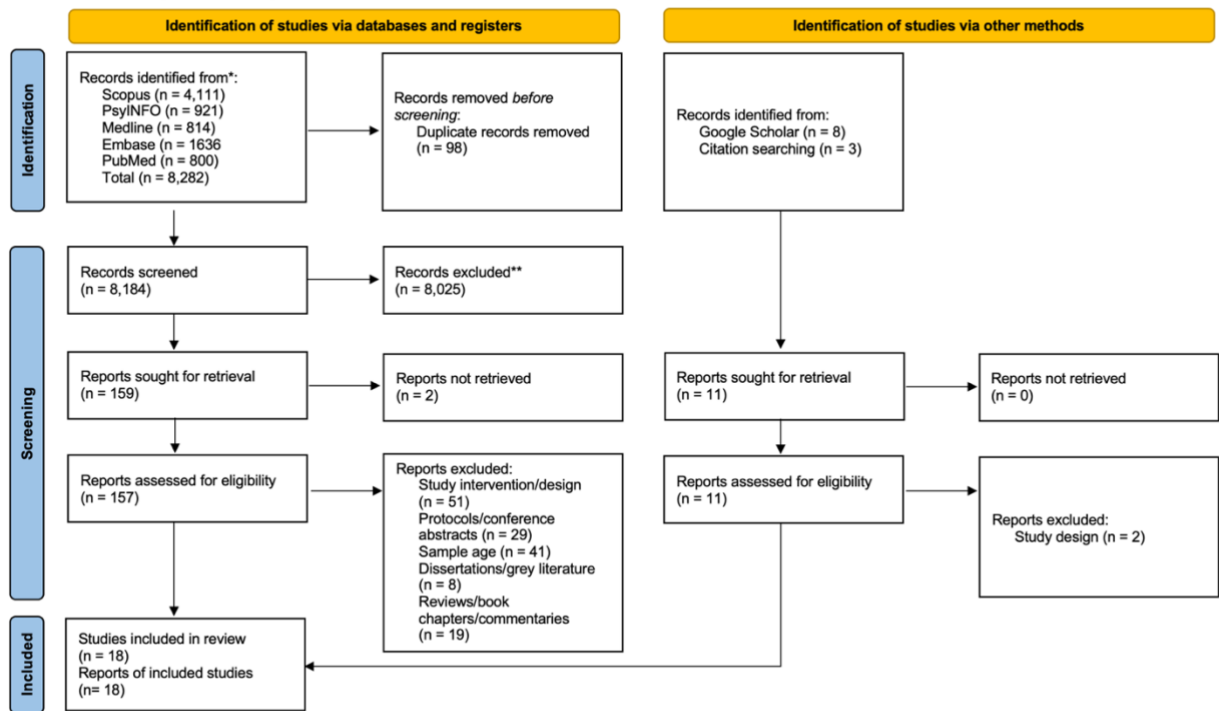
## 2.3. Results

### 2.3.1. Study selection

A flowchart in accordance with the PRISMA (2020) statement (Page et al., 2021) was developed to document the study selection process (Figure 2.1).

**Figure 2.1:** PRISMA (2020) flow diagram (Page et al., 2021) illustrating selection of studies.

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

### 2.3.2. Study characteristics

18 studies were included in the review. Studies were conducted between 2013 and 2022 in the United States (k=8), Canada (k=8), France (k=1), and Iran (k=1). Sample sizes ranged from 6-62 (mean=22.94, SD=15.37). The ages of children included in MBI groups ranged from 8 to 18 years (mean= 14.69, SD=1.59). Recruitment was almost exclusively carried out via university-affiliated hospitals, and disease specific-clinics and centres (k=17), in some cases, combined with social media (Lovas et al., 2017; Young et al., 2022), and k=1 study recruited pupils enrolled at a specialised school for children with chronic pain conditions (Lagor et al., 2013).

Demographic information was collected, such as race and ethnicity (k=8 studies), and study samples included participants who were White (n=114), Asian (n=20), African American and Black (n=17), multiracial (n=2), Hispanic Latino/Latina (n=4), American Indian or Alaskan Native (n=2), and 'unknown' or 'other' (n=17). However, k=10 studies did not report on race or ethnicity. All studies provided some information on gender of participants. Studies included children living with conditions such as: mixed chronic pain and chronic conditions (n=133, k=9), cancer (n=54, k=2), heart conditions (n=56, k=2), headaches (n=20, k=1), esophageal atresia (n=19, k=1), IBD (n=80, k=2), and polycystic ovary syndrome (PCOS; n=51, k=1).

**Table 2.1:** Summary of n=18 studies included in review.

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Abedini et al. (2021): Iran	n=40, mean age=12.18 (MBCT-C) mean age=12.06 (TAU) Race NR. 8 male, 9 female (MBCT-C), 8 male, 8 female (TAU)	Completed parent- proxy measures	Cancer: paediatric cancer hospital	RCT	MBCT-C (modified ) 4 weeks: 20 sessions (45 minutes) 5 times per week. Face-to- face, group	n=1 dropouts	TAU	Psychiatric disorders: K-SADS-PL/ parent-child clinical interview. Problem behaviours/ emotional states: CBCL/YSR	Pre- intervention/ baseline, post- intervention, 2-month follow-up	CBCL internalizing problems Baseline: Cohen's $d=0.51$ , Post-intervention: Cohen's $d=3.49$ , Follow-up: Cohen's $d=3.39$ , CBCL attention problems Baseline: Cohen's $d=0.29$ , Post-intervention: Cohen's $d=2.25$ , Follow-up: Cohen's $d=2.45$ , YSR internalising problems Baseline: Cohen's $d=0.14$ , Post-intervention: Cohen's $d=3.98$ , Follow-up: Cohen's $d=3.69$ , YSR attention problems Baseline: Cohen's $d=0.20$ ,

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Ahola Kohut et al. (2019): Canada	n=18, mean age=14.59 Race NR, 55.6% male	One time 2-hour workshop	Inflammator y Bowel Disease: tertiary paediatric hospital	Prospectiv e, mixed- methods, uncontrolle d	MBI-A (modified )8 weeks, 120 minute sessions. Face-to- face, group	n=2 attended one session/ withdrew	None	Disease activity: IMPACT-III. Anxiety: MASC Depression: CDISC Self- efficacy: SEQ Mindfulness : CAMM Psychologic al inflexibility in pain: PIPS Peer relationship s: PROMIS, Focus groups	Baseline, post- intervention, 3 month follow-up	Post-intervention: Cohen's $d=2.29$ , Follow-up: Cohen's $d=2.52$ NR

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Ali et al. (2017): United States	n=15, mean age=14.80 13 White, 2 unknown, 13 non- Hispanic Latino, 2 Hispanic Latino. 4 male, 11 female	n=15 completed parent- proxy measures, attended concurrent group	Chronic pain: university/ community clinician referral	Pilot feasibility	MBSR. 8 weeks: 90 minute sessions, and 4 hour retreat. Face-to- face, group	n=2 dropouts, 83% completi on	None	Qualitative evaluation Functional disability: FDI QoL: PedsQL-4 Mindfulness : CAMM Stress: PSS Anxiety: MASC2 Symptoms: FIQR/SIQR Parent/child interviews	Baseline, post- intervention, 12-week follow-up	NR
Andreotti et al. (2017): France	n=19, mean age=10.00 (MBCT) mean age=10.70 (WLC) Race NR. 50% female (WLC),	Children accompa nied by parent, n=18 completed parent- proxy measures	Esophageal atresia: clinical database	Randomiz ed, two- group	MBCT (modified ). 42-days of daily practices from 4 - 12 minutes, formal practice	n=9 lost to follow- up (MBI)	Wait list	Mindfulness : CAMM/ MAAS-A Affect: STAI-C Depression: CDI Emotion regulation: CERQ-k Qualitative evaluation	Pre- intervention, follow-up phone call every 1-2 weeks, post- intervention	Mindfulness: 0.54, Positive affect: 0.45 Negative affect: 0.58, STAI-State: 0.60 STAI-Trait: 0.73, Depression: 0.76, Acceptance: 0.40, Rumination: 0.64, Positive refocusing: 0.40, Positive reappraisal: 0.39,



Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
	50 % female (MBCT)				every 6 days. Website					Parent positive affect: 0.82, Parent negative affect: 0.72, Parent STAI-State: 0.87, Parent STAI- Trait: 0.80
Chadi et al. (2016): Canada	n=19, mean age=16.10 (experimen- tal) mean age=15.60 (control)  16 White, 2 Hispanic, 1 Black. 10 female (experimen- tal) 9 female (control)	No	Chronic pain: university affiliated hospital	Pilot randomize d trial	MBSR/ MBCT (modified ). 8 weeks: 90 minute sessions Face-to- face, group	n=4 dropouts, 17% attrition rate	Wait list	QoL: PedsQL 4.0 Depression/ Anxiety: BDI-Y-II Pain: visual analogue pain scale VAS Psychologic al distress: IDPESQ-14 Stress: salivary cortisol Post intervention questionnair es	Baseline, and weeks 1, 8, 11,18	QoL: $\eta^2=0.01$ , depression: $\eta^2=0.13$ , anxiety: $\eta^2=0.05$ , pain perception: $\eta^2=0.01$ , psychological distress: $\eta^2=0.09$ , salivary cortisol level: $\eta^2=0.77$

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Chadi et al. (2019): Canada	n=14, mean age=15.30 6 White, 2 Asian, 1 African American (MARS-A), 7 White, 1 Asian, 1 African American (eHealth). 2 male, 7 female (MARS-A), 2 male, 7 female (eHealth)	No	Chronic illness: tertiary paediatric hospital	Mixed method, RCT	MARS-A. 8 weeks: 90 minute sessions. Face-to- face, group or online	n=4 dropouts after random- isation	eHealth platform	Mindfulness : MAAS-A Mood/anxiety: DASS-21 Self- esteem: RSE Illness perception: PI Salivary cortisol: non- invasive sampling Semi structured interview	Baseline, pre-and post- intervention, 2-month follow-up	eHealth Mindfulness: Cohen's $d=0.260$ , Mood/anxiety: Cohen's $d=0.592$ , Self-esteem: Cohen's $d=0.278$ , Illness perception: Cohen's $d=0.722$ , In-person Mindfulness: Cohen's $d=0.195$ , Mood/anxiety: Cohen's $d=0.398$ , Self-esteem: Cohen's $d=0.303$ , Illness perception: Cohen's $d=0.157$
Freedenberg et al. (2015): United States	n=10, mean age=15.00 Race NR 6 male	No	Heart diseases: cardiology clinic	Pilot, descriptive , prospective, one- group	MBSR. 6 weeks, 90-120 minute sessions. Face-to- face, group	0% dropouts, 100% completion	None	Anxiety/ depression: HADS. Stress and coping strategies: RSQ	Baseline, post- intervention	Anxiety: $\eta^2=0.59$ , primary engagement control coping: $\eta^2=0.07$ , secondary engagement control coping: $\eta^2=0.01$

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
								Interview/ qualitative evaluation		
Freedenberg et al. (2017): United States	n=46, mean age=15.10 (MBSR) mean age=14.50 (video) Race NR 8 male, 18 female (MBSR), 9 male, 11 female (video)	No	Cardiac disease: cardiology clinic	Randomized, two- group prospective	MBSR. 6 weeks, 90-120 minute sessions. Face-to- face, group	2% dropouts	Video online support group	Emotional distress: Anxiety/ depression: HADS Coping strategies: RSQ Qualitative interviews	Pre- intervention, post- intervention	NR
Hesse et al. (2015): United States	n=20, mean age=14.15 94% White 100% Female	Completed parent- proxy measures	Headache: academic neurology clinic	Pilot non- randomized clinical trial	Mindful Schools Curriculum(modified). 8 weeks, 120 minute sessions.	25% dropouts	None	Headache disability: PedMIDAS Anxiety: MASC Depression: CES-S-DC QoL: PedsQL Chronic	Pre- intervention, post- intervention	NR

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Jastrowski Mano et al. (2013): United States	n=6, mean age=15.00 (MBSR) mean age=12.50 (psycho- education) 2 White, 1 African American, 1 unknown (MBSR), 1 Latina, 1 Multiracial (psychoed ucation) 3 female (MBSR), 2 female (psychoed ucation)	One time concurrent session, completed parent- proxy measures	Chronic pain: paediatric pain clinic	Randomiz ed, controlled pilot	Face-to- face, group  MBSR. 6 weeks, 90 minute sessions. Face-to- face, group	62% attendanc e, 18% dropouts	Psych o- educati on	pain acceptance: CPAQ-A Child/Parent qualitative evaluations  QoL: PedsQL 4.0 Pain: PFSD Pain Catastroph izing: PCS-C Anxiety: STAI-C Mindfulness : MSES Qualitative analysis	Pre- intervention, post- intervention, 4 week follow-up, 12 week follow-up	NR

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Lagor et al. (2013): Canada	n=15, mean age=13.00 11 Black/ African American, 2 White, 1 Multiracial, 1 Hispanic/ Latino. 6 male, 9 female	No	Chronic illnesses: specialised school for children with chronic illnesses	Feasibility, pre-post- test, uncontrolle d	MBI (modified ). 6 weeks, 50 minute sessions. Face-to- face, group	0% dropouts	None	Mindfulness : CAMM. Health related QoL: PedsQL. Depression symptoms: BYI-II Semi structured interview	Pre- intervention, post- intervention	NR
Lovas et al. (2017): Canada	n=7, mean age=15.30 Race NR, 1 male, 6 female	No	Chronic pain: paediatric clinics/social media	Single- arm, non- randomize d pilot	MARS-A. 8 weeks, 90 minute sessions. Face-to- face, group	0% dropouts	None	Pain: retrospectiv e diary Somatic Symptoms: CSI Functional Disability: FD Depression/ . anxiety: RCADS	Pre- intervention, post- intervention, 3 month follow-up	Pain intensity Pre-post: Cohen's $d=0.666$ , Pre-3 month: Cohen's $d=0.672$ , Post-3 month: Cohen's $d=0.039$ , Pain duration Pre-post: Cohen's $d=0.014$ , Pre-3 month: Cohen's $d=0.180$ , Post-3 month: Cohen's $d=0.163$ Somatic symptoms

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Malboeuf- Hurtubise et al. (2016): Canada	n=14, mean age=15.60 (experimen- tal) mean age=15.30 (control)	No	Cancer: university affiliated hospital	Prospectiv e quasi- experiment al pre-test- post-test, two groups	MBI (modified )SR. 8 weeks, 90 minute sessions.	n=8 withdrew, mean absences / participan t=2.1.	No treatm ent	Depression/ anxiety: BDI/BAI QoL: PedsQL Sleep: PSQI Mindfulness : CAMM	Pre- intervention, post- intervention, 6 month follow-up	Pre-post: Cohen's $d=0.25$ , Pre-3 month: Cohen's $d=1.255$ , Post-3 month: Cohen's $d=0.907$ , Functional disability Pre-post: Cohen's $d=0.309$ , Pre-3 month: Cohen's $d=1.077$ , Post-3 month: Cohen's $d=0.774$ , Depression/anxiety Pre-post: Cohen's $d=0.111$ , Pre-3 month: Cohen's $d=0.453$ , Post-3 month: Cohen's $d=0.514$ Depression: $\eta^2=0.13$ , Anxiety: $\eta^2=0.02$ , QoL: $\eta^2=0.00$ , Sleep: $\eta^2=0.12$ , Mindfulness: $\eta^2=0.00$ , Positive affect: $\eta^2=0.07$ ,

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Ruskin et al. (2015): Canada	Race NR 37.5% male, 62.5% female (experimen tal)14.3% male, 85.7% female (control) n=16, mean age=15.75 Race NR, 100% Female	Parenting component	Chronic pain: university affiliated hospital	Feasibility, one-group, pre- test/post- test	Face-to- face, group MBSR-A. 8 weeks, 120 minute sessions. Face-to- face, group	19% dropouts	None	Affect: PANAS Qualitative feedback Pain: pain characteristi cs questionnair e Mindfulness : CAMM/MAA S Psychologic al inflexibility: AFQ- Y Acceptance of pain: CPAQ	Baseline, post- intervention	Negative affect: $\eta^2=0.00$ NR

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
								Psychologic al inflexibility in pain: PIPS Qualitative evaluation		
Ruskin et al. (2017): Canada	n=21, mean age=15.52 Race NR. 1 male, 20 female	Parenting component	Chronic pain: Paediatric tertiary care clinic	Prospectiv e pre-post	MBI-A (modified ) . 8 weeks, 120 minute sessions. Face-to- face, group	0% dropouts	None	Pain characteristi cs: PCQ Pain catastrophiz ing: PCS Pain acceptance: CPAQ-R Anxiety: MASC Depression: CDS Post- session questionnair es	Baseline, post- intervention, 3 month follow-up	Functional disability: Cohen's $d=-0.31$ , Anxiety: Cohen's $d=-0.16$ , Depression: Cohen's $d=-0.01$ , Pain catastrophizing: Cohen's $d=-0.01$ , Mindfulness: Cohen's $d=-0.12$ , Activity engagement: Cohen's $d=0.47$ Pain willingness: Cohen's $d=0.54$ , Total pain acceptance: Cohen's $d=0.55$ Social support: Cohen's $d=0.20$ ,



Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
Waelde et al. (2017): United States	n=20, mean age=15.10 Race NR 10% male	Completed parent- proxy measures	Chronic pain: tertiary pain clinic	Pilot non- randomize d clinical trial	MBI (modified ) . 6 weeks, 60 minute sessions. Face-to- face, group	n=4 attrition, n=2 lost to follow- up	None	Satisfaction questionnaire Focus group Functional disability: FDI Mindfulness : CAMM Pain intensity: NRS Depression: CDI Functional Disability: FDI Pain functioning: Teen SPPFI/ Parent SPPFI Qualitative evaluation	Baseline, post- intervention	Current pain: Cohen's $d=-0.18$  Usual pain: Cohen's $d=0$ , Most severe pain: Cohen's $d=0$ , Depression: Cohen's $d=0$ , Functional disability: Cohen's $d=0.20$ , Pain functioning: Cohen's $d=0.30$ , Parent/child's pain causing worry: Cohen's $d=0.75$
Wren et al., (2021):	n=62, mean age=15.60	No	Inflammator y bowel disease:	Pilot feasibility/ Virtual	Mindfulne ss-based Virtual	Attrition 80%, completio	None	Anxiety: VAS Pain: VAS	Baseline, post- intervention	NR

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
United States	58% White, 17.7% Asian/Sout h Asian, 1.6% African American, 22.6% other, 92% non- Hispanic. 58% male		children's IBD center	acceptabilit y study	Reality (MBVR) one-off session, 6 minutes.	n rate 75% (60% participati on rate)		Satisfaction survey Semi- structured interview		
Young et al. (2022): United States	n=51, mean age=18.50 (MBI) mean age=17.40 (control) 7 Non- Hispanic White, 3 Asian, 1 American Indian or Alaskan Native	No	Polycystic ovary syndrome: adolescent medicine clinic/social media	Pilot RCT	'PCOS Kind Mind.' 5 weeks, 60-75 minute sessions. Face-to- face, group (later moved online)	n=15 dropouts	Wait list	Self- esteem: RSE Psychologic al distress: DASS-21 Mindfulness : CAMM Nutrition Self- Efficacy: DIET-SE Physical activity self- efficacy	Baseline, post- intervention	Self-esteem: Cohen's $d=0.31$ , 95% CI [- 0.67-4.88] Depression: Cohen's $d=0.61$ , 95% CI [- 3.86-8.25] Stress: Cohen's $d=0.11$ , 95% CI [- 5.32-7.71] Anxiety: Cohen's $d=0.04$ , 95% CI [- 6.20-7.50] Mindfulness: Cohen's $d=0.61$ , 95% CI [- 1.73-6.43]

Authors/ location	Sample	Parents involved	Health condition/ recruitment	Study design	MBI/ delivery	Dropout/ attrition	Control group	Outcome measures	Frequency of measures	Effect sizes/confidence Intervals (95% CI; where reported)
	(MBI). 6 Non- Hispanic White, 1 Black or African American, 3 Asian, 1 American Indian or Alaskan Native (control). 100% Female.							strategies: PACE subscales Exit interviews		Nutrition self-efficacy: Cohen's $d=0.48$ , 95% CI [1.71-11.28] Physical activity self- efficacy: Cohen's $d=0.46$ , CI 95% [0.07-0.88 Physical activity strategies: Cohen's $d=0.67$ , 95% CI [0.04-0.79]

*Note:* NR, not reported; MBI, mindfulness based intervention; TAU, treatment as usual; MBSR, mindfulness-based stress reduction; MBCT, mindfulness-based cognitive therapy; CI, Confidence Interval, PCQ, pain characteristics questionnaire; PCS, pain catastrophizing scale; CPAQ-R, chronic pain acceptance questionnaire – revised; MASC, multidimensional anxiety scale for children; CDS, Columbia depression scale; FDI, functional disability index; CAMM, child and adolescent mindfulness measure; PedsQL, pediatric quality of life inventory; DASS-21, depression anxiety stress scales; LEIDS-R, Leiden index of depression sensitivity; RPA, responses to positive affect; ATS-R, attitudes towards self - revised; FCRI, fear of cancer reoccurrence inventory severity subscale; HADS, hospital anxiety and depression scale RSQ, responses to stress questionnaire K-SADS-PL, kiddie schedule for affective disorders and schizophrenia-present and life- time version; CBCL, child behaviour checklist; YSR, youth self-report; PFSD, pain-frequency-duration scale; PCS-C, pain catastrophizing scale for children; STAI-C, state-trait anxiety inventory for children; MSES, mindfulness self-efficacy scale; IMPACT-III, questionnaire; CDS, Columbia depression scale; , SEQ, self-efficacy questionnaire; PIPS, psychological inflexibility in pain scale; PROMIS, peer relationship short form; BYI-II, Beck youth inventories second edition;

CSI, childhood somatization inventory; FDI, functional disability inventory; RCADS, revised child anxiety and depression scale; MAAS, mindful attention and awareness scale; PSS, perceived stress scale; CRSQ, children's response style questionnaire; CAS, cognitive assessment system; CWS, colour-word Stroop; ES, emotion Stroop; MASC2, multidimensional anxiety scale for children second edition; FIQR, fibromyalgia impact questionnaire revised; SIQR, analogue symptom impact questionnaire revised; MAAS-A, mindful attention awareness scale for adolescents; STAI-C, Spielberger state-trait anxiety inventory – child version; CDI, children's depression inventory; CERQ-k, cognitive emotion regulation questionnaire kids version; SSSS, MacArthur scale of subjective socioeconomic status; DMS, diabetes management scale; BGM, blood glucose meter; CES-D, center for epidemiologic studies depression scale; PSS-Fr, perceived social support friends scale; PCQL-32-PF, pediatric cancer quality of life inventory; BIS, body image scale; BDI-Y-II, Beck youth depression and anxiety scales second edition; IDPESQ-14, psychological distress scale; RSE, Rosenberg self-esteem scale; PI, youth-validated illness perception questionnaire (brief version); PedMIDAS, pediatric migraine disability assessment; CPAQ-A, chronic pain acceptance questionnaire adolescent version; AFQ-Y, avoidance and fusion questionnaire for youth; CPAQ, chronic pain acceptance questionnaire; PIPS, psychological inflexibility in pain scale; NRS, numeric rating scale; CDI, children's depression inventory; SPPFI, Stanford pediatric pain functioning inventory; CHIP-AE, child health and illness profile adolescent edition; SCL-90R, symptom checklist-90 revised; BDI, Beck depression inventory; BAI, Beck anxiety inventory; PSQI, Pittsburgh sleep quality index; PANAS, positive and negative affect schedule; DIET-SE, Diet Self-Efficacy Scale; PACE, Adolescent Physical Activity Survey; VAS, visual analogue scale.

### **2.3.3. Certainty of evidence in individual studies**

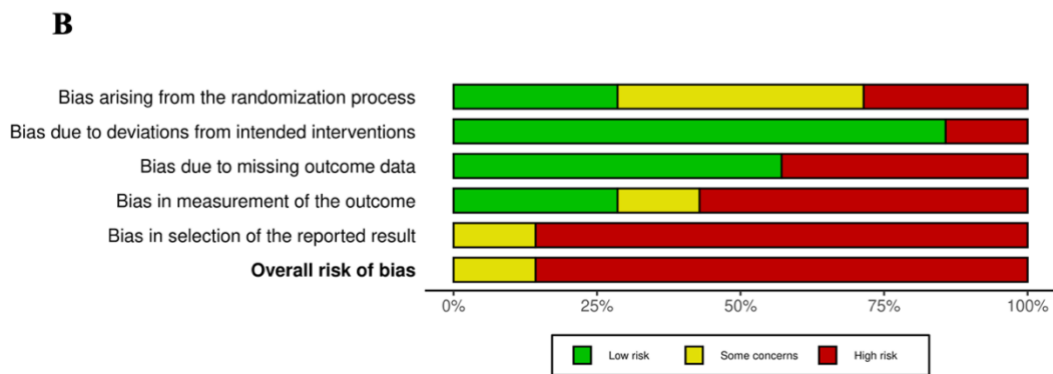
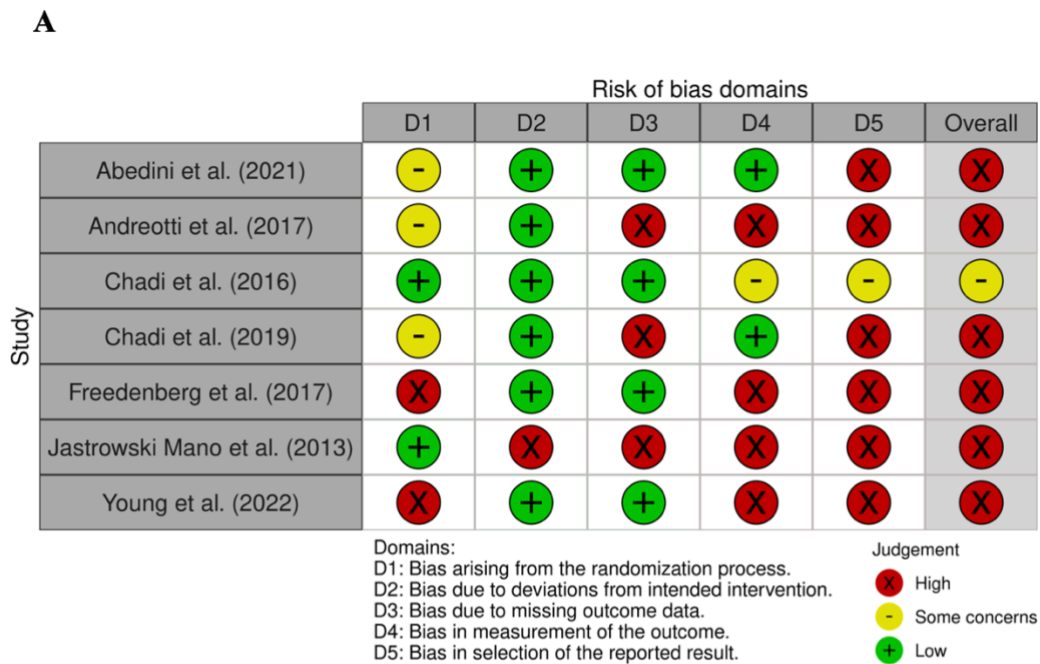
All studies (n=18) met the majority of criteria on the STROBE checklist for cohort, case-control, and cross-sectional studies (combined) (n=11), CONSORT for parallel group randomized trials (n=2), and the CONSORT extension for randomised pilot and feasibility trials (n=5).

### **2.3.4. Risk of bias in individual studies**

Of the included studies, k=7 randomised participants to either an MBI or control group, and k=11 were nonrandomised designs. The RoB 2 (Sterne et al., 2019; Higgins et al., 2011) assessed randomised studies across five specific domains: (1) randomisation process; (2) deviations from intended interventions; (3) missing outcome data; (4) measurement of the outcome, and (5) selection of the reported result (Sterne et al., 2019; Higgins et al., 2011). The ROBINS-I (Sterne et al., 2016) assessed nonrandomised studies across seven specific domains: (1) bias due to confounding; (2) bias due to selection of participants; (3) bias in classification of interventions; (4) bias due to deviations from intended interventions; (5) bias due to missing data; (6) bias in measurement of outcomes, and (7) bias in selection of the reported result.

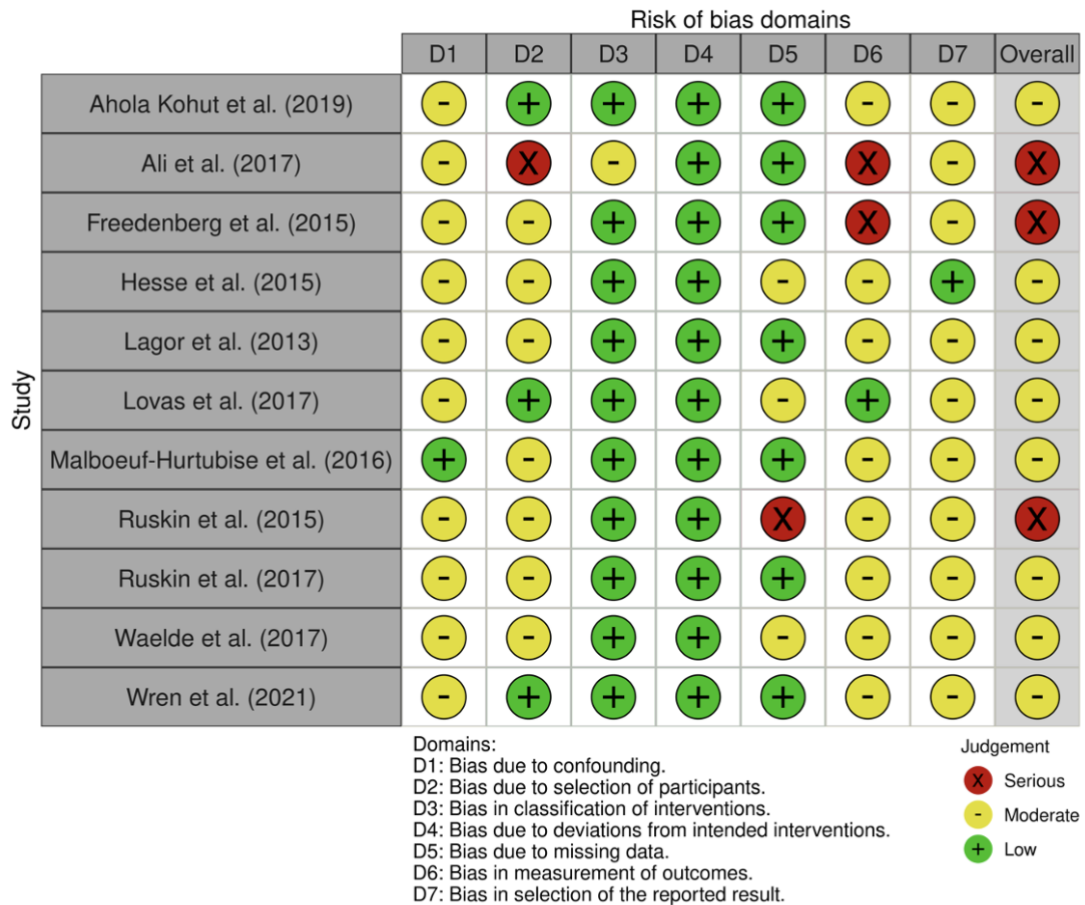
Graphical depictions were created by uploading the RoB 2 and ROBINS-I assessment form results generated with Microsoft excel into Robvis software to visually display the risk of bias assessment (McGuinness & Higgins, 2020). The RoB 2 results are presented in Figure 2.2(A) & (B), and the ROBINS-I results are presented in Figure 2.3(A) & (B). The RoB 2 provided overall judgements for k=6 randomised studies as 'high risk' of bias, and k=1 as 'some concerns.' The ROBINS-I overall judgements suggested k=8 studies were at 'moderate' risk of bias, k=2 were at 'high' risk and k=1 was 'low ' risk. The ROBINS-I (Sterne et al., 2016) provided overall judgements for k=11 studies, as k=3 'serious' risk, and k=8 'moderate' risk.

**Figure 2.2:** (A) Risk of Bias for randomised trials (RoB 2). (B): Risk of Bias for randomised trials (RoB 2) (Sterne et al., 2019; Higgins et al., 2011).

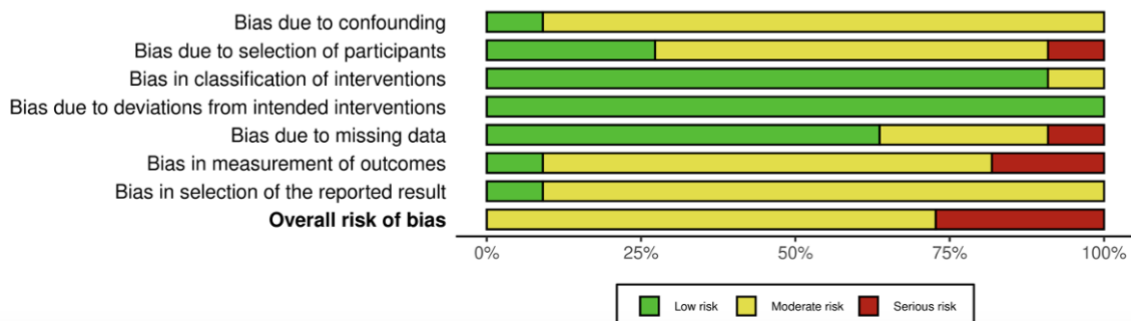


**Figure 2.3:** (A) Risk of Bias in Nonrandomised studies-of Interventions (ROBINS-I). (B): Risk of Bias in Nonrandomised studies-of Interventions (ROBINS-I) (Sterne et al., 2016).

**A**



**B**



### **2.3.5. Mindfulness-based interventions**

Table 2.2 (Appendix A.3.) presents a summary of the content of MBIs. Nearly all studies involved face-to-face group delivery (k=16). Two were digitalised or involved online components, including mindfulness-based virtual reality (MBVR; k=1) and a dedicated website (k=1). The majority of MBIs delivered to children and adolescents were modified (k=13) for developmental age (e.g., Mindfulness-based Cognitive Therapy for Children; MBCT-C, and Mindful Awareness and Resilience Skills for Adolescents; MARS-A) and physical health condition (e.g., PCOS Kind Mind), or MBSR (k=4), MBVR (k=1). Although several studies described following standardised MBSR and MBCT protocols when adapting/designing interventions, the inclusion of fidelity checks was limited (k=5) (Table 2.2). The duration of MBI interventions ranged from a brief, one-time session (k=1, Wren et al., 2021), to longer interventions lasting 4 weeks (k=1), 5 weeks (k=1), 6 weeks/42 days (k=6), and 8 weeks (k=9). The lengths of MBI sessions ranged from 4 minutes to 2 hours in length (mean=79.16 minutes, *SD*=34.46). Session frequency ranged from a one-off session to 42 days of daily practices. One study included a mindful retreat, lasting 4 hours (Ali et al., 2017).

### **2.3.6. Parent caregiver involvement in MBIs**

Across the 18 studies, the involvement of parents varied in extent (k=10). Level of involvement ranged from parents completing parent-proxy measures (Abedini et al., 2021; Ali et al., 2017; Andreotti et al., 2017; Hesse et al., 2015; Waelde et al., 2017), and two studies (Ruskin et al., 2015; Ruskin et al., 2017) incorporated a parenting component recognising caregivers reinforce children's coping. Three studies offered parents a concurrent group for familiarity and explanations of homework (Jastrowski Mano et al., 2013; Ahola Kohut et al., 2019; Ali et al., 2017). Only one study by Andreotti et al. (2017) involved complete parental participation in the MBI alongside their child.

### **2.3.7. Child anxiety and depression**

Ten studies reported significant improvements in measures of anxiety, and six reported significant improvements in depression following participation in MBIs. All



studies reported effect sizes, but Andreotti et al. (2017) did not specify which effect size calculation was used, and only one study (Young et al., 2022) reported individual 95% CIs. For children with chronic conditions participating in an adapted MBI, there were significant decreases in anxiety from pre-to-post intervention ( $p=0.028$ ), although no other significant differences for depression or quality of life were found (Lagor et al., 2013). Chadi et al. (2019) results suggested a significant reduction in anxiety and depression scores of adolescents with chronic illness immediately post-intervention for MARS-A via eHealth, with a large effect size ( $p=0.048$ , Cohen's  $d=0.934$ ), but this was not maintained as significant at 2-month follow-up. Improvements were recorded in 80% of children with somatic syndromes for anxiety and 60% for stress after MBSR, and anxiety scores remained statistically significant at 12-week follow-up ( $p=0.47$ ) (Ali et al., 2017). For IBD, there was a significant decrease in anxiety post-MBI ( $p<0.001$ ), and pain ( $p=0.001$ ) which was investigated based on age, and was significant for adolescents over, and under the age of 18 years (Wren et al., 2021).

Similar findings were reported for adolescents with IBD by Ahola Kohut et al. (2019), with significant differences in emotional functioning following participation in an MBI-A group, and improvements in depression. There were significant reports of reduced rumination (effect size 0.64), and decreases in anxiety and depression in children with esophageal atresia after participation in a home-based MBI (Andreotti et al., 2017). Freedenberg et al. (2015) found a significant decrease in anxiety in adolescents with implantable cardioverter defibrillators and pacemakers, following MBSR with a large effect size ( $\eta^2=0.59$ ), and anxiety decreased from baseline to post-intervention with 90% of adolescents reporting lowered anxiety, but depression did not change significantly. However, this was not followed up in a later study by the same authors, and neither anxiety or depression scores were significant following MBSR or video groups (Freedenberg et al., 2017). Conversely, Hesse et al. (2015) reported no reduction in anxiety scores, but did find decreased depressive symptoms in adolescents with headaches, which could be explained by differences in intensity of home practice.

Not all studies identified significant differences. Chadi et al. (2016) measured psychological outcomes in female adolescents with chronic pain following MBI and

reported no significant changes to scores of psychological distress, depression, anxiety, pain perception, or quality of life. Similar findings were reported by Ruskin et al. (2015) and no significant differences were reported for negative emotionality following MBI. Young et al. (2022) found no significant differences after MBI for depression, anxiety, stress, mindfulness, or self-esteem in adolescents with PCOS. Similarly, Malboeuf-Hurtubise et al. (2016) found no significant differences between groups of adolescents with cancer for mood from pre-to post-intervention, but did report a significant difference in levels of negative emotionality pre-to post-intervention in the control group ( $p=0.04$ ). Findings regarding follow-up were mixed, however, MBCT-C showed significant reductions in internalizing symptoms (Cohen's  $d=3.39$ ) and attention problems in children hospitalized with cancer from baseline to follow-up (Cohen's  $d=2.52$ ) when compared to TAU from pre-intervention to follow-up with large effect sizes (Abedini et al., 2021).

### **2.3.8. Parent caregiver stress and anxiety**

Waelde et al. (2017) found that parental worry regarding their child's pain significantly decreased over the six-week MBI period, with a large effect size (Cohen's  $d=0.75$ ). Parents reported the value of concurrent caregiver sessions, and felt that incorporating mindfulness into their own lives and connecting with other parents had helped to reduce stress (Ali et al., 2017). For the family, there were reports of increased bonding, and feelings of calm (Andreotti et al., 2017). This positive impact for the family was supported by qualitative evaluations conducted by Hesse et al. (2015) where out of 15 parents, 93.3% felt participation in MBI had been beneficial for their child, with 20% describing increased calmness in their children, an increased ability to cope with stress, depression, and pain, and better relations between siblings and parents in the household. However, some caregivers expressed worry about an illness-focused group potentially triggering distressing memories for their child (Jastrowski Mano et al., 2013; Chadi et al., 2016; Malboeuf-Hurtubise et al., 2016).

### **2.3.9. Feasibility and acceptability of MBIs**

There were several barriers to recruitment, including difficulties in getting to the location of the MBI, and living too far from the location of the intervention (Malboeuf-

Hurtubise et al., 2016; Ruskin et al., 2015; Chadi et al., 2016). For example, Waelde et al. (2017) reported four of 20 participants not meeting attendance criteria, because of transport difficulties, and health problems. In some cases, the MBI was at the end of school-term and conflicted with events (Malboeuf-Hurtubise et al., 2016). Issues were also reported by Ahola Kohut et al. (2019) with 56.8% of approached participants declining from scheduling conflicts. Some studies encountered more difficulties than others. Jastrowski Mano et al. (2013) reported a recruitment rate of 49.2%, with 80.7% of approached participants withdrawing before the start of the study, resulting in the cancellation of a treatment wave, and data being individually plotted.

Despite these challenges, Freedenberg et al. (2015) succeeded with 100% of participants completing the MBI and study measures, which was similar in further study by Freedenberg et al., (2017) with a 95% completion rate. There were no dropouts in a study by Lovas et al. (2017). Andreotti et al. (2017) reported 57% of exercises were completed with one or two parents (mean parental help=67.3%) but only four of 19 children were regularly joined by parents at sessions. From parental feedback, this was explained by parents being surprised at the effort required in assisting their child in attending sessions (Andreotti et al., 2017). Similar findings were reported by Ali et al., (2017), with inconsistent participation, and parents only attending 66% of sessions.

The acceptability of MBIs could have been influenced by delivery. When comparing in-person MBI delivery with eHealth, participants in an eHealth group had significant pre-post mindfulness reduction in salivary cortisol levels (Chadi et al., 2019). One study had to change the delivery of mindfulness from face-to-face group sessions to online via video conferencing software after difficulties were encountered with travel and participants' time (Young et al., 2022). However, the efficacy of MBSR was compared with an online support group for cardiac disease, and no differences were found between groups as the intervention group had significantly higher baseline anxiety and depression scores, which could have been a result of inaccurate randomisation (Freedenberg et al., 2017). Chadi et al. (2019) implemented measures against preferences affecting randomisation, and excluded adolescents who based expressed a preference for eHealth or refused to participate

in face-to-face MBI (e.g., if they thought they lived too far), supporting the suggestion that digital interventions could increase accessibility for participants living within a reasonable distance of a location offering in-person sessions. Studies that conducted intervention evaluation feedback and exit interviews, reported on children's experiences of mindfulness.

Preferences for session length were mixed, with some children preferring 60-minute sessions (Waelde et al., 2017), and others favouring 90-minute sessions instead of two-hour sessions (Ahola Kohut et al., 2019). This was also true for meditation, as some children did not enjoy long practices (Ahola Kohut et al., 2019). Despite this, one study reported suggestions for extending the MBI by several weeks (Freedenberg et al., 2017). Other suggested improvements included having immediate exercises for dealing with flare-ups of pain (Ruskin et al., 2015). Across studies, participants had varied responses to different mindfulness-based exercises. For example, one study reported participants had mixed views on meditation and yoga exercises (Freedenberg et al., 2017), and others preferred real-life examples to metaphorical exercises (Ahola Kohut et al., 2019). 'Wise mind', painting (Ruskin et al., 2015), breathing exercises, meditation, and relaxation (Freedenberg et al., 2017) were also preferred by children. Group-delivery was favoured for same-age peer interactions and allowing participants to speak openly about their feelings (Malboeuf-Hurtubise et al., 2016; Waelde et al., 2017; Ahola Kohut et al., 2019; Lagor et al., 2013). Ruskin et al. (2017) reported a 90.5% completion rate, with all adolescents reporting being highly satisfied and would recommend MBI-A to a friend.

## **2.4. Discussion**

Using narrative synthesis, we aimed to (1) synthesise the most recent literature for this patient demographic (Ahola Kohut et al., 2017; Abujaradeh et al., 2018), and (2) address a knowledge gap in an understudied area, and investigate the feasibility, acceptability and efficacy of MBIs for improving depression, anxiety and parental stress in families affected by childhood illness. Specifically, this review identified six new research studies published since 2017. A total of 18 studies met eligibility criteria and were selected for inclusion. MBIs may be effective for improving the psychological wellbeing in children and adolescents with physical health conditions, with evidence suggesting promising outcomes related to illness. Mindfulness showed

promise in improving anxiety associated with chronic pain (Ali et al., 2017; Lagor et al., 2013), and cardiac disease (Freedenberg et al., 2015; Freedenberg et al., 2017), improved depression in adolescents with headaches (Hesse et al., 2015), improved emotional functioning in (IBD) (Ahola Kohut et al., 2019; Wren et al., 2021), and alleviated distress in chronic pain (Chadi et al., 2016).

However, while promising, there were mixed findings (Malboeuf-Hurtubise et al., 2016) and some studies reported a worsening of symptoms (Ruskin et al., 2017; Waelde et al., 2017). The worsening of symptoms may have been a consequence of learning mindfulness techniques as a beginner and might be expected to lessen with practice and gaining experience. The discrepancies in significance (Chadi et al., 2016) could suggest mindfulness teaches the adolescent skills to cope with and manage pain, as evidenced by reports of feeling less alone and learning to manage negative affect (Ahola Kohut et al., 2019; Ruskin et al., 2015) but that efficacy depends on variables such as willingness and commitment to practice. The heterogeneity of interventions and range in sample sizes makes it difficult to determine how effective mindfulness is, as some interventions involved larger groups, were developmentally tailored, and ranged in length and delivery. This could have resulted in some children gaining greater mindfulness skill, which may have been additionally influenced by the inconsistent inclusion of mindfulness retreats (Ali et al., 2017). As well as this, inconsistencies were reported in the completion of homework and home practices indicating that some children were practicing and reinforcing skills more than others (Malboeuf-Hurtubise et al., 2016).

Importantly, when considering the overall quality of studies included in this review, the risk of bias assessments indicated several studies were at moderate or high risk of bias (Sterne et al., 2016; Sterne et al., 2019; Higgins et al., 2011). The absence of control groups, lack of clarity regarding intervention fidelity, combined with differences in facilitator qualifications could have added to the risk of bias in already underpowered study samples, and meant a meta-analysis and overall generalisations could not be determined by pooling results (Jastrowski Mano et al., 2013; Ruskin et al., 2015). However, Zoogman (2015) suggests that instructor experience, intervention design, and session length do not moderate outcomes in mindfulness, but sample origin could (e.g., clinical/non-clinical). Thus, MBIs may be

more therapeutic for certain health conditions (Zoogman et al., 2015), however, the heterogeneity of study designs adds complexity to determining the efficacy of mindfulness with different health conditions.

Evidence for the value of mindfulness with families affected by physical health conditions was limited. Previous reviews into the use of MBIs with children have reported similar findings showing a lack of parental involvement in such programmes, and have suggested the potential importance of including caregivers in MBI to promote the use of mindfulness in daily life (Bockmann & Yu, 2022). Involving parents in MBIs could increase completion of homework, and reinforce practice in the home environment (Bockmann & Yu, 2022). Although limited, this review indicates that including parents in interventions may be associated with reduced parental worry (Waelde et al., 2017; Hesse et al., 2015); reduced disease burden on other family members, and increased problem solving and coping behaviour (Martire & Helgeson, 2017; Law et al., 2019). It was difficult to establish generalisations regarding intervention modality and duration as the findings were mixed without clear patterns. Several barriers to participation were highlighted, such as participants not feeling comfortable with a group format and travel restrictions (Ruskin et al., 2015) which could suggest the value of offering a choice of delivery. Indeed, digitally delivered MBIs were reportedly acceptable for adolescents, which could support the use of an online format for children and their families.

#### **2.4.1. Limitations**

The findings from this review should be cautiously interpreted because of the variation in study designs including several of the studies being pilot investigations, methods used, and intervention characteristics. There is a clear need for more rigorous scientific evidence investigating the role of mindfulness mechanisms with larger sample sizes, standardised, comparable outcome measures, and control groups. A meta-analysis was not possible due to the inconsistency in reporting of effect sizes and the heterogeneity of studies, which makes assessing the role of mindfulness for improving the quality of life of families difficult and resulted in this review being primarily a narrative synthesis with commentary and description of the available literature. The search strategy could also be replicated with a rigorous list

of common childhood illnesses as disease descriptors specifically named as terms in the databases.

#### **2.4.2. Recommendations for future research**

Children and adolescents with physical health conditions may experience psychological distress from living with illness. Mindfulness has shown potential for alleviating the disease-related burden, depression, anxiety, and parental stress. Our findings could have clinical implications in terms of supporting the need for the inclusion of tailored services delivering dyadic, psychological interventions for children and families affected by childhood physical illness in both clinical and non-clinical settings to improve patient outcomes.

However, clinical practice should ensure MBIs are appropriate for the symptoms associated with the condition diagnosed. More research with empirically robust methods, such as homogenous intervention designs, fidelity checking, and control groups is needed to understand the role mindfulness could play in assisting adaptive adjustment to physical health conditions. From the risk of bias assessments, the findings from this review suggest that in order to fully assess the efficacy of MBIs for children with physical health conditions and their families, further large scale RCTs are needed. This would allow a robust examination of the potential for clinically meaningful change after participation in an MBI, as most of the studies identified in this review relied on small, single-groups of participants. Future research should endeavour to focus on dyadic research with families affected by childhood physical health conditions to better capture the mechanism underlying intervention efficacy. MBIs should be collaboratively constructed (involving children and their families) to allow insight into how barriers to participation (such as mode of delivery, length of sessions, nature of exercises) can be addressed.

#### **2.4.3. Conclusion**

This systematic review addresses important gaps in the evidence base and provides an assessment of the most recent findings for the use (and delivery) of MBIs (e.g., including developments of MBVR/online platforms) (Young et al., 2022;

Chadi et al., 2019) that have not been investigated in previous reviews (Abujaradeh et al., 2018; Ahola Kohut et al., 2017). This shift from traditional face-to-face MBIs could be an effective alternative, as in many cases, parent caregivers will be responsible for transporting children; and busy family schedules could hamper attendance as a result. Therefore, online delivery could be viable to enhance feasibility of an MBI from overcoming practical challenges (e.g., transport) that could affect attrition. More research is needed to determine the effectiveness of digital MBIs for improving outcomes in physical health conditions (Young et al., 2022). The findings from this review could provoke new ways of thinking in the field of mindfulness and contribute to the evidence for targeting childhood physical illnesses systemically with family-focused interventions.

Most importantly, systematically searching the literature base has revealed how there do not appear to be any existing studies investigating the use of MBIs with children and adolescents affected by skin conditions. Indeed, this systematic review has identified a gap in the evidence surrounding psychological support for families affected by skin conditions and further research is needed to investigate the feasibility and acceptability of mindfulness-based interventions for families affected by skin conditions. Chapter 3 presents a qualitative study using dyadic interviews with parents and children to determine the relevance of the provision of mindfulness-based support for the family unit.



## Chapter 3

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

### 3.1. Introduction

Childhood conditions that affect appearance and require intensive care can have implications for both a child and their family, with a secondary impact on parents' daily life and psychological wellbeing (Thornton et al., 2021; De Maeseneer et al., 2019; Basra & Finlay, 2007). Caring for a child with a skin condition may place a demand on parents, and social events or life pursuits might be missed to upkeep care routines and appointments (van Scheppingen et al., 2008; Tollefson et al., 2016). Parents may experience disruption to their careers or choose specific jobs in order to dedicate time to caring for their child; In severe cases, they may not be able to work (Cheung & Lee, 2012). In which case, meeting intense care needs could undermine parental self-care and result in burnout, or carers encountering their own health problems. For example, Angelhoff et al., (2018) studied sleep loss in parents of children with AD and found they experienced significant difficulties (Moore et al., 2006) from the disruption of waking up to attend to their child's skin, which often led to parental tiredness.

Perhaps as a result of the disruption to daily life, increased levels of depression and anxiety have been reported in carers of children with AD, psoriasis, and vitiligo (Manzoni et al., 2013). The nature of the skin condition itself may exacerbate domestic pressures, as caring for a child with severe or flaky skin may increase housework (e.g., laundry or cleaning) from administering unpleasant treatments (Ho Na et al., 2019; Chamlin et al., 2004). It could be for these reasons that symptoms of depression have been found in mothers of children with psoriasis (Żychowska, 2020) and impairments to quality of life in parents of children with vitiligo, and alopecia (Andrade et al., 2020; Moss et al., 2020; Amer et al., 2015; Putterman et al., 2019).

The burden placed on the child's main caregiver was suggested by Marciniak et al. (2017) who found that childhood eczema had a greater impact on mothers' quality of life than fathers, and the child's condition had altered parents' 'social lives,' amount of free time, and 'increased financial expenditure'. Similarly, Gieler et al., (2017) found mothers of children with eczema have lower life satisfaction than mothers living with partners and may experience greater stress when compared to mothers of healthy children. Although, these results relied on small sample sizes and warrants further investigation. Despite this, mothers caring for a child with a skin condition may feel alone even if they are not separated from their partner, suggesting mothers might bear the burden of care when they are in a position of being a child's main caregiver (van Scheppingen et al., 2008).

However, the psychological impact for parents may be significant, regardless of dynamics, with parents (in extreme cases) questioning having other children through fears of another child developing the same skin condition (Chamlin et al., 2004). In this case, it could be that parental experience could depend on disease severity, which has been shown to be similarly estimated between parents and clinicians (Mitchell et al., 2015; Balkrishnan et al., 2003; Al Shobaili, 2010). This implies that parents responsible for treating their child's skin condition are vigilant to progression and could become more distressed if it is chronic (Mitchell et al., 2015). However, levels of parental stress could be influenced by the cohesion of functioning between family members, rather than the condition itself (Yamaguchi et al., 2019).

Family relationships may be strained in the context of an unwell child. The parent-child relationship could shift to a nurse-patient dynamic from the time taken to care for inflamed skin while parent attention and play could be replaced by treatment regimens (Ring & Palos, 1986, in Al Shobaili, 2010). Su et al. (1997) estimated that it takes approximately 2-3 hours a day to treat childhood eczema, affecting time spent with other family members, potentially fostering jealousy from siblings, or in extreme cases, could lead to parental divorce (van Scheppingen et al., 2008; Yang et al., 2019). As a result of the closeness of time spent providing ongoing medical care at home, relations between parent and child could be affected. For example, the amount of time spent together could lead to conflict or the development of unhelpful parenting styles that can negatively affect the child's mental health (Emerson &

Bögels, 2017). Despite the suggestion of lengthy treatment regimens straining parent-child relationships, there is evidence to suggest they may strengthen bonds from the amount of time spent together, with parents describing a need to hold their child's hand to stop them from scratching (Ablett & Thompson, 2016; Chamlin et al., 2004).

As well as a skin condition being stressful for the child and the consequential stresses potentially exacerbating many skin conditions, for those caring for a child with a skin condition, low-efficacy combined with exposure to daily challenges associated with aiding a family member, could result in low-grade inflammation and poor health outcomes (Gouin et al., 2012; Mausbach et al., 2011). Not only could this exacerbate caregiver stress, but place further strain on the relationship between the child and parent. For example, the daily parent-child interactions combined with the psychological state of the caregiver could alter the child's HPA axis function (Albers et al., 2008; Lupien et al., 2000; Lupien et al., 2009),

The way in which a parent responds to their child could mediate their stress response, as sensitive maternal parenting behaviour has been associated with more child control over the HPA system and greater cortisol regulation (Albers et al., 2008; Lupien et al., 2009). If the interactions between parent and a developing child are not sensitive, the child's cortisol recovery could be prolonged, which could influence HPA functioning and exacerbate skin severity (Albers et al., 2008; Lupien et al., 2009). Thus, any targeted psychological interventions could usefully include elements that the parent participates in.

Despite the challenges associated with living with a skin condition, the psychological burden for children remains under researched. Along with the lack of psychosocial interventions for children with skin conditions and their families, there is also a gap in the use of patient accounts when compared to support for other health conditions. 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. There is an increasing need for further dyadic (or triadic) research including primary caregivers to focus holistically on the psychological impact of childhood

illness on the family unit to investigate the impact of childhood illness on families and to investigate which types of psychosocial intervention might be most appropriate to develop and test (Moons, et al., 2020; De Maeseneer et al., 2019; Walsh et al., 2022).

The systematic review presented in Chapter 2 (Hughes et al., 2023) revealed that mindfulness could be an effective intervention for children with a range of physical health conditions, and highlighted a gap in existing literature investigating the use of mindfulness with children and families affected by skin conditions. For example, mindful meditation and exercises have shown success in adults with skin conditions (Kabat-Zinn, 1998; Fordham et al., 2015; D'Alton et al., 2019; Gallo et al., 2017). However, for children with skin conditions, there is a paucity of research investigating the role of mindfulness. In addition, much of the existing research into mindfulness in skin conditions has focussed on psoriasis with adult populations.

### **3.1.2. The current study aims**

The aims of this study were threefold: (1) to identify any issues surrounding caring for a child with a skin condition, and current available psychological support resources; (2) to gain feedback on what is needed from a psychological intervention; and (3) specifically examine the relevance of offering a mindfulness-based online support resource to children affected by skin conditions, and their families.

## **3.2. Method**

### **3.2.1. Design**

This study was approved by Cardiff University School of Psychology Research Ethics Committee (EC.21.04.20.6335R2A4) (Appendix B.1.) and used qualitative inquiry with dyadic semi-structured interviews (combined with consultation from experts-by-experience) to investigate parent and child (8-11 years) experiences of skin conditions.

### **3.2.2. Inclusion criteria**

#### **3.2.2.1. Children**

For children to be eligible for participation, they must have been a) aged 8-11 years, b) have had a diagnosis made by a medical practitioner of a skin condition, and c) an English language speaker. This study selected the period of middle childhood as a moment to investigate opportunities for intervention, as children have not yet transitioned to secondary school which brings additional challenges surrounding homework and assessments, as well as other time pressures.

#### **3.2.2.2. Parent/carer**

For caregivers to be eligible for participation, they must have been a) aged 18 years, or above, b) the main caregiver(s) of the child, and c) an English language speaker.

### **3.2.3. Recruitment**

Parents/carers of children with skin conditions were recruited with an online advertisement (see Appendix C.1.) circulated on social media. The advertisement asked carers if they had a child aged 8-11 years old, and if they would like to take part in a study investigating their experiences of psychosocial support for childhood skin conditions. Skin-related charities were contacted to share the advertisement, and those who were interested in taking part responded by email to the researcher. Examples of charities that shared the advertisement on their websites and media platforms included the Psoriasis Association, British Skin Foundation, National Eczema Society, Vitiligo Society, Skin Care Cymru, HealthTalk.org, and the Ichthyosis Support Group. The study was additionally shared through the university's internal channels, newsletter, several charity/university internal emailing lists of participants interested in research opportunities, 'the Primary Times' magazine, and two village parish magazines.

During the recruitment phase (for both the present study, and Study 3; Chapter 5), the researcher experienced a phenomenon of receiving fraudulent participant volunteer emails. The researcher was targeted with automated emails from Gmail

accounts, with generic phrases such as *“hello researcher I wish to take part.”* The emails were intrusive and arrived in clusters, over a period of hours (e.g., over one weekend, the researcher received 291 emails). During the interviews with parents and children, one parent and child dyad attempted to falsify consent/assent forms. When the researcher scheduled a video call and attempted to take consent/assent, it became clear the participants were two adults impersonating ‘five-year old’ children. Although this problem rarely arises in qualitative research as participants are generally ‘screened’ for eligibility (which deters fraud as anonymity is not guaranteed) this issue has recently begun to receive more attention in the field of qualitative research (Ridge et al., 2023) and researchers are beginning to highlight the problem of ‘imposter participants.’ Indeed, the issues surrounding careless and fraudulent responses have been widely reported in internet-mediated survey studies and can pose significant ethical challenges for researchers (Chandler et al., 2020; Teitcher et al., 2015).

According to Braun and Clarke (2021a), meaning in qualitative research is established from subjective interpretations, which makes collecting data an iterative process that cannot be pre-determined with estimates of required interviews numbers through concepts such as data saturation alone (Braun & Clarke, 2021a; Braun & Clarke, 2021b; Saunders et al., 2018; O’Reilly & Parker, 2013). Therefore, based on the study aims and the theoretical basis of the project clearly showing a gap in support provision, combined with the strength of interview dialogue, the data gained during recruitment was regularly assessed for information power by the researchers until consensus was reached regarding the study having sufficiently addressed the aims (Malterud et al., 2016; Braun & Clarke, 2021a).

#### **3.2.4. Participants**

The adequacy of a sample size of n=23 participants was justified, as unlike quantitative research where statistically based power analysis’ guide appropriate size rationales, qualitative research tends to focus on smaller samples to reflect each case analysis in rich detail (Vasileiou et al., 2018; Santer et al, 2012; Santer et al, 2015; Santer et al, 2016). Participants were recruited with purposive sampling via social media using an advertisement posted by several collaborating skin charities,

professional bodies, and the research team. See Table 1 for parent demographics, and Table 2 for child demographics.

**Table 3.1.** Participant characteristics: 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 3.2.** Participant characteristics: 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: Children's Dermatology Life Quality Index.

### 3.2.5. Expert-by-experience involvement

As described in Chapter 1, this thesis adopted a consultative approach to expert-by-experience involvement (Faulkner, 2012). In accordance with this, the present study procedure was informed by involvement from two parent-child dyads with relevant experience of living with a skin condition. This included piloting the interview schedules, and iterating the final questions to ensure they were relevant. From the pilot interview, it was suggested that the researcher added a video to explain the concept and practice of mindfulness to children. The interview schedule was amended to include a link to a short cartoon.



### 3.2.6. Semi-structured interviews

Participants were sent study information sheets (see Appendix C.2. for parent/carer study information sheet, and Appendix C.3. for children’s study information sheet) consent forms (see Appendix C.4. for parent/carer consent form, and Appendix C.5. for children’s assent form) and questionnaires to complete and return prior to the interview, or alternatively bring them to the interview. Two flexible interview schedules were written to cover key areas of concern, including stress, school, experience of treatment, seeking help, and managing symptoms such as sleep, and itch (see Table 3 and Table 4) (see Appendix C.6. for full parent/carer interview schedule, and Appendix C.7. for full children’s interview schedule). Considerations were made when writing the schedules to ensure that the questions were respectful, especially as the topic could cause distress if participants were struggling to cope with the skin condition.

All 11 interviews were held online and recorded with Zoom (Zoom Video Communications Inc., 2023) to capture the discussion and non-verbal cues. The researcher agreed a date and time for interview with the participant and sent them a Cardiff University link to the meeting. Prior to commencing interviews, consent was either reconfirmed or taken if the forms had not already been returned. This approach provided participants with two opportunities to ask the researcher any questions they may have had prior to participating.

**Table 3.3:** Parent/carer interview questions.

Question
<ul style="list-style-type: none"><li>• Could you tell me a bit about *child’s name* skin condition? When did it start?</li><li>• Has anything in your life or daily routine changed since *child’s name* skin condition first developed?</li><li>• How does *child’s name* skin condition impact on their pattern of sleep? Or the family’s bedtime routine?</li><li>• How does *child’s name* skin condition impact them at school?</li><li>• What would you say are the main issues you have experienced in managing your child’s skin condition?</li><li>• Overall, regarding *child’s name* skin condition, what is it like to be the main caregiver for *child’s name*?</li></ul>

- Have you ever been offered any psychological support or information for yourself or \*child's name\* on how to manage their skin condition?
  - From your experience, what do you think are the issues surrounding current available support options for children with skin conditions and their families?
  - Have you tried any techniques or approaches yourself to try and address these issues associated with \*child's name\* skin condition?
  - In terms of managing your child's skin condition on a day-to-day basis, how do you manage any stresses or emotions that may arise from being their main carer?
  - 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?
  - What are your thoughts on parent and child activities if we were to ask you to do some activities together as a family?
  - Have you got any reservations about mindfulness-based interventions or exercises?
- 

**Table 3.4:** Child interview questions.

Question
<ul style="list-style-type: none"> <li>• Can you tell me a little bit about yourself?</li> <li>• Your mum/dad/carer told me you've got *skin condition*, can you tell me a little bit about your *skin condition*?</li> <li>• 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?</li> <li>• Some children that have *skin condition* say that it affects them in school, and some children say that it doesn't. What's it like for you?</li> <li>• Can you tell me a bit about what it's like trying to sleep with your *skin condition*?</li> <li>• Some children say that their *skin* causes certain feelings when others don't notice as much – what's that like for you?</li> <li>• Has anybody given you anything in to try and help with what we've just been talking about with your *skin condition*?</li> <li>• Some of those feelings and ways you feel in your body and mind, and the things you've described sound a bit tricky, is there anything you do to manage these feelings?</li> <li>• What do you think would help you deal with your skin better?</li> <li>• 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?</li> <li>• What do you think about learning to manage your worries or tricky thoughts about your skin?</li> <li>• What do you think about learning to manage the feelings in your skin you described earlier, such as itchiness and soreness?</li> </ul>

- 
- How would you feel about learning how to be kind to yourself and other people around you?
  - How would you feel about learning some techniques to help you with sleeping?
- 

Parents/carers were interviewed first, and upon completion they were asked to invite their child to be interviewed. Children were asked a separate set of age appropriate questions and shown a YouTube video explaining mindfulness to provide background on the approach (see Appendix C.7.). Adults and children were interviewed separately, as parents/carers may not have felt comfortable discussing the impact of their child's condition with them involved in the conversation. Along with this, children may have had different views which would be recorded, as children would be able to talk about their experiences without their carers steering the conversation or answering on their behalf.

Participants were given the choice to have their webcam on or off during the interview to ensure that all people involved were comfortable. Participants were also given the option to consent to the researcher using their video footage or photographs from the interviews for use in academic publications, presentations, and teaching. With permission, the videos have potential to be incorporated into an intervention or could be used to raise the profile of the research. It was explained that this was *entirely* voluntary (on an opt-in basis), and if participants did not feel comfortable, the researcher would delete the footage after transcription. All participants were appropriately debriefed (see Appendix C.8. for parent/carer debrief sheet), thanked for their time, and asked if they were interested in continuing participation in later studies related to this project. All children were sent a certificate of participation (see Appendix C.9.), and each participating dyad was given an expression of gratitude in the form of a £20 'Love2Shop' voucher.

### **3.2.7. Measures**

Quality of life measures were administered to carers and children to contextualise the study sample in terms of assessing the level of psychological impact. Licenses to use the questionnaires were granted by Cardiff University (FLDQI license ID: CUQoL3095; CDLQI license ID cartoon and text-only versions:

CUQoL3097, CUQoL3098). The scores on these scales were totalled to provide a reflection of how participating families were managing with the child's skin condition.

### **3.2.7.1. Demographics**

Carers were asked to provide background information (see Appendix C.10. for demographic questions) including age, gender, ethnicity, geographic location, employment status, type of skin condition, and length of time with the skin condition.

### **3.2.7.2. Parental quality of life**

To provide additional contextual information regarding the impact of the skin condition on parents, the Family Dermatology Life Quality Index (FDLQI: Basra et al, 2007; Basra & Finlay, 2005) was used. The FDLQI is a self-report questionnaire consisting of 10-items covering how the family member's skin condition might impact on quality of life, including psychosocial impact and physical impact. The items are measured on a 4-point Likert scale ("not at all" to "very much"). The FDLQI has good internal consistency (Cronbach  $\alpha=0.88$ ) and test-retest reliability (intraclass correlation =0.94) (Basra et al., 2007).

### **3.2.7.3. Child quality of life**

In order to provide further contextual information regarding the study sample, the Children's Dermatology Life Quality Index (CDLQI: Lewis-Jones & Finlay, 1995) (cartoon version) was also used. The CDLQI is a self-report questionnaire with 10-items assessing quality of life across 6 areas that can be affected by skin conditions (symptoms/feelings, leisure, school/holidays, relationships, sleep, treatment). The items are measured with a 4-point Likert scale ("not at all" to "very much"). The CDLQI has good internal reliability and test-retest reliability ( $r=0.86$ ) (Lewis-Jones & Finlay, 1995) in children aged 4-16 years.

### **3.2.8. Ethical considerations**

As this study involved children as a vulnerable group, it was outlined that any issues of safeguarding would be passed to the research supervisors immediately,

who may have taken appropriate action depending on the level of risk. The researcher also had a recent Disclosure and Barring Service (enhanced) certificate issued through Cardiff University. To reduce the chances of children being coerced into taking part, the researcher asked for assent from children, confirming they were happy to participate and understood what they would be doing. In addition, the British Psychological Society (BPS, 2013) code of human research ethics, the BPS ethics guidelines for internet-mediated research (2017), and the University's guidelines on data storage and transcription were adhered to. The Society for Research in Child Development (SRED, 2007) ethical standards for research with children were also adhered to.

### **3.2.9. Thematic analysis**

Data were analysed using thematic analysis (Braun & Clarke, 2006;2021). This approach was appropriate for the study aims, as it has been previously used to investigate a range of health-related conditions affecting appearance, including people with burn injuries (Watkins et al., 2022), visible difference (Egan et al., 2011), and skin conditions (Keary et al., 2020). A dual deductive-inductive approach was taken, with consideration of existing literature surrounding the psychological burden of skin conditions, but allowing the consideration of new information to shed light on the shared family burden (Joffe, 2012).

Data analysis began with the researcher listening to the interview audio to immerse themselves in participants' narratives. The audio recordings were transcribed verbatim, identifying features were removed from the textual datasets, and pseudonyms were assigned to protect identities. The transcripts were read individually and annotated by hand, with key phrases highlighted to form preliminary codes. This was followed by systematic coding across all transcripts, with common codes compiled. Themes were then developed based on shared meanings, grouped into main themes and subthemes, and cross-referenced with the raw data for accuracy (see Appendix C.11. for photographic evidence of analysis process).

### **3.2.10. Quality control process**

It is important to acknowledge my personal experience of the area investigated in this study, and how this was used when interpreting the data. For example, the narrative from one child with psoriasis in school was very similar to mine (e.g., not removing their blazer, not raising their hand in class, never volunteering, and not knowing another person with psoriasis). Although there were emotion-provoking narratives being collected, I was mindful of checking the extent to which my pre-existing assumptions drawn from my personal experiences were affecting the analysis. I regularly corroborated between coding themes and the raw dataset to ensure that this was not the case.

In keeping with the critical realist stance of the thesis, an audit process was utilised as an approach to ensure Lincoln and Guba's (1985; 1986) qualitative criteria for reliability and validity were achieved and the findings were warrantable to establish trustworthiness. During the audit process, the research supervisors looked at the collected evidence to ensure each stage of the analysis had been adhered to and confirm labelling of themes were accurate (Spencer & Ritchie, 2012). Any differences in interpretation were discussed and amended.

### **3.3. 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 analysis of qualitative data showed that nearly all participants had experienced some degree of 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. However, this finding could have been a result of other stresses or other individual difference variables within the parents, as there is not necessarily a direct relationship between child and parent QoL.

The thematic analysis led to the creation of five themes and seventeen subthemes (see Table 3.5). These are discussed and evidenced with participant quotes below, and were selected in terms of representativeness from being particularly salient to the key issues within the identified themes (P; for ‘parent’, and C; for ‘child’, page number, line numbers). These themes will be discussed in detail and evidenced with quotes (‘parent’/‘child’, age and skin condition, and transcript number; page number; line number).

**Table 3.5:** Main themes and subthemes, and the corresponding participant transcript number the theme was reported in.

Main Theme	Subtheme	Transcript Number
1. Caregiver burden of childhood skin conditions	1.1. Living with uncertainty: The unknowns of treatment decisions and condition progression	5, 11, 8, 9, 7, 10, 6, 2, 3, 1
	1.2. Impact on mood and affect	9, 6, 2, 11, 5, 4, 8, 1, 10, 3
	1.3. “Extra leg work” of additional considerations, housework, and costs	10, 1, 11, 6, 4, 7, 8, 3, 5, 9
	1.4. Being more prepared: Parents as experts by experience	1, 5, 7, 8, 9, 10
2. Skin condition overshadowing childhood	2.1. Skin influencing mood and flaring from emotion	10, 8, 6, 1, 2, 4, 7, 11, 9, 5, 3
	2.2. Low confidence and shame: Negative appraisals from other people	6, 11, 3, 10, 9, 1, 2, 3, 5, 7, 8, 4
	2.3. Impeding daily life: Sleep, school, and clothing choices	6, 2, 9, 7, 8, 11, 1, 3, 4, 10, 5
	2.4. Better with older age: Challenges of caring for a younger child	2, 11, 5, 8, 4, 7
3. Battling for recognition and lack of support	3.1. Not offered psychological support	1, 2, 3, 4, 5, 6, 7, 8, 10, 11
	3.2. Feeling dismissed and marginalised as a parent carer	11, 9, 3, 4, 10, 2, 1, 8
4. Naturalistic use and understanding	4.1. Feeling safe and accepted with friends	5, 3, 9, 4, 11, 6, 1, 2, 5, 7, 8, 10
	4.2. Breathing through the stress	6, 7, 11

of mindfulness in everyday coping	4.3. Self-compassion with affirmations and a positive mindset	1, 3, 4, 5, 6, 7, 8, 9, 10, 11
	4.4. Focused attention and mental imagery	11, 9, 5, 7, 3, 6, 8, 1, 2, 4, 10
5. Openness and relevance of offering a mindfulness-based intervention	5.1. Familiarity with concept of mindfulness	5, 7, 10, 11, 9, 1, 3, 4, 8
	5.2. Thoughts on trying a mindfulness-based intervention	10, 5, 6, 11, 9, 1, 2, 3, 4, 8, 7
	5.3. Dyadic needs and expert recommendations for a useful resource	2, 5, 10, 11, 8, 7, 6, 9, 1, 3, 4

## **Theme 1: Caregiver burden of childhood skin conditions**

Parents described the psychological burden of providing daily care for a child with a skin condition, including managing treatment regimens and coping with fluctuations in severity “on top of the usual parenting” (Parent [7] of child aged 8 with eczema, 8;177-179).

### **1.1. Living with uncertainty: The unknowns of treatment decisions and condition progression**

Parents discussed the difficulties of being in a situation where it is “very hard to reassure a child and say, ‘it’s going to be fine’ when actually you have no idea” (Parent [8] of child aged 9 with eczema, 16;389). There were uncertainties surrounding whether the appropriate approach to treatment had been decided:

This internal voice inside me going ‘am I doing the right thing?’...that’s pretty much a constant voice...it’s certainly affected my quality of life (Parent [5] of child aged 9 with vitiligo, 12;298-300).

Participants reported concerns about allowing their child to take strong medication for their skin condition, and were worried about the potentially harmful side effects:

That was a really tough time as a parent, making her take something that you’re hoping is making her better and not making her worse with side effects...are we doing the right thing? (Parent [9] of child aged 10 with psoriasis, 14-15;348-352).

The unknowns of skin condition progression were discussed, with parents



describing distress from not knowing how much the condition may worsen or spread:

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...that's what you have to do because there is so much uncertainty (Parent [11] of child aged 8 with ichthyosis, 43;1065-1073).

Now it's on his face I do worry about that going into his hair and his eyebrows...I do worry for the future (Parent [3] of child aged 9 with vitiligo, 13;312-313).

## **1.2. Impact on mood and affect**

The impact on participants mood and mental health appeared to be significant, with some describing experiencing a "rollercoaster of emotions" (Parent [11] of child aged 8 with ichthyosis, 22;526):

It is a form of stress...it's a small dark cloud...it's just a thought, and sometimes that thought floats into my head, stays there for a while, and then floats out (Parent [5] of child aged 9 with vitiligo, 15-16;374-377).

There is that seed of worry that sits in the back, and sometimes it's more prominent (Parent [9] of child aged 10 with psoriasis, 20;494-495).

In some cases, parents reported blaming themselves for passing on a hereditary condition to their children, and reported feeling 'guilt' from not being able to ease their painful symptoms:

It is hard, because you feel guilty...it's hereditary (Parent [6] of child aged 11 with psoriasis, 14;343).

There is a lot of guilt...guilt that if I said yes to the wrong thing...or the guilt that I've got to take you for another blood test...it is a guilt...that I can't take this away from you (Parent [9] of child aged 10 with psoriasis, 19;464-469).

In some cases, conflict was reported between parents and children:

It changes the relationship...you're nagging him and reminding him to go and put his cream on and asking if he's done it instead of doing it for him...it's

almost the straw that breaks the camel's back...he does get upset (Parent [7] of child aged 8 with eczema, 7;155-165).

She'll say, 'why are my legs still so dry after I've had a bath?' and I'll say, 'well it's because you've rubbed your cream off'...and that'll cause conflict because she has a different opinion (Parent [10] of child aged 10 with ichthyosis, 13;310-312).

### **1.3. “Extra leg work” of additional considerations, housework, and costs**

Parents reported the burden of having to make additional considerations in order to ensure their child was prepared when away from the home environment. This included balancing the “juggling act of work, childcare, go to appointments” (Parent [9] of child aged 10 with psoriasis, 21;505-508) which added to the strain of coping with a chronic skin condition:

That's time consuming and stressful...there's so many extra things to think about, you can't just get up and go (Parent [11] of child aged 8 with ichthyosis, 38;942-946).

Having a child with eczema was described as increasing laundry and washing from bleeding skin staining bed sheets, which was reported as upsetting to witness: There's blood all over the bed...you're like 'has something serious happened?'...you have a momentary panic (Parent [1] of child aged 8 with eczema, 9;199-201).

Additional financial costs were mentioned by parents, from using more water to upkeep bathing treatments for eczema, and purchasing sun cream to protect delicate vitiligo patches from the sun:

We will be using a lot more water if we're sticking him in the bath every day...it does add up (Parent [8] of child aged 9 with eczema, 7;154-155).

Sunscreen isn't cheap, and we go through a lot (Parent [3] of child aged 9 with vitiligo, 6-7;149-150).

#### **1.4. Being more prepared: Parent and family as experts by experience**

Many of the skin conditions described by participants had genetic links, and parents similarly had been living with the same conditions as their children, which “having it as well, means that I’m more confident” (Parent [1] of child aged 8 with eczema, 5;113). Parents described how knowing the skin condition was hereditary made them more prepared for the potential of their children developing a skin condition:

I kind of already knew...it was no great surprise (Parent [5] of child aged 9 with vitiligo, 7;171-173).

We’d sort of anticipated that [eczema] was gonna come out in one of our children (Parent [7] of child aged 8 with eczema, 4; 94)

It was also reported how parents were familiar with the treatment routines and symptoms of the skin condition, so were able to bond with their child over their shared experience:

It was helpful that my husband already has psoriasis...it was relatable for her and actually they were like “we’ve got the same” (Parent [9] of child aged 10 with psoriasis, 23;572-573).

In one case, family members were used as examples and positive role models of living well with ichthyosis, providing reassurance and advice to the child when needed:

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 from doing what they want to do...there’s always somebody to sympathize with you...it’s important for her to see other people that are managing it and aren’t too affected by it...I hope that she’s seen me and thinks ‘right ok, I can be normal (Parent [10] of child aged 10 with ichthyosis, 5;112-123).

## **Theme 2: Skin condition overshadowing childhood**

The skin conditions were described by children and their parents as having a profound impact on the child's life and daily routines, influencing their mood, ability to work in school, clothing choices, and overall levels of confidence.

### **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 (Child [11] aged 8 with ichthyosis, 6;131).

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 that I wanted (Child [7] aged 8 with eczema, 26;638-643).

In some cases, the intensity of itch experienced led to behavioural responses from the children in an attempt to reduce the sensation and need to scratch:

He will do what we call 'cricket legs'...rubs his legs together when he's sleeping...he's almost learnt where that point is on his skin where he can scratch it but not actually tear his skin (Parent [7] of child aged 8 with eczema, 5;107-109).

When it's itchy and sore I wiggle...I always wiggle when I'm itchy (Child [11] aged 8 with ichthyosis, 7;155-159). (Corroborated by Parent [11] of child aged 8 with ichthyosis, 24;584-585): Wiggling, she's always moving...sort of shimmying around...it's maybe a reflection of the itch she feels.

It'll feel like I can't do anything, sometimes I just sleep and stay in my pyjamas all day because I don't want to do anything because of it (Child [6] aged 11 with psoriasis, 22;547-548).

Participants described how the overall experience of living with a painful and itchy skin condition impacted on their mood and affect:

I just get annoyed (Child [4] aged 10 with eczema, 14;344).

It can be very very annoying...it pricks it, and it really just annoys me...it's the beginning of anger because I'm annoyed and it's annoying me because it's stopping me from not allowing me to put my full concentration on doing something that I wanted to do (Child [7] aged 8 with eczema, 26;638-643).

Along with itch and negative emotion, children described noticing a relationship between their thoughts and 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 white bits...and with the bad things, when I'm annoyed and fed up, that causes the flakiness (Child [6] aged 11 with psoriasis, 23;553-557).

If it's really bad I get really sad about it because it hurts...you have three levels, I'm usually at the middle level, but now I'm at the lowest level, but if it's at the high level then it's really really sore and it makes me sad...it starts to feel a bit prickly when I'm sad (Child [1] aged 8 with eczema, 25;602-610).

## **2.2. Low confidence and shame: Negative appraisals from other people**

In some cases, parents felt their child had "no confidence" (Parent [6] of child aged 11 with psoriasis, 6;128) and had become "shy and withdrawn" (Parent [11] of child aged 8 with ichthyosis, 35;860) from lowered self-esteem. This was supported by children, who described feeling different to peers, reflecting a desire to 'fit in', and in some cases, had experienced bullying and abusive comments from other children:

I'm kind to other people but to myself it's hard...I feel different to other people (Child [1] aged 8 with eczema, 29; 713-414).

People asked me like 'eww what's that, is it contagious?' and they'd say stuff like that, 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 (Child [6] aged 11 with psoriasis, 21;521-523).

She just doesn't want it...she's like "why does no one else have it mummy?"

and “why is it me?” (Parent [9] of child aged 10 with psoriasis, 9;200-201).

Of note, two children described feeling a quasi-sensory hyperawareness/hypervigilance to other people ‘staring’ at them for having a visibly different appearance:

Every place I go...I can always feel someone staring at me, and I get this weird thought that tells me that people are staring, and people are talking about me (Child [6] aged 11 with psoriasis, 26;629-631).

Sometimes I think someone is going to be behind me and watching me (Child [11] aged 8 with ichthyosis, 13;324-325).

Parents and children reported experiencing malevolently motivated comments from other parents and children, which added to feelings of shame and embarrassment about having a skin condition:

Kids saying “don’t let Darcy touch you” because if you get the “Darcy touch” then your skin will turn wrinkly (Parent [10] of child aged 10 with ichthyosis, 8;182-184).

We’ve had parents call him a “freak” and ask, “what’s wrong with him?” Because they’re worried about their children coming into contact with him (Parent [3] of child aged 9 with vitiligo, 7;173-174).

Alternatively, there was also evidence of (self)-stigmatization from parents, who felt their child had been “lucky” to have not been bullied by peers at school, implying that they expected their child to receive more negative reactions:

Megan is really lucky...they don’t tease her, they don’t bully her (Parent [5] of child aged 9 with vitiligo, 10;244-245).

He’s been very lucky with his classmates to come out of it without name calling...that’s luck more than anything else (Parent [8] of child aged 9 with eczema, 14;344-346).

### **2.3. Impeding daily life: Sleep, school, and clothing choices**

Children and their parents described the shared impact that having a skin condition had on their daily life, including intense itch at nighttime causing a disruption to both the child's sleep and the family unit's pattern of rest, along with co-sleeping for comfort:

It's sort of the pain, and also the itch...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 (Child [2] aged 10 with eczema, 20;479-481) Corroborated by parent: He's really unsettled...has to have one of us lying next to him...he's got into that pattern of not falling asleep on his own because he gets so itchy (Parent [2] of child aged 10 with eczema, 6;132-135).

In addition to itch interrupting rest, one child described staying awake at night and picking the visible scales off her psoriasis plaques in an attempt to make the scales less noticeable to other people:

When I'm trying to get to sleep...I pick off the flaky bits, because I think if I get rid of them then it will be not as visible, so I sit there and I pick them all off which really hurts, so that keeps me awake...when I'm in my bedroom there's not anyone else in there...if I just get it over and done with now, then no one will know...I just keep myself awake...so I don't have to do it outside with other people (Child [6] aged 11 with psoriasis, 22;527-536).

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

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 or words for the sentence that I'm writing (Child [8] aged 9 with eczema, 22;528-529).

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 (Child [6] aged 11 with

psoriasis, 21;501).

The demanding nature of intensive treatments in one case, led to a child feeling like they were 'missing out' on schooling and time with friends:

She has got upset...“what am I missing in school?” “I’m missing my friends”, “I’m missing my break”...she’s got quite emotional (Parent [9] of child aged 10 with psoriasis, 8-9;197-202).

#### **2.4. Better with older age: Challenges of caring for a younger child**

Parents discussed how the burden of caring for their child with a skin condition had eased with them growing older. As the children’s age increases, they were more able to take responsibility and ownership over the treatment of their own skin, instead of parents having to manage the regime for them:

It’s different now she’s a little bit older...she’s 10 she can do it herself (Parent [4] of child aged 4 with eczema, 5;117).

When she was a small baby...it was extremely intensive and time-consuming to deal with all of her skin needs...but as she’s gotten older, she’s taken more of a hand in doing that herself (Parent [11]of child aged 8 with ichthyosis, 27-28;674-680).

It was described how the child becoming verbal and being able to effectively articulate the problem and communicate with their parents had helped with determining when their skin needed treating:

My child wasn’t sleeping, I assumed that he had bad sleeping patterns, but it wasn’t, it was his skin itching...when he could start talking, I knew what the problem was (Parent [2] of child aged 10 with eczema, 11-12;272-274).

#### **Theme 3: Battling for recognition and lack of support**

Parents described the struggle of getting a diagnosis from doctors, having to “fight” (Parent [3] of child aged 9 with vitiligo, 5;105) for the correct treatment and “battle to try and explain” (Parent [3] of child aged 9 with vitiligo, 16; 389) how the skin condition impacts their child. In many cases, participants felt they had not been



fully acknowledged by medical professionals, which added to the emotional burden of caring for a child without support.

### **3.1. Not offered psychological support**

Of the eleven dyads interviewed, nine had not been offered any specialised psychological support options:

I've not had any support from a doctor (Child [1] aged 8 with eczema, 21;616). There's just nothing available to help...it's seen as cosmetic rather than something that affects them mentally...it's overlooked as not having an impact on them...but out of everything, it affects them mentally and their mental health more...there's no support (Parent [6] of child aged 11 with psoriasis, 13-14;319-329).

One parent described being offered support from a clinical psychologist related to their baby born with ichthyosis being treated on a special care unit:

It was from the special care unit...it wasn't very focused on the specifics of having a baby with such a visible difference (Parent [11] of child aged 8 with ichthyosis, 42;1033-1038).

However, one parent described how her child was offered counselling for her psoriasis:

She was offered some counselling...but at the time that didn't feel quite right...that was possibly kind of a tick box exercise, rather than we're treating you like an individual person (Parent [9] of child aged 10 with psoriasis, 26;643-646).

### **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 skin-specific 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 (Parent [9] of child aged 10 with psoriasis, 22-23;546-564).

It would be lovely if there was just something...for children, so they could read it, rather than me trying to read all the scientific stuff, and then having to dull it down...there isn't really anything out there for children (Parent [3] of child aged 9 with vitiligo, 16-17;398-405).

There were reports of not feeling listened to, or acknowledged, by not being offered the appropriate level of support as a carer of a child with a severe skin condition:

The GP just patted my knee and said, "you'll be okay, you'll be fine" you know "we can't really do very much for you"...that was as close as I got to asking for support...I wasn't made to feel like it was an option (Parent [11] of child aged 8 with ichthyosis, 41;1027-1030).

#### **Theme 4: Naturalistic use and understanding of mindfulness in everyday coping**

When discussing current coping methods for dealing with their skin condition on a daily basis, children and parents described naturalistically using strategies overlapping with mindfulness-based concepts, such as acceptance, compassion, and the use of focused attention.

##### **4.1. Feeling safe and accepted with friends**

Children described having a supportive informal network of friends who provided them with comfort and a sense of belonging during periods of distress related to their skin. The importance of being accepted by friends was discussed. Feeling accepted appeared to create a sense of safety for children during school and social events, who found comfort and reassurance from having their friends with them:

I can't do anything on my own...I always need someone there just in case someone does stare at me (Child [6] aged 11 with psoriasis, 20;476-478).

I also feel like happy and like safe...I feel okay about it because I know that my friends make me happy when I'm sad, and they can stand up for me (Child [10] aged 10 with ichthyosis, 24;580).

This was also discussed from a parent perspective:

We can't be there the whole time to support her, and I think that's what she looks to her friends for when we're not there (Parent [11] of child aged 8 with ichthyosis, 36;879-880).

#### **4.2. Breathing through the stress**

Parents and children discussed using controlled breathing techniques as a method of managing stress related to caring for their child with a skin condition, and calming down from the daily challenges encountered:

I've tried breathing techniques...to try and calm myself...I'll sit and think "take a deep breath" (Parent [6] of child aged 11 with psoriasis, 15;354-358).

Taking a breath and just stop doing everything...take 5 minutes to think about one thing, and focus (Parent [11] of child aged 8 with ichthyosis, 44;1096-1097).

One child metaphorically described how they had noticed a direct relationship between slowing their breathing, and the physical sensation of the level of itch intensity felt in their eczema:

I breathe in and out slowly and that makes it go...my breathing slowly makes the itch go away...it calms my skin down...it slowly washes the eczema away...it washes it out of my body (Child [7] aged 8 with eczema, 23-24;572-586).

#### **4.3. Self-compassion with affirmations and a positive mindset**

The majority of children reported the significance of other people's judgements, and feeling different to peers, which was discussed as being managed by rehearsing positive affirmations. Children reported adopting a positive mindset to having a skin condition, and embracing being unique:

It doesn't matter if you have things going on with your skin, you're just like other people (Child [3] aged 9 with vitiligo, 28;682).

If I was thinking about being so different from everybody else, then I would

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', because if there's a person who's super super pretty and has everything good but she's really mean then nobody will want to be her friend, even if she's really rich, but if there's a person that doesn't look that nice, but they're really really kind then people will want to be their friend (Child [5] aged 9 with vitiligo, 29;715-719).

You should try and be positive...listen to the people that are telling you it's fine and ignore the people that are trying to make you feel worse (Child [10] aged 10 with ichthyosis, 32;790-795).

In addition, some parents described adopting 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 (Parent [11] of child aged 8 with ichthyosis, 22-23;550-551).

#### **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:

My favourite way of calming down or taking my mind off something is a car game...taking my mind off [the eczema] and focusing on something else and concentrating on stuff makes me focus differently (Child [1] aged 8 with eczema, 29;702-705).

In particular, one child used a technique of mentally shifting their energy to control itching, which showed an awareness of the relationship between the skin and the mind:

I use my concentration to fight [the itch], so it doesn't affect my schoolwork...to make it go away...I have this method of imagining what it's like and moving your energy to different parts of your body, so it does something...the energy

burns out the eczema and the itch (Child [7] aged 8 with eczema, 24-25;598-605).

Using focused attention, and moving concentration away from the skin was reported as changing the physical experience of the skin condition itself:

When I focus on one thing, I don't focus on my ichthyosis so I can't feel it as much and that helps, and I can't feel it as much because I'm focusing on one thing but when I focus on the itchiness I feel it more, and I notice it more (Child [11] aged 8 with ichthyosis, 17;404-405).

## **Theme 5: Openness and relevance of offering a Mindfulness-based intervention**

Some children reported already engaging in mindfulness-based activities during school, as part of their curriculum, including mindful colouring, 'cosmic yoga', 'square breathing'/breathing techniques, and apps, which parents felt would have been useful "if that had been something that we could have incorporated into our routine...as a way of helping him manage his skin" (Parent [7] of child aged 8 with eczema, 19-20;464-475).

### **1.1. Familiarity with concept of mindfulness**

Children described how participating in mindfulness in school had helped them, and discussed the feelings they had noticed in their body when being mindful. Nevertheless, some of these descriptions highlighted a degree of misunderstanding of the theoretical concept of mindfulness:

I do [a mindfulness app]...to take your mind off stuff...it really makes me feel more comfortable...it just takes my mind off itching, and it makes me focus on whatever I'm doing...it just stops me from thinking about itching...then I don't really get distracted by it (Child [1] aged 8 with eczema, 27-28;667-677).

We did square breathing...and that helped me calm down...I just wasn't in the mood for thinking about things, I just focused on being calm (Child [4] aged 10 with eczema, 19;460-468).

I already do mindfulness at school...the thing we do is colouring...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 (Child [7] aged 8 with eczema, 31-32;768-787).

## **1.2. Thoughts on trying a mindfulness-based intervention**

Parents and children described the relevance of mindfulness to their skin conditions, and reported how they thought practicing the technique could promote adaptive coping. Again, these quotes demonstrate some fundamental misunderstandings are held 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 (Child [5] aged 9 with vitiligo, 30;740-741).

If she's feeling in a better emotional state...that will help her manage stress and anxiety on a day to day basis and she can use those tools to help with some of those flare ups (Parent [9] of child aged 10 with psoriasis, 29;708-710).

[Mindfulness] would diffuse things...if she could learn some techniques for if she feels the anger rising, then that's something that she could try in order to calm herself down...it would give her some tools to manage anger...if we could have fewer angry moments that would be great (Parent [10] of child aged 10 with ichthyosis, 17;401-405).

## **1.3. Dyadic needs and expert recommendations for a useful resource**

Parents and children provided suggestions as experts by experience regarding what they would find most helpful from a mindfulness-based intervention as families affected by skin conditions, whilst also describing potential barriers to participation:

These mindfulness apps that doctors have recommended they're about like ADHD or just calming down in general...I just need something that is going to help me think positively about my skin...rather than just some breathing ins and outs (Child [6] aged 11 with psoriasis, 25;617-620).

Something that can fit into routine...if you think about moisturization, you put loads on, and then you're kinda like 'what am I supposed to do now?' but maybe...if you put your creams on, and then 'you kind of do this', and then by the time it's finished your creams have dried...that could be a constructive thing (Parent [1] aged 8 with eczema, 19-20;472-486).

Participants described a desire for activities to manage the stresses associated with living with a skin condition:

Something with breathing methods and how to like relax, how can I calm down (Parent [2] of child aged 10 with eczema, 15;365-367).

A way to deal with those anxieties that allows you to just get away from them for a bit without physically getting away from them (Parent [11] of child aged 8 with ichthyosis, 45;1108-1109).

We should start developing something that stops people itching the skin, because if you start itching it might hurt you and it might spread faster (Child [3] aged 9 with vitiligo, 28;689-690).

It would be a really good way forward, just to have some particular exercises you could do just to de-stress when you need it (Child [4] aged 10 with eczema, 12;275-276).

When asked if there were any reservations about trying a psychological support resource, a potential barrier highlighted by parents was finding the time to allocate to an intense and time-consuming intervention, as such, there was a preference expressed for short mindfulness exercises that could be accessed easily:

Short [exercises] that you can dip in and out of, that will work in different contexts, so on a smartphone...immediately accessible (Parent [11] of child aged 8 with ichthyosis, 45;1128-1129).

For me...the shorter [the exercises] the better, but for Darcy, not necessarily so much because she's got more time on her hands...something you can do for ten minutes here and there (Parent [10] of child aged 10 with ichthyosis,

17;418-419).

Parents also described how they would need an intervention to be easily accessible, as often, their child's distress emerged suddenly or at moments of short-notice, and parents felt an online format could assist with this:

I'd like a link to a page...a helpline...someone you could just ring and talk to or even just email...online support (Parent [2] of child aged 10 with eczema, 14;326-334).

The main thing that takes my mind off it is screens, because I'm a big fan of technology and if I'm doing something on a computer, I just completely forget about all of my thoughts (Child [1] aged 8 with eczema, 28;690-693).

Whilst parents suggested the benefits of participating in mindfulness-based activities together as a family, in promoting bonding and having a positive shared experience together as a parent and child dyad:

With ichthyosis...it can bring you together as a family because you spend so much time together...it would be nice to share those types of activities...rather than being always the parent like "do this, do that"...it would bring a different dimension to the relationship that could be quite healthy (Parent [11] of child aged 8 with ichthyosis, 47;1172-1176).

However, when specifically asked about mindfulness, and their views on the approach itself, some parents felt they did not know enough about the technique, and would like more information about the theory behind mindfulness:

I don't know enough about it if I'm honest...it can't harm you, so I can't see anything bad, if it doesn't work, it doesn't work, it's not going to do anything a detriment so no, I wouldn't have any reservations (Parent [8] of child aged 9 with eczema, 19; 451-453).

Last, in some cases, parents described providing care for their child as being "quite isolating, we don't really know anyone" (Parent [1] aged 8 with eczema, 32;780). This feeling of being alone led to many participants expressing a desire to meet other families of children with skin conditions:



It would be cool if I had a club where I could talk about how you're feeling (Child [2] aged 10 with eczema, 22;542).

The ability to meet some other kids with similar conditions...less for Darcy because she's got a family with the same thing but if it was just her, I think it would be quite lonely, so just being able to see that you're not the only one and being able to see that some kids have got it worse...to have a bit of a network would be really useful (Parent [10] of child aged 10 with ichthyosis, 15;370-372).

### **3.4. Discussion**

This study aimed to identify the issues surrounding being a child/providing care to a child with a skin condition, investigate parent and child experiences of current psychological support services, including what is needed, and determine the relevance of offering a mindfulness-based resource. The main themes identified from thematic analysis suggest that living with a skin condition can have a significant psychological impact for children diagnosed with skin conditions and their parents. The findings are supportive of previous literature (Ablett & Thompson, 2016) indicating a range of challenges exist for parents caring for their child (van Scheppingen et al., 2008; Tollefson et al., 2016). These challenges were wide ranging, including having to make extra considerations when leaving the house, managing uncertainty surrounding condition progression and triggers for flare, adherence to treatment, extra housework (Ho Na et al., 2019; Chamlin et al., 2004), increased financial expenditure, and in one case, this had also been factored into a decision to reduce working hours (Cheung & Lee, 2012).

These challenges reportedly reduced parental quality of life by adding to the pressures of parenting, influenced mood from lowered affect, and perpetuated stress (Basra & Finlay, 2007; Manzoni et al., 2013; Żychowska, 2020; Andrade et al., 2020; Moss et al., 2020; Amer et al., 2015; Putterman et al., 2019). Many parents described experiencing a feeling of 'guilt' for passing on a hereditary condition, which has been previously reported in parents of children with chronic conditions affecting appearance (Ablett & Thompson, 2016; Thornton et al., 2021), and other physical

illnesses such as lymphedema (Moffatt et al., 2019). Related to feeling guilty, parents described a sense of self-doubt emerging from questioning whether they were doing enough as a caregiver to help their child and if they were taking the right approach to treatment, supporting previous reports from parents of children with eczema feeling overwhelmed and like they are 'failing' (Capozza et al., 2020; Santer et al., 2016). In some cases, more serious mental health outcomes were described, such as potentially clinical levels of depression, which has been similarly reported in carers of children with other chronic health conditions (Cohn et al., 2020).

However, the challenges of parenting a child with a skin condition were countered by positive outcomes and several parents reported rising to the role of caregiver with a sense of pride. Many of the skin conditions described in this study had a genetic component (e.g., ichthyosis and psoriasis) and the parents interviewed had the same skin condition as their child. For these parents, there was a feeling of self-efficacy from being able to successfully manage their own child's condition based on their personal expertise of living with similar symptoms, and not having to rely as heavily on healthcare professionals. Having the same condition as their child may have heightened parents ability to empathise with and respond to their child's needs, and they were able to sympathise and understand the condition from their own insights. Indeed, parents and children could be brought closer in terms of bonding from connecting over a shared experience. For example, children could view their parent as a positive role model for learning to positively adjust to a chronic illness, and seek advice from supportive family members for how to cope with skin-related symptoms.

For children, being diagnosed with a skin condition was experienced as painful and caused a significant amount of itch/scratching and bleeding from broken skin (Reid & Lewis-Jones, 1994; Lewis-Jones, 2006; Papadopoulos & Walker, 2003). Itch was described by the majority of children as the defining feature of their condition, which supports paediatric research into pruritis as one of the main symptoms children need support to manage, potentially from being understudied and less considered in existing literature (El Hachem et al., 2020; Ring, 2021). Children described feeling visibly different to their peers and not 'fitting in', the struggle of being comfortable physically and finding comfortable clothing (Trekels & Eggermont,

2017), and mentioned being distracted from schoolwork and activities they wanted to engage in. These daily challenges influenced children's mood (Cheung & Lee, 2012; Kemp, 2003) by causing frustration and anger (Hughes & Hunter, 2022a, Hughes & Hunter, 2022b) from their concentration being interrupted by intense itch, a feeling of sadness when their skin flared, a hypervigilance to other people staring, and distress from instances of bullying (Titman, 2005; Papadopoulos & Walker, 2003).

The narratives of parents and children often overlapped which suggests a shared burden between family members. There were some reports of conflict arising from resistance to treatment (Santer et al., 2013), a joint account of finding the negative judgements of other people equally distressing (Trekels & Eggermont, 2017), and disruptions to household sleeping patterns (Angelhoff et al., 2018; Moore et al., 2006; Reid & Lewis-Jones, 1994; Lewis-Jones, 2006; Fennessy et al., 2000). There was evidence of self-stigmatisation, with parents discussing the 'luck' of their child not experiencing more malicious encounters with peers. Parents and children similarly described the negative impact the skin condition had on the child's confidence and self-esteem, with reports of children missing events, not fully engaging in school, or feeling self-conscious in public places. However, it was difficult to establish the full extent of how the skin condition had influenced the child's development, as parents reported in most cases, the skin condition had been present since birth, or developed during infancy, which made separating the child's experience of their condition and their innate personality traits difficult.

Although, there were reports in some cases of children being resilient and several families appeared to be coping well. Parents and children both described how the psychological impact of the skin condition had lessened with the child growing older and taking more responsibility for treating their skin, which supports previous research suggesting that parents of children with skin conditions requiring more treatment could result in greater psychological distress (Mitchell et al., 2015). The reports of parents finding their child's condition harder to manage psychologically when they were younger and less able to communicate the extent of the problem and take control of treatment was evidenced by parent and child quality of life scores (FDLQI/CDLQI) which were most frequently scored as 'low' to 'moderate'. The lessened psychological impact with age could suggest the

importance of earlier intervention with children from a younger age (for example, <8-11 years). However, although parents acknowledged in many cases the child's skin had improved, concerns were raised regarding their child progressing through adolescence and puberty (De Vere Hunt et al., 2020; Cheung & Lee, 2012).

Of the 23 participants interviewed, only one dyad was offered a psychological intervention in the form of structured counselling. Another dyad had brief contact with a clinical psychologist associated with a special care baby unit, but it was not relevant to their child's skin condition. The remaining nine dyads similarly described a lack of psychological support for their child and themselves in managing the skin condition, supporting findings from the APPGS (2020). Parents expressed a desire for a more holistic approach in current dermatological care, to integrate the psychological assessment into the treatment pathway. In addition, the desire for more psychological support was further highlighted by several parents describing how being interviewed for the current study was the closest form of support they had experienced. Importantly, this was the first study to our knowledge, to investigate the relevance of offering parents and children a mindfulness-based intervention. Some children had a pre-existing understanding of mindfulness concepts and a familiarity with the approach from practicing exercises such as 'cosmic yoga', 'square breathing', and mindful colouring in school, as classroom-based activities. Besides mindfulness in an educational setting, children appeared to be practicing kindness to themselves with positive affirmations, reminding themselves to embrace their difference and that they are the same as everyone else. By reciting rehearsed statements, children were actively building self-compassion, a facet of mindfulness, which has been found to improve symptoms of skin conditions in adults (Sherman et al., 2019).

The successful use of self-compassionate techniques is supportive of previous literature suggesting that the approach could have a buffering influence on negative affect, improve psychological wellbeing, and could limit self-objectification (Neff, 2003; Neff, 2007; Tiggeman & McGill, 2004; Clark & Tiggeman, 2007; Tiggeman & Slater, 2015; Calogero, 2012). The reports of children living well with their skin condition, could also be explained with the mindfulness facet of acceptance, from themselves and peers, reducing reactivity to negative affect (Lindsay & Creswell,

2017). Thus, many children may have adjusted well to their skin condition, from building resilience and reducing feelings of worry about their appearance (Neff, 2003; Neff, 2007; Montgomery et al., 2016; Russell et al., 2019; Maddock et al., 2020a; Maddock et al., 2020b). Unexpectedly, some children appeared to be practicing naturalistically strategies overlapping with mindfulness concepts such as positive affirmations building self-compassion, a facet of mindfulness that has been found to reduce shame and improve quality of life in adults with skin conditions (Muftin et al., 2022). For example, one child with eczema described using a technique to mentally shift their energy around their body, away from itch, which is a concept practiced in the mindful 'body scan' (Analayo, 2020).

Nearly all children described an awareness of how the intensity of itch increased when they thought about their skin condition and the feelings in their body, which became more prominent and caused them to worry (Montgomery & Thompson, 2018). This cycle could potentially be targeted with mindfulness, as previous research into itch, and worry about itch in patients with AD has suggested a relationship between the mindfulness facet "acting with awareness" and itch catastrophizing (Lüßmann et al., 2021). A mindful approach to itch could involve noticing the itch and the related impulses (e.g., to scratch the itch), but not to act on the 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 AD/eczema with audio-visual distraction techniques (Leibovici et al., 2009). Thus, adopting a mindfulness approach and acting with more awareness to body sensations could reduce reactivity in terms of automatic scratching as a response to itch (Lüßmann et al., 2021). Similarly, parents described the benefits of using controlled breathing techniques, taking time for themselves with activities such as walking, being outdoors, having a bath, yoga, running, and catching up with friends, to lessen stress levels and have some time away from caring duties. Indeed, strategies based on positive psychology for the self-management of emotions, such as hope and gratitude have been found to

correlate significantly with depression in parents of children with developmental disorders (Martin et al., 2019).

The findings suggest that a mindfulness-based resource would likely be useful and well-accepted for children with skin conditions and their parents, and there was no mention of any concerns at trying the technique, although potential barriers to participation were highlighted, such as length of time commitments, and format of delivery. As such, there was a plethora of useful suggestions for the design of an intervention. Parents expressed how there would be challenges in committing to an intense and time consuming intervention on top of their daily routines of care, and felt exercises should be of a length that could fit into their busy daily schedules and the family's 'routine' of treatment. Having to make time for a substantial daily activity could be unachievable for many carers, when combined with their existing treatment-related responsibilities, domestic duties, and other life commitments. Similarly, the merits of having short mindfulness exercises that can grab the attention of the child quickly and keep them engaged and focused on the activities was mentioned.

Parents described accessibility as a potential barrier, and there was a need for exercises to be easily available when needed, in times of distress or intense itch, and allowing the child to have control and access to the resource independently. Parents felt this could be solved by having an on-demand resource with online delivery. There was an expression of the benefits of an intervention being presented with an online format supporting previous research findings (Ilfie & Thompson, 2019; Heapy et al., 2020), and parents and children jointly reporting the usefulness of screens and technology for distracting themselves away from physical symptoms. Along with a preference for an online intervention, parents described the desire to connect with other parents and children with skin conditions. There were reports of some parents feeling isolated from providing care to their child, and not knowing anyone else experiencing the same concerns. Thus, having an opportunity to build a support network with other carers, and children, was described as necessary.

The relevance of having an intervention that targets the associated stresses of living with a skin condition was deemed as necessary. Both parents and children responded favourably to the idea of participating in dyadic exercises and felt that

spending time with their child in a constructive way would bring a positive dimension to their relationship, besides from having treatment-orientated communications (Ring & Palos, 1986, in Al Shobaili, 2010). Parents engaging together with their children in mindfulness could also have a positive influence on reducing levels of parental over-reactivity, which has been previously suggested as having a negative impact on parental mental health, and fuelling conflict, and was described in this study as arising from parents and children having opposing views on treatment application (Morgan et al., 2002, in Emerson et al., 2019; Lippold et al., 2021; Bögels et al., 2013; Bögels & Restifo, 2014).

Although some children provided useful insights of how mindfulness could effectively be used to manage their skin condition (e.g., with an 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 (Kelly, 2022; Luberto et al., 2020). It was difficult in the present study to ascertain the overall understanding of the concept of mindfulness, and future studies are needed to investigate this issue further.

### **3.4.1. Limitations**

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 transferability to other conditions might be limited. Further, the diversity of the sample also limits transferability, and there was a significant underrepresentation of fathers in our study, which was also focused entirely with a British sample. This could be a result of mothers commonly being the primary caregivers of children with skin conditions and experiencing a greater impact to quality of life, as suggested in previous research (Marciniak et al., 2017; Gieler et al., 2017; van Scheppingen et al., 2008).

Therefore, the conclusions drawn about mindfulness may not be shared across groups and cultures. Although the interview questions were asked in an open way

regarding needs for future psychological support, asking specifically for views on 'mindfulness' may have led to some demand characteristics and reduced the likelihood of negative views about this specific approach being elicited. There is a need to purposively sample participants to ensure research is inclusive of fathers and people from a wider range of ethnic backgrounds. Our findings also demonstrate the potential for misconceptions about mindfulness based interventions (Monteiro et al., 2015) that should be considered when planning service delivery.

### **3.4.2. Recommendations for future research**

Future research should investigate the effectiveness of mindfulness for children with skin conditions and their families, with a larger sample size, and a targeted recruitment strategy to reach a more diverse sample of ethnicities and carer dynamics. For example, eleven out of the twelve carers interviewed in this study were mothers, with only one father participating in the dyadic discussions, and the majority of mothers identifying themselves as the primary carer for their child. Although this supports previous research suggesting that providing care for childhood skin conditions may have a greater impact on mothers' quality of life (Marciniak et al., 2017; van Scheppingen et al., 2008), it would be interesting for further research to explicitly target a more diverse sample of families and fathers, to investigate the role of carers within each unit.

As a result of the understudied area of children with skin conditions, more research is needed to examine the long term impact of childhood skin conditions on the development of children later in life (e.g., with cohort or longitudinal studies). This study has found a need for psychological interventions that might specifically target parental stress. Importantly, the current research study has highlighted that a mindfulness-based intervention could be well-received by parents and children, and an online resource could improve psychological wellbeing.

Future research should aim to investigate the effectiveness of piloting a mindfulness-based intervention for children with skin conditions and their parents, to determine if the approach might hold promise as hoped by participant narratives. A full range of intervention development designs should be utilised to build and test



mindfulness (MRC; Skivington et al., 2021). For example, it would be useful to collect further expert opinion as to what is needed from other key stakeholders such as healthcare professionals. In addition, pilot testing recently developed forms of mindfulness based interventions using methods that enable assessment of change in nuanced forms of parental stress are needed. The present study has shown that the challenges experienced by families could be unique to each parent and their child's age/diagnosis, and could warrant idiographic measurement of stress in future studies.

### **3.4.3. Conclusion**

Overall, the study findings suggest that childhood skin conditions can have a negative impact to both children and their carers' mood, schooling, sleep, and can present daily challenges from managing negative reactions from other people, and demanding treatment routines. There is a lack of psychological support available for children with skin conditions, which needs to be addressed in the dermatological care pathway. Herein, a mindfulness-based support intervention may be well-accepted, as children in this study frequently engaged in mindful techniques in school and described adopting a mindfulness mindset in everyday life to reduce stress and manage itch. Suggestions were made for future psychological support resources, including exercises of a suitable length to fit in with daily routines, an online delivery, and connecting with other parents and children. Chapter 4 picks up on these needs in further detail by reporting an investigation of healthcare professionals' views on psychological support for families affected by skin conditions.

## Chapter 4

# Healthcare Professionals' Views on Psychological Support for Children and Families Affected by Skin Conditions: A Qualitative Study

### 4.1. Introduction

It is not only parents and families of children with skin conditions who should be involved in delivering a psychological intervention. Healthcare professionals are likely to be central to the process of ensuring an intervention meets target user needs and is effective for promoting behavioural change (Thompson, 2009; 2014). Healthcare professionals (HCPs) working with target users may be able to provide insights into the patient experience and presentation from their expertise of working with patients, shed light on what might be most useful by way of support, and highlight protocol problems or foreseen barriers to adherence (Lyon & Koerner, 2016). These professional insights could be essential for ensuring a psychological intervention is sustainable, cost effective, and relevant (Lyon & Koerner, 2016), and particularly important for ensuring content is appropriate (Norris et al., 2021).

Stakeholder input to the design of health interventions has been promoted in the PBA (Morrison et al., 2018) for the development of interventions for conditions such as eczema (Santer et al., 2014), diabetes (Muller et al., 2017) and asthma (Bruton et al., 2018) with patient and public involvement (PPI) via stakeholder panels of experts to contribute during all stages, and to offer feedback to researchers and co-designers. The approach of recruiting experts from relevant fields into the research process and assisting with the co-design of interventions has been used previously for a range of different resources, and is commensurate with the broader MRC intervention development cycle (Skivington et al., 2021). Examples of where co-design with experts has been used includes designing a self-compassion intervention for family carers of dementia patients (Murfield et al., 2022), the exploration of optimal characteristics for health-based websites (Schneider et al.,

2012), developing school-based interventions for mental health and inclusion (Lyon et al., 2014; Maciver et al., 2021), and designing an intervention for people with excessive alcohol consumption (Heather et al., 2004).

Professional involvement in co-design can have various aims from increasing engagement to traditional expert review, including intervention fidelity checks, review of need and consensus on treatment, and co-design/involvement focussed on intervention development that will be targeted at health professionals, or be delivered by them. By including professional stakeholders in research, important factors that could influence the feasibility of a resource can be identified, such as expert's previous experience of having a qualified facilitator deliver an intervention to manage relationships between participants when group sessions are used, and the need for a trained mental health professional to be involved in delivery (Murfield et al., 2022).

Incorporating expert HCP views into the planning of interventions could be particularly relevant in dermatology practice because research has indicated that dermatologists' and health professionals' own beliefs could impact how they approach patient care (Hewitt et al., 2022; Nelson et al., 2013; Nelson et al., 2014). Dermatologists provide specialist treatments for skin conditions. Including these HCPs will allow for the collection of data on how children are routinely cared for, how skin conditions could affect children during their transition into adulthood, and what this might mean for treatment and support, to enhance delivery and implementation.

Importantly, Chapter 3 of this thesis has highlighted the challenges faced by parents and children from their first-hand accounts of living with a skin condition. Findings from the previous study suggest that families encounter significant daily challenges in providing care for a child for a skin condition, and would likely require an intervention that is easily accessible, online, and the opportunity to connect with other parents/children experiencing similar health concerns (Hughes et al., 2022). Families appeared to be receptive to the suggestion of engaging in mindfulness-based activities, and this could be usefully further explored with input from clinicians. Parents also described the additional stresses arising from seeking support from healthcare professionals, and the difficulties of getting an accurate diagnosis for their children (Hughes et al., 2022). Therefore, gathering data from dermatologists about their experiences of treating children with skin conditions could mitigate the effects of

personal biases (Chisholm et al., 2016) on the delivery of an intervention and/or the management of a skin condition. For example, findings from a qualitative online survey by Wheeler et al. (2021) of UK individuals living with skin conditions showed that respondents felt that their needs and issues were not fully understood by other people, including their HCPs. It was also reported there was a lack of psychological support available, and there was a need to develop appropriate services and awareness in HCPs of the psychological burden of skin conditions (Wheeler et al., 2021). This gap in care has been suggested by Blackstone et al. (2022) as partly due to a lack of awareness of the limited available services for people with skin conditions, combined with challenges of 'early-identification'. Potentially contributing to the lack of recognition could be how people with skin conditions often trivialise their symptoms as 'non-life limiting' or not 'severe' enough to seek medical assistance (Blackstone et al., 2022). It is for these reasons that HCPs may need more specialist training, resources and support to evaluate the impact skin conditions are having on a person's psychological wellbeing (Blackstone et al. 2022).

Herein, it is the role of a practitioner psychologist to provide expert mental health support for individuals, and consulting these HCPs alongside dermatologists could highlight gaps in service provision, current psychological approaches, and enhance understanding of what is needed to deliver a sustainable healthcare intervention. Importantly, the inclusion of expert psychologists with experience working with children and families affected by skin conditions could yield valuable feedback on how their mental health is managed, to increase understanding of what is important to prioritise. Thus far, only a small number of book chapters exist that describe some of the work of such psychologists (Titman, 2005) and there is a need to gather psychologists' insights into running psychological interventions, as this will provide valuable information about the feasibility and acceptability of interventions. There are a range of therapeutic approaches that could be usefully applied to children with skin conditions, including mindfulness, but further research is needed in order to determine acceptability (Hughes et al., 2022). It is also important to consider geographical factors because healthcare delivery and funding differs within and between countries.

### **4.1.1. The current study aims**

The findings of this chapter will be considered in relation to the conclusions of Chapters 2 and 3 (Hughes et al., 2022; 2023) to determine if mindfulness could be a feasible or desirable intervention for families affected by skin conditions. We had two aims. First, we investigated the experience of most relevant HCPs (dermatologists, dermatology nurses, liaison psychiatrists, practitioner psychologists, and primary care psychological workers) in the NHS in addressing the psychological needs of children with skin conditions and those of their families (e.g., identify HCPs experience of seeing psychological and social issues associated with childhood skin disease, identify how such issues are identified by HCPs in routine practice, and identify the statutory/non-statutory interventions and service pathways utilised by HCPs). Our second aim was to gain expert opinion on the relevance of offering specific forms of psychological intervention (e.g., systemic interventions, cognitive behavioural therapy [CBT], and MBIs).

## **4.2. Method**

### **4.2.1. Design**

This study was approved by Cardiff University School of Psychology Research Ethics Committee (EC.22.09.20.6617R) (Appendix B.2.). This study was a qualitative investigation using semi-structured interviews to produce novel insights in the form of in-depth reports from individual healthcare professionals' perspectives experiences of working clinically with children affected by skin conditions, and their parents.

### 4.2.2. Participants

Fifteen HCPs took part in semi-structured interviews (see Table 1 for participant characteristics). The sample was sufficient for thematic analysis (Braun & Clarke, 2013) in successfully achieving data saturation (Saunders et al., 2018; O'Reilly & Parker, 2013; Vasileiou et al., 2018). The relevance of data to answering the research question was regularly assessed by the research team with frequent appraisals of information power (Malterud et al., 2016). Unlike quantitative research relying on statistical power analysis' to pre-determine sample size requirements, qualitative inquiry typically uses smaller samples to gather cases likely to provide sufficient detail relevant to the research question (Vasileiou et al., 2018). Thus, recruitment ended with consensus between researchers that enough information has been gathered to suitably address the research questions (Malterud et al., 2016).

**Table 4.1.** Participant characteristics (n=15).

Characteristic	Number
Gender	
Female	11
Male	4
Job role	
Dermatologist	4
Dermatology nurse consultant/specialist	4
Clinical psychologist	4
Liaison psychiatrist	2
Children's psychological wellbeing practitioner	1
Age (years)	
30-40	5
40-50	2
50-60	6
60-70	2
Ethnicity	
White British	11
White British German	1
White German	1
Indian	1
White Irish	1
Geographic location	
England, UK	13
Wales, UK	2

### **4.2.3. Recruitment**

HCPs were recruited with an online advertisement (see Appendix D.1.), shared on social media. The advert asked for HCPs such as psychologists and dermatology professionals if they would like to take part in a study investigating their experiences working with children and families, and their opinion on psychological support. HCPs responded by email to the researcher, and known experts in the field were directly approached (see Appendix D.2. for research participation invitation).

Upon email to the researcher, HCPs were sent a study information sheet explaining eligibility criteria and the research process (see Appendix D.3. for information sheet) and a consent form (see Appendix D.4. for consent form). Participants completed the consent form and returned it to the researcher via email, prior to the interview. The researcher agreed a convenient date and time for interview with the participant and sent them a Cardiff University Zoom link (Zoom Video Communications Inc., 2023). Out of the fifteen HCPs that took part, n=1 participant responded to the online advert, and n=14 were recruited via email invitations.

### **4.2.4. Inclusion criteria**

To be included in this study, participants were required to be healthcare professionals (e.g., practitioner psychologists, liaison psychiatrists, dermatologists, specialist dermatology nurses) with experience of working clinically with children affected by skin conditions, practicing in the UK, over 18 years of age, and an English speaker.

### **4.2.5. Expert-by-experience involvement**

In line with the consultative approach to expert-by-experience involvement adopted in this thesis (Faulkner, 2012), the study design was informed by one of the Cardiff University research supervisors with a dual role of supervisor and expert-by-experience as a practicing clinical and health psychologist working with families affected by skin conditions. This included piloting interview questions to ensure they were comprehensive.

#### 4.2.6. Semi-structured interviews

In this study, individual interviews were chosen as an appropriate method of gathering in-depth data from HCPs as a result of the target group of participants being expert clinicians with specific experience in paediatric psychology/dermatology. As such, the number of clinicians working in the field of psychodermatology is small in comparison to other medical specialities, especially when considering the lack of provision of psychological support. For these reasons, it was decided by the research team that alternative interview methods (e.g., focus groups) were not suitable. For example, although group interviews could have provided useful data in terms of promoting constructive discussions, clinicians were likely to know of each other/have working relationships, which could have influenced how HCPs portrayed their own services.

Interviews lasted approximately one hour and were held online (via Zoom; Zoom Video Communications Inc., 2023). Holding the interviews remotely allowed the researcher to collect a range of insights from HCPs based in different locations across the UK. Demographic information was collected at the beginning of the interview to initiate the discussion (see Appendix D.5). After background information was gathered, the researcher began the interview. A flexible interview schedule was developed to cover key areas of interest, and divided into topic areas (see Table 2 for example questions) (see Appendix D.6. for full schedule). To clarify that HCPs shared the same definition of mindfulness, the researcher included a preamble to provide a definition and overview of the approach (see Chapter 1), before asking questions about how relevant mindfulness may be for children with skin conditions.

At the end of every interview, each HCP was appropriately debriefed (see Appendix D.7.), and the discussions were later transcribed by the researcher from listening to the audio recordings.

**Table 4.2:** Example interview questions.

Question
<ul style="list-style-type: none"><li>• Could you tell me about the psychological issues associated with having a skin condition that you see in children?</li></ul>



- 
- What are the implications for parent/carers and families of children with skin conditions?
  - Can you tell me about the psychological services that you are aware of for children and families?
  - What are your thoughts on offering a mindfulness-based intervention involving exercises such as slow breathing, meditation, or focussing attention on one thing in the mind, to children with skin conditions and their families?
  - What do you think are the issues surrounding current available support options for children with skin conditions and their families?
- 

#### **4.2.7. Ethical considerations**

To uphold confidentiality, HCPs were asked to anonymise all clinical case examples of patients they spoke about during the interviews. It was agreed that in the event of a disclosure of unprofessional practice or a safeguarding concern, the supervisors would to be notified immediately, and would decide how to respond with by notifying the appropriate authorities (e.g., the General Medical Council, the Nursing and Midwifery Council, or local safeguarding services).

#### **4.2.8. Thematic analysis**

Thematic analysis was conducted on all transcribed sets of data (Braun & Clarke, 2006; 2013; 2021). Using NVivo 12 (released March 2018). A dual deductive-inductive approach was adopted (Joffe, 2012), with consideration of existing evidence for the lack of psychological services (e.g., APPGS, 2020) whilst remaining open to novel insights of HCPs personal experiences of providing care. To begin data analysis, transcripts were uploaded into NVivo (NVivo 12; released March 2018) and read individually.

The transcripts were then annotated, and key phrases were highlighted and grouped. This was followed by a systematic coding across all transcripts, with common themes collectively labelled. Once the themes were labelled and grouped into main themes and subthemes, they were cross-referenced with the raw data, to ensure rigour and accuracy of interpretation (see Appendix D.8. for evidence of NVivo analysis, NVivo 12; released March 2018).

#### **4.2.9. Quality control process**

My personal experiences of receiving care from HCPs were similar to those reported in this Chapter. For example, HCPs explained how children were more likely to have adverse educational outcomes, less esteemed jobs, and poorer social relationships from the impact of skin disease, which was challenging to listen to as someone whose education was interrupted by psoriasis. It was equally difficult to hear dermatologists discuss harmful side effects of treatments, as these are worries I encountered. To limit bias in interpretation, I remained considerate of their experiences, I did not disclose my experience, and I carried out frequent comparisons with the raw dataset to corroborate meanings.

In addition, a member validation process was carried out to enhance trustworthiness of data (Nowell et al., 2017). This involved participants having the opportunity to review their excerpts to check and corroborate meanings accurately reflected the discussions had during the interviews (see Appendix D.9. for member checking form). Out of the fifteen participants, three HCPs made minor revisions to their interview quotes (including rephrasing single sentences). Although I had already anonymised the data, this gave participants the chance to correct any misinterpretations. This process was appropriate with consideration of the small group of expert clinicians working in the field of psychodermatology in the UK, as it allowed participants the chance to remove any features they felt might still be identifiable. Indeed, the researchers did not apply this process to Study 1 (Chapter 3) or Study 3 (Chapter 5) as a result of participant characteristics (i.e., the high prevalence of childhood skin conditions) having an influence on sample specificity (i.e., smaller cohort of clinicians to recruit from).

#### **4.3. Results**

Thematic analysis led to the development of four themes and ten subthemes (see Table 4.3). These themes are discussed with supporting quotes from participant interviews (job role; interview number, page number, line numbers).

**Table 4.3:** Main themes and subthemes.

Main Theme	Subtheme
1. Psychological impact of skin conditions	1.1. Implications for children and adolescents 1.2. Shared burden for parents and the family unit 1.3. Dynamics between parent and child
2. Identifying distress in families	2.1. Initial assessment and approach to treatment 2.2. Standardised measures vs. questions
3. Level of support provision	3.1. Current available psychological therapies 3.2. Lack of access to specialist services 3.3. Healthcare professional recommendations for improving care
4. Relevance of a mindfulness-based intervention	4.1. Potential benefits of mindfulness 4.2. Barriers to engagement in mindfulness

### **Theme 1: Psychological impact of skin conditions**

From working clinically with children, HCPs discussed the wide-ranging impact of skin conditions on the psychological wellbeing of children and their families, including how all aspects of their daily lives and development can be affected.

#### **1.1. Implications for children and adolescents**

The psychological burden of childhood skin conditions can be profound, as the “skin and mind are intimately connected” (dermatologist; interview 10: 2, 33). HCPs described how skin conditions have “huge impacts on the wellbeing, the long-term effects of young people’s ability to integrate, socialize, to be motivated, and every aspect of life” as “it’s not only skin, it’s more than skin deep” (dermatology nurse consultant/specialist; interview 1: 10, 238-240).

This included disruptions to schooling and socialisation from a lack of sleep and pain, and ultimately, “academically, these children will not do as well” (dermatology nurse consultant/specialist; interview 8: 5, 104):

Teenagers that won’t leave the house because of how they look, not going to school, some that won’t even socialize with family or won’t even come out of their bedrooms (dermatology nurse consultant/specialist; interview 1: 14, 325-327).

I see children who have never learned to swim...because their skin has been too sore, or they're too embarrassed...and what's happened in the past just piles on into the future and their life choices become limited...you can almost map what's going to happen to them, they're going to have poor social relationships, they're going to have poor education...and I'm looking at them at five years old thinking there's all that bad in front of them (dermatology nurse consultant/specialist; interview 7: 13, 306-315).

Many HCPs felt the psychological burden of living with a skin condition was exacerbated as “it’s a really crucial age as adolescence you’re going through a period of immense changes with your identity and the way your brain changes, and you’re hardwired to be super sensitive to peer judgement and you want to fit in” (clinical psychologist; interview 4: 2, 40-42):

You have this image of perfection on social media and that's what children want to look like...they're not having that, and they feel insecure, their self-esteem goes down, they're tearful, they're moody, they get depressed (dermatology nurse consultant/specialist; interview 8: 2, 33-36).

These experiences were reported to have a significant impact on psychological wellbeing, and could be distressing for a child who feels ‘different’, as “we know that that many young people struggle with mental health without adding a stigmatized skin condition into it” (dermatologist; interview 10: 3, 54-55).

In many cases, HCPs described how they had seen clinical levels of distress in young patients, and felt “the common factors are things like anxiety, depression, suicidal ideation, self-esteem” (dermatologist; interview 5: 2, 39-40), and self-harm:

The acne patients, I’ve had quite a few who from a psychological point of view, their acne has caused massive problems with their mood, suicidal thoughts, and self-harming, just because they don’t want to look the way that they look (dermatology nurse consultant/specialist; interview 3: 10, 235-238).

However, the psychological impact was not always related to severity. Interviewees described the relationship between the level of distress and clinical rating of the skin condition as complex, and not always associated. The data

revealed both the complexity of this in relation to psychological distress, the range of opinion, and continuing lack of clarity:

The skin condition has such an impact, and it doesn't match on to what you might objectively see, some of the people might have what is medically considered a mild skin condition, but their experience can be very profound (clinical psychologist; interview 14: 8, 192-194).

HCPs reported there was often a clear link between the experience of stress leading to the “propagation or to the exacerbation” (dermatologist; interview 5: 10, 226) of skin condition symptoms:

Children describe a really clear link between their emotional state and itch scratch cycles...it becomes more difficult to manage on a day when they're feeling anxious or stressed (clinical psychologist; interview 13: 3, 50-53).

Another HCP described the relationship between skin conditions and systemic inflammation, and how “we're still trying to understand the links between skin inflammation, itching, sleep disturbance and potential brain inflammation...some of the anxiety and the depression is potentially driven by that systemic, inflammatory process that might be happening in the in the brain, but we don't obviously know that for sure” (dermatologist; interview 9: 2, 47-50):

They can't concentrate...it causes chemical release of various cytokines that have been linked to systemic inflammation...an organic process is started because you have the direct link between the neurons that are harmful, and the sensory nerves that proliferate in the skin, and that's a direct link to the brain...it's not only that you might have cutaneous inflammation that spills over into systemic inflammation that you can measure in the blood, but you've got the direct, sensory input through the sensory nerves from the periphery, to the spinal cord, and then into the brain (dermatologist; interview 9: 3, 55-61).

## **1.2. Shared burden for parents and the family unit**

HCPs described how the burden of living with a childhood skin condition was shared by a child's family, and “impact on mum and dad and siblings” (dermatology

nurse consultant/specialist; interview 8: 2, 36-37). The impact on the family unit included a disruption to patterns of rest, and significant sleep loss:

We've seen parents who've had to change their job because of the impact of not being able to sleep properly themselves, and the demands that the toddler is placing on them (dermatologist; interview 2: 2, 48-49).

From working with families, HCPs described noticing how the condition "runs their life" and "everything has got to be planned around their treatments" (dermatology nurse consultant/specialist; interview 3: 4, 90-91). In many cases, HCPs felt that for parents providing care for a child with a skin condition, the additional burden of managing treatment, "can lead to mood disturbances and affective disorders in other members of the family" (dermatologist; interview 5: 4, 80):

Parents can feel mostly they want to help, and mostly they want to make things better, they can feel quite guilty sometimes...if it's an inherited condition (dermatologist; interview 10: 6, 124-125).

Worry about fragility of the baby around damaging their skin and hurting them or causing pain...when a young person says 'no, I don't want it' or 'no, it hurts', it's really challenging for parents to hold in their mind that the child needs the treatment (clinical psychologist; interview 14: 3, 73-76).

This included worries surrounding treatment and the associated side effects:

The parental concern is really, really heightened, and that's partly because we know all the side effects of steroids and isotretinoin... (dermatology nurse consultant/specialist; interview 7: 4, 74-76).

This included a feeling of sadness from having an unwell child:

Parents often just feel really sad that their child has this skin condition and that it's having a negative impact on them...there's maybe a bit of a process of grieving what they hoped life might be like for their child, and coming to terms with some of the ways that that might look different (clinical psychologist; interview 13: 3, 71-75).

However, it was not only parents who shared the burden of the skin condition, as HCPs described that siblings might also be impacted by having an unwell family member:

Siblings may be affected if a lot of parental attention is needed and spent with creaming, bathing, oiling, hospital appointments and special skin care. Siblings may feel like losing out on parental 1:1 time and seek it directly or indirectly, presenting with demands on parents, sometimes with aches and pains and possible psychosomatic complaints (liaison psychiatrist; interview 15: 4, 84-87).

### **1.5. Dynamics between parent and child**

The stresses associated with caring for a skin condition was described by HCPs as having the potential to result in “all sorts of consequences including family dysfunction or even breakdown of families, in parents, or within a relationship between parents and children” (dermatologist; interview 5: 4, 76-78):

You've got relationship breakdowns because there may be differences in what the mum and dad think, you've got the sibling joining in because they're not getting any attention...that kind of arguments carrying on (dermatology nurse consultant/specialist; interview 8: 4, 97-100).

Indeed, treating the skin condition can add to the pressures of care. One HCP described how “the skin care regime can cause a lot of ruptures in family life and the disruption is partially due to the pain or inconvenience or challenge associated with the treatment” (clinical psychologist; interview 14: 2, 40-42) and gave an example of how a parent and child dyad had been negatively affected:

A young person had a daily skin treatment regime that needed to be completed by the parent...there had been shouting and arguing and they ended up living a split life, where during the day they had this great relationship, and then at the point of treatment, they just completely fell apart and were two people causing each other extreme distress...the young person had become more violent towards their sibling, and it had led to a breakdown in the family (clinical psychologist; interview 14: 13, 306-313).

HCPs highlighted the importance of the attitude of parents to their children's skin conditions, as it's "not just about the child and their skin, it's about the family that's around them" (clinical psychologist; interview 12: 6, 142-143). HCPs felt the way in which parents respond to their children's condition can determine how a child adapts and copes:

Parents who've been much more bothered about the alopecia or the vitiligo than young person...allowing them to be okay is something that's really important for parents to be able to do, and not feel that they're somehow substandard because they've got a skin condition (dermatologist; interview 10: 6, 133-136).

Where the parents are very supportive and they talk very openly about skin conditions, that it's just another thing, it's not a big deal, those children are much more malleable (clinical psychologist; interview 12: 2, 46-47).

Asides from conflict, HCPs discussed noticing skewed parental boundaries and the development of "very complex parental relationships" (dermatologist; interview 10: 7, 152-153):

Dysfunctional family relationships...it's difficult to disentangle what's driving what, but there are very odd behavioral patterns that have evolved over the years...because one or several children in a family have got severe eczema and parents co-sleep (dermatologist; interview 9: 2, 36-39).

HCPs described how in the cases of hereditary skin disease, having a parent with the same condition could be helpful and also unhelpful:

Some of the parents have the same skin condition...it can be helpful where they can empathize with the challenges, but less helpful if they feel like "well, I'm able to deal with it why can't you?" (clinical psychologist; interview 14: 4, 81-83).

HCPs felt that the parent's stress levels could have potential to impact on the severity of the child's skin condition, as in cases where the "parents are very stressed by the skin condition, that comes out in the children and the whole thing becomes a bit of an entanglement" (clinical psychologist; interview 12: 3, 53-54):



When a parent is stressed...it causes a flare up in the child's skin condition, and we know that there's a direct biological link between the skin and stress, and it happens both ways, when the skin has flared, that causes stress with the child, and the parent (clinical psychologist; interview 12: 5, 112-114).

In one example, a psychologist described working with a child whose skin was directly affected by the stresses experienced by the family unit. This phenomenon was speculated to have happened "in terms of transference...as the child was impacted so much by the parent behaviour, that they would then feel very stressed when the parent was stressed, and it had a knock-on effect" (clinical psychologist; interview 12: 5, 117-119):

[The child] had eczema and her skin would flare up, it was as if she was experiencing stress, and it was an indirect stress...the child didn't feel the stress first, the parent felt the stress first, and then it went on to the child, and she felt stressed because she could see her parents were feeling stressed...then it came out in her skin condition (clinical psychologist; interview 12: 6, 130-133).

Of note, one dermatologist felt that parents could be overlooked when treating their child's skin condition:

We don't ask the parents enough about 'what do you do to cope with your child's eczema?', 'What do you do to look after yourself?' We tend to focus on the child (dermatologist; interview 9: 8, 176-177).

## **Theme 2: Identifying distress in families**

HCPs described how they would identify psychological distress in children and their parents during consultations.

### **1.1. Initial assessment and approach to treatment**

HCPs reported what they look for in terms of body language and signs of psychological distress, and how they would manage a child that required input from specialist services. HCPs reported the importance of beginning treatment by validating their mental health concerns. This involved acknowledging the

psychological challenges, and to “not hide away from it, because it's very difficult as a professional sometimes to go down this road” (dermatology nurse consultant/specialist; interview 8: 7, 149-150):

Parents report they get comments like, ‘well, at least it's not life threatening’, and I think that that has a very dismissive impact so there’s something about offering a psychological intervention that says, ‘no, hang on, it sounds like it is having an impact, let's think about that (clinical psychologist; interview 14: 9, 202-206).

Indeed, risk assessment is critical in dermatological practice and there may be a certain amount of reluctance from many clinicians, potentially a result of a lack of confidence to address mental health. HCPs described seeing the need for open discussions and sought to do this with all patients:

You have to be frank, if you're talking about suicide, you use the suicide word, if you feel a child or adolescent is at risk of suicide, then you go more into the conversation of “are you a stage where you are going to go home tonight and commit suicide?” You have to be really honest with them, you can't cover up the cracks (dermatology nurse consultant/specialist; interview 8: 8, 133-136).

In acknowledging the mental health challenges for many children and their families, HCPs described the need to manage expectations surrounding treatment outcomes, as “we can confirm a diagnosis, we can explain what’s going on, and we can try and be positive about the prognosis...but beyond that there’s not much we can do” (dermatologist; interview 2: 13, 311-313):

Honesty that we have lots of good treatments...but also that acceptance and helping children and young people to realize they're brilliant with or without a skin condition (dermatologist; interview 10: 13, 308-311).

HCPs noted there were several signs in terms of body language they often relied on to determine the level of psychological distress:

The way they're sitting, the way they're acting, the way they're behaving...but sometimes the clues are more subtle, things like they're behind in their milestones (dermatology nurse consultant/specialist; interview 7: 8, 186-189).

HCPs described how they would approach a treatment plan, for children who were experiencing psychological distress and could benefit from an intervention:

For severe depression with suicidal ideation, there's a need to start antidepressants, and then getting direct input from our adolescent psychiatrist (dermatologist; interview 9: 11, 253-254).

We would look at whether low mood is the main result or whether it's anxiety based, and then we'd offer the intervention that's relevant or a mixture of both, we often find that the children with anxiety have got low mood as well, because they're withdrawing from everything (children's psychological wellbeing practitioner; interview 11: 9, 202-205).

HCPs discussed the benefits of involving the parents when deciding treatments and having a family-focused approach to care:

That can be quite powerful if everybody is on the same page and working together, but again it really depends on the dynamics (dermatology nurse consultant/specialist; interview 1: 14, 333-334).

[Family] communication can be quite shut down, especially when there's a daily treatment...the inclination is it's just so difficult that once it's over, just to push it away until they have to do it again, so there's kind of relentless cycle where they go from one day to the next...just having space as a whole family to just sit and look at that together with someone else can offer a lot (clinical psychologist; interview 14: 14, 349-353).

However, HCPs highlighted the importance of seeing the child separately from their parents to assess their behaviour independently and identify if there are any unhealthy relationship dynamics:

I tend to see the child separately from the parents or guardian and then see the guardian separately from the child and then see them all together, so I try and pick up on any concerns (dermatologist; interview 5: 5, 104-106).

## 1.2. Standardised measures vs. questions

As recommended by NICE (2017) guidelines, clinicians are encouraged to use a validated measure of quality of life to assess the psychological impact of a skin condition on a patient. However, most of the HCPs described the importance of asking direct questions during consultations alongside the questionnaires, to open a conversation about mental health and coping.

Several different psychometric measures were used by HCPs (e.g., The Children's Dermatology Life Quality Index; CDLQI, Dermatology Life Quality Index; DLQI, The Revised Child Anxiety and Depression Scale; RCADS, The Patient Oriented Eczema Measure; POEM, The Patient-Oriented SCORing Atopic Dermatitis; PO-SCORAD, Hospital Anxiety and Depression Scale; HADS). Despite this, not all scales are appropriate for all patients, or for younger children (e.g., HADS is an adult measure) but illustrated how HCPs were using a range of assessment tools to assist with identifying psychological distress. HCPs described using the quality of life measurements and scores to open up a conversation with children and their parents:

Quality of life screening tools can be quite useful...a starting point for talking about different areas that are going well and areas that might be more difficult (clinical psychologist; interview 13: 4, 78-84).

However, several HCPs acknowledged they did not use the standardised measures as much as they felt they should during clinic:

We do the DLQI questionnaire, probably not enough actually (dermatology nurse consultant/specialist; interview 3: 5, 115).

Other HCPs described using "goal-based outcomes...to track therapeutic aims" (clinical psychologist; interview 14: 5, 117-118):

It can be quite detrimental to give a person too many questionnaires to do, and the way I look at it as 'what's your personal goal?'...and that might be to go swimming (dermatology nurse consultant/specialist; interview 8: 7, 157-159).

Many HCPs felt the quality of life measures were not always the most accurate or appropriate measures to use with children to assess levels of psychological distress, which pointed to the need for training in broader psychosocial assessment skills. They noticed there are sometimes discrepancies between the scores and how a child is coping:

I might see young teenage boys who might have relatively low impact scores of quite severe eczema, but then when we actually put them on a successful treatment, they realize how much it was impacting them, even if they weren't scoring very highly on something like a DLQI or HADS score (dermatologist; interview 10: 5, 103-106).

Indeed, HCPs felt there could be more work done to improve dermatology-specific screening tools:

Skin conditions are so varied that some of them don't work for different populations, so I think that needs more attention (clinical psychologist; interview 14: 5, 110-111).

I don't think that we're as good as we should be about the psychological impact of skin disease, we recognize it, but from a clinical or time point of view, we unfortunately don't spend enough time on it...we probably could do with more tools to identify those psychological problems (dermatology nurse consultant/specialist; interview 3: 5, 116-119).

HCPs often described preferring to assess psychological wellbeing with questioning, and directly asking children and their parents about their mental health, instead of relying on standardised measures and scores:

The best way to find out if there is distress is to ask open ended Socratic questions, so just say "how are you?" "How is the family doing?" "What impact does this have on the family?" (dermatologist; interview 5: 4, 90-91).

Through practice and the work that's being done, the consensus is that it's really about the history, there isn't a kind of scoring system that identifies distress, because people can anticipate the score low or high, it's a combination of their physical demeanour, which starts in the waiting room, what

they look like when they come in, how interactive they are, we do generally do a DLQI, but that's not a score of emotional or psychological distress, but it might give you pointers (dermatologist; interview 10: 7, 170-174).

### **Theme 3: Level of support provision**

#### **3.1. Current available psychological therapies**

When discussing psychological therapies, there were some differences between psychological staff and dermatology healthcare professionals. All psychologists discussed the specific psychotherapeutic approaches they would draw upon to target levels of distress in families, however, dermatologists all spoke of the discrepancies in severity and related psychological impact. Contrastingly, psychologists were clear in their recommendations and what approaches might be usefully applied, but dermatologists described the challenges arising from a lack of clear referral pathways.

When discussing how support would be provided to patients, in the first instance, all HCPs described the value of signposting patients to charities and informal resources to “help fill the gaps” (dermatology nurse consultant/specialist; interview 7: 11, 268):

There are patient support groups, and they're particularly helpful for certain conditions...according to diagnosis we will use all groups like the Ichthyosis Support Group (dermatologist; interview 2: 13, 306-308).

Several of the HCPs had working links with specialised services, and were able to refer patients directly to receive a psychological intervention:

For the adolescent clinic, we have open access to a psychologists (dermatologist; interview 10: 10, 246-248).

There were several different types of interventions available and being offered to children with skin conditions, including mindfulness and acceptance and commitment-based therapies:

Mindfulness is always one that you would mention, because people know about it...we did try it in another hospital and it was successful, we saw there was a

big difference in the people that used it (dermatology nurse consultant/specialist; interview 8: 15, 368-370).

I use ACT with older adolescents...where people are talking about their skin getting in the way of them being able to do the stuff that matters to them, because that is kind of really the focus of ACT, identifying what is important to you and finding ways of moving towards that, despite the challenges you're facing (clinical psychologist; interview 13: 7, 154-157).

Cognitive behavioural therapy (CBT) was used:

CBT, and the programme for low mood is behavioral activation, which is about doing more of what brings you happiness...and then the anxiety treatment is exposure work, so exposing you to the situations that you might be avoiding...and then we also do cognitive restructuring work...we would challenge those thoughts to think about different ways to think about and manage their skin condition (children's psychological wellbeing practitioner; interview 11: 9, 209-216).

However, many of the psychologists often combined different techniques according to the child's preferences and using individual formulation based interventions, as well as using other strategies such as "progressive muscle relaxation" (clinical psychologist; interview 13: 10, 240), and "Habit Reversal" (liaison psychiatrist; interview 6: 8, 175):

We might offer CBT for anxiety, or third wave approach like compassion-focused or acceptance and commitment therapy, and I have been offering some mentalization-based therapy, which has particularly been for conflict in treatment adherence, when there's been a difficulty...and the young person and parent can feel very distant from each other (clinical psychologist; interview 14: 11, 261-265).

When necessary and available, HCPs described how children aged 16 and above have a choice in whether their parents and families are included in the psychological intervention when deciding treatment:

It's good to get the parents involved, but also sometimes it's really unhelpful...when you've got a child that doesn't have a great relationship with their parents (children's psychological wellbeing practitioner; interview 11: 18, 425-429).

The outcomes of involving parents were discussed:

With cognitive behavioral therapy, where you have to do your homework and you have to track your thoughts, if the parents are really motivated and their parents are quite positively involved...I get them to kind of be a side therapist (clinical psychologist; interview 12: 11, 250-254).

It's helpful to include families in some capacity in the treatment, if not to have a whole family focus because it can locate the problem in the young person, and in the young person's skin...and the solution in the child feeling differently about it, and therefore the behaviour is better, and the family is better (clinical psychologist; interview 14: 14, 341-344).

In some cases, nurses and dermatologists themselves took an active role in supporting patient's' psychological wellbeing, and "offer parents, and the children themselves as they grow up, to be that supportive, non-judgmental friend" (dermatologist; interview 2: 6, 134-135):

We do have experienced CNS [clinical nurse specialists] in dermatology...they know a bit of basic behavioral intervention (liaison psychiatrist; interview 15: 8, 181-182).

We've had children who've expressed suicidal thoughts, and we immediately contacted the duty psychiatrist...but if someone contacts us and says they can't cope then we will see them, even if it's just at the end of clinic to sit and chat for 10 minutes, to make them realize there's still people out there who care (dermatology nurse consultant/specialist; interview 7: 16, 385-390).

However, nurses and dermatologists' recognised often felt they could benefit from more in-training in the field of psychology:



You worry about how much you miss, it's not just that we don't have the time but we don't have the skills...we pick up on subtle cues but we are probably missing a lot of important signs (dermatologist; interview 2: 13, 301-303).

Any clinician, including myself, or nursing staff, or other dermatological staff can facilitate basic, affirmative CBT in every consultation...but I think more developments would need a bit more training (dermatologist; interview 5: 10, 242-244).

I'm not a trained psychologist, so they're much better able to unlock certain things...they can get to completely different layers of people's psyche compared to what I can do in my consultation with the patient, and then feed that back to me...so I can understand that patient better (dermatologist; interview 9: 10, 226-230).

### **3.2. Lack of access to specialist services**

All HCPs described the “lack of provision” (clinical psychologist; interview 13: 11, 263) and unequal distribution of specialised psychological support services for children and families affected by skin conditions. Many HCPs noted how “there's just nothing for children with dealing with the psychological effects of their skin condition” (liaison psychiatrist; interview 6: 19, 463-464), and for many services, “it's like a postcode lottery” (clinical psychologist; interview 4: 15, 352-353):

I don't know of any specific psychological services, especially in this area...they've got fabulous psychodermatology services in different areas, but we don't have anything (dermatology nurse consultant/specialist; interview 3: 8, 189-191).

There's a big South/North divide, and the services get less and less as you go further up...there's only 10 psychodermatology centres in the country, and people are travelling from Scotland to go to London (dermatology nurse consultant/specialist; interview 8: 10, 233-236).

The difficulties in patients' accessing specialist services was speculated to be a result of a combination of different factors, including workforce:

We've never had good psychological support in all the places I've worked, there aren't enough psychologists around who understand skin (dermatology nurse consultant/specialist; interview 1: 8, 196-197).

Funding for commissioning was raised as an issue to having greater access to specialised services, which in some cases, meant "patients miss out on really good psychological support" (dermatologist; interview 2: 17, 417-421):

The health board or trust just don't have that money or the staff to set up such a service (dermatology nurse consultant/specialist; interview 3: 13, 320-322).

For all HCPs, although not specialised to skin conditions, child and adolescent mental health services was the main pathway they would aim to access. However, there were frequently issues with waiting times:

Access to support services for young people and families is really challenging at the moment, the waiting lists are huge (dermatologist; interview 5: 4, 85-87).

HCPs highlighted the importance of having tailored psychological support to address the specific symptoms and psychological sequelae associated with skin conditions:

We were always very frustrated with what [general mental health services] would offer as they didn't really understand skin diseases and their impact on the mind (dermatologist; interview 9: 8, 188-189).

### **3.3. Healthcare professional recommendations for improving care**

HCPs provided recommendations for how the pathway of care for children and families affected by skin conditions could be improved, with better access to appropriate psychological support services, as "it's part of seeing someone, it's almost like giving another medication, it's just a fundamental part of holistic care for a problem that's not just in the skin but in the mind as well" (dermatologist; interview 9: 10, 224-225):

Having a direct [psychology] link would be ideal...specific to skin disease rather than just general mental health services...I think we're just a little bit behind in Wales (dermatology nurse consultant/specialist; interview 3: 14, 338-341).

Psychological support should be standard...every single paediatric dermatology department needs to have access to inhouse psychology (clinical psychologist; interview 4: 15, 370-371).

One HCP highlighted the importance of having a combined approach to treatment, considering the psychological impact of living with a skin condition alongside drug therapies:

Healing the mind will have a very positive impact on the skin...with these severe inflammatory skin conditions, we've got increasingly targeted tools available like the biologics or small molecules, but at the same time, we are still suppressing symptoms, and if you ignore a very important part of the skin inflammation which comes from the mental disturbance, then you're not realistically treating the patient and the stress caused by the skin disease...you're depriving the patient from one very important element of their treatment (dermatologist; interview 9: 9, 206-214).

#### **Theme 4: Relevance of a mindfulness-based intervention**

All HCPs were asked for their views on offering children and their parents a mindfulness-based intervention, and whether, from their experience, they thought that this approach might be acceptable. HCPs were asked to give their insights into potential benefits and barriers of delivering mindfulness to families affected by skin conditions.

##### **4.1. Potential benefits of mindfulness**

HCPs described a range of potential therapeutic outcomes for children diagnosed with skin conditions for managing the symptoms associated (e.g., itch) and for negative thoughts and affect arising from living with a visible difference:

[Mindfulness] can just centre you, make you feel calmer about life, it can help with anxiety, it can help with repetitive thoughts (dermatologist; interview 10: 15, 370-371).

Mindfulness makes sense in terms of reducing anxiety and reducing stress and finding different ways of coping with those emotions, and in relation to the itch scratch cycle, I know some young people really like mindfulness and the breathing exercises as an alternative behaviour when they notice they're feeling stressed, or they feel like they want to scratch (clinical psychologist; interview 13: 10, 230-233).

Several psychologists gave examples of how they had used mindfulness-based activities previously with children with skin conditions, and "generally, it's very positive, both for CBT and for mindfulness" (dermatologist; interview 9: 13, 305-306):

The one I use most frequently is body scanning and relaxing the muscles to prepare the body for rest rather than being in the fight and flight mode when they are experiencing anxiety (children's psychological wellbeing practitioner; interview 11: 15, 372-373).

We do mindfulness bubbles a lot for the little ones, we use bubble machines...within a skincare routine...whilst they're waiting for their cream to sink in...they breathe up and breathe down when the bubbles are moving up and down (clinical psychologist; interview 12: 12, 283-291).

One family were reported to have completed a mindfulness-based activity together:

One parent...painted [a rainbow] on their kids wall, and they all used to sit down and do breathing together...they were all involved and the whole family calmed down as a whole, and it helped them in every way, it wasn't just about the child's skin condition (clinical psychologist; interview 12: 15, 367-370).

However, although HCPs were favourable to the use of mindfulness with children, several felt the approach might be beneficial if it was "more for the

parents...to help families find that space to develop mindfulness skills” (clinical psychologist; interview 14: 16, 386-390):

We don't think about the parents enough, so that that would be lovely for them, to have the opportunity to learn these mindfulness techniques themselves to cope better (dermatologist; interview 9: 14, 327-329).

If you package [mindfulness] as helping you to be a better parent, doing the creams, doing all the bandages, doing all the medication, helping you with that, helping your child...you might get better engagement (clinical psychologist; interview 4: 14, 345-348).

[Mindfulness] would be more beneficial for some of the parents to be able to take five minutes, where it's not just all about the skin disease (dermatology nurse consultant/specialist; interview 3: 12, 289-291).

One psychologist gave an example of a parent who had taken part in a mindfulness-based intervention:

There's a mindfulness group that runs in the hospital for parents...we did have a parent who was struggling to tolerate the uncertainty of their child's diagnosis...this parent did go on the mindfulness group for seven weeks, and then a few months later, they reached the top of the wait list and then didn't opt for psychological input because they were feeling better (clinical psychologist; interview 14: 16, 377-384).

Several dermatologists speculated how mindfulness could promote positive physiological changes in the body with potential to improve the skin condition itself, although “we don't know how the brain or the mind-skin axes really work, so there could be implications for reducing inflammation if you can calm your mind, but we need more evidence” (dermatologist; interview 10: 16, 375-376):

Mindfulness techniques cannot just help with the whole affective problem of living with a skin disease...mindfulness can help with the skin disease too, not just with the skin disease but with the repair of the damage from the skin disease, because repair is different from ongoing inflammation...if you have excoriations or erosions...the repair is facilitated by relaxation techniques...so

you can reduce the inflammatory burden through relaxation techniques and also you can reduce the psychological burden... (dermatologist; interview 5: 11, 257-268).

[Mindfulness] would relax you more...the chemical release in the skin would go down, so less protogens being secreted, and less interleukins, as a chemical explanation... (dermatologist; interview 9: 13, 318-321).

HCPs felt that an online delivery of a mindfulness-based intervention could be effective for families affected by skin conditions:

[Mindfulness] doesn't have to be face to face but something that is real time patients would prefer...real time interventions give patients a very specific responsibility to attend...if you have something where you are going to be seen in a real-time environment then adherence is likely to be much better (dermatologist; interview 5: 12, 283-294).

As well as this, HCPs felt that a less-intensive, less-formal mindfulness intervention might be more well-suited to families:

The tenants of mindfulness are useful but maybe not in the very formal way that the pure mindful person would want it to be, such as the breathing, the calming, and the centring (dermatologist; interview 10: 17, 416-418).

Embedding it in things that are already part of somebody's routine tends to work...most people who I've worked with who have a regular mindfulness practice have tagged it onto something that's already part of their routine (clinical psychologist; interview 13: 10, 247-249).

HCPs felt mindfulness could be embedded into clinical practice, with additional training of staff:

You could train clinical nurse specialists quite easily to deliver mindfulness techniques to children and their families, you wouldn't have to have a psychologist...these things should be possible to offer in every pediatric dermatology service in the country, not just in a few more specialized ones (liaison psychiatrist; interview 6: 19, 456-461).

## 4.2. Barriers to engagement in mindfulness

HCPs usefully highlighted several barriers and anticipated the challenges that could arise in offering a mindfulness-based intervention to families affected by skin conditions. This included parents perhaps being more reluctant to try something for themselves, to help their child by-proxy:

A lot of comments that we get from parents when we recommend things...you might get 'I don't have time to do that', or 'I have other things to do', and they tend to be really on board for helping the child, but in terms of trying actual techniques themselves, there's a bit of resistance (children's psychological wellbeing practitioner; interview 11: 16, 392-395).

HCPs also highlighted how "you have to make the time for it, it doesn't work if you just do ten minutes once a week" and "for busy parents with lots of caring needs, making that time, they might struggle" (clinical psychologist; interview 4: 14, 333-335), to fit practices into their care routines:

Parents are like 'I can't do this', 'I don't have the time to do this', 'I don't have the time to do this properly or apply this cream', so probably asking them to do something else, may be a bit of a tricky thing (dermatology nurse consultant/specialist; interview 3: 13, 300-302).

How do you get people to do enough of it for it to be useful? And how do you embed practice? I think that's always the tricky bit with mindfulness...some people really get it and find it helpful, and other people are like 'it's just not for me', and that can be really tricky to know how much do we persist with this? And see how you get on after a bit more practice? Or do you just say, actually for some people, it's just not the right fit? (clinical psychologist; interview 13: 9, 214-219).

HCPs highlighted that for some children and adolescents, the idea of sitting with your thoughts and body sensations in a non-judgemental way could be difficult or even 'intensify their experience of itchiness" (liaison psychiatrist; interview 15: 11, 264-266):

Things like itch, I wonder whether mindfulness might make it worse? If you focus in the moment, on your body and how it's feeling, it could actually be horrendous if you've got a lot of itch (liaison psychiatrist; interview 6: 16, 396-398).

There could be barriers in terms of socio-economic status and accessibility:

Mindfulness is quite accessible for quite highly educated, non-socially-deprived people...for some young people in very difficult circumstances, telling them to accept things that aren't acceptable can be quite tricky (dermatologist; interview 10: 14, 336-340).

HCPs speculated how families “might have their own stigma attached to mindfulness”...but “would embrace it as a healthcare practice, and also as a parent or a patient I would embrace it too” (dermatologist; interview 5: 12, 274-276):

Mindfulness has become more mainstream...it can be helpful because people are like, ‘oh, I've already heard of that I'd be willing to give it a try’, or it means that people are coming with a lot of baggage or misconceptions about what it is...and that can be a barrier (clinical psychologist; interview 13: 11, 255-259).

Importantly, one dermatologist spoke of how they had referred patients to try mindfulness, and it had mixed reviews as some patients found other activities better for managing anxiety. This could suggest that there could be individual differences in terms of treatment preferences, and how well children respond to interventions:

Young people have found it quite difficult to engage with mindfulness because they are busy, and their brain can't settle...our experience has been mixed in terms of people continuing, they might do it in clinic, but then they might not continue (dermatologist; interview 10: 16, 377-381).

#### **4.4. Discussion**

The aims of the present study were to investigate the experience of expert HCPs of addressing the psychological needs of children with skin conditions and their families, including the psychosocial issues, how these issues are identified, and the types of available support. The study also sought to gain expert opinion on the relevance of offering specific forms of psychological intervention.



In keeping with the extant literature, the participants all described encountering significant psychological burden in some children diagnosed with skin conditions (Hughes et al., 2022; Barlow et al., 2023), including social withdrawal, interruptions to education, lack of sleep, and co-morbid mental health conditions, such as anxiety, depression, and in severe cases, suicidal ideation and self-harm. The burden was described as equally profound for parents, who often shared in their child's distress, experienced disruptions to sleep, stress from overseeing treatment, and sadness from their child missing out on a 'normal' childhood (Moss et al., 2020; Ablett & Thompson, 2016).

All HCPs felt services were unequally distributed across the UK and were not meeting demand of patients (APPGS, 2020), particularly in Wales. This was speculated to be for a range of reasons including a lack of: (1) mental health training, (2) funding for specialist psychological practitioners (e.g., clinical psychologists), and (3) unclear referral pathways to specialist child clinical health psychological services. As a result, HCPs described offering a helpline or nurses delivering basic behavioural strategies to boost patient support. Offering these additional services to compensate for the shortfall in professional psychological support was often challenging in terms of both HCP's level of training, as well as having sufficient time in clinic to attempt to implement some basic psychological support.

Interestingly, the different lenses of assessment between psychology and dermatology healthcare professionals provided evidence for the wide-ranging burden observed in children. For example, dermatologists focusing on treatment of the primary skin disease all noted the discordance between skin objective ratings of skin condition severity and level of psychological distress seen in paediatric patients. Whilst psychology practitioners noticed how physical symptoms bidirectionally contributed to vicious cycles of affect and safety behaviours, even in young patients of the general population. For example, a psychology practitioner described seeing children who had not been directly referred as a result of distress arising from their skin, but eventually uncovering during psychological formulation how their condition was contributing to the primary experience of anxiety or low mood.

There was consensus in recognition of the need to conduct thorough assessments and this was demonstrated with reference to consideration of assessing for self-harm and within the use of a range of assessment tools and skills (measures and clinical observation and interviewing). Consistent with previous research, HCP's discussed how although psychometric measurements for dermatology-specific quality of life are recommended by NICE (2017) guidelines, they may not be conclusive for determining levels of psychological distress (Blackstone et al., 2022). Instead, it seems that HCPs felt that the most comprehensive way to assess how distressed a child and their family are, was to spend time asking them questions about their mental health and coping, using the standardised measures as a guide for the conversation. However, although this appeared to be the favoured approach to initial screening, there could be restrictions in terms of timing pressures for how long a clinician can spend talking to families during scheduled clinic appointments.

Further, and importantly, HCPs must feel confident enough to have open discussions with children and their parents about their mental health. If clinicians are regularly asking paediatric patients about their mental health and identifying problems, it is imperative that there is somewhere to refer them to for the appropriate level of psychological support. Although in this study, patient needs appeared to be well-understood (Wheeler et al., 2022), it could be that many clinicians are avoidant of asking about the psychological symptoms, as they are aware of the lack of adequate resources to manage what could be disclosed. In this case, there is a need for psychological training to be built into dermatology and nursing curriculums. In any event, if we are encouraging HCPs to ask more open questions about mental health, families who are experiencing distress must be provided with suitable care and cannot be dismissed. This is problematic with the current pathway of treatment, long-waiting lists, limited funding, and difficulties accessing mental health services. HCPs also made recommendations for how the current pathway of dermatological care must be improved with additional training and commissioning of services. All HCPs felt there is an immediate need for standardised access to psychological support for all paediatric patients and their families (Wheeler et al., 2022; APPGS, 2020).

HCPs were routinely recommending a range of psychological support interventions. Trained psychologists typically discussed their experience of delivering a range of therapies (e.g., CBT, ACT, mindfulness, mentalization-based therapy, family/systemic therapy), whilst dermatology professionals described using more simple single therapeutic techniques (e.g., habit reversal, progressive muscle relaxation), sometimes alongside offering complimentary approaches (e.g., yoga). However, every HCP highlighted the lack of availability of these psychological interventions and in particular substantive psychological therapies. In most cases, medical and nursing HCPs reported how they would signpost to skin-related charities for access to evidence-based informal support or would instruct patients to seek access via referral from their GP to mental health services. But waiting lists were lengthy and the interventions were not specific enough to the concerns encountered by people with skin conditions.

The majority of HCPs felt mindfulness would be accepted by children and could be helpful for young people to manage their anxiety and worry about their skin condition (Hughes et al., 2022; Heapy et al., 2022). In some cases, mindfulness was currently being integrated into psychological therapies by several clinical psychologists, who spoke of achieving favourable outcomes for children and families. However, some of the HCPs who had experience of offering MBIs to patients discussed how they had received mixed feedback, and not all patients had engaged with the practices. For example, one dermatologist had noticed how some children preferred other activities as a form of distraction from their skin-related symptoms. HCPs speculated that these mixed views reflected a combination of factors, including previously highlighted myths and misconceptions surrounding the nature of mindfulness (Kelly, 2022), and the potential for discomfort when focusing on the physical sensations of the body (e.g., intensity of itch).

Several dermatologists described how mindfulness-based exercises could assist with physical symptoms and could have potential to reduce inflammation and upregulate healing processes, as stress can impair wound healing (e.g., biopsychosocial model) (Hunter et al., 2015). Although stress activating cytokine release and biological mechanisms was primarily discussed by HCPs in a theoretical manner, there were anecdotal examples given of stress being observed as a

precipitating factor in the exacerbation of patients' symptoms and maintenance of vicious cycles of scratching behaviour. Indeed, when the body's stress response is activated, the hormone cortisol is released, and there have been associations with alterations to the body's hypothalamic-pituitary-adrenal (HPA) axis resulting in impaired cortisol production in people with psoriasis (Gisondi et al., 2021). Activities such as mindfulness meditation have been associated with less activation of the sympathetic nervous system, and lower cortisol levels in the blood (Pascoe et al., 2017). It is for these reasons that stress management should be considered in the treatment plan of families affected by skin conditions (Christensen & Jafferany, 2023). However, there is limited research to support this as the stress-inflammation pathway is complex. Although there is preliminary evidence to suggest mindfulness might be effective for targeting the stress pathways related to inflammatory disease risk, further research is required not only to test the efficacy of this approach, but also to understand the underlying mechanisms and which elements would be the target of an intervention (Lindsay, 2021).

HCPs provided suggestions for how mindfulness could be delivered to families, including using an online format, in real-time, to promote commitment to the intervention (Hughes et al., 2022). Participants felt a more informal mindfulness programme might be easier for parents and children to engage with, as they often had intense treatment routines which might limit how much time they have to practice an intensive intervention. Indeed, similar findings have been previously reported by parents of children with skin conditions themselves (Hughes et al., 2022). Thus, incorporating mindfulness into daily activities could be the most appropriate strategy to increase feasibility.

Several HCPs felt that mindfulness would be more appropriate for the children's parents, and could be useful for them for managing levels of parenting stress, and there is some emerging evidence to support this (Heapy et al., 2021; Heapy et al., 2022). In targeting parents stress directly, HCPs speculated there could be benefit for the caregiver, and a positive secondary outcome for the child, in terms of reduced conflict and greater family cohesion. HCPs reported that parents are often overlooked during consultations, and the focus is primarily on the child presenting with skin symptoms. Although it was noted how time demands could be a

barrier to parental engagement, along with an observed sense of reluctance from parents to dedicate time to their own self-care. Both dermatologists and psychologists highlighted the importance of taking a systemic approach to care, and considering the child in the context of their family environment and how the dynamics of relationships could be contributing to the psychological burden. This would suggest that alternative psychotherapeutic approaches also warrant development and testing, such as family therapy.

#### **4.4.1. Limitations**

The study does have several limitations, and whilst the sample size was considered to be appropriate for this design, many of the participants had specific expertise and interest in psychodermatology, which may affect the transferability of the findings. For example, as HCPs were self-selecting and expert clinicians, they may have been highly confident in identifying psychological distress from their own areas of interest, and not reflect standard practice. However, there were some benefits of this, in so far as this is likely to have meant that those who participated had very good knowledge of existing services, nevertheless additional surveys might compliment this study by considering the extent to which the findings are mirrored in other services. Although the study did incorporate expert-by-experiences into the study design, there could have been additional involvement during planning phases.

Additionally, social desirability could have been an influencing factor on participant narratives, as HCPs might have sought to paint a positive picture of their own service. Further, this study did not include any participants from Northern Ireland or Scotland, so the views reported in this study are only reflective of HCPs working in England and Wales. As well as this, the study sample consisted of more clinical psychologists than other types of mental health professional, so could have been less representative of other divisions of healthcare.

#### **4.4.2. Recommendations for future research**

The study findings raise the issue of how a range of psychological intervention types need developing and testing. Importantly, the study highlights the potential for MBIs as a therapeutic approach to alleviate levels of psychological stress associated

with childhood skin conditions. However, it is difficult to determine how effective mindfulness could be for this patient demographic, as a result of the limited evidence-base. Future research should focus on robustly testing the feasibility and acceptability of a range of psychological interventions, including mindfulness, with families affected by skin conditions. For example, the present study has shown that the burden experienced by parents could vary for each family and their relational dynamics, which suggests the need for idiographic measurement of stress.

#### **4.4.3. Conclusion**

Overall, the findings suggest that dermatology and practitioner psychology healthcare professionals openly recognise the significant burden experienced by children and their parents, but are often limited in terms of providing the appropriate level of psychological support. Although many clinicians across England were able to refer/deliver specialised services, the provision was not equally accessible and was determined by location in the UK.

There was consensus in the sense of urgency for the commissioning of psychological support for families affected by skin conditions; HCPs felt there would be value in the integration of specialised psychological support, and there is a need for the development of further interventions, including mindfulness. Integrating psychological support into the dermatological pathway of care as a national standard could promote healthy coping, and be an integral part of developing a holistic approach to treatment. Chapter 5 reports a study investigating the use of a novel mindfulness-based intervention for parents of children with skin conditions.

## Chapter 5

# Mindfulness for Parents of Children with Skin Conditions: A Single Group Cases Series

### 5.1. Introduction

It has been well-evidenced that parents providing care for an unwell child can experience a significant demand in meeting care requirements and being responsible for often complex treatment regimens (Hughes et al., 2022). In many cases, parents might need to draw upon their own levels of resilience and self-compassion to meet the needs of their child, at the expense of their own psychological resources and self-care (Cousineau et al., 2019).

The current study has been informed by parent and child feedback (Hughes et al., 2022) to deliver a mindfulness-based intervention to parents of children with skin conditions. The findings from Chapters 2, 3 and 4 indicated that mindfulness could be an effective intervention for parents of children with several different physical health conditions (Ruskin et al., 2021), including chronic pain (Anclair et al., 2018; Seidman et al., 2019), cancer (Mehranfar et al., 2012), cerebral palsy (Mak et al., 2019; Barogh et al., 2011; Barogh et al., 2015), and for parents of babies in neonatal intensive care (Marshall et al., 2019). As Chapter 2 showed, while there is a growing body of literature using mindfulness with children with chronic physical health conditions and their parents (Ruskin et al., 2021), little evidence exists about the use of mindfulness for parents of children with skin conditions.

Parents and children experience significant daily demands from managing a skin condition, and have previously expressed desires for a support intervention that can fit into their treatment routines, with an online format to increase accessibility (Hughes et al., 2022). Interviews with dermatology healthcare professionals (Chapter 4) suggested that the delivery of a mindfulness-based intervention might be more suitable for parents in the first instance, rather than children themselves. It was described in Chapter 4 how parents encounter a significant mental health burden,

and often display strong emotions during clinic appointments from the pressures of making treatment-related decisions and sleep deprivation, combining in the stresses of care. As well as this, parents of children with skin conditions may experience social isolation from other people not understanding the additional considerations required to meet care needs (Moss et al., 2020; Hughes et al., 2022). Similar results with a mindfulness-based intervention for parents of children with cystic fibrosis have been reported by Harris et al. (2021), where mothers appeared to benefit from being in a group setting with other parents experiencing similar health-related concerns. Parents who experienced clinically significant improvements in their symptoms of anxiety and depression were able to connect with other parents in a supportive setting, which helped to promote acceptance (Harris et al., 2021).

Promoting healthy coping in parents is important for maintaining quality of life, and by targeting parents' wellbeing with mindfulness, levels of self-compassion and psychological flexibility could be increased to act as a buffer against parenting stress (Cousineau et al., 2019; Ruskin et al., 2018). There may also be benefits in relation to parenting behaviour. For example, higher levels of parental mindfulness have been found to predict less daily worry about hypoglycaemia and lower levels of protective behaviour in parents of children with type 1 diabetes (van Gampelaere et al., 2019). Indeed, mindfulness practices might also assist help parents maintain adherence to treatment whilst also paying attention to their child's (van Gampelaere et al., 2019). Russell and Guite (2020) found that participation in a 'Parents as Coping Coaches' mindfulness programme was related to reductions in authoritarian parenting styles, or controlling and intrusive behaviour. They concluded that targeting parents' emotions and ability to regulate their own stress levels could have a positive impact on parent-child interactions (Russell & Guite, 2020).

The stress experienced by parents as a result of the psychological burden of providing care for a child could therefore be targeted with mindfulness. MBSR for caregivers of chronically ill children has been found to decrease substantial stress symptoms and mood disturbance (Minor et al., 2006). Further, a study by Anclair et al. (2017) compared mindfulness and CBT for parents of children with chronic health conditions, and found both groups of parents improved in health-related quality of life. Another study by Anclair et al. (2018) similarly compared the effectiveness of



mindfulness and CBT for parents of children with chronic conditions, and found that both interventions were efficient for significantly reducing stress and burnout. The study showed that parents' perceived stress levels and the degree to which situations were evaluated as stressful reduced, suggesting mindfulness could play a role in altering how parents respond to distress (Anclair et al., 2018). Reducing parental reactivity could lead to beneficial outcomes for children, and there could be a secondary effect on the child's mental health from having a calmer, and more attentive caregiver (Dieleman et al., 2021). Higher levels of parental stress have been associated with higher levels of internalizing and externalizing problems in children with inflammatory health conditions, such as asthma (Verkleij et al., 2015). This is particularly relevant for children with inflammatory skin conditions and for parents learning to cope with fluctuations in severity and the stresses of unpredictable flares.

As highlighted in Chapter 4 of this thesis, HCPs reported how parents are often overlooked during dermatology consultations, as the focus is mainly on the unwell child. For these reasons, it has been suggested that it could be effective for the family unit to target parent's mental health with a psychological intervention to build their own coping strategies to tolerate living with the uncertainty of their child's diagnosis and the associated negative emotion (Cousineau et al., 2019). Indeed, Heapy et al. (2021) found that parental dispositional mindfulness could be associated with greater wellbeing in parents of children with psoriasis or eczema, and their children. More recently, Heapy et al (2022) delivered a mindful parenting intervention to parents of children with eczema and psoriasis, and found the approach showed promise for reducing parental stress. However, mindful parenting is a time-intensive intervention, and the study suggested future research could alter the format of delivery to lessen the burden on parents, and limit the amount of time spent away from home (Heapy et al., 2022). To increase the feasibility of future mindfulness-based interventions, the intensity of sessions and amount of formal practice required could be reduced, or replaced with exercises that can fit into pre-existing daily routines (Heapy et al., 2022; Hughes et al., 2022).

With consideration of qualitative feedback in Chapter 3 from parents and children affected by skin conditions (Hughes et al., 2022), to and make mindfulness

more achievable for busy parents, there is a need for short, accessible interventions with an online delivery (Hughes et al., 2022). One novel approach to introducing mindfulness into daily life is with the 'Living in the Present' curriculum for adults, unlike traditional mindfulness-based interventions that require formal practices to be completed alongside teaching (The Present Courses, 2022). Indeed, engaging in these exercises can be time-consuming, so the Present curriculum takes a different approach and allows peoples to practice mindful intentions through daily life activities (The Present Courses, 2022). Previous study findings presented in Chapter 3 and Chapter 4 have shown how the challenges experienced by parents could be unique to each family (Hughes et al., 2022) (e.g., child's age, diagnosis, relational dynamics) and suggests the need for idiographic measurement of stress.

Therefore, this study used mixed methods, including a single cases experimental design (SCED) to allow the collection of idiosyncratic data, and qualitative exit interviews subjected to thematic analysis to gather in-depth intervention feedback. In this study, the main outcome variable was a bespoke measure of parental stress related to parenting a child with a skin condition (Morley, 2017). Although parents were the main target, their children also completed quality of life measures. It was hypothesised that participation in the Present curriculum would reduce levels of parenting stress, and improve parent and child quality of life.

### **5.1.1. The current study aims**

The aims of this pilot study were to: (1) investigate whether delivering the 'Living in the Present' mindfulness intervention to a group of parents of children with skin conditions reduces levels of parental stress; (2) investigate whether mindfulness increases both parental and child wellbeing and quality of life, and (3) determine the acceptability of mindfulness.

## **5.2. Method**

### **5.2.1. Pre-registration**

The study was pre-registered on the Open Science database:  
[https://osf.io/uyrtw/?view\\_only=ae2c14b15ca14082974f6a80eb306690](https://osf.io/uyrtw/?view_only=ae2c14b15ca14082974f6a80eb306690). Several

revisions have been made to the protocol post-registration, including updates to the literature review, and to the target sample in reflection of the recruitment process.

### **5.2.2. Design**

This study was approved by Cardiff University School of Psychology Research Ethics Committee (EC.22.04.26.6558RA3) (Appendix B.3.). In line with the study aims, mixed methods were used to investigate the Living in the Present curriculum with parents of children with skin conditions. A mixed methods approach was adopted in line with the nature of this study being a pilot investigation, to yield sufficient data to examine the effectiveness of the Present curriculum with parents of children with skin conditions and strengthen findings surrounding the relevance of mindfulness (Harper, 2012).

This study involved SCED to investigate idiosyncratic parental stress, combined with qualitative semi-structured exit interviews to assess feasibility and acceptability via individual discussions surrounding personal changes (Elliott et al. 2001; 2008; 2012). As shown in Sekhon et al. (2017) theoretical framework of acceptability, there are several constructs that can be used to support the implementation/evaluation of healthcare interventions with qualitative and quantitative data. This includes the use of semi-structured interviews during pilot and feasibility phases of research with target users, in order to gather insights on intervention content throughout all stages of development (Sekhon et al., 2017).

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). SCED was chosen as appropriate for this research as the study examined a small group of parents over a set period of time, and measured target outcomes across each phase (Morley 2018; Krasny-Pacini & Evans, 2018). By gathering and analysing data from a baseline period, SCEDs are used to repeatedly measure participant behaviour both in the presence and absence of an intervention, with each participant acting as their own control (Krasny-Pacini & Evans, 2018). This was especially pertinent to this study sample as SCEDs make it possible to gather high-quality data with small populations

in order to assess an intervention's effectiveness using patient demographics rather than clinical impressions to guide day-to-day clinical practise (Morley, 2018; Krasny-Pacini & Evans, 2018). Studies piloting novel interventions with “atypical cases” or samples of people who are not the intended targets of the intervention can particularly benefit from this (Morley, 2018; Krasny-Pacini & Evans, 2018). As well as this, SCED have been used previously to investigate the efficacy of mindful parenting for parents of children with skin conditions (Heapy et al., 2022) and MBCT for adults with alopecia (Heapy et al., 2023).

This study included a one-week baseline period, followed by the delivery of an eight-session Present programme over an eight week period and a follow-up period of one week. Thus, the criteria used by this pilot study 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).

### **5.2.3. Participants**

A sample of n=20 participants was sought, as this is the largest and most appropriate group size to facilitate the Present curriculum (e.g., personal communication with trained teacher), and cohort sizes have been used for a single mindful parenting intervention (Bögels et al., 2014). Further, single cases series only require small sample sizes, and this is not seen as a limitation, as every participant serves as their own control and datapoints are analysed and aggregated across the dataset to identify whether the intervention effect has been replicated (Heapy et al., 2022).

The recruitment for this study involved a staggered approach, over a period of 17 weeks (May-September 2022). In the first instance, parents of children with ichthyosis (and other rare genetic conditions such as EB, and Ectodermal dysplasia) were targeted to take part in this study, with support from skin-related patient charities (e.g., the Ichthyosis Support Group). The costs of the study were partially funded by a small grant from the Ichthyosis Support Group. An advertisement was

posted on social media by the researcher (see Appendix E.1.) and shared by relevant organisations. Secondly, to ensure the appropriate sample size was recruited, parents of children with other skin conditions were later included. Parents of children with psoriasis, eczema, and vitiligo who took part in the first study connected to this PhD project (n=10 parents, n=9 children) were additionally recontacted by the researcher.

Participants who expressed an interest were emailed a study information sheet (see Appendix E.2.), registration form, consent form (see Appendix E.3.) and child assent form (Appendix E.4.). A total of n=131 parents were sent study information, including n=121 parents who enquired via email, and n=10 who were re-invited. Of these, n=26 declined, n=9 were ineligible (child's age, unavailable for more than two sessions, and global time differences), and n=76 did not respond. N=21 parents were signed up to the course and completed consent, assent, and registration forms, but n=11 dropped out during the baseline period. Six parents did not begin the course and dropped out before the first session. This left n=15 parents who started the first session. Of these parents, n=2 dropped out after the first session and n=3 dropped out between sessions two and seven for reasons including not having enough time to commit to the course, family illness, and busy work schedules. This left a final sample of n=10 participants who completed all study measures from baseline to follow-up (see Table 1 for n=10 participant characteristics). Of these parents, n=8 children completed quality of life measures.

#### **5.2.4. Inclusion criteria**

##### **5.2.4.1. Parent/carer**

Parents were required to be over 18 years old and parents/primary carer to a child (under 16 years), diagnosed with a skin condition such as ichthyosis, alopecia, Epidermolysis bullosa (EB), Ectodermal dysplasia (ED), psoriasis, eczema, vitiligo, acne etc.

##### **5.2.4.2. Children**

Children were required to be under 16 years old and be diagnosed with a skin condition such as ichthyosis, alopecia, EB, ED, psoriasis, eczema, vitiligo, acne etc.

### **5.2.5. Expert-by-experience involvement**

The study design was informed by the previous study (Chapter 3) and incorporated parent and child feedback into the following intervention delivery. The mindfulness teacher was involved during all stages of study design and provided their expert advice on delivering MBIs to a range of different groups. Regular meetings were held with the researcher and research supervisors to discuss session timings, online delivery, dates, iterate study adverts, and gather feedback on participant materials.

**Table 5.1.** Characteristics of n=10 parent participants who completed the intervention, and their children.

Parents							Children		
ID	Age range (years)	Gender	Ethnicity	Employment	Marital status	Sessions attended (out of 8)	Age (years)	Skin Condition	Gender
1	30-40	Female	White British	Part-time	Married	6	10	Ichthyosis	Male
2	40-50	Female	Black African	Full-time	Married	3	5	Eczema	Male
3	30-40	Female	White British	Part-time	Married	8	2	Eczema	Female
4	40-50	Female	White British	Full-time	Married	6	10	Eczema	Male
5	40-50	Female	White British	Part-time	Married	6	9	Eczema	Female
6	40-50	Female	White British	Full-time	Married	7	10	Eczema	Male
7	40-50	Female	White British	Part-time	Married	8	5	Ectodermal dysplasia, Eczema	Female
8	40-50	Female	White American	Homemaker	Married	7	13	Alopecia areata	Male
9	40-50	Female	White British	Full-time	Married	8	12	Eczema	Female
10	40-50	Female	Black African	Full-time	Single	6	1	Ichthyosis	Female

## **5.2.6. Measures**

### **5.2.6.1. Idiographic parental targets**

SCED involves repeated measurements of variables of interest. The main outcome variable was a bespoke measure of parental stress. Parents were asked to identify targets of 'parental stress' (in consent form; Appendix E.3.) including one positive target (any aspect related to parenting a child with a skin condition, that the participant would like to improve) and one negative target (any aspect related to parenting a child with a skin condition, that the participant would like to reduce). For example, the participants were asked: "If this 'stress' wasn't there, what you be doing more of that you're not doing now, or what would it be like?"

Participants provided their phone numbers, and the measures were taken via personalised text messages (Janet txt; PageOne Communications, 2023) to each participants' mobile phone four times weekly (Monday, Wednesday, Friday and Saturday). The text messages took approximately 1-minute to answer, and parents replied to each question on a 0-100 scale, with higher scores indicating greater success and stress. An example text message sent to each participant:

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"). Thank you.

Olivia Hughes, Cardiff University.

### **5.2.6.2. Standardised measures of quality of life, stress, and mindfulness**

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 the appropriate time points for completion, and took approximately 15 minutes to complete. Questionnaires were administered using Qualtrics (Qualtrics, Provo, UT), and each participant was sent a secure Cardiff University link to access and complete the online surveys. Intervention acceptability and feasibility was assessed with qualitative exit interviews gathering participant feedback on the programme.

#### **5.2.6.3. Mindfulness**

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). The subscales' internal consistency have ranged from Cronbach  $\alpha=0.45$  to  $\alpha=0.66$ , while the whole scales' internal consistency has previously been determined as Cronbach  $\alpha=0.72$  (Duncan, 2007).

#### **5.2.6.4. Parental quality of life**

The Family Dermatology Life Quality Index (FDLQI; Basra et al, 2007; Basra & Finlay, 2005) 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 on quality of life. The FDLQI has previously shown good internal consistency (Cronbach  $\alpha=0.88$ ) and test-retest reliability (intraclass correlation=0.94) (Basra et al., 2007). The licence was granted by Cardiff University (ID CUQoL3677).

#### **5.2.6.5. Child quality of life**

This was the only measure completed by children when age appropriate. 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). The CDLQI has previously shown good internal reliability in children with skin disease (Aziah et al., 2002) and excellent internal consistency (Cronbach  $\alpha=0.92$ ; Aziah et al., 2002). Children were given either the cartoon or text version of the CDLQI. The license was granted by Cardiff University (ID CUQoL3676).

#### **5.2.6.6. Parental stress**

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 validity of the PSI-SF has previously established (Abidin, 2012; Haskett et al., 2006), and internal consistency has been found acceptable (Cronbach  $\alpha=0.84$  to  $\alpha=0.68$ ; Haskett et al., 2006).

#### **5.2.6.7. Depression**

The Patient Health Questionnaire (PHQ-9; Spitzer et al, 1999) is comprised of 9 items, corresponding with the DSM criteria for depression (Spitzer et al., 1999). The PHQ-9 has previously shown excellent internal consistency (Cronbach  $\alpha=0.89$ ) within different populations including primary care (Spitzer et al, 1999), and within the general population (Martin et al, 2006; Kroenke et al., 2001).

#### **5.2.6.8. Anxiety**

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. The GAD-7 has been used to assess levels of anxiety in the general population, and has demonstrated excellent internal consistency (Cronbach  $\alpha = 0.92$ ) (Löwe et al. 2008).

#### **5.2.6.9. Demographic information**

Parents provided information (see Appendix E.5.) 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.

#### **5.2.6.10. Qualitative exit interviews**

During individual exit interviews, parents were asked about their overall experience of the Present programme. The Elliott et al. (2001; 2008; 2012) Client Change Interview was used, with the aim of qualitatively assessing client understandings of personal changes following completion of a therapeutic intervention, the questions were modified to evaluate the mindfulness sessions and investigate changes in the context of parenting a child with a skin condition. Once parents had described the changes noticed, they were asked to rate each change on a 5-point Likert scale. Participants were given debrief sheets (Appendix E.6.) at the end of each interview, and all discussions were recorded for transcription verbatim.

The interview transcripts were subjected to thematic analysis (Braun & Clarke, 2006; 2021) to identify patterns and common themes. A dual deductive-inductive approach was taken, with consideration of existing evidence for the use of mindfulness with parents of children with skin conditions (e.g., Heapy et al., 2022; Hughes et al., 2022), but allowing for the consideration of new information to be gathered on delivering a novel intervention (Joffe, 2012). Using NVivo 12 (released March 2018), the data was first read, and coded with a line-by-line analysis of participant narratives, followed by complete coding of the entire dataset. Common patterns were identified, compared, and organised into themes reflecting parent experiences of mindfulness (see Appendix E.7. for evidence of NVivo analysis, NVivo 12; released March 2018).

#### **5.2.6.11. Multiple stakeholder involvement**

In order to assess participant accounts of taking part in the Present sessions, the mindfulness teacher was also individually interviewed. This allowed the researcher to compare the mindfulness teacher's observations with the narratives reported by parents, and determine if there were any differences in accounts of taking part vs. delivering the intervention. A separate section of questions was built into the interview schedule specifically tailored for the mindfulness teacher, and they were able to give their account of teaching the curriculum, including changes they had noticed in participants. As well as this, advice was sought from Elliott (2023,

personal communication) regarding presentation and analysis of parental change ratings.

#### **5.2.6.12. Treatment fidelity**

The intervention was delivered by a qualified teacher with advanced training in mindfulness, and training in the 'Living in the Present' curriculum. The mindfulness teacher received regular supervision sessions over the course of the intervention from one of the intervention co-founders. Assessing treatment fidelity is important to determine if an intervention is being delivered as intended and is recommended in health research to monitor the consistency and accuracy of real-life implementation (Smith et al., 2007; Heapy et al., 2022).

To assess the fidelity of the mindfulness intervention, sections of two of the group sessions were audio recorded with permission from participants (not video recorded, to protect participant identities), and reviewed by one of the Present programmes co-founders. It was decided that session two and five would be recorded to enable scrutiny of the participants and teacher's engagement with the course content.

#### **5.2.7. Procedure**

##### **5.2.7.1. Registration**

Upon registration, each participant completed a series of questions for screening purposes. Participants were asked to disclose if they had any significant or stressful life events, physical health conditions, 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 individual participant to discuss their participation.

##### **5.2.7.2. Baseline period**

There was a baseline period of data collection to sufficiently illustrate stability of participant measures. At baseline, questionnaire measures (see below) were completed by parents and children over the period of one week (7 days), which

acted as a control comparison for data collected during and after the interview. The frequency of measurement was deemed to be sufficient given the frequency of the problems encountered by parents of children with additional treatment and medical needs.

### **5.2.7.3. Follow-up period**

At follow-up, the measures (above) were repeated, and completed over the period of one week (7 days), to allow comparisons with baseline, and intervention phases. Parents, and the mindfulness teacher were then individually invited to take part in qualitative exit interviews.

### **5.2.7.4. Mindfulness intervention**

The 'Living in the Present' is a novel mindfulness programme developed for adults and based on MBSR and MBCT (The Present Courses, 2022). The Present curriculum was designed to introduce mindfulness into daily life, as opposed to traditional MBIs that demand regular personal practices of up to one hour per day, in addition to session attendance (The Present Courses, 2022).

The Present approach gives participants the freedom and flexibility to choose how they learn mindfulness through what is important in their lives, which may even strengthen commitment (The Present Courses, 2022). The curriculum has been previously delivered in education and corporate settings, within the NHS, and in prisons (The Present Courses, 2022). This approach was chosen as appropriate 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 by incorporating practices into activities carried out on a daily basis might make the intervention more achievable for parents.

The Present curriculum introduces mindfulness in weekly themes, as foci for practice: 'Here and Now', 'Focusing', 'Coming Home to The Human Body', 'Coming Home to The Human Mind', 'Connection', and 'Noticing Choice and Noticing Change'

(The Present Courses, 2022). The Present curriculum 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 taking part in the group sessions were given the option of attending group sessions with partners but were free to attend alone if preferred.

#### **5.2.7.5. Statistical analysis**

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 was used to examine data non-overlap in idiographic measures between intervention phases. Tau-U is used for single case designs with the following online programme (Parker et al., 2011; Vannest et al., 2011): <http://www.singlecaseresearch.org/calculators/tau-u>. To assess if an intervention has had a significant impact on symptoms, Tau-U combines the Kendall Tau and Mann Whitney U tests to compute a percentage of non-overlap in data. With minimal data assumptions, Tau-U computes data trends, levels of non-overlap between baseline and the intervention, and both in combination (Parker et al., 2011; Vannest et al., 2011; Morley et al., 2018). Tau-U also computes the standard error and effect size, which makes case aggregation possible (Parker et al., 2011; Vannest et al., 2011; Morley et al., 2018).

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 in participant scores 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.

## **5.3. Results**

### **5.3.1. Idiographic measures**

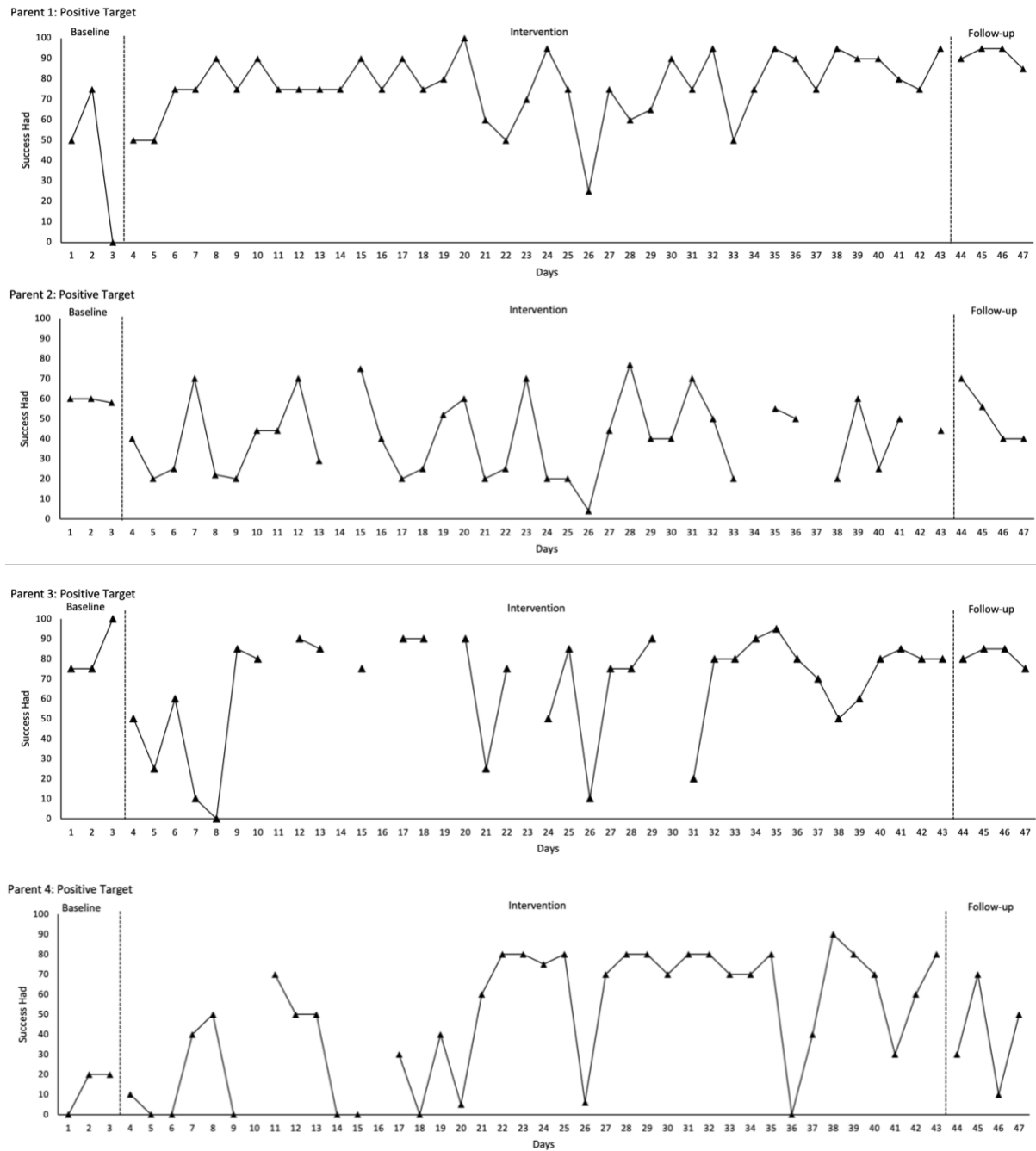
#### **5.3.1.1. Visual analysis**

Data from each individual parent's idiographic measure can be seen in Figure 5.1 and 5.2. Further detail is also available in Appendix E.8./E.9. which shows parental graphs with trendlines. 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, five 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.

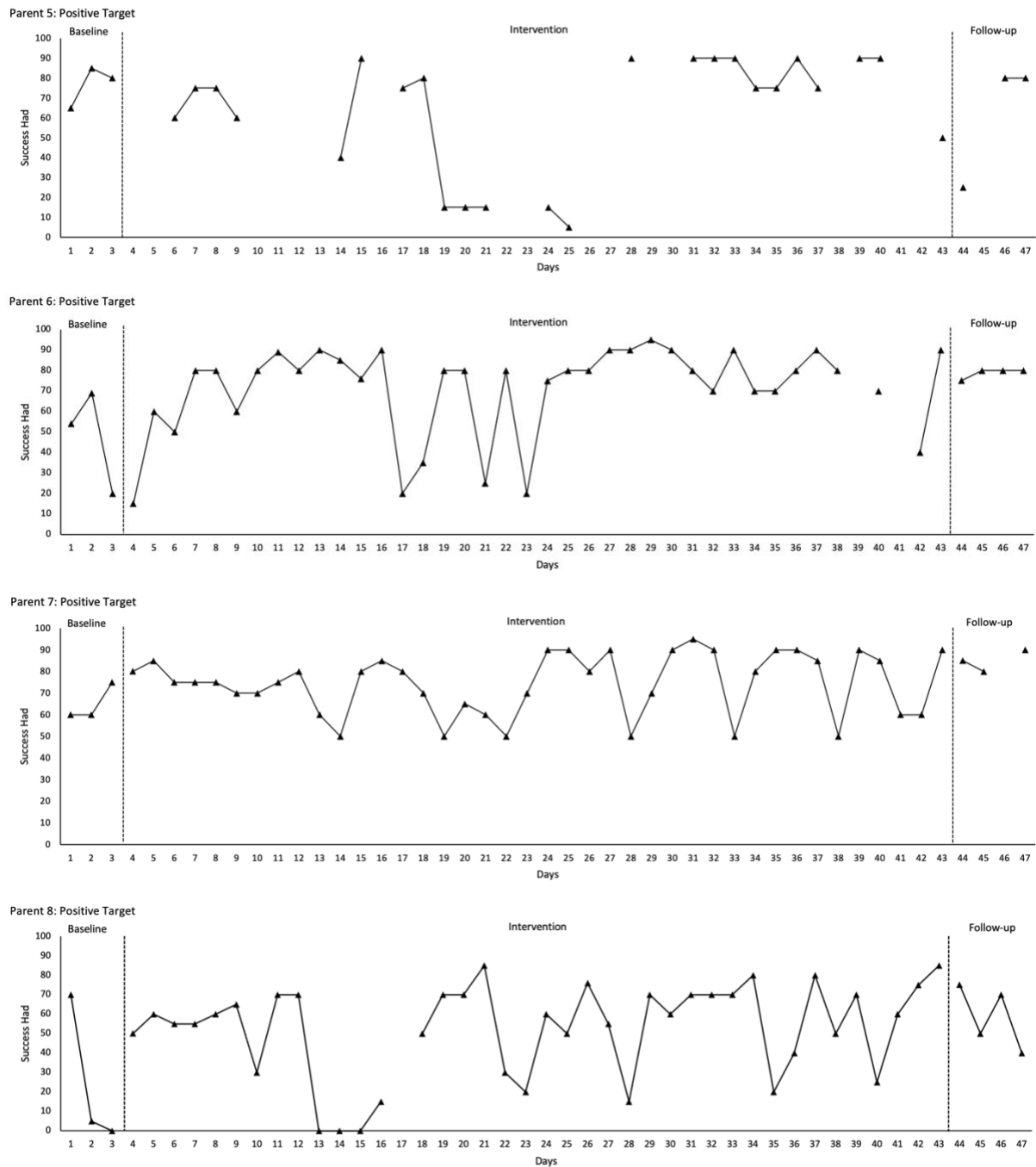
One parent (2) remained stable across the intervention phase. However, one parent (9) showed a slight upward trend across the intervention phase. Three parents continued to show downward trends at follow-up (4, 5, 6). Two parents remained stable at follow-up (7, 9). However, four parents (1, 2, 3, 8) showed upward trends at follow-up.

**Figure 5.1.** Positive targets: Scores (4 times weekly) for success-framed idiographic parenting stress questions. Higher scores indicate greater success (0-100). Question 1: Positive target: How much success have you had today with \*target\* with \*child's name\*

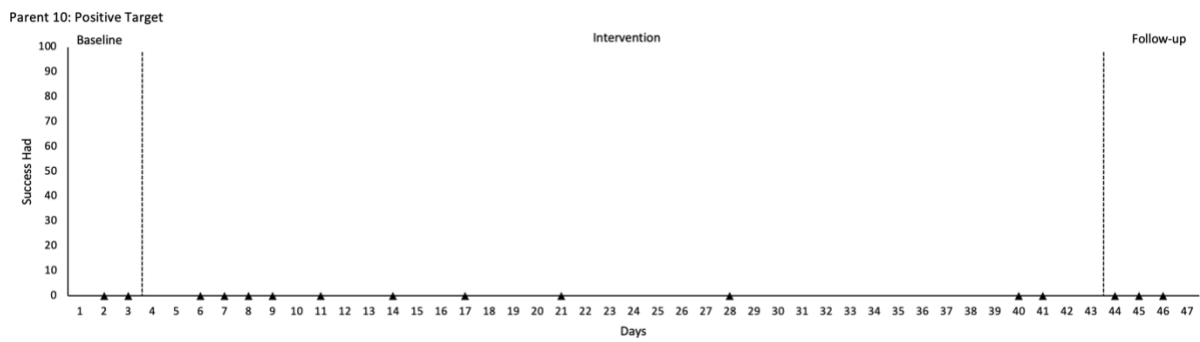
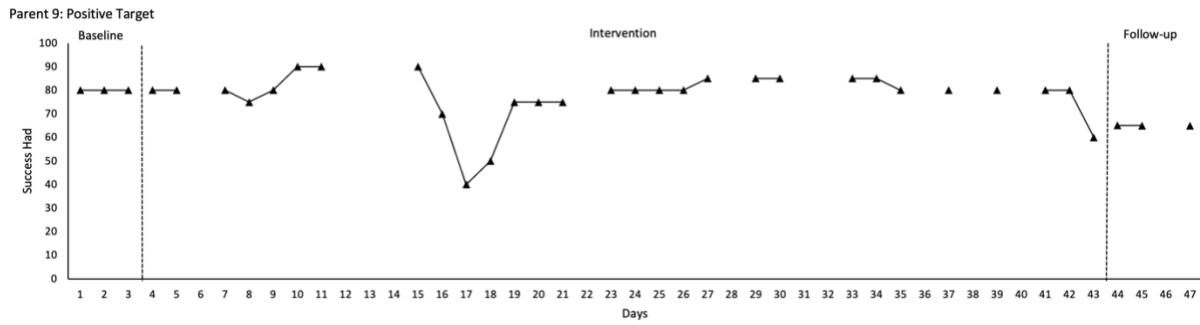




**Figure 5.1. (Continued).** Positive targets: Scores (4 times weekly) for success-framed idiographic parenting stress questions. Higher scores indicate greater success had (0-100). Question 1: Positive target: How much success have you had today with \*target\* with \*child's name\*

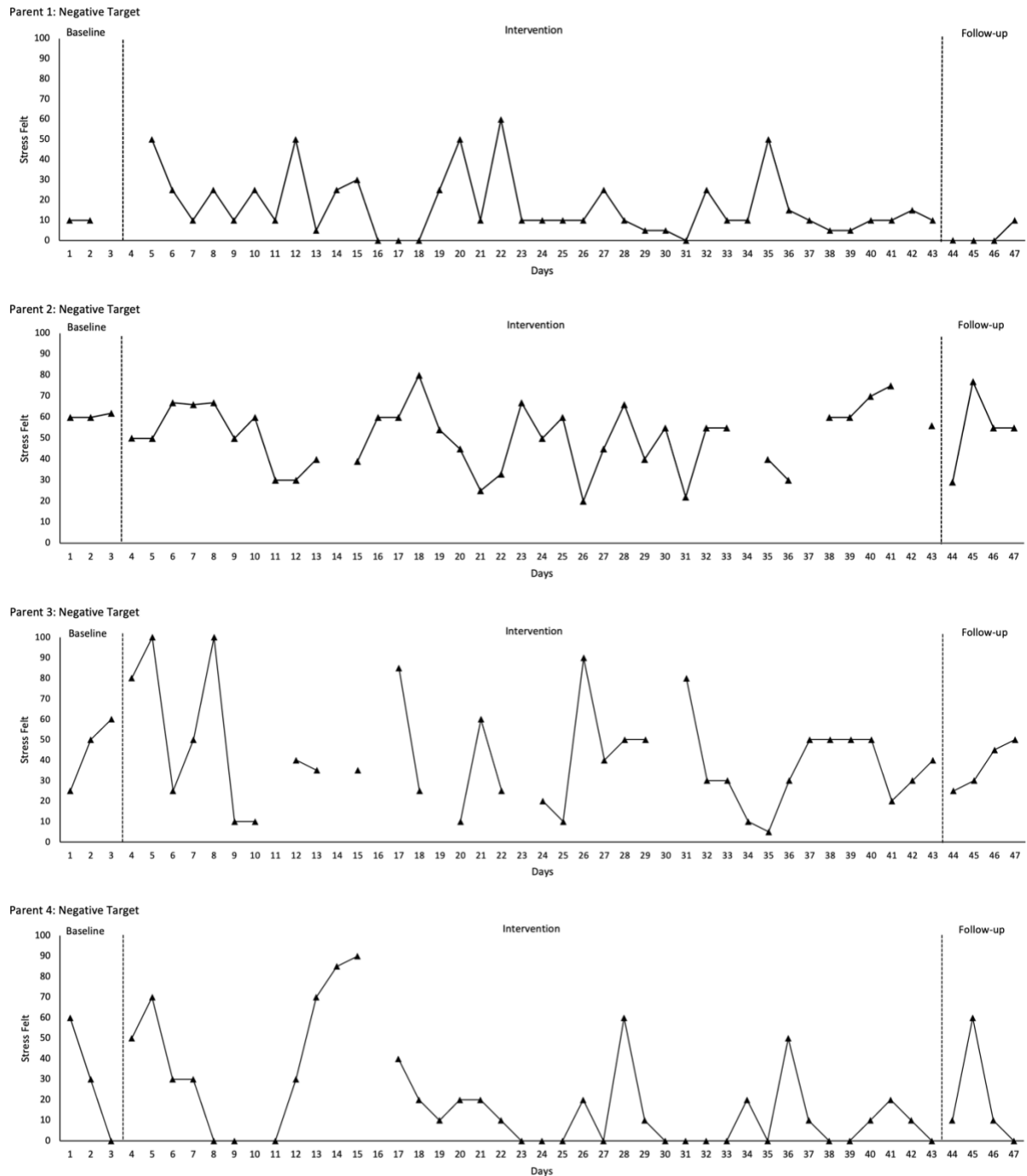


**Figure 5.1.** (Continued). Positive targets: Scores (4 times weekly) for success-framed idiographic parenting stress questions. Higher scores indicate greater success had (0-100). Question 1: Positive target: How much success have you had today with \*target\* with \*child's name\*

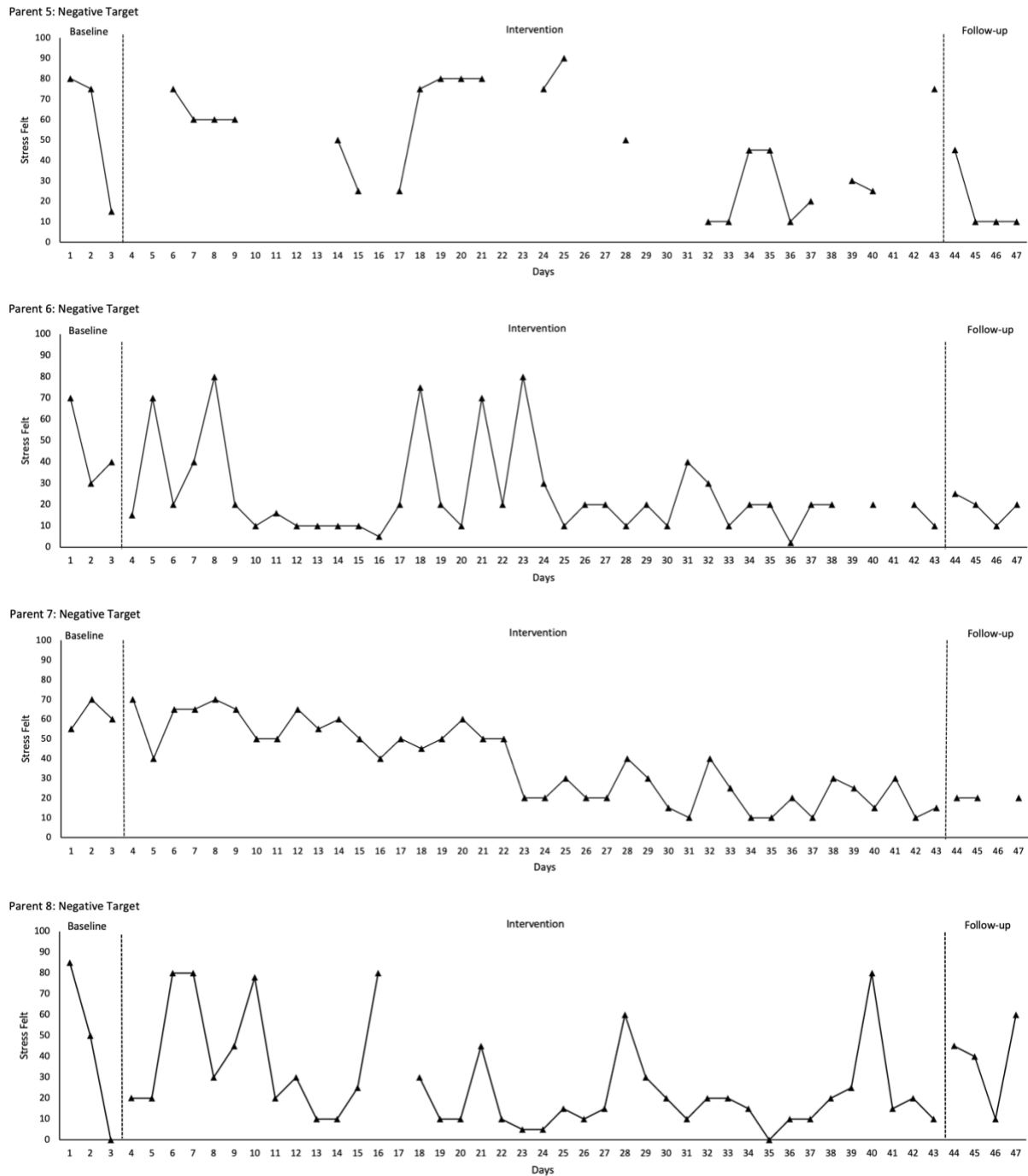


**Figure 5.2.** Negative targets: Scores (4 times weekly) for stress-framed idiographic parenting stress questions. Higher scores indicate greater stress felt (0-100).

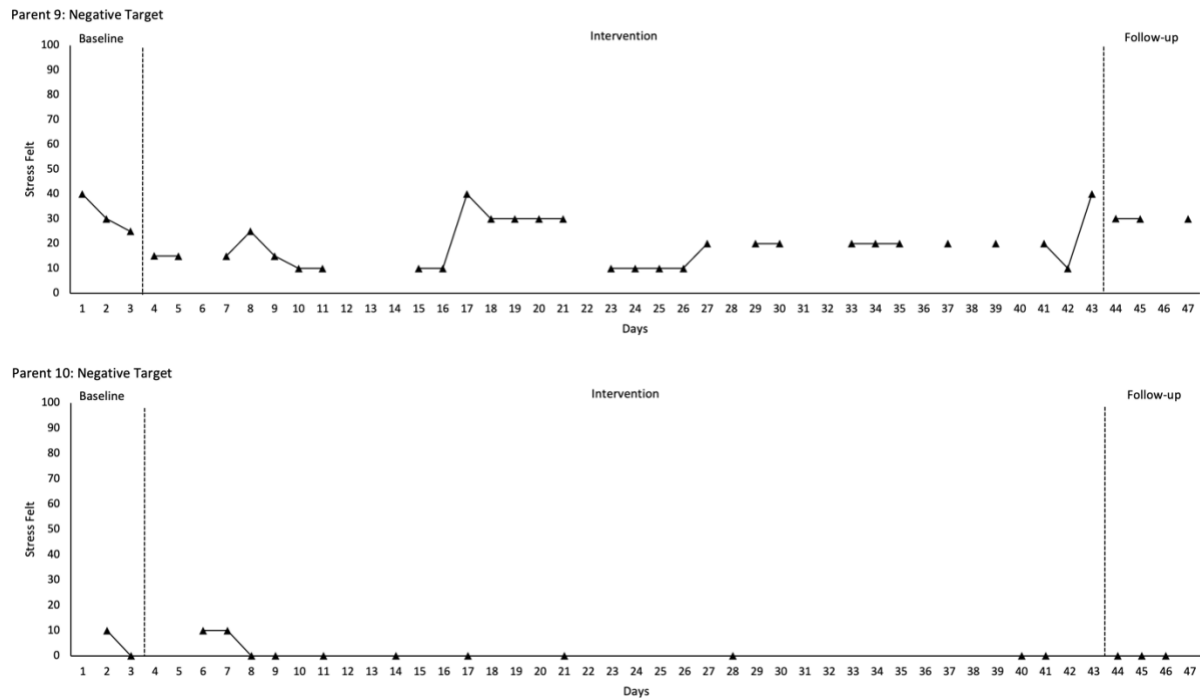
Question 2 – Negative target: How much stress did you feel today from \*target\* with \*child’s name\*?



**Figure 5.2. (Continued).** Negative targets: Scores (4 times weekly) for stress-framed idiographic parenting stress questions. Higher scores indicate greater stress felt (0-100). Question 2 – Negative target: How much stress did you feel today from \*target\* with \*child’s name\*?



**Figure 5.2. (Continued).** Negative targets: Scores (4 times weekly) for stress-framed idiographic parenting stress questions. Higher scores indicate greater stress felt (0-100). Question 2 – Negative target: How much stress did you feel today from \*target\* with \*child’s name\*?



### 5.3.1.2 Tau-U analysis

Baseline trends were corrected for (see Appendix E.10. for non-baseline-corrected Tau-U output). 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.

Five 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 5.2.** Mean Tau-U scores for parent’s positive targets (Question 1). Higher scores indicate greater success had (0-100).

Parent ID	Mean Tau-U scores for positive targets		
	Baseline	Intervention	Follow-up
1	41.60	76.50	91.25
2	59.30	36.50	51.50
3	83.30	56.63	81.25
4	13.30	46.40	40.00
5	76.60	38.13	46.25
6	47.60	67.63	78.75
7	65.00	74.50	63.75
8	25.00	50.90	58.75
9	80.00	56.38	48.75
10	0.00	0.00	0.00

**Table 5.3.** Mean Tau-U scores for parent’s negative targets (Question 2). Higher scores indicate greater stress felt (0-100).

Parent ID	Mean Tau-U scores for negative targets		
	Baseline	Intervention	Follow-up
1	6.60	16.75	2.50
2	60.60	45.80	54.00
3	45.00	35.63	37.50
4	30.00	19.63	20.00
5	56.60	28.88	18.75
6	46.60	23.58	18.75
7	61.60	37.38	15.00
8	45.00	26.20	38.75
9	31.60	13.88	22.50
10	3.30	0.50	0.00

**Table 5.4.** Tau-U results for parent participant positive success-framed targets (Question 1).

Parent ID	Comparisons	Tau	SD <i>Tau</i>	<i>p</i>	CI (90%)
1	Baseline to intervention	0.6833+	0.3496	0.0506*	0.108<>1
	Baseline to follow-up	1.0833+	0.4714	0.0216*	0.308<>1
	Intervention to follow-up	0.6125	0.3062	0.0455*	0.109<>1
2	Baseline to intervention	-0.5926	0.3514	0.0917	-1<>-0.015
	Baseline to follow-up	-0.5	0.4714	0.2888	-1<>0.275
	Intervention to follow-up	0.3056	0.3081	0.3213	-0.201<>0.812
3	Baseline to intervention	-0.2353+	0.3524	0.5043	-0.815<>0.344

4	Baseline to follow-up	0+	0.4714	1	-0.775<>0.775
	Intervention to follow-up	0.2279	0.3092	0.461	-0.281<>0.737
	Baseline to intervention	0.5702+	0.3504	0.1037	-0.006<>1
5	Baseline to follow-up	0.5+	0.4714	0.2888	-0.275<>1
	Intervention to follow-up	-0.2105	0.3071	0.493	-0.716<>0.295
	Baseline to intervention	-0.1389+	0.36	0.6997	-0.731<>0.453
6	Baseline to follow-up	-0.4444+	0.5092	0.3827	-1<>0.393
	Intervention to follow-up	0	0.36	1	-0.592<>0.592
	Baseline to intervention	0.693+	0.3504	0.048*	0.117<>1
7	Baseline to follow-up	1.0833+	0.4714	0.0216*	0.308<>1
	Intervention to follow-up	0.0066	0.3071	0.9829	-0.499<>0.512
	Baseline to intervention	0.4167+	0.3496	0.2333	-0.158<>0.992
8	Baseline to follow-up	0.7778+	0.5092	0.1266	-0.060<>1
	Intervention to follow-up	0.425	0.3496	0.2241	-0.150<>1
	Baseline to intervention	0.4615+	0.35	0.1873	-0.114<>1
9	Baseline to follow-up	0.8333+	0.4714	0.0771	0.058<>1
	Intervention to follow-up	0.0962	0.3066	0.7538	-0.408<>0.601
	Baseline to intervention	0	0.3556	1	-0.585<>0.585
10	Baseline to follow-up	-1	0.5092	0.0495*	-1<>-0.162
	Intervention to follow-up	-0.7931	0.3556	0.0257*	-1<>-0.208
	Baseline to intervention	0	0.4606	1	-0.758<>0.758
Weighted average	Baseline to follow-up	0	0.5774	1	-0.950<>0.950
	Intervention to follow-up	0	0.3892	1	-0.640<>0.640
	Baseline to intervention	0.1922	---	0.0954	0.0026<>0.3818
	Baseline to follow-up	0.2484	---	0.1122	0.0088<>0.5056
	Intervention to follow-up	0.0774	---	0.4598	0.0949<>0.2497

Note: \*Indicates significance. +Indicates baseline trend corrected.

**Table 5.5.** Tau-U results for parent participant negative stress-framed targets (Question 2).

Parent ID	Comparisons	Tau	SD Tau	p	CI (90%)
1	Baseline to intervention	0.1538	0.4237	0.7165	-0.543<>0.851
	Baseline to follow-up	-0.75	0.5401	0.1649	-1<>0.138
	Intervention to follow-up	-0.7115	0.3066	0.0203*	-1<>-0.207
2	Baseline to intervention	-0.4444	0.3514	0.2059	-1<>0.134
	Baseline to follow-up	-0.5	0.4714	0.2888	-1<>0.275
	Intervention to follow-up	0.0694	0.3081	0.8217	-0.437<>0.576
3	Baseline to intervention	-0.2157+	0.3524	0.5405	-0.795<>0.364
	Baseline to follow-up	-0.5833+	0.4714	0.2159	-1<>0.192
	Intervention to follow-up	-0.0294	0.3092	0.9242	-0.538<>0.479
4	Baseline to intervention	-0.193+	0.3504	0.5818	-0.769<>0.383
	Baseline to follow-up	0.0833+	0.4714	0.8597	-0.692<>0.859
	Intervention to follow-up	0.0132	0.3071	0.9658	-0.492<>0.518
5	Baseline to intervention	-0.1304+	0.3612	0.718	-0.725<>0.464
	Baseline to follow-up	-0.5833+	0.4714	0.2159	-1<>0.192

6	Intervention to follow-up	-0.7065	0.3185	0.0265*	-1<>-0.183
	Baseline to intervention	-0.6754+	0.3504	0.0539*	-1<>-0.099
	Baseline to follow-up	-0.9167+	0.4714	0.0518*	-1<>-0.141
7	Intervention to follow-up	0.0592	0.3071	0.8471	-0.446<>0.564
	Baseline to intervention	-0.725	0.3496	0.0381*	-1<>-0.150
	Baseline to follow-up	-1	0.5092	0.0495*	-1<>-0.162
8	Intervention to follow-up	-0.475	0.3496	0.1742	-1<>0.100
	Baseline to intervention	-0.2137+	0.35	0.5415	-0.789<>0.362
	Baseline to follow-up	0.0833+	0.4714	0.8597	-0.692<>0.859
9	Intervention to follow-up	0.3397	0.3066	0.2679	-0.165<>0.844
	Baseline to intervention	-0.7011+	0.3556	0.0486*	-1<>-0.116
	Baseline to follow-up	0.3333+	0.5092	0.5127	-0.504<>1
10	Intervention to follow-up	-0.7931	0.3556	0.0257*	-1<>-0.208
	Baseline to intervention	-0.3182	0.4606	0.4897	-1<>0.439
	Baseline to follow-up	-0.5	0.5774	0.3865	-1<>0.450
Weighted average	Intervention to follow-up	-0.1818	0.3892	0.6404	-0.822<>0.458
	Baseline to intervention		---		-0.5500<>-
	Baseline to follow-up	-0.3563		0.0025*	0.1626
	Intervention to follow-up	-0.4294		0.0064*	0.1705
		-0.0924		0.3716	0.2624<>0.0777

Note: \*Indicates significance at  $p < .05$ . +Indicates baseline trend corrected.

### 5.3.2. Standardised measures of quality of life, 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; PSISF-4=15.00; PHQ-9=6.00; GAD-7=4.00; FDLQI=6.15; CDLQI=5.08 (Heapy et al., 2022) (see Table 5). Scores were calculated by entering standard deviation and reliability data from reference samples using each standardised measure into a reliable change criterion calculator (<https://www.psyctc.org/stats/rcsc1.htm>) (Heapy et al., 2022).

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. Parents 1, 2, 6, 8 and 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. Parents 1, 2, 3, 6, 7, and 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. Parents 1, 6 and 7 showed reliable improvements in depression from baseline to post-intervention, and maintained from baseline to follow-up. Parents 1, 2, 6, 7, and 10 showed reliable improvements in quality of life from baseline to post-intervention, and parents 1, 2, 6, 7, 8, and 10 showed reliable improvement from baseline to follow-up. Parents 4, and 9 did not show any improvements across the intervention phases.

Children 2, 5, and 8 showed reliable improvement in quality of life 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 quality of life 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 5.6.** Scores at four time points for measures of parenting stress, anxiety, depression, mindfulness, parent quality of life, and child quality of life.

Dyad ID	Timepoint	Parenting Stress (PSI-SF-4)	Anxiety (GAD-7)	Depression (PHQ-9)	Mindful parenting (IEM-P)	Parent quality of life (FDLQI)	Child quality of life (CDLQI)
1	Baseline	83.00	13.00	7.00	37.00	18.00	10.00
	Pre-intervention	91.00	11.00	3.00	37.00	11.00	9.00
	Post-intervention	78.00	6.00*	2.00*	36.00	10.00*	7.00
	Follow-up	79.00	4.00*	1.00*	38.00	9.00*	6.00
2	Baseline	76.00	7.00	4.00	36.00	23.00	17.00
	Pre-intervention	69.00	6.00	5.00	39.00	22.00	21.00
	Post-intervention	49.00*	0.00*	0.00	42.00	8.00*	8.00*
	Follow-up	41.00*	2.00*	0.00	44.00	10.00*	12.00*
3	Baseline	97.00	12.00	10.00	36.00	15.00	
	Pre-intervention	95.00	17.00	10.00	33.00	19.00	
	Post-intervention	85.00	18.00+	13.00	42.00	18.00	
	Follow-up	88.00	8.00*	6.00	40.00	15.00	
4	Baseline	76.00	4.00	1.00	32.00	11.00	3.00
	Pre-intervention	89.00	9.00	3.00	30.00	11.00	2.00
	Post-intervention	80.00	2.00	2.00	34.00	7.00	2.00
	Follow-up	75.00	4.00	2.00	37.00	7.00	1.00
5	Baseline	63.00	6.00	5.00	34.00	13.00	11.00
	Pre-intervention	50.00	5.00	3.00	36.00	14.00	13.00
	Post-intervention	60.00	4.00	4.00	34.00	12.00	5.00*
	Follow-up	57.00	5.00	4.00	39.00	14.00	7.00
6	Baseline	105.00	17.00	18.00	28.00	23.00	12.00
	Pre-intervention	125.00	14.00	11.00	24.00	19.00	12.00
	Post-intervention	89.00*	6.00*	3.00*	32.00	5.00*	10.00
	Follow-up	107.00	5.00*	4.00*	34.00	9.00*	7.00*

7	Baseline	117.00	6.00	9.00	33.00	10.00	4.00
	Pre-intervention	113.00	6.00	8.00	29.00	8.00	1.00
	Post-intervention	98.00*	4.00	3.00*	36.00	4.00*	1.00
	Follow-up	101.00*	1.00*	4.00*	35.00	4.00*	1.00
8	Baseline	89.00	6.00	4.00	27.00	7.00	11.00
	Pre-intervention	94.00	6.00	9.00	27.00	8.00	7.00
	Post-intervention	75.00	2.00*	3.00	32.00	6.00	2.00*
	Follow-up	81.00	4.00	4.00	36.00*	1.00*	2.00*
9	Baseline	50.00	0.00	0.00	42.00	5.00	6.00
	Pre-intervention	43.00	0.00	2.00	40.00	4.00	6.00
	Post-intervention	53.00	2.00	0.00	40.00	6.00	9.00
	Follow-up	43.00	5.00+	3.00	43.00	6.00	9.00
10	Baseline	46.00	5.00	2.00	42.00	13.00	
	Pre-intervention	36.00	0.00	0.00	46.00	8.00	
	Post-intervention	42.00	0.00*	0.00	46.00	6.00*	
	Follow-up	36.00	0.00*	0.00	42.00	3.00*	

*Note:* \*Indicates reliable change from baseline to post-intervention, and baseline to follow-up. +Indicates reliable deterioration from baseline to post-intervention, and baseline to follow-up. Range of questionnaire scores: PSI-SF-4 (36–180); GAD-7 (0–21); PHQ-9 (0–27); IEM-P (10–50); FDQLI (0–30); CDLQI (0–30). Higher scores indicate higher levels of parenting stress, anxiety, depression, and mindfulness. Higher scores indicate poorer parent and child quality of life.

### 5.3.3. Qualitative feedback

Three themes and seven subthemes were identified as central to describing n=9 parents' experiences of taking part in the Present mindfulness group (n=1 parent could not attend the exit interview for personal reasons), combined with n=1 course teacher observations (see Table 5.7). Each theme will be discussed with supporting quotes taken from individual interviews (participant number; page numbers, line numbers/ 'T' for teacher). See Appendix E.11., for parental change ratings.

**Table 5.7.** Main themes and subthemes, and the corresponding participant number from individual interviews with n=9 parents, and n=1 mindfulness teacher.

Main Theme	Subtheme	Participant
1. Noticing the benefits of mindfulness	1.1. Shifts in parental mood and attitude	1,3,4,5,6,7,8,9,10, T
	1.2. Healthier interactions with child	1,3,4,5,6,7,8,9,10
2. Acceptability of mindfulness exercises	2.1. Bringing mindfulness into daily life	1,3,4,5,6,7,8,9,10
	2.2. Preferences for different course components	1,3,4,5,6,9, T
	2.3. Suggestions for future interventions	1,3,4,5,6,7,8,9,10, T
3. Challenges of taking part in an intervention	3.1. Pros and cons of a group format	1,3,4,5,6,7,8,9,10, T
	3.2. Pressures of time limiting ability to immerse in mindfulness	1,3,6,7,8,9,10, T

Note: 'T'= Teacher.

#### 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

Most parents described how mindfulness helped them to cope more adaptively with the daily stresses associated with providing care for their child's skin condition, often noticing they were "calmer and more aware of how you're feeling" (1; 2, 40-42):

I could take myself out of a situation if I'm extremely frustrated, because the main frustration for me is getting appointments for my daughter, so just getting

through that mindfulness session, it gets your mind off things and you feel renewed (10; 10, 70-72).

I just felt more relaxed, and less stressed, and generally happier and more content (3; 5, 109).

It was the change in mindset...how these feelings are normal, but we can control them in a certain way and tune into how your body's feeling...mindfulness brings it back to you...because if you don't look after yourself as a carer and as a mum, how are you going to then be able to look after your child to the best of your ability? (7; 8, 183-190).

The mindfulness teacher noticed there were visible differences in the behaviour of parents as the weeks progressed, and those that “attended regularly, they were very enthusiastic” (T; 2, 33):

Most of the participants that attended regularly, you could visibly see less of a frenetic body language...and they would report quite a lot of everyday situations where they noticed and paused...that was coming through every week (T; 5, 121-125).

However, two parents described the journey to seeing the benefits of practicing being more aware of their thoughts, as “a mixed blessing, because it's nice to notice good stuff...but you also notice all the things that are not great” before “ultimately getting to a better place” (4; 3, 60-65).

You're not always going to notice happy feelings, so some things have made me a little bit down because I've realized that I'm not living genuinely...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 (8; 4, 75-79).

Two parents also reported noticing other people's interactions changing, with more people engaging in conversation with them, which was seen as a positive and a negative:

I think I'm pretty empathetic, so if I'm becoming more aware of other people's feelings, that's helped with the listening, and having people open up more (8; 10, 231-232).

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? (4; 5, 102-106).

## **1.2. Healthier interactions with child**

In some cases, parents had noticed transferrable outcomes for their children, with improved communication since they had learnt “not to overreact” (1; 5, 122). Parents attributed this to how their mood influenced their children’s behaviour, with many children becoming stressed when they “feed off” their emotions (6; 5, 109) and “mirrored” their feelings (3; 5, 114):

I've realized not to press his buttons...it's okay if he's at home and his skin is a mess, but if he's going to school then that's the time I have to step in...I'm more mindful that I don't want him getting upset...the communication has improved (1; 5, 115-119).

Me and Charlie used to wind each other up and it would escalate, or I would have to leave the room...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 (6; 2, 38-41).

Some parents described how interactions surrounding treatment regimens had become more manageable, and had found they were “dealing with it better” (3; 4, 84).

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 so I'm more mindful about our relationship (7; 4, 84-86).

She would get less frustrated and she'd be easier to deal with when we were doing all the creams for her eczema, because as a family we were more relaxed (3; 5, 118-119).

Other parents commented on involving their children in learning mindfulness exercises and the research:

Encouraging him to notice his skin condition and how he feels...with eczema, he gets a tingle first and then it breaks out, so noticing that (4; 6, 128-130).

[Erin's] loved doing all this with you [researcher] filling in the questionnaires, so all of that has just made her such a happier kid (5; 2, 30-31).

## **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, including learning the underlying theory, breathing exercises, and meditation.

### **2.1. Bringing mindfulness into daily life**

Parents discussed how they had incorporated mindful activities into their daily routines and everyday life, with a willingness to “try anything to help” (6; 7, 171) their children:

In our family...being present is what we always try and do if we're having an escalation of worry, we try and just bring it back to 'okay, what's happening right now'...we've had a lot of trauma in our life and your brain takes you to the worst-case scenario...that fight or flight response, just kind of dial it down (1; 9, 211-216).

The breathing techniques when I'm not able to get to sleep at night, because I'm thinking about what's going on (7; 3, 65-67).

I drive a lot to take the kids different places that stresses me out normally, 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...slowing down, that's been a big thing (8; 3, 49-53).

However, one parent (10) described how they felt less stress currently, and was taking part in the intervention as a preventative measure, to have the skills to cope if their young child's skin got worse in the future:

I just wanted to be equipped for the future, when things get tough, I just thought, I need something now, because if I had waited to do this, and then things get bad, I might not have been able to cope... (10; 5, 99-101).

## **2.2. Preferences for different course components**

However, opinions on mindfulness exercises were mixed, and some were received better than others, as some parents described “prioritizing the practical stuff” (1; 8, 197-198) and not responding 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? And why is he telling us to be more kind? (4; 9, 219-221).

The theory bit when he got in detail about the brain, some of the words I could hardly even read...I'm just not sure of the relevance (5; 16, 383-384).

I find it much easier to when I'm actually moving...I found just sitting still and thinking about being mindful was quite frustrating (9; 3, 58-60).

The comments of the mindfulness teacher mirrored some of the parents and they had also noticed that “some of the theory didn't gel for everyone” (T; 11, 263), which, they speculated could have been related to level of practice or possibly compounded by being online and lack of personal connection:

It might have been influenced by how much practice they were doing...if you're not practicing then it's just cognitive and not experiential, so I wonder if that was it? It was suddenly cognitive, and it was me almost lecturing, whereas normally it's speaking to their experience (T; 11, 269-273).

## **2.3. Suggestions for future interventions**

Parents provided some useful suggestions for how mindfulness could be amended and tailored to their specific needs for future interventions, including reducing the intensity in terms of length of sessions:



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 (9; 10, 236-238).

The majority of parents favoured an online format. However, one parent described how they “miss body language” (5; 15, 361) with online delivery, although acknowledged feeling more comfortable practicing exercises with more control over visibility:

I'd say in person every time...but I suppose I would have felt silly in a group...like standing on one leg and shifting your weight (5; 15, 361-368).

Importantly, another parent described how they would not have been able to participate in the intervention if it had involved travelling to a location, highlighting the inclusivity of digital delivery:

I wouldn't have taken part if I had to travel because of the resources, I could not have managed that with children (10; 9, 207-208).

The mindfulness teacher agreed that although “the time wasn't ideal for many, perhaps there isn't an ideal time” (T; 2, 42) for parents juggling work and childcare commitments. The mindfulness teacher also highlighted the benefits of online delivery:

We've got to keep it as accessible as possible, so therefore, 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 (T; 7, 152-154).

### **Theme 3: Challenges of taking part in an intervention**

Although the mindfulness sessions were generally well-received, parents highlighted challenges and barriers to participation.

#### **3.1. Pros and cons of a group format**

The feedback on the delivery of mindfulness in a group format was varied, with some parents appreciating connecting with other parents:

Everyone else thinks 'oh he's gonna grow out of it', so being with people that understand about the hospital appointments, and the creams, and the potions and lotions (6; 9, 206-208).

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 (8; 12, 276-281).

It's nice to know that it's not just you who's kind of juggling dermatologist appointments and ordering repeat prescriptions, and having to spend all that time helping them to moisturize (9; 9, 216-218).

Other parents discussed finding it "hard to open up sometimes" from feeling "self-conscious" as when "in a group I just tend to be a bit quiet" (6; 9, 214-216). Of note, one parent of a child with ichthyosis did not want to "burden" other group members, as "different conditions have different stresses and strains on different families, but we're on the extreme side of it" and other people are "not living that same life" (1; 4, 85-87):

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 (1; 4, 77-82).

The mindfulness teacher's observations supported parental reports of peer support within the group setting:

There was a lot of interest and motivation...they particularly enjoyed turning up each week and spending time with a group and guiding the activities as facilitated, and then a strong and supportive group formed (T; 3, 57-59).

### 3.2. Pressures of time limiting ability to immerse in mindfulness

One of the challenges faced by parents was finding the time in their busy family schedules to practice mindfulness, which appeared to be related to the significant burden of care. Subsequently, some parents “didn't do a lot of the homework...for timing reasons ” (1; 11, 264):

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 (1; 3, 56-57).

With a young child and having a weekly commitment for eight weeks is quite a big ask, but saying that, I didn't miss a session (3; 8, 182-183).

Sometimes I would get stressed because of the timing, but there's nothing with the course in itself that I didn't enjoy (8; 12, 288-289).

The mindfulness teacher similarly reported that for some parents, there was “difficulty committing and attending the sessions regularly” (T; 2, 24-25), despite, “one of the reasons why we thought this would be useful is the extra pressures and the demands and the stresses and strains in their context”. The challenge of making time to attend “did show up through the course, even though this mindfulness course is designed to be accessible, and as minimal as possible” (T; 2, 27-30):

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 (T; 4, 87-92).

The range of pressures on the time of the practices, given that they were busy parents, and most of them were working but also with the extra pressures of caring for their children's skin conditions...my perception is...they picked two or three of the most accessible ones, which is part of this approach, to offer choice and start with what feels accessible...let's make this meaningful, let's work this into our lives so we can see how it can be beneficial...but this group...as we worked through the course and started suggesting longer practices, only a few of them really showed that they'd managed to squeeze those in (T; 5, 105-112).

For example, one parent (3) provided an explanation for their deterioration in anxiety scores from baseline to post-intervention as being a result of worry about their child with eczema starting nursery at the same time as the mindfulness course:

I felt bad doing the surveys, because it probably seemed to you like it wasn't helping me but that was because we were going through a lot of changes with the nursery, so it's been quite a stressful time for us, but I had to answer them honestly, because it said for the last two weeks...but that's not a reflection on the course (3; 3, 70-73).

#### **5.3.4. 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 full sessions from the mindfulness group intervention were audio recorded, and independently reviewed by one of the Present programme co-founders. Consensus was reached between researchers that the course content was being delivered as per protocol, and sufficiently met the requirements on the checklist to confirm fidelity.

#### **5.4. Discussion**

This was a pilot study investigating the Living in the Present mindfulness-based programme for parents of children with skin conditions. To do this, a single-case experimental design was used with parental bespoke targets being collected four-times weekly, and measures of parent and child wellbeing collected at baseline, pre-intervention, post-intervention, and at follow-up. To determine feasibility and acceptability, qualitative exit interviews were held with each individual parent and the mindfulness teacher to discuss their experience of the intervention.

Analysis of parental bespoke measures revealed three parents showed some significant improvements in positive success-framed measures, and five parents showed some significant improvements in negative stress-framed measures. For the standardised measures of quality of life, eight parents and four children showed reliable improvements in at least one phase of the intervention. One parent showed

improvement in mindful parenting at follow-up. Three parents showed improvement in parenting stress from baseline to post-intervention, and this was maintained by two parents at follow-up. Seven parents showed improvement in anxiety, including: six parents showed improvements in anxiety from baseline to follow-up, and five parents showed improvements in anxiety from baseline to post-intervention. Three parents showed improvements in depression from baseline to follow-up. Six parents showed improvement in quality of life, including: five parents showed improvements in quality of life from baseline to post-intervention, and six parents showed improvement from baseline to follow-up. Four children showed improvement in quality of life: three children showed improvement in quality of life from baseline to post-intervention, and three children showed improvement from baseline to follow-up. However, two parents and four children showed no reliable improvements, and two parents showed a reliable deterioration in anxiety from baseline to post-intervention, and baseline to follow-up.

Although several of the children with skin conditions appeared to derive benefits from mindfulness, the impact of skin conditions on the quality of life of children varied. The child with the greatest impairment to quality of life (Child 2) showed improvement, as did their mother. The children of the parents who did not show reliable improvement in standardised measures of quality of life (Parents 4 and 9) also did not show any improvements across intervention phases (Child 4 and 9). Child 7 had the lowest impact scores to quality of life, so it was not possible to measure (reduction of 5), and Child 1 did decrease by 4 scores, but did not meet the threshold for reliable improvement. Despite this, and perhaps one of the most noteworthy findings, was how several parents noticed favourable outcomes in their children over the duration of taking part in mindfulness sessions. Many of the parents found communication with their children improved, which had resulted in less family stress, and greater quality time spent together from responding differently to situations (Portnoy et al., 2022; Ruskin et al., 2018). For the parents who noticed positive changes in their children, there was an increased sense of calmness in their relationship, less distress arising from the pressure of treatment regimens (van Gampelaere et al., 2019), and a reduction in conflict in the household.

For parents themselves, the qualitative data suggested all participants were able to take something useful away from the mindfulness intervention, and all

parents were able to identify a plethora of positive changes in themselves since taking part. One parent described taking part in the mindfulness group as a preventative measure for the future, to be able to cope with the unpredictable nature of their child's rare skin condition as they grew older. During the exit interviews, parents described the benefits they had experienced from learning mindfulness exercises, including feeling calmer and more relaxed in the immediate days following a group session, corroborated by the mindfulness teacher who noticed a visible difference in several of the parent's demeanour over the weeks they spent together.

In terms of acceptability, the group format was generally well-received, and parents enjoyed connecting with other families with shared experiences (Heapy et al., 2022; Hughes et al., 2022). Being in a group of parents who had similar health concerns about their children was reassuring, and parents felt that their worries were validated from connecting with people who understood their concerns (Ruskin et al., 2018). Similar findings were reported in a qualitative investigation of a mindfulness-based intervention with parents of children with chronic illnesses, who discussed how being in an accepting and supportive group allowed them to feel less alone and more able to give themselves permission for self-care (Portnoy et al., 2022).

Most parents favoured an online format for accessibility, saving on travel expenditures, and feeling more comfortable practicing exercises in the privacy of their own homes, although the disadvantage of missing out on body language was raised. Previous findings comparing the effectiveness of MBIs delivered face-to-face or online have shown there may be little difference in terms of delivery (Portnoy et al., 2022), so an online format could be viable. However, some parents noted the challenges of the timing of the intervention being in the evenings, where they were undertaking bedtime routines with their children. This was difficult, as offering an intervention during daytime hours would have affected recruitment and meant that parents in employment would not have been able to participate. Although most parents successfully incorporated mindfulness exercises into their daily routines, opinions on certain techniques varied. In this case, parents provided some useful suggestions for how future mindfulness programmes could be tailored to their specific needs, including a reduction in the intensity of length and number of sessions. The experience of mindfulness could have depended on the type and

severity of skin condition affecting the individual families. For example, a parent of a child with ichthyosis felt it was more difficult to connect with other group members, as rarer symptoms were involved. This could also be true of upholding personal practice. For some parents, finding the time to attend sessions and carry out practices outside of the group was a challenge in their busy routines.

Despite previous participant 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. Indeed, parents lacking time to practice could explain the variation in psychological outcomes. This is not unusual when considering the additional demands placed on parents (Hughes et al., 2022), and has been reported in previous MBIs for parents of children with other health conditions (Harris et al., 2021). If parents did not have time to complete homework exercises outside of the mindfulness group sessions, they may not have built up the necessary training to demonstrate reliable change across the intervention period.

Although the Present programme does not require formal practices (The Present Courses, 2022), there needs to be some mindful activity during everyday life to embed the approach. The challenges reported by parents in practicing activities mindfully outside of scheduled sessions could have impacted on engagement with course content. This could have been a reason for both parents and the mindfulness teacher narratives' highlighting how several participants did not enjoy the theory components of sessions. Whilst the theory is important for psychoeducation, some parents did not respond to the use of metaphors. Although metaphors are commonly used in a range of psychotherapeutic approaches (e.g., cognitive behavioural therapy) to explain concepts in abstract ways (Mathieson et al., 2016), many people may prefer to learn in more concrete ways.

Another potentially related outcome was how several parents described having an increased awareness of thoughts was challenging, as they had also noticed the 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). Similar findings were reported by Harris et al. (2021) where a mindfulness-based

intervention was delivered to parents children with cystic fibrosis, and qualitative findings revealed one mother chose to stop practicing at home as it made her feel bad about herself, but accepted it 'with kindness.' Practicing mindfulness is associated with psychological flexibility (Ruskin et al., 2019), and the ability to stand back and separate from negative thoughts rather than being caught up in them. In order to change the impact of distressing inner experiences, mindfulness must be practiced and embedded into daily routine by noticing thoughts and cultivating an attitude of acceptance, instead of reactivity, which could improve over time with practice (Lomas et al., 2015). Despite the challenges that might be initially encountered, mindfulness has the overarching aim of teaching people to engage with all thoughts, including difficult and unpleasant ones (Engler 2003, in Lomas et al., 2015).

Unexpectedly, parents also found that more people were conversing with them in public over the course of the intervention. It could be possible that this phenomenon of being approached by other people was happening before they began the intervention, and they perhaps just began to notice it more since taking part in mindfulness and started to develop an attitude shift towards acting with more awareness. For example, qualitative research with men has shown that many felt they had become more sensitive to both their inner world and the external world around them after meditating, as a result of being disconnected from their environments (Lomas et al., 2015). Alternatively, it could be that parents began to appear visibly more relaxed and open to new experiences (as a less frenetic demeanour was highlighted by the mindfulness teacher), so these parents might have been more likely to be approached by other people from having friendly or welcoming body language.

A deterioration in anxiety was seen in two parents (Parent 3 and Parent 9). For parent 3, they scored high for anxiety at baseline (score of 12), which increased pre-intervention (score of 17), again at post-intervention (score of 18) but reduced at follow-up (score of 8). This parent attributed their increased anxiety scores to experiencing stress as a family unit at the same time as the mindfulness programme, as their child with eczema was starting nursery. However, Parent (9) reportedly had no anxiety at baseline or pre-intervention and scored their self-report measure as



zero, which increased post-intervention (score of 2) and again at follow-up (score of 5). One explanation for this parent's result, could be that they started to become more aware and better connected with their physiological sensations over the course of the intervention.

Importantly, neither of these parents' spoke of their anxiety increasing during exit interviews as a result of the intervention, so it could be possible they were developing more mindfulness skills and were becoming more aware of what was happening in their body in a more accepting way. For example, there could have been more of an attentional focus developing, with parents engaging in more accurate reporting of symptoms. Indeed, acceptance and non-judgement are facets of mindfulness, and one of the core concepts of the approach is not to reduce or target anxiety, but to be more aware of the body with kindness and self-compassion. Parents could have been previously underestimating their emotions and might have got better at identifying their feelings as the course progressed. Indeed, there could be an association between learning mindfulness, and the theoretical framework of emotional regulation, or the processes involved in how an individual experiences their emotions, including the ways in which emotions are noticed and processed (Gross, 1999, in Lomas et al., 2015). However, there is little evidence investigating the challenges and downsides associated with learning mindfulness and the explanations for individual differences (Lomas et al., 2015).

When determining the relevance of providing support services, prudent healthcare should only offer interventions that are useful, but usefulness is hard to determine. Although not every parent demonstrated reliable improvements or significance in QoL scores between study phases, all of the parents were able to identify positive outcomes at interview. This was one of the strengths of adopting a mixed methods approach, as although parent scores did not all strongly indicate meaningful change, every parent that completed the intervention reported they enjoyed the mindfulness course, would recommend it to a friend, and described how they would be sharing with their children many of the skills they had learned. Parents were also able to contextualise less favourable scores (e.g., deterioration in anxiety) and provide detailed information on the physiological changes they had noticed. However, it is important to consider that there could have been an influence in terms

of social desirability, with parents reporting overly positive experiences during exit interviews. Although steps were taken in an attempt to reduce this (e.g., the researcher did not attend intervention sessions to remain impartial from the group, and the mindfulness teacher was separately interviewed), some of the parents could have been biased in their responses.

#### **5.4.1. Limitations**

The participants who formed the study sample might limit generalisability, as the study may have attracted people with specific experience or interest in mindfulness-based approaches and could affect external validity. For example, the mothers who volunteered could have had pre-existing knowledge of mindfulness, and could have been highly-motivated to take part in the intervention from their own areas of interest. Similar findings have been reported in previous studies investigating mindfulness with parents, with a lack of participation from fathers potentially resulting in an underrepresentation of gender-based differences in parenting styles (e.g., caregiver roles, parenting stress, mental health) (Russell & Guite, 2020). Although parents completed screening with dedicated forms (in line with the British Association of Mindfulness-based Approaches [BAMBA], 2023 guidelines), there could have been discrepancies between parental expectations of how much practice would be required to support learning. It would be useful for future studies to carry out registration via individual interviews as an in-depth method of screening for eligibility and to limit the risk of sampling bias.

Despite this study being a pilot investigation, the study had a short, predefined baseline period and consequently could have been more vulnerable to threats to internal validity. This might have been avoided had a longer multiple baseline design been used to enable possible greater stability and limit baseline trends. However, this was not feasible within the timeframe with consideration of pragmatic issues associated with the availability of the intervention, and there was also indication that this might not have been tolerated by the sample population (e.g., busy parents with additional care demands). As well as this, although SCED and change interview remain robust in identifying actual engagement and potential for effectiveness, there could have been further consideration of a framework approach to inform criteria. Last, it is difficult to draw conclusions on the impact of mindfulness on childhood skin

conditions from subjective self-report questionnaires, and could have been additionally assessed with clinician ratings. It is also important to remember that this study investigated the use of a complex intervention with multiple elements including different facets of intervention and was also delivered in a particular format (i.e., online group). Further studies might begin to explore which elements are most important/effective.

#### **5.4.2. Recommendations for future research**

This study investigated the delivery of a mindfulness-based intervention to parents and is a welcome step in the expansion of support interventions for families affected by skin conditions. However, it is important to remember that these findings only represent one curriculum, so it is difficult to determine efficacy. MBIs require further intensive research, and this study has highlighted several design features that could be changed to enable future trials (e.g., RCTs). There is a need for larger sample sizes and control groups to robustly investigate outcomes for this participant demographic and corroborate findings for improved parent/child communication. For example, the role of peer support could be usefully investigated with a comparison cohort, in order to determine whether engagement with mindfulness practices or peer support (e.g., WhatsApp group) were responsible for improving psychological outcomes. Levels of mindfulness could also be robustly evaluated as the primary outcome measure with alternative psychometric tools. Although bespoke measures of parental stress were the main target in this study, low Cronbach alphas (e.g., IEM-P; Duncan, 2007) could have impacted results.

Although there is increasing evidence to support the investigation of mindfulness with trials, there remain concerns about feasibility and delivery (e.g., online format) in terms of the time commitment for parents of children with skin conditions. As a result, further studies could focus on reducing the burden placed on families. Future research might also seek to purposively sample fathers, to represent caregiver roles equally and limit chances of recruitment bias. It could also be advantageous to run multiple groups at different times during the day to offer more flexibility for parents to select a time that fits with their family routines, as there would be value in collecting further practice based evidence from running additional groups with parents.

### **5.4.3. Conclusion**

This pilot study of the Living in the Present mindfulness curriculum adds to a number of other studies increasingly demonstrating the potential effectiveness of mindfulness with parents of children with a range of different skin conditions. Nevertheless, further research is required, and the intervention requires further testing before any determinations can be made.

### **5.4.4. Funding**

This research was supported by the Ichthyosis Support Group to fund the mindfulness teacher costs for delivering the intervention and fidelity checks.

## Chapter 6

### General Discussion

The research presented in this thesis sought to investigate online-based mindfulness support for children and families affected by skin conditions. The aims of the thesis were to systematically review the existing literature using MBIs with children with physical health conditions; to investigate parent and child experiences of skin conditions, and the relevance of offering MBIs; to investigate dermatology and psychology healthcare professionals' experiences of working clinically with families affected by skin conditions, and views on psychological support; and lastly, to assess the acceptability and feasibility of delivering a mindfulness-based intervention to parents of children living with skin conditions. Discussion of each of the individual studies are included in the previous chapters. This current chapter presents a general discussion of the conclusions that can be drawn from the research, including the relevance of mindfulness for families affected by skin conditions, the implications for clinical practice, strengths and limitations, future directions, and researcher reflections.

#### **6.1. The relevance of mindfulness for families affected by skin conditions**

Childhood skin conditions can have a profound impact on a young person (Ablett & Thompson, 2016), as Chapter 1 highlighted. This was supported by the research findings of Study 1 (Chapter 3) where interviews with parent and child dyads revealed the challenges living with a skin condition, including interruptions to daily life, lack of sleep, and emotional disturbances (Hughes et al., 2022). The findings are consistent with previous studies and highlight how skin conditions can overshadow childhood and cause distress during a critical time for development (De Vere Hunt et al., 2020; Linthorst Homan, 2008). The experiences reported by children are broadly suggestive of a negative impact to self-esteem, self-worth, and confidence (Harter, 1983, 1999, in Slater & Bremner, 2017). However, it is difficult to determine how these early experiences might impact on adult personality, and there is a need for longitudinal studies to assess the long-term impact of childhood skin conditions during later life. This study also illustrated how it is not just the child with

the skin condition that encounters challenges, but how their parents share the stresses of providing care (Hughes et al., 2022). Parents caring for their children appear to experience a significant psychological burden from overseeing intensive treatments, worry from living with uncertainty, increased expenditures and housework, and in some cases, mood disturbances (Hughes et al., 2022).

The impact to both children and their parents was corroborated by reports from a range of dermatology and psychology healthcare professionals, in Study 2 (Chapter 4). HCPs frequently observed clinical levels of distress in children, with anxiety, depression, and in severe cases, suicidal ideation and self-harm. Whilst for parents, HCPs often noticed their levels of distress, with emotional outbursts, breakdowns, exhaustion, caregiver burnout, and anger at the situation they are dealing with. The implications for siblings was also highlighted, with HCPs reporting how other children in the family unit often get overlooked, and can sometimes develop psychosomatic symptoms to get attention from their parents. Interestingly, it appears that the impact of skin conditions on the siblings of children diagnosed have received relatively little attention in the literature. It was also evidenced by several HCPs how parental coping can impact directly on the child's skin condition. Recent research by Kobusiewicz et al., (2023b) has similarly reported a significant positive correlation between quality of life in mothers of children with AD and severity of disease in the child.

Findings from the systematic review presented in Chapter 2 have shown that for many physical health conditions including chronic pain, and chronic conditions (e.g., cancer, heart conditions, headaches, esophageal atresia, IBD, PCOS) mindfulness-based approaches could be effective for reducing the associated emotional burden, including targeting caregiver stress, and child anxiety and depression. However, the systematic review illustrated gaps in the existing evidence base (Hughes et al., 2023). The heterogeneity of study designs meant it was difficult to make generalisations about the effectiveness of MBIs, and pointed towards the need for further research to rigorously test the approach with robust methods (e.g., RCTs) (Hughes et al., 2023). However, the review usefully highlighted how (1) there appears to be a lack of parental involvement in MBIs, and (2) there have been no

existing studies, to our knowledge, delivering a mindfulness-based intervention directly to children and adolescents with skin conditions.

The interviews with parent and child dyads carried out in Study 1 (Chapter 3) have shown that the main targets of an intervention could be the stresses associated with caring for a child with a skin condition, managing painful symptoms (e.g., itch) and the associated negative affect (Hughes et al., 2022). Children appeared to be receptive to the suggestion of trying mindfulness-based exercises, and many of those interviewed were familiar with the approach from school. Indeed, some of the children were already practicing self-compassion (Hughes et al., 2022). With the use of positive affirmations, children were able to cope with the negative affect arising from living with a skin condition. In support of this, a recent network analysis by Vasiliou et al., (2023) revealed how levels of anxiety can contribute to stigma, and increased psychological flexibility and being open to the experience of stigma rather than avoidance could result in less stigmatization. If the facet of self-compassion could be strengthened with mindfulness practices, there could be potential to reduce the psychological burden in children.

Indeed, it was an unexpected finding that many children were already naturalistically relying on strategies overlapping with mindfulness, and this could support the future delivery of mindfulness-based interventions from there being a pre-existing familiarity with the approach. Children also described the use of mental imagery to manage their symptoms, including itch, which may point towards the effectiveness of mindfulness for controlling bodily sensations. In his most recent work, Jon Kabat-Zinn (2023) describes how mindfulness meditation can be used to manage pain associated with chronic health conditions. Kabat Zinn (2023) outlines how people can learn to live with pain by cultivating a different relationship with uncomfortable body experiences. Instead of attempting to resist pain, an attitude of openness and acceptance can be adopted by “befriending” the unpleasant experience, rather than focusing on what is “wrong” with the body (Kabat-Zinn, 2023). With regular practice, this approach can reduce reactivity from the “uncoupling of distressing symptoms” from the domain of “suffering” (Kabat-Zinn, 2023).

Along with children, parents were also open to practicing mindfulness, and welcomed additional support to reduce their levels of caregiver stress (Hughes et al., 2022). Parents experienced a range of intense emotions, from sadness, helplessness, hopelessness, anxiety, worry, to guilt (Hughes et al., 2022). Given the fact that many skin conditions are lifelong and have potential to affect children throughout the entirety of their childhood and beyond adolescence, parents must be equipped to manage the associated stresses with sustainable coping mechanisms that can be drawn upon during times of need (e.g., after a failed treatment, or during a flare-up). If parents stress levels can be directly targeted with psychological interventions, such as mindfulness, there could be an opportunity to reduce the stresses arising from caring for a child with a skin condition. Parents described difficulties in acquiring the appropriate level of support and the lack of psychological awareness in the dermatology treatment pathway.

The reports from children and parents were supported from a HCP perspective in Study 2 (Chapter 4), and it was promising to interview clinical psychologists who provided their insights into how they had previously used mindfulness with children and families to promote positive therapeutic outcomes (e.g., increased family cohesiveness, and reduction in stress). For example, several clinical psychologists felt mindfulness could promote bonding between parents and children, and gave examples of families they had encouraged to engage in group exercises together. Clinical psychologists mirrored parent and child reports of the need to incorporate mindfulness exercises into existing daily routines, and sought to do this by developing games for children using mindful exercises. These included 'mindful bubbles' with children practicing breathing exercises to the rhythm of a bubble machine, whilst waiting for their moisturizer to sink in; and a 'mindful rainbow' being painted on a child's bedroom wall to guide breathing exercises as a family unit. Examples were also given of mindfulness being used in clinical settings, with group interventions running for parents of children attending outpatient departments, seemingly successfully supporting parents enough for them to not require referral to specialist services (see Chapter 4).

Dermatologists speculated how there could be positive physiological changes in the body from children with skin conditions practicing mindfulness, such as



reducing inflammation (Carlson et al., 2007; González-Moret et al., 2020; Black & Slavich, 2016) and upregulating skin healing from reducing stress (Hunter et al., 2015). A recent review by Cameron et al., (2023) explored the relationship between inflammation, sleep disturbance, and psychological outcomes in AD, and highlights how sleep deprivation can affect the functioning of the immune system with the expression of inflammatory cytokines/biomarkers, and also lead to the dysregulation of the HPA axis. As outlined in Study 1 (Chapter 3), this could be particularly relevant for families affected by itchy skin conditions, such as AD, as parents and their children often experience significant disruptions to sleep from children waking in the night to scratch their skin, parents having to co-sleep, and applying topical treatments at regular intervals.

Additionally, there is evidence to suggest a bidirectional relationship between inflammation, sleep and stress, acting as disease modifiers and increasing susceptibility to psychological conditions (Cameron et al., 2023; Maes et al., 1993; Bullmore, 2018; Beurel et al., 2020). For example, mental health conditions can potentially affect sleep and neuroinflammatory processes, and sleep disturbance itself can contribute to a range of mental health conditions (Cameron et al., 2023). Indeed, it is well-evidenced that psychological co-morbidities such as anxiety, depression and suicidality are already more likely to occur in children and adolescents with skin conditions (Cameron et al., 2023; Barlow et al., 2023; Wright et al., 2022; Rønnstad et al., 2018). Importantly, Cameron et al. (2023) speculate how mindfulness and meditation could be used to improve sleep quality and quality of life of people affected by AD (Jhaveri et al., in the National Eczema Association, 2023). However, research is ongoing to further understand the complex links between inflammation and mental health conditions and how the cutaneous/systemic inflammatory/neuronal pathways might be affected by sleep disruption (Cameron et al., 2023).

Despite the growing focus on the biopsychosocial model of skin conditions and the biological role of inflammation (e.g., Cameron et al., 2023), which might be tackled by arousal reduction (and eventually drugs), it is important to not lose sight of the other parts of the model (e.g., psychological and social factors) and the need to tackle external stressors (such as stigma) with the use of psychologically informed

interventions to tackle important psychological variables implicated in maintaining distress. There are individual differences between people that can contribute to increasing inflammation in the body (e.g., diathesis-stress, psychological resilience, allostatic load etc.) and there is a need to address both the physical biomarkers and psychological stressors to holistically treat skin conditions and promote long-term management. For example, the underlying mental health burden could interfere with treatment adherence, and if a person has experienced clinical levels of distress, the psychological sequela could remain even after successful treatment with drug therapies. Thus, although drugs are the most effective treatment for alleviating physical symptoms of skin conditions, developing interventions to target individual psychological variables is equally important as focusing on biological outcomes (Thompson et al., 2020).

When considering how to best support families affected by skin conditions, participants provided some useful suggestions. Parents and children expressed desires for short, accessible exercises that could be incorporated into their busy family/treatment routines, along with the opportunity to connect with other families, and an online format (Hughes et al., 2022). HCPs also felt an online/real-time intervention would be most likely to increase adherence from giving participants a responsibility to attend, and they also mirrored family reports of the need for exercises to fit into pre-existing daily routines. Most notably, several HCPs suggested that a mindfulness-based intervention might be more appropriate for parents in the first instance, as they would benefit from learning mindfulness techniques to manage their stress levels arising from caring for their children. Many HCPs also usefully drew attention to the fact that the well-being of parents does not routinely get discussed during consultations, as clinic appointments are usually focused completely on the treatment of the unwell child.

The findings from parent and child dyads in Study 1 (Chapter 3) and insights from HCPs in Study 2 (Chapter 4) were combined to inform the delivery of a mindfulness-based intervention in Study 3 (Chapter 5). The Present curriculum (The Present Courses, 2022) was selected as an appropriate introduction to mindfulness theory, as many parents might not be familiar with the approach as suggested by several misconceptions existing surrounding the fundamental nature of mindfulness

(Hughes et al., 2022; Kelly, 2022; Luberto et al., 2020). The Present curriculum was designed to allow participants to incorporate mindfulness-based exercises into daily routines from assigning practices to activities they value (The Present Courses, 2022). Indeed, the course was specifically designed for “busy people” (The Present Courses, 2022) and was deemed to be suitable for parents managing additional care needs. The pilot intervention study presented in Chapter 5 aimed to recruit a maximum of approximately 20 parents to form a group (e.g., from personal communication with trained mindfulness teacher; and Bögels et al., 2013) and allow parents to connect together from their shared experiences, form bonds, and act as a safe space to learn. Feedback from the previous studies (Chapters 3 and 4) regarding delivery was considered, and the course sessions were delivered online, to reach as many parents across different geographic locations as possible.

As described in Chapter 5, there were some promising results; all parents were able to identify positive changes in themselves and provided comments on their overall experience of taking part in the Present curriculum. Parents described how they felt calmer in the immediate days following the intervention sessions, would be continuing their practices, sharing the techniques with their children, and all would recommend the approach to a friend (see Chapter 5). Parents responded favourable to the delivery of mindfulness online and several felt they would not have been able to attend an in-person group due to restricted resources, although there were some comments regarding missing out on body language. Most parents enjoyed the group format as a result of the social interactions and connections formed with other caregivers (resulting in the creation of a parental WhatsApp group), however, some parents found it harder to share their experiences and bond with other group members as a result of the differences in severity of their children’s skin conditions. These findings could suggest the use of WhatsApp (in a moderated form) alongside briefer guided self-help could be a useful design for future psychological interventions. From interviewing the mindfulness course teacher, most parental accounts were corroborated, as they also noticed parents’ body language had become less frenetic as the intervention progressed.

There were also benefits reported regarding the parent and child relationship. Caring for broken skin can place pressure on the relationships between family

members, and there can be resistance from a child if the treatment is unpleasant or causes pain (e.g., changing bandages, or side effects from medication) (see Chapter 4). In many cases, there can be conflict between a child and their primary caregiver during times of treatment (see Chapter 4). Herein, findings from Chapter 5 supported speculation that mindfulness could work to repair damaged relationships, by facilitating healthier communication between parents and their children. If parents engage in regular mindfulness practice and learn to develop an attitude of non-reactivity to their child's resistance, it could ultimately make treatment routines less stressful.

Indeed, the findings presented in Chapter 5 regarding improved communication between parents and children, combined with the positive feedback from Chapter 3 whereby parents speculating how mindfulness could promote family bonding is supportive of previous studies regarding attachment (Bowlby, 1969; Krasuska et al., 2018). Previous research has suggested that skin conditions can affect the quality of attachments formed (Demirci et al. 2020; Szabó et al., 2017; Tomas-Aragones, 2018; Krasuska et al., 2018; Robles et al. 2013). The findings from parents in Chapter 5 could suggest that mindfulness might assist in fostering healthier, more secure relationship dynamics. For example, parents described how they were able to change their automatic response patterns of reacting to their children's behaviour, and instead, they were able to pause before responding to situations (Yang & Oka, 2022). Thus, developing mindful attention could lessen attachment avoidance and attachment anxiety from developing a non-judgmental attitude and increasing psychological resilience (Yang & Oka, 2022). This could also have explained why several of the children's quality of life scores improved in Chapter 5, perhaps as a result of the reduction in parental stress leading to positive secondary outcomes for the children and the parent/child relationship. As well as mindfulness potentially increasing parent and child bonding, there was some evidence in Chapter 3 to suggest that parents and children could be brought closer together when there is a hereditary skin condition, from connecting over a shared experience. However, as highlighted by HCPs (Chapter 4), there could be certain family dynamics where systemic approaches are not suitable, such as families living apart, poor relationships, or parents sharing care of children.

Whilst this doctoral research had the main focus of investigating the use of mindfulness, the research has remained open to the consideration of other forms of psychological intervention (e.g., CBT, family-focused/systemic, ACT) and has sought to include alternative therapies in discussions to ensure a balanced representation of the current state of psychological support. It is clear that a range of psychological interventions could be usefully applied with families affected by skin conditions. Importantly, this research has shed light on potential barriers to the delivery of mindfulness. From delivering a pilot intervention to parents of children with a range of skin conditions, data has illustrated the importance of psychological interventions being easily accessible and flexible to fit into daily routines. Including HCPs in the project has informed this research further, as expert insights revealed there could be challenges in delivering interventions to patients with complex care needs, and supported reports from parents that there can often be misconceptions surrounding the nature of mindfulness (Hughes et al., 2022; Kelly, 2022; Luberto et al., 2020). Indeed, delivering an MBI to parents of children with skin conditions did shed light on several areas that could be tailored in future.

For example, the pilot study findings suggest that mindfulness might not be appropriate for all people, and some individuals might find the concept difficult to learn as a beginner. As a result, there are unanswered questions surrounding who is attracted to mindfulness, what prevents and supports engagement, and what might make practicing the approach challenging for some people (Ainsworth et al., 2023). Particularly, people affected by chronic and severe physical health conditions might be even more difficult to reach with targeted interventions. For example, a study by Crane et al. (2014) investigated outcomes between home practice and MBCT outcomes and discovered that people who reported doing formal daily practice three days a week were nearly half as likely to experience a relapse of depression. For parents managing the additional responsibilities of treatment regimens, finding the time to practice could be difficult. Indeed, several parents reported finding it difficult to make the time to attend the Present sessions, which was designed to be a less-intensive intervention.

There were also negative outcomes reported by some parents taking part in the Present curriculum, including having an increased awareness of negative aspects of

their lives, noticing other people talking to them more, and a deterioration in anxiety scores (see Chapter 5) (Lomas et al., 2015; Farias & Wilkholm, 2016; Harris et al., 2021). Although the deterioration in anxiety was contextualised by participants in exit interviews as not being a result of the intervention, there is increasing evidence to suggest that for some people, mindfulness can increase symptoms of anxiety (Binda et al., 2022). Despite this, there is a lack of systematic methods to describe adverse events in meditation randomized trials (Binda et al., 2022) which could mean many participants' unwanted experiences are not recorded. For example, Van Dam et al. (2018) carried out a critical evaluation of MBIs and found that adverse effects had been reported in 20 published studies, perhaps as a result of methodological designs consisting mostly of case studies, case series, and observational studies, without a control group.

Adverse events are classified as an event that has led to serious harm or hospitalisation (Binda et al., 2022), yet 83% of clinical trials investigating meditation do not report if any adverse events occurred as a result of the intervention (Binda et al., 2022; Britton et al., 2021). However, the lack of data surrounding adverse events after participating in mindfulness could suggest that serious events as a direct result of mindfulness are rare, and MBIs are safe for most people (Binda et al., 2022). For example, increases in anxiety could be a temporary symptom and a transient experience that would be expected from developing awareness of body sensations without causing harm (Binda et al., 2022; Baer et al., 2019). This could be a potential explanation for the lack of reporting of adverse events in clinical trials, as increases in physiological symptoms could be accepted as part of the therapeutic process (Peterson et al., 2013).

It is also important to remember that these issues are not exclusive to MBIs (Davidson & Dahl, 2018), and an intervention is not intended to remove distress completely as physical conditions (such as skin conditions) are medical diseases that will often require lifelong treatment. Research by Kobusiewicz et al., (2023a) found that although mothers of children with AD experience greater levels of stress, anxiety, and depression (Kobusiewicz et al., 2023b) than mothers of children without skin conditions, they do not rely on different coping strategies. This suggests that the stress experienced by mothers is not caused by maladaptive coping, but from the

nature of the child's chronic illness (Kobusiewicz et al., 2023a). The target for interventions should be ensuring parents are practically supported to manage stress levels from diagnosis, with the strengthening of coping techniques from the beginning of treatment (Kobusiewicz et al., 2023a).

Parent experiences of taking part in mindfulness illustrate the importance of assessing participants for suitability when delivering MBIs, including pre-existing mental health conditions that could be exacerbated. Although mindfulness is recommended for the treatment of less severe depression (NICE, 2022), it could be contra-indicated for people experiencing social anxiety as a result of engagement in internally-focused activities. Therefore, NICE (2022) guidelines advise against routinely offering interventions including MBCT and MBSR for the treatment of adults with social anxiety disorder. Indeed, social anxiety could be heightened from a fear of evaluations, which might be particularly salient for parents of children with visible skin conditions who do frequently encounter negative comments from other people. More research is needed to carefully develop and test MBIs with in-depth psychological screening processes, consideration of content, delivery, and time spent practicing (Baer et al., 2019).

In relation to the difficulties encountered during recruitment for Study 3 (Chapter 5), it could have been that the study sample of parent carers were a particularly stressed group of people managing a significant burden, and being given extra tasks (e.g., answering text messages and questionnaires) to complete as part of the group intervention was not manageable for everyone. Thus, the demands associated with the study itself could have increased levels of parental anxiety. In terms of recruitment of families with intensive treatment/care needs, there could be additional considerations needed when planning and delivering psychological support interventions. Kling et al. (2021) synthesised the recruitment process of adolescents with visible difference to take part in an online psychosocial intervention RCT. They concluded that the most successful methods of recruitment were using direct letters sent to participants' homes from patient/charity organizations, via hospital departments, and specialised resource centres. This raises the question of using social media for recruitment, and whether online platforms are the most effective way of achieving a representative sample of potential participants.

## **6.2. Implications for clinical practice**

When considering the findings from the studies associated with this doctoral research, it can be concluded that MBIs could be appropriate for some families affected by skin conditions, as well as illustrating how there could be a range of situations depending on parent/child dynamics that might not be appropriate for targeting with a systemic intervention. In these cases, the research has highlighted the issue of psychological assessment in dermatology, and the urgent need for better psychological testing and routine screening of patients (including parents) during clinic appointments (Kobusiewicz et al., 2023b). If patients are regularly psychologically assessed for clinical levels of distress, they can then be appropriately referred for the most suitable pathway of support.

Although many clinicians are aware of the psychological sequela associated with skin conditions, the current available screening tools may not be comprehensive enough to accurately measure the impact to the mental health of a patient. As such, further work is required to develop screening tools, and there could be necessity for the provision of a psychological screening toolkit to guide clinicians to identify signs of psychological distress. This would promote identification of psychosocial comorbidities, and increase chances of facilitating early intervention. Deciding on therapy and the type of intervention to offer a child and their parents is highly individualised, and it is difficult to determine if one approach would be suitable for all families without formulation and consideration of patient needs and preferences.

The research adds to existing evidence illustrating the gaps in provision and commissioning of specialist psychological services for children and families affected by skin conditions (APPGS, 2020; Blackstone et al., 2022; Wheeler et al., 2022). The psychological burden of skin conditions has been clearly shown from the findings of Study 1 (Chapter 3) and Study 2 (Chapter 4), with reports from children and parents themselves expressing their profound distress and desire for greater awareness of how difficult daily life can be with a skin condition. The need for further support provision was corroborated by every HCP interviewed for this thesis, and dermatologists and psychologists all recognised the need to address mental health alongside physical symptoms. However, clinicians are limited in their ability to refer patients to receive psychological support, depending on their geographic location



within the UK (APPGS, 2020; Blackstone et al., 2022; Wheeler et al., 2022). This thesis provides evidence that underscores the need for increased funding for the establishment of accessible psychodermatology clinics, for further training of HCPs to identify psychological distress, and for greater awareness and training within clinical practice of the burden of skin conditions beyond physical symptoms (APPGS, 2020; Blackstone et al., 2022; Wheeler et al., 2022).

### **6.3. Strengths and limitations**

One of the strengths of adopting a mixed methods approach has been how the data collected has demonstrated differences between statistical outcome measures and qualitative feedback. Although parents did not all display significant outcomes in Study 3 (Chapter 5), every parent was able to discuss positive changes during exit interviews. The thesis has included a range of participants to investigate the use of mindfulness in as much detail as possible, with contributions from parents, children, and a range of healthcare professionals. Including patients themselves, and clinicians, to allow a detailed and careful analysis of the potential effectiveness of mindfulness for families. The research was carried out by an expert patient with psoriasis, who was able to use their own insights to enhance data collection from understanding in-depth the lived experience of growing up with a skin condition.

There are several limitations to this research that are important to address. Delivering a psychological intervention has the aim of teaching people behavioural skills to manage levels of distress and cope with the psychological demands of care. As shown in Study 3 (Chapter 5) parental scores of stress, depression, anxiety, and quality of life, combined with qualitative interview data all point towards the significant burden encountered by parents of children with skin conditions. Although there were findings to suggest mindfulness could be a promising intervention, it takes time to build practices. For people learning mindfulness as beginners, there could be a longer period of time needed to develop and embed skills in order to feel the benefits of stress reduction. We did not measure the time participants spent practicing mindfulness exercises outside of sessions, so it is difficult to determine if there could have been a relationship between embedded practices and

psychological outcomes, and longer baseline and follow-up periods could have been employed to assess change over time.

Despite the researcher carrying out all qualitative interviews in a nuanced and balanced manner, with open-ended/flexible interview schedules, it is difficult to completely rule out the chances of social desirability influencing data. For example, reports from parents and children might have been overly positive in their views of mindfulness, resulting from a desire to present themselves in a favourable manner. As well as this, HCPs were asked to provide comment on their own clinical practice and training competencies in identifying psychological distress in their patients, so could have been more likely to report their services as proficient. Last, another aspect that could have influenced data collection, were the demographics of participants in the study samples, which largely consisted of British mothers. Although this research did specify explicitly that more than one parent was invited to join the dyadic qualitative interviews in Study 2 (Chapter 3), and participate in group MBI sessions in Study 3 (Chapter 5), only one father took part in the research presented in this thesis, and there was an underrepresentation of male caregivers. Similar findings have also been reported elsewhere in the broader physical health literature. For example, in a systematic review by Costa et al. (2021) of psychosocial intervention groups for parents of children with visible difference, it was reported how study samples mostly consisted of mothers, with the exception of one study by Morawska et al. (2017) who focused on male caregivers of children with asthma and eczema.

#### **6.4. Future directions**

The findings from this doctoral research, in conjunction with reviewing the literature surrounding the use of MBIs for children/parents with physical health conditions, has shown there is a need for further high quality investigation. This research has highlighted how individual psychological formulations and patient preferences are central to determining how successful an intervention is, and demonstrates the need for future work to develop and test a range of psychotherapeutic interventions for families affected by skin conditions. Although there has been some limited work investigating the effectiveness of mindfulness with parents of children with skin conditions (Heapy et al., 2022), there does not appear

to be any existing studies delivering MBIs directly to children with skin conditions. Indeed, further research is needed to maximise the potential of psychological interventions for families and support implementation into routine dermatological practice. This research has drawn attention to the lack of empirical research using control groups to compare intervention effects (Hughes et al., 2023; Van Dam et al., 2018). Further work should compare the effectiveness of MBIs with comparison groups, to determine if therapeutic outcomes are a result of mindfulness, or other variables. It could be useful to compare the effectiveness of a mindfulness-based intervention to a support group (i.e., peer support), as my findings show that families with skin conditions can often feel socially isolated. Comparing interventions could shed light on which component is most effective (e.g., socialising) as having the chance to connect with people with shared experiences could also promote positive change toward adaptation. Indeed, social connectedness and whether an intervention is endorsed by other group members has been found to increase motivation and user engagement with digital mental health interventions (Borghouts et al., 2021).

There are several aspects of this research that could be usefully adapted in future studies. To increase engagement of families, future MBIs could be tailored to address the specific concerns encountered from caring for a child with a skin condition. This could be important, as the type of intervention and whether or not participants like what is presented is crucial to ensuring target user satisfaction (Borghouts et al., 2021). To do this, content could be co-designed and tested with direct input from parents, as participants taking part in the MBI reported in Study 3 (Chapter 5) how those with children with rarer skin conditions (e.g., ichthyosis) found it difficult to relate to parents of children with milder disease (e.g., AD/eczema) as a result of the different levels of treatment intensity required. It would also be practical to run several mindfulness-group sessions at different times (e.g., evening and afternoon) and allow parents a choice of timing to fit around their daily schedules of work and childcare/bedtime routines. Further, the underrepresentation of male caregivers could be addressed with targeted sampling.

## **6.5. Researcher reflections and acknowledgment of reflexivity**

Developing personal professional self-awareness is central for understanding intersubjective dynamics between researcher and data (Finlay & Gough, 2003; Biggerstaff & Thompson, 2008). Reflecting on carrying out this research, at all times, I remained fully aware of my role as a researcher. I was careful to avoid disclosing my own experience or bring my opinions into discussions. I collected participants' personal accounts and asked the appropriate questions to gather accurate reflections of their narratives, without skewing the data with personal subjectivity. Although reflexivity does involve using personal experiences rather than just steering around them (e.g., asking questions such as 'in what way is this like or not like my experience?' Or 'in what way does this fit or not fit with my pre-existing assumptions?') to limit bias, new insights can also be established (and checked in the data). This has made me a much stronger researcher, and I have been able to remain objective whilst also utilising my personal experience and acknowledging this as expertise. However, in future, this approach could be further documented with journaling.

## **6.6. Conclusion**

The body of research presented in this thesis had the aim of investigating the use of an online mindfulness-based intervention for families affected by skin conditions. Study 1 highlighted the significant psychological burden experienced by children with skin conditions, and their parents, and suggested that mindfulness could be an effective intervention to reduce distress and promote healthy coping. Study 2 incorporated the experiences of dermatology and psychology healthcare professionals' of working clinically with families, and their views on the relevance of mindfulness-based support. These findings were considered in Study 3, with a pilot investigation of the Present mindfulness curriculum for parents of children with skin conditions. Overall, the findings of this thesis suggest that mindfulness could be a promising intervention for reducing parental stress and improving quality of life of families affected by skin conditions. However, further research into the effectiveness of mindfulness with robust study designs is warranted.

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## Appendix A

### Systematic Review Materials

#### A.1. Digital search strategies (last updated 5<sup>th</sup> August 2022).

##### Scopus

child\* OR paediatric OR pediatric OR adolescen\* OR youth\* OR infant OR parent\* OR caregiver OR famil\* AND physical AND health AND condition OR chronic AND condition OR disease OR disorder OR illness\* OR health OR physical AND mindful\* OR mindfulness AND based OR mindfulness AND based AND stress AND reduction OR mbsr OR mindfulness AND based AND cognitive AND beh\* AND therapy OR mbct OR meditation AND ( LIMIT-TO ( DOCTYPE , "ar" ) ) AND ( LIMIT-TO ( LANGUAGE , "English" ) ) AND ( LIMIT-TO ( SRCTYPE , "j" ) )

##### APA PsycINFO via Ovid

1(child\* or paediatric or pediatric or adolescen\* or youth\* or infant or parent\* or caregiver or famil\*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] 1432889

2((((physical and health and condition) or chronic) and condition) or disease or disorder or illness\* or health or physical).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] 1425516

3(((((((mindful\* or mindfulness) and based) or mindfulness) and based and stress and reduction) or mbsr or mindfulness) and based and cognitive and beh\* and therapy) or mbct or meditation).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] 10436

1 and 2 and 3 921

### Medline Via Ovid

1 (child\* or paediatric or pediatric or adolescen\* or youth\* or infant or parent\* or caregiver or famil\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 5341611

2((((physical and health and condition) or chronic) and condition) or disease or disorder or illness\* or health or physical).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 8276715

3(((((((mindful\* or mindfulness) and based) or mindfulness) and based and stress and reduction) or mbsr or mindfulness) and based and cognitive and beh\* and therapy) or mbct or meditation).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 7461

1and 2 and 3 814

## Embase via Ovid

1 (child* or paediatric or pediatric or adolescen* or youth* or infant or parent* or caregiver or famil*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	5875859
2 (((physical and health and condition) or chronic) and condition) or disease or disorder or illness* or health or physical).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	14017008
3 (((((((mindful* or mindfulness) and based) or mindfulness) and based and stress and reduction) or mbsr or mindfulness) and based and cognitive and beh* and therapy) or mbct or meditation).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	12356
1 and 2 and 3	1636

## PubMed

((child\* OR children OR paediatric OR pediatric OR adolescent OR adolescence OR youth OR infant OR parent OR caregiver OR family OR families) AND (physical AND health AND condition OR chronic) AND (condition OR disease OR disorder OR illness\* OR health OR physical) AND (mindfulness OR mindful OR mindfulness) AND (based OR mindfulness) AND based AND stress AND reduction OR (mbsr OR mindfulness) AND (based AND cognitive AND behavioural AND therapy) OR mbct OR meditation

*Filters applied: Full text, Journal Article, Humans, English, Child: birth-18 years, Newborn: birth-1 month, Infant: birth-23 months, Infant: 1-23 months, Child: 6-12 years, Adolescent: 13-18 years, Preschool Child: 2-5 years.*

## A.2. PRISMA (2020) checklist.

Section and Topic	Item #	Checklist item	Location where item is reported
<b>TITLE</b>			
Title	1	Identify the report as a systematic review.	Title.
<b>ABSTRACT</b>			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract.
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	2.1. Introduction.
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	2.1. Introduction.
<b>METHODS</b>			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	2.2. Method: 2.2.2 Eligibility criteria.
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	2.2. Method: 2.2.3. Information sources and search strategy.
Search strategy	7	Present the full search strategies for all databases, registers and websites,	Appendix A.4.

Section and Topic	Item #	Checklist item	Location where item is reported
		including any filters and limits used.	
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	2.2. Method: 2.2.4. Selection process.
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	2.2. Method: 2.2.5. Data collection process and data items.
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	2.2. Method: 2.2.5. Data collection process and data items.
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	2.2. Method: 2.2.5. Data collection process and data items.
Study risk of bias	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether	2.2. Method: 2.2.7. Study risk of bias assessment.

Section and Topic	Item #	Checklist item	Location where item is reported
assessment		they worked independently, and if applicable, details of automation tools used in the process.	
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	2.3. Results: Table 2.1.
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A.
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A.
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	2.2. Method: 2.2.5. Data collection process and data items.
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	N/A.
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A.



Section and Topic	Item #	Checklist item	Location where item is reported
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A.
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	2.2. Method: 2.2.7. Study risk of bias assessment.  2.3. Results: 2.3.4. Risk of Bias in studies, Figure 2.2(A) & (B) and Figure 2.3(A) & (B).
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Method 2.5 Certainty of evidence assessment.
<b>RESULTS</b>			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	2.3. Results: 2.3.1. Study selection, Figure 2.1.
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	N/A.
Study characteristics	17	Cite each included study and present its characteristics.	2.3. Results: Table 2.1.

Section and Topic	Item #	Checklist item	Location where item is reported
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	2.3. Results: 2.3.4. Risk of Bias in studies, Figure 2.2(A) & (B) and Figure 2.3(A) & (B).
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	2.3. Results: Table 2.1.
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Results.
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A.
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	2.3. Results: 2.3.4. Risk of Bias in studies, Figure 2.2(A) & (B) and Figure 2.3(A) & (B).
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A.

Section and Topic	Item #	Checklist item	Location where item is reported
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	2.3. Results: 2.3.4. Risk of Bias in studies, Figure 2.2(A) & (B) and Figure 2.3(A) & (B).
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	2.3. Results: 2.2.6. Certainty of evidence in individual studies.
<b>DISCUSSION</b>			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	2.4. Discussion.
	23b	Discuss any limitations of the evidence included in the review.	2.4. Discussion: 2.4.1. Limitations.
	23c	Discuss any limitations of the review processes used.	2.4. Discussion: 2.4.1. Limitations.
	23d	Discuss implications of the results for practice, policy, and future research.	2.4 Discussion: 2.4.2. Recommendations for future research.
<b>OTHER INFORMATION</b>			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	2.2. Method: 2.2.1. Registration and protocol.
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	2.2. Method: 2.2.1. Registration and protocol.

Section and Topic	Item #	Checklist item	Location where item is reported
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	2.2. Method: 2.2.1. Registration and protocol.
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	No funding.
Competing interests	26	Declare any competing interests of review authors.	No competing interests.
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Upon request.

*From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. [For more information, visit: http://www.prisma-statement.org/](http://www.prisma-statement.org/)

**A.3. Table 2.2: Summary of the content of n=18 mindfulness-based interventions included in the review.**

Study	Content of intervention	Facilitator(s)	Fidelity checks?	Home practice?
Abedini et al. (2021)	MBCT-C modified for hospitalized children/reduced to 4 weeks. Topics: several activities removed (mindful eating, yoga, moving mindfully). Notebooks for children/worksheets for parents	Researcher/family therapist trained in MBSR and MBCT	Monitored by clinical supervisor, but not empirically measured	N/A
Ahola Kohut et al. (2019)	MBI-A developed for paediatric chronic pain. Topics: mind-body connection, effects of stress on pain, living in the present, focussed awareness, responding vs. reacting to pain, approaching, coexisting with physical symptoms, non-judgement, gratitude, kindness, compassion to self/others	Facilitated by two of the researchers	NR	Encouraged
Ali et al. (2017)	MBSR developmentally modified for adolescents	Led by MBSR trained instructor	NR	Required 10-to-15-minute audio guided practices
Andreotti et al. (2017)	MBI developed from MBCT for children. Topics: body scans, mixed meditations, mindful breathing/walking, mixed meditations, informal practices (observations, mindful tooth brushing/eating/drawing)	NR	NR	Encouraged
Chadi et al. (2016)	MBI based on MBSR/MBCT modified for adolescents. Topics: present moment/body awareness, pain/five senses, mixed meditations, breathing exercises, poetry, pleasant events/sensations, stress reactivity, coping with pain/difficult sensations, awareness of thoughts,	Two psychiatry residents with mindfulness training	Sessions video recorded and reviewed by expert with certification in mindfulness	Encouraged

Study	Content of intervention	Facilitator(s)	Fidelity checks?	Home practice?
Chadi et al. (2019)	response to stress, recognizing/responding to difficult emotions, loving kindness, compassion, integrative pain meditation. Mindful awareness and resilience skills (MARS-A) based on MBSR/MBCT, modified for adolescent chronic illness. Topics: mixed meditations, mindful movement, informal practices (gratitude, handling difficult emotions, self-care)	Researchers with experience in MBI/trained in MARS-A	Sessions video recorded and reviewed by external reviewer	Required, list of daily practices to complete between sessions
Freedenberg, et al. (2015)	MBSR modified for adolescents. Topics: deep breathing, guided imagery, meditation, yoga.	Researcher trained in MBSR	NR	Required between sessions with provided apparatus Required daily for 10-15 minutes
Freedenberg, et al. (2017)	MBSR. Topics: deep breathing, meditation, yoga, discussions around cardiac issues/body image, device, disease, restrictions to activity, stress-related symptoms, fears related to illness, physical symptoms/sensations, behavioural responses	Led by researcher, trained in MBSR	NR	Required between sessions with provided apparatus Required daily for 10-15 minutes
Hesse et al. (2015)	MBI modified for headaches. Topics: group discussions, two 15-minute didactic lessons, 10–15-minute ‘food for thought’ break whilst having a snack, followed by another didactic lesson, a 10-minute discussion on home practices, and a closing mindfulness practice. 1-2 journal writing opportunities	Three instructors with Mindful Schools training, and psychiatrist trained in MBSR	NR	Encouraged daily practices lasting 10-15 minutes
Jastrowski Mano et al. (2013)	MBSR. Topics: body awareness, yoga, relaxation, diaphragmic breathing, body scans, walking meditations, appreciation of the self, non-judgement, gratitude	Practitioner trained as MBSR facilitator	NR	Required 30 minutes 6 days a week
Lagor et al. (2013)	MBI developmentally modified. Topics: awareness of the self, focus on breath, mind in jar, mindful smelling/listening/drawing/eating/walking/touching,	Manual reviewed by doctoral-level	NR	Encouraged

Study	Content of intervention	Facilitator(s)	Fidelity checks?	Home practice?
	awareness of self, sensory exercises, visual imagery, playful curiosity	supervisors with expertise in mindfulness/ paediatric psychology		
Lovas et al. (2017)	MBCT/MBSR modified for adolescents 'Mindful Awareness & Resilience Skills' (MARS-A). Topics: discussing stress/role in somatic symptoms, mindfulness, and mixed meditations.	Child psychiatrist trained in MBSR and MBCT	NR	Required, in daily life
Malboeuf-Hurtubise et al. (2015)	MBSR-T modified for teenagers. Topics: body scans, emotions, mixed meditations, mindful movement/yoga, acceptance of thoughts/emotions/ physical sensations, breathing with focus on thought/judgements, senses, inhibition activity, judgements, discussion on self-care, distribution of pebble stone	Graduate student in psychology with MBSR-T training, and a social worker trained in MBSR	Manual was reviewed and approved by a clinical psychology faculty with knowledge of mindfulness	Required homework assigned/daily practice encouraged
Ruskin et al. (2017)	MBI modified for adolescents/body pain. Topics: mind-body connection, effects of stress on pain, living in the present, focussed awareness, responding vs. reacting to pain, approaching/coexisting with pain, non-judgement, gratitude, kindness, compassion to self/others	Two facilitators with MBI training	Considered with session guide, but not empirically measured	Encouraged
Ruskin et al. (2015)	MBSR modified for chronic pain. Topics: acceptance strategies, skill building, valued living, mind-body connection, effects of stress on pain, living in the present, focussed awareness, responding vs. reacting to pain and/or difficult situations, approaching/co-existing with pain, non-	Researcher trained in MBSR/ experienced in delivering	NR	Encouraged daily practices lasting five minutes

Study	Content of intervention	Facilitator(s)	Fidelity checks?	Home practice?
Waelde et al. (2017)	judgement, gratitude, kindness/compassion to the self/others, mixed meditations MBI modified for adolescents. Topics: guided body tour, tension release, mixed meditations, breath-focused imagery, repetition of cue words, discussions, therapist teachings of didactic material/how to apply practice	mindfulness to adolescents Clinical psychologist/clinical psychology doctoral student trained and supervised in the MBI	NR	Encouraged daily practices, lasting 15-minutes each
Wren et al. (2021)	MBI application 'MediMindfulness-Transitions', brief intervention delivering guided mindful practice based on MBSR. MBI centred around developing focused attention and present moment awareness, bringing awareness to the breath and a natural virtual environment, including the presentation of a waterfall.	Digital/narrated voiceover	NR	None
Young et al. (2022)	MBI modified for adolescents/polycystic ovary syndrome, 'Kind Mind for PCOS' adapted from 'Taming the Adolescent Mind (TAM) protocol. Topics: introduction to ROAM (regulate attention, observe inside and outside, acceptance without judgement, being mindful), observing the present moment, acceptance, being mindful, and mindfulness and beyond. Domains included mindfulness, nutrition content, physical activity, and sleep. Medication adherence tracked with a free app.	3 interventionists trained in psychology, nursing, and social work.	NR	Required


*Note:* NR, not reported; MBSR, mindfulness-based stress reduction; MBCT, mindfulness-based cognitive therapy; MBI, mindfulness-based intervention.



# Appendix B

## Ethical Approval for all Studies

### B.1. Ethical approval for Study 1.

 psychethics  
Wed 13/10/2021 17:31

To: Olivia Hughes  
Cc: Andrew Thompson; Katherine Shelton

Dear Olivia,

The Ethics Committee has considered the revised amendment to your PG project proposal: *Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families (EC.21.04.20.6335R2A4)*.

Your amendment has received a **Favourable Opinion** based on the information described in the revised proforma and supporting documentation.


**Conditions of the favourable opinion**  
The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk) within three months of research project completion.

**The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.**

**You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.**

Best Wishes,  
Sean

 This mailbox is monitored by members of the  
Education Team

## B.2. Ethical approval for Study 2.

 psychethics  
To: Olivia Hughes  
Cc: Andrew Thompson; Katherine Shelton



Tue 04/10/2022 14:42

Dear Olivia,

The Ethics Committee has considered your revised PG project proposal: A Qualitative Study with UK Healthcare Professionals Exploring Psychological Support for Children and Families Affected by Skin Conditions (EC.22.09.20.6617R).

Your revised project proposal has received a **Favourable Opinion** based on the information described in the proforma and supporting documentation.

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk) within three months of research project completion.

**The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.**

**You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research Involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.**

Kind regards,  
Deborah

### School of Psychology Research Ethics Committee

<https://cf.sharepoint.com/teams/InsidePsych/Ethics/>

Cardiff University  
Tower Building  
70 Park Place  
Cardiff  
CF10 3AT

Tel: +44(0)29 208 70707  
Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)


The University welcomes  
correspondence in Welsh or  
English. Corresponding in Welsh  
will not lead to any delay.

Prifysgol Caerdydd  
Adeilad y Tŵr  
70 Plas y Parc  
Caerdydd  
CF10 3AT

Ffôn: +44(0)29 208 70707  
E-bost:  
[psychethics@caerdydd.ac.uk](mailto:psychethics@caerdydd.ac.uk)

Mae'r Brifysgol yn croesawu  
gohebiaeth yn Gymraeg neu yn  
Saesneg. Ni fydd gohebu yn  
Gymraeg yn creu unrhyw oedi.

## B.3. Ethical approval for Study 3.

 psychethics  
To: Olivia Hughes  
Cc: Andrew Thompson



Wed 30/11/2022 15:06

Dear Olivia,

The Ethics Committee has considered the amendment to your PG project proposal: Mindfulness for Parents of Children with Ichthyosis and Other Visible Skin Conditions: A Single Group Case Series (EC.22.04.26.6558RA3).

Your amended project proposal has received a **Favourable Opinion** based on the information described in the proforma and supporting documentation.

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk) within three months of research project completion.

**The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.**

**You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.**

Kind regards,  
Deborah

**School of Psychology Research Ethics Committee**  
<https://cf.sharepoint.com/teams/InsidePsych/Ethics/>

Cardiff University  
Tower Building  
70 Park Place  
Cardiff  
CF10 3AT

Tel: +44(0)29 208 70707  
Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

The University welcomes  
correspondence in Welsh or  
English. Corresponding in Welsh  
will not lead to any delay.

Prifysgol Caerdydd  
Adellad y Tŵr  
70 Plas y Parc  
Caerdydd  
CF10 3AT

Ffôn: +44(0)29 208 70707  
E-bost:  
[psychethics@caerdydd.ac.uk](mailto:psychethics@caerdydd.ac.uk)

Mae'r Brifysgol yn croesawu  
gohebiaeth yn Gymraeg neu yn  
Saesneg. Ni fydd gohebu yn  
Gymraeg yn creu unrhyw oedi.

## Appendix C

### Study 1 Materials

#### C.1. Study advertisement for social media.



**CARDIFF UNIVERSITY**  
**PRIFYSGOL CAERDYDD**

**Does your child have a skin condition?  
Are they aged between 8 and 11 years?**

*We would like to interview you and your child about  
the impact of childhood skin conditions such as  
eczema, psoriasis, vitiligo or ichthyosis*

**£20 VOUCHER**

The study will involve taking part in an online interview  
lasting 1 hour. If interested, please email  
**Olivia Hughes**  
[hughesoa@cardiff.ac.uk](mailto:hughesoa@cardiff.ac.uk)



## **C.2. Parent/carer study information sheet.**

### **Parent/Carer Information Sheet**



#### **Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families.**

##### **What is this study about?**

We are inviting you and your child to take part in this interview study, exploring your experiences of psychological support for managing your child's skin condition.

During the interview, you will be asked about any support options you have been offered or received. Along with this, you will be asked about what you would like to see change in relation to current psychological support, including what you may find helpful or useful from future interventions, including mindfulness.

##### **Am I eligible to take part?**

We are interested in interviewing children aged between 8-11 years of age, and their adult parent(s) or caregiver(s) (above 18 years of age) about their experience of managing their child's skin condition. The child involved in this research must have been diagnosed with a skin condition and be comfortable with speaking about their experience with the researcher. Two parents/carers are welcome to participate, although this is entirely flexible and up to the carers to decide which parent/carer (or two) takes part.

##### **What will we be doing?**

You will have been sent two questionnaires measuring quality of life (one for parents/carers and one for children) to be completed along with consent/assent forms before the interview can take place. Once these have been filled out, you will be invited to an online meeting (via a Cardiff University Zoom link) and you will be asked a series of questions by the researcher. If you have any difficulty completing these forms, or if you prefer to bring them along to the interview, please let the researcher know and we can arrange completion together before the start of the interview.

We would like to interview parents/carers first without children present, to gain your insights. After the discussion with parents/carers ends, we would like to interview your child on their own, where they may answer as many questions as they feel comfortable with. The interview will last approximately one-hour and you will have the opportunity to ask any questions that may arise. You and your child will be given an electronic £20 'Love2Shop' voucher as a token of gratitude for your participation.

### **Who will be interviewing us?**

The researcher, Olivia Hughes, will be speaking with you and your child and asking you questions. Olivia is a PhD student in Cardiff University's School of Psychology and is carrying out this study as part of her doctorate. Olivia is interested in researching how people live with and manage skin conditions.

### **Do we have to participate?**

It is completely up to you to decide whether this study would be of interest to you and your child. This information sheet has been written to provide you with the details of the study so you can make a choice about whether this research is something you and your child would like to take part in. If you do decide to participate, and later change your mind - you may withdraw your data up until the point of transcription without an explanation (but please let the researcher know as soon as you can).

### **Will we be recorded?**

Yes, all interviews will be video recorded using Zoom software for the purposes of later transcription, and data analysis. Depending on whether you opt-in to having

your video footage used for research purposes, it will be deleted immediately after transcription has taken place. Alternatively, you do not have to switch your computer webcam/camera on if you are not comfortable with the researcher seeing you and your child.

### **Will our information be anonymous?**

The interviews will be video recorded with Zoom and only accessed by the researcher and research supervisor. The footage of the interviews will be transcribed, and at this point, pseudonyms will be assigned to every participant and any identifying details will be altered to protect identities. You will be asked if you are willing for your video footage to be used for educational and research purposes, however, this is optional and if you do not opt-in and give permission for the researcher to keep hold of your interview footage, the recording will be deleted immediately after transcription. However, in the case you do opt-in and agree, although we will not associate your names with the video recordings there is a chance that you may be recognised from footage.

### **Will our information be confidential?**

Only the researcher, and the research supervisors will have access to your information. confidentiality will always be upheld. However, in the instance of a safeguarding issue, the researcher has a duty of care and responsibility to discuss any concerns with the research supervisors and inform the University safeguarding officer who may decide on seeking an appropriate course of action depending on the level of risk or threat observed to the participants.

### **Are there any risks involved with taking part?**

We will be discussing your child's skin condition and experience of psychological support, although there are no specific risks identified for this study, if you or your child become distressed or upset at any point, you may take a break, re-start the interview at another time, or end your participation.

### **Storage and destruction of participant data**

All data will be collected and stored securely in compliance with GDPR. The interview (with your permission) will be video recorded using Zoom software for later transcription and data analysis. At this point, all identifying features including names will be anonymised, and pseudonyms will be assigned to the textual datasets. These coded, anonymised data may be stored for 7 years and could be made publicly available in accordance with open science practices, but they will not be linked to you or your child.

With your permission, the researcher would like to use the video recordings of you and your child for educational and research purposes within or outside of a laboratory. This may strictly include professional use at conferences, for teaching, or for academic presentations. The videos will be stored securely on a Cardiff University OneDrive, for approximately 7 years. You will be asked to give consent for this on a separate consent form. No names will be associated with the video recordings. However, there is a chance that people may recognise you. This will only be done with your approval, and if you are not comfortable with the researcher using video footage of you and your child, you can opt-out by not consenting on the dedicated form. This is *entirely* up to you, and if you do not opt-in or consent to having your video footage used for these purposes, it will *not* affect your ability to take part in this study, and the researcher will delete your video footage immediately after the interview has been transcribed. All data will be stored securely and only the main researcher, and research supervisors will have access to your data.

### **What will happen to the results?**

The results of this study will be written up in academic research papers, and possibly published in a scientific journal. All excerpts used will be anonymous and your name will be changed to protect your identity. If you would like to be updated and sent a copy of the finished paper, please ask the researcher and we will be happy to forward the work on to you to read once finished.

### **What should I do if I have more questions?**

You will have the chance to ask any questions or clarify any details with the researcher prior to participating. You may also ask any questions freely throughout



the interview, should they arise. If you think of anything after we have finished the interview, please do not hesitate to email the researcher on the contact details provided on this sheet.

### **I am interested – what should I do now?**

If you have read this study information sheet, and you are happy and feel comfortable taking part in this research, please email Olivia on the contact details provided below, and organise a convenient date and time for interview with you and your child.

### **Consent and Approval**

The study has been assessed and given approval from Cardiff University's School Research Ethics Committee. As this study requires child participation, the researcher has attained a Disclosure & Barring Service (DBS) (enhanced) clearance check in accordance with the UK Government.

**What if I have concerns about this study?** If you have any concerns, please contact us on the details provided below. You can also directly contact the University Ethics Committee by emailing [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

### **Contact Details**

Researcher	Research Supervisor
Ms. Olivia Hughes School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

### **Privacy Notice:**

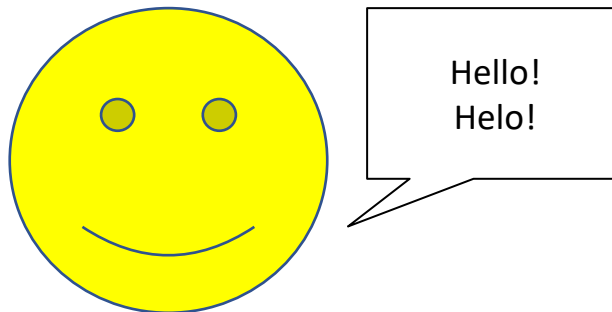
The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer

([inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)). The lawful basis for processing this information is public interest. This information is being collected by Olivia Hughes.

The information on the consent form will be held securely and separately from the research information. Only the researchers will have access to this form, and it will be destroyed after 7 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher and research supervisors will have access to this information. After the study ends the data will be anonymised (any identifying elements removed) and this anonymous information may be kept for 7 years, published, or made publicly available in compliance with open science. With permission, video footage may be used for educational and research purposes including within or outside of a laboratory.

### C.3. Children's study information sheet.

## Child Study Information Sheet



### **What is this study about?**

This study is being done to try and understand what it is like to have a skin condition.

### **Who will be speaking to me?**

Olivia will be asking you questions - she is a student from Cardiff University.

### **What do I have to do?**

To take part, Olivia will be asking you some questions about your skin and will talk to you about your experiences.

### **Who is involved?**

If you have a skin condition, and you are 8-11 years old, you are invited to take part.

### **What will happen to the conversation?**

Olivia will be recording your talk and will type it up later. Your answers will be used in a science paper, but your name won't be mentioned.

### **Do I have to take part?**

No, if you do not want to take part in this study, please tell your mum, dad or carer that you do not want to, and it won't affect anything.

## **What if I feel unhappy during the interview?**

If you are not happy with the interview or feel sad, that's ok, and we can take a break, or you can stop the discussion if you do not want to carry on, just tell Olivia or your parents or carer how you are feeling.

## **What if I'm not happy about something?**

If you are unhappy about anything to do with the study, please let your parents or carer know as soon as you can, tell Olivia if you feel comfortable, or you can speak to the research supervisor, Andrew by email [thompsona18@cardiff.ac.uk](mailto:thompsona18@cardiff.ac.uk).

## **I have more questions**

If you have any questions about the study or would like to know anything else about what Olivia is trying to find out, please ask.

You can talk to Olivia before your chat begins if there's anything you're unsure of. Or, if you feel happier, you can always ask your mum, dad, or carer, and they can speak to Olivia too.

## **I want to take part**

If you are happy and would like to take part, please tell your mum, dad or carer, and they should email Olivia on [hughesoa@cardiff.ac.uk](mailto:hughesoa@cardiff.ac.uk) and we can agree a date and time to chat together.

**Thank you very much for reading this**

***Diolch yn fawr iawn am ddarllen hwn***



#### C.4. Parent/carer consent form.

### Parent/Carer Consent Form



#### Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families

Thank you for your interest in our study. The purpose of this form is to gain your permission for you and your child to take part in this study.

On this form, you will provide consent. But it is important to remember that this does not commit you and your child to taking part, and if you change your mind you are free to withdraw at any time. If you have any further questions about the study, or this form, please email [hughesoa@cardiff.ac.uk](mailto:hughesoa@cardiff.ac.uk)

#### Researcher Details:

Researcher	Research Supervisor
Ms. Olivia Hughes, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

#### Privacy Notice:

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer ([inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)). The lawful basis for processing this information is public interest. This information is being collected by Olivia Hughes.

The information on the consent form will be held securely and separately from the research information. Only the researchers will have access to this form, and it will be destroyed after 7 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher and research supervisors will have access to this information. After the study ends the data will be anonymised (any identifying elements removed) and this anonymous information may be kept for 7 years, published, or made publicly available in compliance with open science. Video footage may be used for educational and research purposes including within or outside of a laboratory.

<b>I confirm that:</b>	<b>Please Initial</b>
I have read and understood the study information sheet.	
I have been given the opportunity to ask any questions regarding the study, and any questions I have asked, have been appropriately answered (the researcher can be contacted by email <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a> ).	
I understand that participation in this study from both myself and my child is entirely voluntary and that we can withdraw from the study at any time, without giving a reason and without consequence. I also understand that we can withdraw our data from the study up until the point of transcription by informing the researcher.	
I am happy for my computer webcam/camera to be switched on during the entirety of the interview.	
I understand that myself and my child are free to ask questions at any time. We are free to withdraw or discuss our concerns with the researcher (Olivia Hughes) or the supervisor (Professor Andrew Thompson).	
I understand that myself or my child can pause the interview by requesting a break without giving a reason or end our participation without explanation or consequence.	

I understand that the research data being collected will include sensitive information regarding my child's skin condition. I specifically consent to this information being processed for the purposes of research including using anonymous excerpts from my interview for academic papers and other formal research outputs.	
I understand that the personal data will be processed in accordance with GDPR regulations (see privacy statement).	
I understand that at the end of the study we will be provided with additional information and feedback about the purpose of the study.	
I give my consent to participate in this study.	

There is likely to be a second part to this research study, which will involve testing a prototype resource for children and their families living with skin conditions, if you would be happy for the researcher to keep your contact details, and be re-contacted to take part in this next stage, please give your consent by initialling in the box below:

I give permission for the researcher to contact me and my child in future with related studies following on from this research, and I am happy for the researcher to keep our contact information.	
--	--

In the next section, you will be asked for your permission for you and your child to be audio and video recorded for the purposes of data analysis. All recorded data will be stored securely and will only be accessed by the researcher and the research supervisors, unless you indicate that you are happy for your videos to be used for research and educational purposes.

<b>Audio and video recording for the purposes of data analysis</b>	<b>Please Initial</b>
I give my permission for myself and my child to be video recorded using Zoom software.	

**I parent/carer (name)** \_\_\_\_\_  
**consent to participate in the study conducted by Olivia Hughes, School of**

**Psychology, Cardiff University with the supervision of Professor Andrew Thompson**

Parent/carer date of birth \_\_\_\_\_

Parent/carer signature \_\_\_\_\_

My contact email is \_\_\_\_\_

Date \_\_\_\_\_

Please provide consent below, for your child to participate in this study.

<b>Consent for child</b>	<b>Please Initial</b>
I give consent for my child to participate in this study <i>‘Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families.’</i>	
I understand that my child’s personal data provided will be processed in accordance with GDPR regulations (see privacy statement).	

**I parent/carer (name)** \_\_\_\_\_

**consent for my child to participate in the study conducted by Olivia Hughes, School of Psychology, Cardiff University with the supervision of Professor Andrew Thompson**

My relationship to the child \_\_\_\_\_

My child’s first name is \_\_\_\_\_

My child’s last name is \_\_\_\_\_

My child’s date of birth is \_\_\_\_\_

Your Signature \_\_\_\_\_

Date \_\_\_\_\_



# Parent/Carer Photo, Audio and Video Consent Form



## Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families

The interview will be audio and video recorded for the purposes of data analysis. In this next section, you will be asked to provide your permission to use or display video footage or photographs from your interview for research and educational purposes, in and outside of the laboratory, including lectures, conferences, presentations, leaflets, or posters. This is completely voluntary and does not affect your participation in the study. The videos will be stored for approximately 7 years on a secure Cardiff University OneDrive. Neither yours, or your child's names will be associated with the data, but there is a possibility that you or your child may be recognised. If you do not consent to the use of your video footage, the videos will be deleted as soon as the interviews have been transcribed for data analysis. You may choose to have your video and audio footage removed at any time, or you may opt-out later, please let the researcher know if this is the case.

### Researcher Details:

Researcher	Research Supervisor
Ms. Olivia Hughes, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

**Privacy Notice:**

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer ([inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)). The lawful basis for processing this information is public interest. This information is being collected by Olivia Hughes.

The information on the consent form will be held securely and separately from the research information. Only the researchers will have access to this form, and it will be destroyed after 7 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher and research supervisors will have access to this information. After the study ends the data will be anonymised (any identifying elements removed) and this anonymous information may be kept for 7 years, published, or made publicly available in compliance with open science. With permission, video footage may be used for educational and research purposes including within or outside of a laboratory.

<b>Permission to use audio/video data, I give permission for:</b>	<b>Please Initial</b>
I give my permission for video footage of my interview to be used or displayed for educational and research purposes including within or outside of a laboratory including lectures, conferences, presentations, leaflets, or posters.	
I give my permission for photographs of my interview to be used or displayed for educational and research purposes including within or outside of a laboratory including lectures, conferences, presentations, leaflets, or posters.	
I give my permission for audio of my interview to be used or displayed for educational and research purposes including within or outside of a laboratory including lectures, conferences, presentations, leaflets, or posters.	
I give my permission for video footage of my child's interview to be used or displayed for educational and research purposes including within or outside of a laboratory including lectures, conferences, presentations, leaflets, or posters.	

I give my permission for photographs of my child's interview to be used or displayed for educational and research purposes including within or outside of a laboratory including lectures, conferences, presentations, leaflets, or posters.	
I give my permission for audio of my child's interview to be used or displayed for educational and research purposes including within or outside of a laboratory including lectures, conferences, presentations, leaflets, or posters.	
I understand that no names will be associated with the videos or photographs of you and your child, but there may be a chance of somebody recognising you or your child.	
I understand that it is my decision whether or not I agree to allowing video footage and photographs of myself and my child to be used for educational and research purposes, and I can decide to have these images or videos removed. If you decide to opt out at a later date, please let the researcher know as soon as possible ( <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a> ).	

I parent/carer (name) \_\_\_\_\_

**consent for my photographs, audio, and video from this study to be used for research and educational purposes either in or outside of the laboratory by Olivia Hughes, School of Psychology, Cardiff University with the supervision of Professor Andrew Thompson**

Parent/carer date of birth \_\_\_\_\_

Parent/carer signature \_\_\_\_\_

My contact email is \_\_\_\_\_

Date \_\_\_\_\_

Please provide consent below, for your child's data to be used.

<b>Consent for child</b>	<b>Please Initial</b>

I give consent for photographs, audio and video recordings from my child's interview to be used for research and educational purposes.	
I understand that my child's personal data provided will be processed in accordance with GDPR regulations (see privacy statement).	

**I parent/carer (name)** \_\_\_\_\_

**consent for my child's photographs, audio, and video from this study to be used for research and educational purposes either in or outside of the laboratory by Olivia Hughes, School of Psychology, Cardiff University with the supervision of Professor Andrew Thompson**

My relationship to the child \_\_\_\_\_

My child's first name is \_\_\_\_\_

My child's last name is \_\_\_\_\_

My child's date of birth is \_\_\_\_\_

Your Signature \_\_\_\_\_

Date \_\_\_\_\_

C.5. Children's assent form.

## Child Assent Form



I have some things to check with you...

**Hello!**

**My name is Olivia. I really want to know your opinion on living with a skin condition and how you and your mum/dad/carer are managing your skin. I will be recording our conversation and writing it up later, but your name won't be linked to anything you tell me. If you have any questions about the study, please ask Olivia, or your parents/carers. If you are happy with speaking to Olivia, please draw a BIG tick in the box below!**

**I am ok with this**

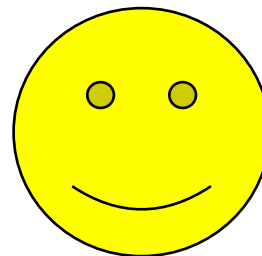
Your name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_



**Thank you!**  
***Diolch***



## C.6. Parent/Carer interview schedule.

### Interview Schedule: Parent/Carer



## Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families

### Preamble/welcome:

Thank you for answering those questions about your family. Can I just confirm please that you have completed the consent form and you are happy to proceed with the interview? The plan is to speak to you first, and then *\*child's name\** afterwards. Just to let you know before we start that you are in charge of your own household and if for any reason you need to pause the interview to go and check on your child or sort anything out, that's fine, just let me know and we can take a break. Do you have any questions before we begin?

### Background questions about skin

In the first part of the interview, I'm going to ask you some questions about *\*child's name\** skin condition to understand how the diagnosis has impacted on your family, and how you are managing it.

To begin, could you tell me about *\*child's name\** skin condition? When did it start?

*Prompts: What were you thinking? How did you feel when it first started?  
How severe is it? How does it present? What are the main symptoms they  
experience?*

What has changed in your life or daily routine since *\*child's name\** skin condition first developed?

*Prompts: Can you talk about any changes there may have been in your life since they were diagnosed? How do you feel about those things? How do you think your child feels about them?*

How does *\*child's name\** skin condition impact on their pattern of sleep? Or the family's bedtime routine?

*Prompts: Can you tell me if your sleep has been interrupted? What about other family members in the household, have they had disruptions to their sleep?*

How does *\*child's name\** skin condition impact them at school?

*Prompts: What is \*child's name\* school life like? What's it like for them making friends in school?*

What would you say are the main issues you have experienced in managing your child's skin condition?

*Prompts: What have been the most significant challenges? What have the reactions of other people been like? What have the reactions of teachers/people in school/friends or family been like? How do other people's reactions to your child's condition make you feel? How have you managed this?*

Overall, regarding *\*child's name\** skin condition, what is it like to be their main caregiver?

*Prompt: Can you tell me if you get chance to take time for yourself?*

### **Type of help or support interventions that may (or may not) have been received**

In the next part of the interview, we're going to discuss types of support you may or may not have been offered. Particularly, psychological support from any health professionals, and how helpful you might have found this, or if you would find some extra support useful. Have you ever been offered any psychological support or information for yourself or *\*child's name\** on how to manage their skin condition?

*Prompts: **If yes** - What was involved? What did you find most helpful? Was there anything you didn't like? **If no** – How would you feel about having more available psychological support?*

From your experience, what do you think are the issues surrounding current available support options for children with skin conditions and their families?

*Prompts: For you, what has been most noticeable? Can you tell me if there is anything you feel needs improving or addressing?*

Regarding the things we were discussing earlier, have you tried any techniques or approaches yourself to try and address these issues associated with \*child's name\* skin condition?

*Prompts: Apps? Websites? Books? Can you tell me a bit about that? What sort of things have you tried to manage these issues?*

### **Current coping techniques and support that may be beneficial**

In terms of managing your child's skin condition on a day-to-day basis, how do you manage any stresses or emotions that may arise from being their main carer?

*Prompt: What makes you feel better?*

What do you think would be the most helpful aspect to include in future support or psychological support?

*Prompts: What would you like? What would you find useful from a future intervention?*

### **Thoughts and opinions on a Mindfulness-based intervention**

We are aiming to create a set of resources designed to help children and their parents with managing their skin condition, possibly using mindfulness and mindfulness-based exercises. Mindfulness involves learning to pay attention to things more closely, being kinder to the self, practicing focussing the attention on the present, and we use techniques such as meditation and breathing exercises to help people relax and calm down. We're really interested in asking you about what you would find most helpful, and what we could do to help support you and \*child's name\* in managing their skin condition with this technique.



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?

*Prompt: Can you tell me if you think this is something your child would participate in too?*

What are your thoughts on parent and child activities if we were to ask you to do some activities together as a family?

Have you got any reservations about mindfulness-based interventions or exercises?

*Prompt: Is there anything you are unsure about?*

**Thank you and debrief:**

That's the end of the interview for the parents, and everything I wanted to ask you/both. I was interested in gaining your experiences of caring for *\*child's name\** skin, so thank you very much for offering your insights and discussing them with me. Is there anything else you would like to add or feel you should mention? Do you have any questions you would like to ask before I proceed to speak to *\*child's name\**?

## C.7. Children's interview schedule.

### Interview Schedule: Children



### Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families

#### Preamble/welcome:

Hello *\*child's name\** thank you for being in this study. I've finished speaking to (mum/dad) now and I'd like to ask you a few questions about your skin, is that ok with you?

#### Background questions about skin:

Can you tell me a bit about yourself?

*Prompts: Do you have any brothers or sisters? Do you have any pets?*

Your mum/dad/carer told me you've got *\*skin condition\**, can you tell me about your *\*skin condition\**?

*Prompts: What is it like having \*skin condition\*? What happened when you first noticed your skin condition? What does your skin feel like? Some children find their skin itchy, dry, or sore, whilst others don't have any feelings, what is yours like?*

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?

*Prompts: What sort of things do you like doing? Does your \*skin condition\* stop you from doing anything? Like what?*

Some children that have \*skin condition\* say that it affects them in school, and some children say that it doesn't. What's it like for you?

*Prompts: Can you tell me if you notice it in school? Does it ever get in the way of doing schoolwork? If so, how? Can you tell me about what your skin is like when you're playing sports? What's it like when you're playing with friends?*

Can you tell me a bit about what it's like trying to sleep with your \*skin condition\*?

*Prompts: Does it ever keep you awake at night? Why? How does this make you feel?*

Some children say that their \*skin\* causes certain feelings when others don't notice as much – what's that like for you?

*Prompts: By feelings, is there a time when you might feel a bit annoyed or angry, fed up or sad because of your skin? Do you ever notice any bodily feelings? By bodily feelings I mean, does your skin ever feel different when you're feeling that way?*

### **Type of help or support interventions that may (or may not) have been received**

Has anybody given you anything in to try and help with what we've just been talking about with your \*skin condition\*?

*Prompt: sometimes doctors give leaflets or apps or websites with tips on how to feel better about your skin, have you had anything like that?*

### **Current coping techniques and support that may be beneficial**

Some of those feelings and ways you feel in your body and mind, and the things you've described sound a bit tricky, is there anything you do to manage these feelings?

*Prompts: What makes you feel better? If your skin does bother you, what do you do when that happens?*

What do you think would help you deal with your skin better?

*Prompts: What would you like? How can we help you the most? What would help children like you deal with their skin conditions better?*

### **Thoughts and opinions on a Mindfulness-based intervention**

We are thinking of putting together some activities for children that might help with some of the things we have been talking about, one of the things we might be using is a thing called 'mindfulness' which involves things like breathing exercises, and relaxing. I'm going to show you a short video explaining what mindfulness is – <https://www.youtube.com/watch?v=5ZzFqAPRcLI> Some of the exercises we might make for kids with skin conditions might include things like moving your attention away from your skin, to focus on other things to make you feel better.

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?

*Prompt: How would you feel about doing some activities like those to help you calm down a bit?*

What do you think about learning to manage your worries or tricky thoughts about your skin?

*Prompt: If you feel worried about your skin, what do you think about learning some ways to deal with that?*

What do you think about learning to manage the feelings in your skin you described earlier, such as itchiness and soreness?

*Prompt: What do you think about that?*

How would you feel about learning how to be kind to yourself and other people around you?

*Prompt: What do you think about learning to send love and happy thoughts to yourself to help you feel better about your skin?*

How would you feel about learning some techniques to help you with sleeping?

*Prompt: What do you think about learning some techniques to help you sleep at night?*

### **Thank you and debrief:**

Ok thank you so much (child's name) that was great! You've really helped me understand what your skin condition is like. Do you have any questions you'd like to ask me? I have a certificate for you, as a special thanks for your help today!

C.8. Parent/Carer debrief sheet.

## Parent/Carer Debrief Sheet



### Parent and Child Experiences of Psychological Support for Skin Conditions: Towards Developing a Support Intervention for Families.

**Thank you very much for participating in this research project, we greatly appreciate you giving up your time to help with this study.**

**Researcher Contact Details:**

Researcher	Research Supervisor
Ms. Olivia Hughes School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

**What did this study aim to find out?**

As described in the study information sheet provided, this study sought to gain insights into the parent and child experiences of psychological support available for managing the child's skin condition. We were interested in asking all participants specifically what they would like to see in future psychological interventions, and what they would find useful or helpful for managing their child's skin condition.

## **Storage and destruction of participant data**

Video and audio data has been collected and will be stored securely in compliance with GDPR. The interview has been video recorded using Zoom software for later transcription and data analysis. At this point, all identifying features including names will be anonymised, and pseudonyms will be assigned to the textual datasets. These coded, anonymised data may be stored for 7 years and could be made publicly available in accordance with open science practices, but they will not be linked to you or your child.

With your permission, the researcher would like to use the video recordings of you and your child for educational and research purposes, either within or outside of a laboratory, for conferences, teaching, or presentations. Your consent will have been taken for this on a separate consent form. No names will be associated with the video recordings. The video recordings will be stored securely on a Cardiff University OneDrive. However, there is a chance that people may recognise you. Video footage will only be kept with your approval, and if you are not comfortable with the researcher using video footage of you and your child, please let them know, and you can opt-out.

If you have not given consent for your video footage used for these purposes, it will not have affected your ability to take part in this study, and the researcher will delete your video footage immediately after the interview has been transcribed. All data will be stored securely and only the main researcher, and research supervisors will have access to your data.

## **If you have concerns regarding this study**

If you have any concerns regarding your participation in this study, please contact the Cardiff University School of Psychology Ethics Committee: *Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, 70 Park Place Cardiff CF10 3AT*

*Tel: +44 (0)29 2087 0360*

*Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)*

**Privacy Notice:**

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer ([inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)). The lawful basis for processing this information is public interest. This information is being collected by Olivia Hughes.

The information on the consent form will be held securely and separately from the research information. Only the researchers will have access to this form, and it will be destroyed after 7 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher and research supervisors will have access to this information. After the study ends the data will be anonymised (any identifying elements removed) and this anonymous information may be kept for 7 years, published, or made publicly available in compliance with open science. With permission, video footage may be used for educational and research purposes including within or outside of a laboratory.

C.9. Children's certificate of participation.

*Cardiff University gives the title of  
'Honorary Expert in Skin' to*

---

*For their excellent help with our study*

*Thank you*





**C.10. Demographic questions.**

**Demographic Information Form**



Welcome: I'd like to take some family information from you if that's ok, please?

Name of parent/carer(s):

Name of child:

How old are you? (Both) parent/carers age, and child's age?

What skin condition does \*child's name\* have?

How long have they had \*skin condition?\* When were they diagnosed?

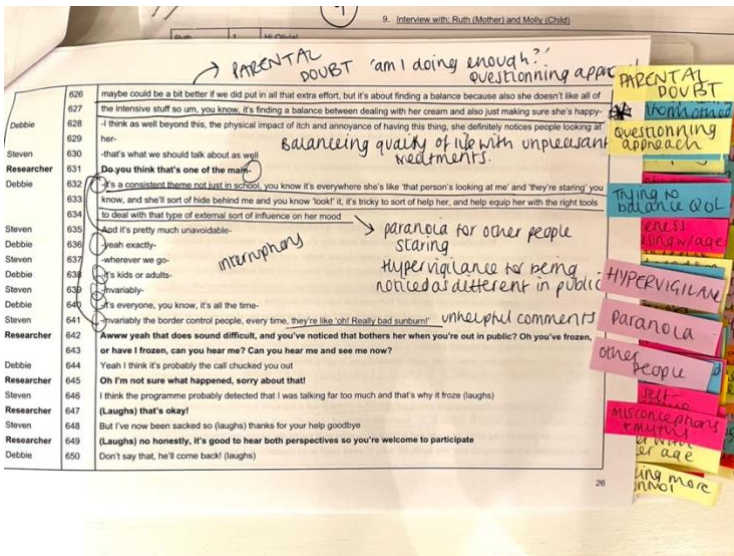
What is your ethnic background?

Employment status?

Genders?

Geographic location? Where are you based/live?

# C.11. Evidence of process of hand annotation of transcripts, and thematic map to develop themes.



## Appendix D

### Study 2 Materials

#### Appendix D.1. Study advertisement for social media.



**CARDIFF UNIVERSITY**  
**PRIFYSGOL CAERDYDD**

## ARE YOU A HEALTHCARE PROFESSIONAL IN THE UK WITH EXPERIENCE IN CHILDHOOD SKIN CONDITIONS?

We would like to online interview practitioner psychologists, dermatologists, and specialist dermatology nurses, with experience working with children and families affected by skin conditions, about your views on psychological support

 Interested?  
Email Olivia Hughes:  
[hughesoa@cardiff.ac.uk](mailto:hughesoa@cardiff.ac.uk)

The advertisement features a blue background with white and red text. On the right side, there is a stylized illustration of a woman with short dark hair, wearing a purple top and white pants, sitting on a stool and talking to a young boy sitting on a pink sofa. A speech bubble is shown between them. The Cardiff University logo is in the top left corner, and a small portrait of Olivia Hughes is in the bottom left corner.

## **Appendix D.2. Research participation invitation.**

Dear [inset name],

My name is Olivia Hughes, and I am a third year PhD student in Cardiff University School of Psychology. I am researching the psychological impact of living with a skin condition, supervised by Professor Andrew Thompson, and Professor Katherine Shelton. We are currently recruiting for a research study interviewing healthcare professionals (including practitioner psychologists, dermatologists, and specialist dermatology nurses) with experience working with children and families affected by skin conditions, and this is why we are getting in touch with you.

We would very much like to speak to you about your experiences of [providing psychological support for children with skin conditions] [working clinically with families] and would therefore like to invite you to take part in a one-to-one discussion via Zoom. I have attached a study information sheet, explaining the study in further detail, along with a consent form to be completed if you are interested in taking part.

If you have any questions, please let me know and I'd be happy to explain things further.

We look forward to hearing from you.

Sincerely,

Olivia Hughes.

cc. Professor Andrew Thompson, and Professor Katherine Shelton.

## **Study Information Sheet**



### **A Qualitative Study with UK Healthcare Professionals Exploring Psychological Support for Children and Families Affected by Skin Conditions**

#### **What is this study about?**

We are inviting you to take part in a one-to-one interview to gain insights into childhood skin conditions. During the interview you will be asked about your experiences of providing care for children with visible skin conditions, your views on current psychological support options (e.g., what you think is important to prioritise in future interventions), and if you think a mindfulness-based intervention might be useful for this patient demographic.

#### **Am I eligible to take part?**

We are interested in interviewing healthcare professionals including practitioner psychologists, dermatologists, and specialist dermatology nurses, with experience working with children and families affected by skin conditions.

If you are currently practicing in the United Kingdom, 18 years of age or over, and an English speaker, you are eligible to take part.

#### **What will I be doing?**

You will have been sent a consent form to complete. Once this has been filled out, you will be invited to an online meeting via a Cardiff University Zoom session and will

be asked a series of questions by a researcher. The interview will last approximately one-hour and you will have the opportunity to ask any questions that may arise.

### **Who will be interviewing me?**

Olivia Hughes will be leading the interviews. Olivia is a PhD student in Cardiff University School of Psychology and is carrying out this study as part of her doctorate. Olivia is interested in researching the psychological impact of skin conditions, and the relevance of offering children and their families a mindfulness-based support intervention.

### **Do I have to participate?**

It is completely up to you to decide whether this study would be of interest to you. This information sheet has been written to provide you with the details of the study so you can make a choice about whether this research is something you would like to take part in. If you do decide to participate, and later change your mind, you may withdraw your data without an explanation, by letting the researcher know as soon as possible.

### **Will I be recorded?**

Yes, all interviews will be video, and audio recorded using Zoom software for the purposes of later transcription, and data analysis and it will be deleted immediately after transcription has taken place. You do not have to switch your computer webcam/camera on if you are not comfortable with the researcher seeing you.

### **Will my information be anonymous?**

The interviews will be video, and audio recorded with Zoom and only accessed by the researcher and research supervisor. The footage of the interviews will be transcribed, and at this point, pseudonyms will be assigned to every participant and any identifying details will be altered to protect identities. During the interview, you will be asked about your experience of providing care to patients. If you do speak about any clinical examples of treating children with skin conditions, please anonymise them so they cannot be identified from your description. If you do

mention a patient name, this will be removed during the transcription process by the researcher, and replaced with a pseudonym.

In order to make sure we reflect your views accurately; we will be carrying out a member validation process. This will involve you having the opportunity to review quotes and excerpts from your transcript that we will be using in our dataset. To do this, your identity will be linked to the pseudonym you have been provided with, in a separate list. Only the research team will have access to this list, and it will be stored separately from the transcripts. The researcher will send you the quotes we are planning to use from you in our data analysis, for you to check and corroborate the meaning. Although the researcher will have already anonymised the data, this will give you the chance to correct any misinterpretations or remove any features from the text you feel might still be identifiable.

### **Will my information be confidential?**

Only the researcher, and the research supervisors will have access to your information. confidentiality will always be upheld. However, in the instance of a safeguarding issue, the researcher has a duty of care and responsibility to discuss any concerns with the research supervisors and inform the University safeguarding officer who may decide on seeking an appropriate course of action depending on the level of risk or threat observed.

### **Are there any risks involved with taking part?**

Although there are no specific risks identified for this study, if you become distressed or upset at any point, you may take a break, re-start the interview at another time, or end your participation.

### **Storage and destruction of participant data**

All data will be collected and stored securely in compliance with GDPR. The interview (with your permission) will be video and audio recorded using Zoom software for later transcription and data analysis. The video and audio will be stored for a period of up to one month before transcription has taken place, and then it will be deleted. At this point, all identifying features including names will be anonymised,

and pseudonyms will be assigned to the textual datasets. These coded, anonymised data may be stored for 7 years and could be made publicly available in accordance with open science practices, but they will not be linked to you.

### **What will happen to the results?**

The results of this study will be written up in academic research papers, and possibly published in a scientific journal. All excerpts used will be anonymous and your name will be changed to protect your identity. If you would like to be updated and sent a copy of the finished paper, please ask the researcher and we will be happy to forward the work on to you to read once finished.

### **What should I do if I have more questions?**

You will have the chance to ask any questions or clarify any details with the researcher prior to participating. You may also ask any questions freely throughout the interview, should they arise. If you think of anything after we have finished the interview, please do not hesitate to email the researcher on the contact details provided on this sheet.

### **I am interested – what should I do now?**

If you have read this study information sheet, and you are happy and feel comfortable taking part in this research, please email Olivia on the contact details provided below, and she will organise a convenient date and time for interview.

### **Consent and Approval**

The study has been assessed and given approval from Cardiff University's School Research Ethics Committee. The researcher has attained a Disclosure & Barring Service (DBS) (enhanced) clearance check in accordance with the UK Government.

### **Researcher contact details**

Researcher	Research Supervisor
------------	---------------------



<p>Ms. Olivia Hughes  School of Psychology,  Cardiff University,  70 Park Place,  Cardiff, CF10 3AT  <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a></p>	<p>Professor Andrew Thompson  School of Psychology,  Cardiff University,  70 Park Place,  Cardiff, CF10 3AT  <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a></p>
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### **What if I have concerns about this study?**

If you have any concerns regarding your participation in this study, you can also directly contact the Cardiff University School of Psychology Ethics Committee:  
*Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT.*  
*Tel: +44 (0) 029208 70707.*  
*Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk).*

### **Privacy Notice:**

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at [inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk). Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain, can be found at the following: <https://intranet.cardiff.ac.uk/staff/supporting-your-work/manage-use-and-protect-data/data-protection>

## Appendix D.4. Study consent form.

### Consent Form



#### **A Qualitative Study with UK Healthcare Professionals Exploring Psychological Support for Children and Families Affected by Skin Conditions**

Thank you for your interest in our study. The purpose of this form is to gain your permission for you to take part in this study. On this form, you will provide consent. But it is important to remember that this does not commit you to taking part. If you change your mind, you are free to withdraw your data, by letting the researcher know as soon as possible. If you have any further questions about the study, or this form, please email [hughesoa@cardiff.ac.uk](mailto:hughesoa@cardiff.ac.uk).

#### **Researcher contact details:**

Researcher	Research Supervisor
Ms. Olivia Hughes, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

**What if I have concerns about this study?** If you have any concerns regarding your participation in this study, you can also directly contact the Cardiff University School of Psychology Ethics Committee: *Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT.*

Tel: +44 (0) 029208 70707.

Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk).

**Privacy Notice:**

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<b>I confirm that:</b>	<b>Please Initial</b>
I have read and understood the study information sheet.	
I have been given the opportunity to ask any questions regarding the study, and any questions I have asked, have been appropriately answered (the researcher can be contacted by email <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a> ).	
I understand that participation in this research study is entirely voluntary, and I can withdraw my data without giving a reason and without consequence.	
I am happy to participate in this research study and I understand what I will be doing during the interview.	
I understand that the interview will be audio recorded.	
I understand that the interview will be video recorded.	
I am happy for my computer webcam/camera to be switched on during the interview.	
I understand that I am free to ask questions at any time. I am free to withdraw or discuss our concerns with the researcher (Olivia Hughes) or the research supervisor (Professor Andrew Thompson).	

I understand that I can pause the interview by requesting a break without giving a reason or end my participation without explanation or consequence.	
I understand that the research data being collected will include information regarding working with children/families affected by skin conditions. I specifically consent to this information being processed for the purposes of research including using anonymous quotes from my interview for academic papers and other formal research outputs.	
I have been informed that the information I provide will be safeguarded, although may not be guaranteed if certain information is divulged.	
I understand that the research data being collected will include information regarding my work. I specifically consent to this information being processed for the purposes of research including using anonymous data from my interview for academic papers and other formal research outputs.	
I understand that the personal data will be processed in accordance with GDPR regulations (see privacy statement).	
I understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.	
I give my consent to participate in this study.	

In the next section, you will be asked for your permission to be audio and video recorded for the purposes of data analysis. All recorded data will be stored securely and will only be accessed by the researchers and the research supervisors.

<b>Audio and video recording for the purposes of data analysis</b>	<b>Please Initial</b>
I give my permission to have my interview video recorded using Zoom software.	
I give my permission to have my interview audio recorded.	

**I (name)** \_\_\_\_\_

**consent to participate in the study conducted by Olivia Hughes, School of**

**Psychology, Cardiff University with the supervision of Professor Andrew  
Thompson.**

Signature\_\_\_\_\_

My contact email is\_\_\_\_\_

Date\_\_\_\_\_

## Appendix D.5. Demographic questions.

### Demographic Information Form



How old are you?

Geographic location? Where do you practice?

What percentage of your time do you work with children with skin conditions?

What is your job title?

What are your qualifications?

How many years have you been practicing?

What is your gender?

What is your ethnic background?

## Appendix D.6. Interview schedule.

### Interview Schedule



#### **A Qualitative Study with UK Healthcare Professionals Exploring Psychological Support for Children and Families Affected by Skin Conditions**

##### Preamble/welcome:

Can I just confirm please that you have completed the consent form and you are happy to proceed with the interview? Just to let you know before we start that you can pause the interview at any time, and you are free to end your participation at any point during our discussion. Do you have any questions before we begin? If you do speak about any clinical examples of treating patients, please anonymise them so they cannot be identified from your description.

##### **Background questions**

In the first part of the interview, I'm going to ask you some questions about the impact of skin conditions on children and what you've observed in clinic.

Could you tell me about the psychological issues associated with having a skin condition that you see in children?

*Prompts: Things like... anxiety, low mood, irritability etc.*

Could you tell me about the social issues associated with having a skin condition that you see in children?

*Prompt: Things like... school issues etc.*

What are the implications for parent/carers and families of children with skin conditions?

*Prompts: What about social issues? What about practical issues? What about parental emotional impact?*

How do you identify psychological distress or issues in children and families who you see in your clinic?

*Prompts: Is there anything you specifically ask? Is there anything you specifically look for? Do you use specific tools (e.g., forms or questionnaires [**if so**, identify name and explore usage such as frequency and circumstances in which used]?)*

What sorts of things do you see children do naturally to cope with their skin condition?

*Prompt: Do they share that they do things to distract themselves or...?*

What sorts of things do you see families and parents do naturally to cope with their skin condition?

*Prompt : Do they share that they have tried certain things...*

### **Type of help or support interventions that you may (or may not) offer patients**

In the next part of the interview, we're going to discuss types of statutory or non-statutory support you may or may not be offering or recommending to your patients: Can you tell me about the psychological services that you are aware of for children and families?

*Prompts: **if yes** – How do you use? What is involved? Why do you think this is important? **if no** – Can you tell me what you think is necessary to provide? Why?*

Are there any other resources that you signpost children with skin conditions and their families to for support?

*Prompts: Apps? Websites? Books? Charities? Can you tell me a bit about that? What sort of things do you recommend to children and their families?*

If you were presented with a child experiencing distress from a skin condition, needing psychological treatment, are there any specific psychological strategies, techniques or therapies that you would personally provide?

*Prompts: Why this technique/approach? **For psychologists:** I'd like to explore the clinical cycle i.e., walk me through what you do? Explore type of therapy –*



*does this approach have a name? Can you tell me how you learnt how to do this? Can you tell me if this has been successful, from your experience with children? How do children respond? What do you think the mechanism for change is?/ What is the primary target of the intervention? Can you tell me if you think there is anything this approach does not address?*

Are there any particular tools or measures you use to measure change in outcome in relation to psychological presenting problems that you work with?

Can you give me a few anonymised examples of recent psychological interventions that you have used?

*Prompts: What were the presenting issues? How did you assess? What was your opinion/formulation? What intervention/s did you use? What was the outcome?*

### **Thoughts and opinions on specific forms of psychological intervention**

We would like to get your expert feedback on the relevance of offering specific forms of psychological intervention. What would your thoughts be on offering systemic or family focused interventions?

*Prompts: Can you tell me if you think there would be value in targeting the family unit?*

What about cognitive behavioral therapy?

Specifically, we are aiming to deliver a psychological intervention to help children and their parents with managing their skin condition, using mindfulness and mindfulness-based exercises.

*(Mindfulness involves learning to pay attention to things more closely, being kinder to the self, practicing focussing the attention on the present, and we use techniques such as meditation and breathing exercises to help people relax and calm down).*

We're really interested in asking you what your views would be on using this approach in clinical practice, with children and their families affected by skin conditions. What are your thoughts on offering a mindfulness-based intervention

involving exercises such as slow breathing, meditation, or focussing attention on one thing in the mind, to children with skin conditions and their families?

*Prompts: Can you tell me if you think this is something you or your colleagues would consider delivering to children? What about their families?*

Have you got any reservations about delivering mindfulness-based interventions or exercises to children with skin conditions and their parent/carers?

*Prompts: Is there anything you are unsure about? Can you tell me if you think there might be any barriers to treatment? Can you tell me if this is something you think children might engage with? What about their families?*

Are there approaches that you think would be preferable?

What do you think are the issues surrounding current available support options for children with skin conditions and their families?

*Prompts: For you, what has been most noticeable? Can you tell me if there is anything you feel needs improving or addressing?*

Can you tell me if you think psychological support, such as mindfulness-based interventions could be incorporated into the current dermatological pathway of care?

*Prompts: **if yes** – how do you think this could this be done? **if no** - why not? What do you think would be the challenges in incorporating more psychological support? How can these challenges be addressed?*

**Thank you and debrief:**

That's the end of the interview, and everything I wanted to ask you. I was interested in gaining your experience of supporting children and families affected by skin conditions, so thank you very much for offering your insights and discussing them with me. Is there anything else you would like to add or feel you should mention? Do you have any questions you would like to ask?

## Debrief Sheet



### **A Qualitative Study with UK Healthcare Professionals Exploring Psychological Support for Children and Families Affected by Skin Conditions**

**Thank you very much for participating in this study, we really appreciate you giving up your time to be interviewed!**

#### **What did this study aim to find out?**

This research study sought to gain healthcare professionals insights into childhood skin conditions, including your experiences/views on providing care for children with skin conditions, your insights on current psychological support options (e.g., what you think is important to prioritise in future interventions), and if you think a mindfulness-based intervention might be useful for this patient demographic. If you would like any more information about the research study, or have any questions you would like to ask, please do not hesitate to contact Olivia Hughes, or the research supervisor, Andrew Thompson, who will be happy to help.

#### **Storage and destruction of participant data:**

In order to make sure we reflect your views accurately; we will be carrying out a member validation process. This will involve you having the opportunity to review quotes and excerpts from your transcript that we will be using in our dataset. To do this, your identity will be linked to the pseudonym you have been provided with, in a separate list. Only the research team will have access to this list, and it will be stored separately from the transcripts. The researcher will send you the quotes we are

planning to use from you in our data analysis, for you to check and corroborate the meaning. Although the researcher will have already anonymised the data, this will give you the chance to correct any misinterpretations or remove any features from the text you feel might still be identifiable.

Video and audio data has been collected and will be stored securely in compliance with GDPR. The interview has been video recorded using Zoom software for later transcription and data analysis. At this point, all identifying features including names will be anonymised, and pseudonyms will be assigned to the textual datasets. These coded, anonymised data may be stored for 7 years and could be made publicly available in accordance with open science practices, but they will not be linked to you. All data will be stored securely and only the main researcher, and research supervisors will have access to your data.

**Researcher contact details:**

Researcher	Research Supervisor
Ms. Olivia Hughes School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

**What if I have concerns about this study?**

If you have any concerns regarding your participation in this study, you can also directly contact the Cardiff University School of Psychology Ethics Committee:

*Secretary of the Ethics Committee,*

*School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT.*

*Tel: +44 (0) 029208 70707.*

*Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk).*

**Privacy Notice:**

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## Appendix D.8. Evidence of NVivo analysis (NVivo 12; released March 2018).

The screenshots illustrate the NVivo 12 interface for analyzing interview transcripts. The top screenshot shows a detailed view of a code node, 'Identifying distress in families', with a list of references and their coverage percentages. The middle screenshot shows a table of all code nodes and their associated references. The bottom screenshot shows a list of interview transcripts with a selected transcript open for viewing.

**Top Screenshot: Code Node Details**

**Code Node:** Identifying distress in families

**Sub-nodes:**

- Identifying distress in families
  - Assessment and stand...
  - Initial assessment and...
  - Level of support provision
    - Clinician recommendati...
    - Current available psych...
    - Lack of access to speci...
  - Psychological impact of s...
    - Dynamics between par...
    - Implications for childr...
    - Shared burden for pare...
  - Relevance of a mindfulness...
    - Barriers to engagement...
    - Potential benefits of mi...

**References:**

- Reference 1: 1.01% coverage  
there is variability between skin conditions, but particularly for something like acne, I see there are parents that can be very supportive, but they can also be quite blamey, they can assume that young people children are picking at their spots, squeezing their sports, not eating a healthy diet, so there can be quite a lot of blame, which is also piled on top of self-blame in the children and young people.
- Reference 2: 0.83% coverage  
most parents I interact with want to help, and want the best for their child, but that doesn't always make them behave in the most effective and helpful way, and I see a lot of parents want to speak for children, young people, when actually, they need to let the child and young person speak for themselves, and there can be a big discrepancy.
- Reference 3: 0.73% coverage  
I've certainly seen parents who've been much more bothered about the alopecia or the vitiligo than young person is, and allowing them to be okay is something that's really important for parents to be able to do, and not feel that they're somehow substandard because they've got a skin condition
- Reference 4: 0.58% coverage  
I've got one patient who is in her 50s, whose mum when she when she got psoriasis, quite severe psoriasis, her mum wouldn't touch her again, which is such a display of repulsion, and you can imagine that's just heartbreaking for a child.
- Reference 5: 1.70% coverage  
I see a lot of parents of younger children kind of assuming that they're going to be bullied, which isn't very helpful either because bullying can happen with or without a skin condition, yes people can say mean things if you've got something like a skin condition that might make you look different, but children can be mean and children can be kind, and I think arming a child or young person to deal with bullying, and to deal with unpleasant people is important, whatever they've got, but there's often an assumption that they're going to get bullied when that might not be

**Middle Screenshot: Code Node Table**

Name	Files	References	Created on	Created...	Modified on	Modified by	Color
Identifying distress in families	0	0	23 Feb 2023 at 10:...	OH	23 Feb 2023 at 11:14	OH	
Initial assessment and approach to treatment	15	131	23 Feb 2023 at 10:...	OH	6 Mar 2023 at 13:56	OH	
Standardised measures vs. questions	15	73	23 Feb 2023 at 10:...	OH	Today, 14:02	OH	
Level of support provision	0	0	23 Feb 2023 at 10:...	OH	23 Feb 2023 at 11:06	OH	
Current available psychological therapies	15	117	23 Feb 2023 at 11:08	OH	6 Mar 2023 at 13:56	OH	
Healthcare professional recommendations for improving care	14	59	23 Feb 2023 at 11:14	OH	Today, 14:03	OH	
Lack of access to specialist services	15	64	23 Feb 2023 at 10:...	OH	6 Mar 2023 at 13:56	OH	
Psychological impact of skin conditions	0	0	23 Feb 2023 at 10:41	OH	23 Feb 2023 at 20:...	OH	
Dynamics between parent and child	11	44	23 Feb 2023 at 12:...	OH	6 Mar 2023 at 13:56	OH	
Implications for children and adolescents	15	174	23 Feb 2023 at 10:...	OH	6 Mar 2023 at 13:56	OH	
Shared burden for parents and the family unit	15	74	23 Feb 2023 at 10:...	OH	6 Mar 2023 at 13:56	OH	
Relevance of a mindfulness-based intervention	0	0	23 Feb 2023 at 10:...	OH	23 Feb 2023 at 20:...	OH	
Barriers to engagement in mindfulness	13	45	23 Feb 2023 at 10:...	OH	6 Mar 2023 at 13:56	OH	
Potential benefits of mindfulness	15	72	23 Feb 2023 at 10:...	OH	6 Mar 2023 at 13:56	OH	

**Bottom Screenshot: Interview Transcript**

**Transcript:** HCP Interview 12

**Researcher 217** So if you were presented with a child experiencing distress from a skin condition needing psychological treatment, can you talk me through what you would do with them?

**Annabelle 218-220** So initially I'd do the assessment to figure out exactly what was going on in terms of the dynamics and in terms of the level of severity, and what else was going on for the child and the family, speaking to the family, and then dependent on the outcome of the assessment, you'd look at different types of therapies, so if they were scratching a lot, for example, I would look at Habit Reversal therapy, if they've got anxiety, or depression, I would look at cognitive behavioral therapy, and really adapting those therapies specific to the client and linking in their skin condition. so I do a lot of work with the dermatologist, and kind of looking at their skincare routine and how that affects them in terms of their stress, and see if we can look at making a more easy routine for them to follow, because often you find it may be the wrong cream that they're using, or it's a good cream, but it may not be good for their routine, like there's so many different creams out there they could try something that's more appropriate for the way in which they live, for example, that's one big thing, if there are family issues, then I look at systemic family therapy, and for those who are stressed, as we know that stress has a big impact on their skin, we also look at relaxation techniques, and I integrate with the Habit Reversal anyway, so for example, the child who did a lot of drawing and coloring, I changed them into mindfulness coloring sheets, so depending on their age, bringing in age appropriate strategies, so it may be mindfulness, for example, but it will be mindfulness coloring, or it may be mindful breathing or doing bubbles, you have to change it according to the age of the child

**Researcher 226** And how do the children normally respond to the therapy? And are there some that are more accepted than others? Or once certain components that are more preferred? How do you find they respond?

**Annabelle 229-231** I think trial and error, some children will like the homework and the CBT, but some children hate that altogether, and week after week they won't be doing their homework, and then you need to change it up a bit, or they might like doing the bubbles, for example, the breathing bubbles or the breathing mindfulness strategies, and I've got these mindfulness cards that they like, and positive affirmations that we stick up, so there's ways of doing more direct things versus indirect strategies and I like to talk about it with them, and I give them the option, I'll say 'should we go down this route?' Or, 'should we try a bit of this?' or we do a bit of both and mix it up a bit, I'm a bit more fluid when it comes to the children, because I like to have a bit of input in terms of what they want to do, and I find they engage better if they've chosen that task for that week, for example, they're more likely to do it, so I'll put two things in front of them and say look 'I've got these mindfulness cards and they're brilliant, they're just these little cards on how to do a breathing rainbow', for example, or I'll say, 'okay, let's think about something else', and they'll choose or they'll go away and try it, they'll either take both and try both, or whatever, so I kind of try and not them as involved as possible, but I find different strategies work for different people, and the c...

**Appendix D.9. Confirmation of member checking process.**

I \_\_\_\_\_ (name) confirm the following (please tick or initial):

I have received the proposed anonymous quotes taken from my interview with Olivia Hughes, Cardiff University for the project titled: 'A Qualitative Study with UK Healthcare Professionals Exploring Psychological Support for Children and Families Affected by Skin Conditions'

I have had the opportunity to carefully read my anonymous excerpts

I have had the opportunity to make comments on the data presented to me, and I have made any amendments I feel necessary

I confirm my interview data accurately represents my views, and I am happy with the level of detail reported in the quotes

Date \_\_\_\_\_

Full name \_\_\_\_\_

Signature \_\_\_\_\_

## Appendix E

### Study 3 Materials

#### Appendix E.1. Study advertisement for social media.



**Does your child have ichthyosis?**

We are offering carers of children under 16 years with ichthyosis an online mindfulness course, to improve stress and wellbeing

  **Ichthyosis Support Group**  
People who care about ichthyosis

 **£20 Voucher**  
Interested? Email Olivia Hughes:  
[hugheso@cardiff.ac.uk](mailto:hugheso@cardiff.ac.uk)

Funded by the Ichthyosis Support Group

The advertisement features a background illustration of a person in a meditative pose surrounded by various tropical leaves and plants in shades of blue and teal.



## **Study Information Sheet**



### **Mindfulness for Parents of Children with Ichthyosis and Other Visible Skin Conditions: A Single Group Case Series**

#### **What is this study about?**

We are inviting you to take part in an 8-week mindfulness course, looking at reducing levels of stress associated with parenting a child with a skin condition such as ichthyosis, psoriasis, eczema, or vitiligo.

#### **What is mindfulness?**

Mindfulness is an approach based on Buddhist principles and is being used widely in the field of psychology and other sectors to improve wellbeing and reduce stress. Mindfulness involves learning to pay attention to things more closely, learning to be kinder to the self, and practicing focussing your attention on the present. To achieve this, mindfulness includes the use of techniques such as meditation and breathing exercises to help people relax and calm down. We're really interested in how this approach could help you with managing your child's skin condition.

#### **What is this mindfulness course?**

The mindfulness course that will be delivered is a program called 'Living in The Present.' 'Living in the Present' is a new and novel approach to introducing mindfulness in daily life, which is different to traditional mindfulness-based programs that require attendance at sessions to be supported with regular personal practice (the Present Courses, 2022). Engaging in personal practice can be challenging to

upkeep, so the present approach allows people to learn mindfulness through what is valued in their lives and helps with commitment by the person having relevance to their practices (the Present Courses, 2022). This approach was chosen as appropriate for carers of children with ichthyosis and other visible skin conditions, as previous studies with parents of children with skin conditions has highlighted the daily pressures of care, including attending dermatology appointments, upkeeping treatment regimens, caring for other children in the household, and working. These daily demands may result in parents having busy daily schedules which might make allocating time for personal mindfulness practice difficult (the Present Courses, 2022). By using the Present approach to introducing mindfulness and incorporating practices into activities that would be carried out on a daily basis, it may make the program more achievable for parents (the Present Courses, 2022).

### **Who will be teaching us?**

The course will be delivered by [a Mindfulness Teacher]. [The Mindfulness Teacher] is an external, qualified mindfulness practitioner and is listed on The British Association of Mindfulness Based Approaches website as compliant with the Good Practice Guidelines for Mindfulness Teachers. [The Mindfulness Teacher] has been trained to teach the Present by a co-founder of The Present (also listed on The British Association of Mindfulness Based Approaches website as compliant with Good Practice Guidelines for Mindfulness Teachers).

### **What will we be doing?**

The Present program will be delivered online in 8 sessions (lasting 8-weeks), once a week (during the evenings) in a group format. Start dates and times will be sent to you separately. Some segments of the sessions will be audio recorded for consistency checks to be carried out (ensuring the program is being delivered as intended). However, you will be informed by [The Mindfulness Teacher] in advance of recording commencing. Before you begin the Present program, you will be asked to complete a consent form and a registration form for [The Mindfulness Teacher] to confirm your place on the course (attached with this information sheet). Your child will also be asked to complete an assent form, giving their permission to complete questionnaires for the study.

To assess the effectiveness of the Present program, you and your child will be asked to answer a series of questionnaires. These questionnaires will measure parent and child psychological wellbeing and quality of life, including mindfulness, parental stress, parental depression, parental anxiety, parental quality of life, and child quality of life. These questionnaires will be filled out by you and your child at **four** time points (prior to beginning the program, just before the program starts, after the program ends, and several weeks after completing). The questionnaires will take approximately 15-20 minutes to complete each time. Along with this, **your own bespoke targets** of 'parental stress' for change will be established. You will be asked to identify *one positive target* (any aspect related to parenting a child with a skin condition that you would like to improve) and *one negative target* (any aspect related to parenting a child with a skin condition that you would like to reduce). These targets will be measured daily over the course of the study. To do this, you will be sent daily text messages, taking approximately 1-minute to complete each day. The researcher will be using the Page One Janet Txt text messaging service, and your data will be stored securely in line with the Data Protection Act 1998. After the 8-week course finishes, you will be invited for an 'exit interview' with Olivia Hughes. You will take part in a one-to-one discussion about your experience of the Present program. The interview will be held online, and will last approximately one hour. The interview will be video and audio recorded, and transcribed for data analysis. **As a token of appreciation for participating in this study, you will be given a £20 Love2Shop voucher.**

### **Am I eligible to take part?**

If you are the primary caregiver (over 18 years) to a child (under 16 years) diagnosed with a skin condition such as ichthyosis, psoriasis, eczema, or vitiligo, then you are invited to take part in this study.

### **Do we have to participate?**

It is completely up to you to decide whether this study would be of interest to you. This information sheet has been written to provide you with the details of the study so you can make a choice about whether this is something you would like to take part in. If you do decide to participate, and later change your mind - you may

withdraw without giving an explanation (but please let the researcher/instructor know as soon as you can).

### **Will we be recorded?**

To check the program is being delivered as intended, several sections of sessions will be audio recorded for assessment. Along with the sessions, the interview with the researcher upon course completion will be video and audio recorded using Zoom software for transcription. You do not have to switch your computer webcam/camera on if you are not comfortable with the researcher seeing you.

### **Will our information be anonymous?**

The session recordings will be listened to by one of the co-founders of the Present program to ensure the course was delivered as intended, and then the audio files will be deleted. The exit interviews will be video and audio recorded with Zoom, and only accessed by the researchers. Footage will be stored on a Cardiff University secure research database, and only the researcher, and research supervisors will have access to this. During transcription, pseudonyms will be assigned, and any identifying details will be altered to protect your identity.

### **Will our information be confidential?**

Only the researchers will have access to your information, and confidentiality will always be upheld. However, in the instance of a safeguarding issue, the researcher has a duty of care to discuss any concerns with the project supervisors and inform the University safeguarding officer who may decide on seeking an appropriate course of action depending on the level of risk or threat observed.

### **Are there any risks involved with taking part?**

This study will not require parents to talk openly in the group about any distressing experiences, however, in the case that any distress does arise, you will be able to leave the group, pause, or end your participation at any time, without giving a reason.

## **Storage and destruction of participant data**

All data will be collected and stored securely in compliance with GDPR. The session recordings will be stored securely, and shared with the co-founder of the Present, for quality control purposes, and then deleted. Only the research team, and mindfulness teacher will have access to your data. The interview will be video, and audio recorded using Zoom software for later transcription and data analysis. At this point, all identifying features including names will be anonymised, and pseudonyms will be assigned to the textual datasets. Footage will be deleted after the interviews have been typed up. The coded, anonymised data may be stored for 7 years and could be made publicly available in accordance with open science practices, but they will not be linked to you or your child.

## **What will happen to the results?**

The results of this study (including quotes) will be written up in academic research papers, and possibly published in a scientific journal. All information used will be anonymous and your name will be changed to protect your identity. If you would like to be updated and sent a copy of the finished paper, please ask the researcher and we will be happy to forward the work on to you.

## **What should I do if I have more questions?**

You will have the chance to ask any questions or clarify any details with the researcher prior to participating. You may also ask any questions freely throughout the course of the study, should they arise. If you think of anything after taking part in the mindfulness sessions, please do not hesitate to email the researcher on the contact details provided on this sheet.

## **I am interested – what should I do now?**

If you have read this study information sheet, and you are happy and feel comfortable taking part in this research, please email Olivia to confirm your place on the course, and discuss the next steps involved in beginning the study.

## Consent and Approval

The study has been assessed and given approval from Cardiff University's School Research Ethics Committee. The researcher has attained a Disclosure & Barring Service (DBS) (enhanced) clearance check in accordance with the UK Government.

## Researcher contact details

Researcher	Research Supervisor
Ms. Olivia Hughes School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

## What if I have concerns about this study?

If you have any concerns regarding your participation in this study, you can also directly contact the Cardiff University School of Psychology Ethics Committee:  
*Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT.*

*Tel: +44 (0) 029208 70707.*

*Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk).*

## Privacy notice:

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer ([inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)). The lawful basis for processing this information is public interest. This information is being collected by Olivia Hughes.

The information on the consent form will be held securely and separately from the research information. Only the researchers will have access to this form, and it will be destroyed after 7 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher and research supervisors will have access to this information. After the study ends the

data will be anonymised (any identifying elements removed) and this anonymous information may be kept for 7 years, published, or made publicly available in compliance with open science. With permission, video footage may be used for educational and research purposes including within or outside of a laboratory.

## Appendix E.3. Consent form.

### Consent Form



#### **Mindfulness for Parents of Children with Ichthyosis and Other Visible Skin Conditions: A Single Group Case Series**

Thank you for your interest in our study. The purpose of this form is to gain your permission for you to take part in this study. On this form, you will provide consent. But it is important to remember that this does not commit you to taking part, and if you change your mind, you are free to withdraw at any time. If you have any further questions about the study, or this form, please email [hughesoa@cardiff.ac.uk](mailto:hughesoa@cardiff.ac.uk).

#### **Researcher contact details:**

Researcher	Research Supervisor
Ms. Olivia Hughes, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

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The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form, and it will be destroyed after 7 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher and research supervisors will have access to this information. After the study ends the data will be anonymised (any identifying elements removed) and this anonymous information may be kept for 7 years, published, or made publicly available in compliance with open science. Video footage may be used for educational and research purposes including within or outside of a laboratory.

<b>I confirm that:</b>	<b>Please Initial</b>
I have read and understood the study information sheet.	
I have been given the opportunity to ask any questions regarding the study, and any questions I have asked, have been appropriately answered (the researcher can be contacted by email <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a> ).	
I understand that participation in this 8-week study is entirely voluntary, and I can withdraw at any time, without giving a reason and without consequence.	
I am happy to participate in the 8-week mindfulness group and I understand what I will be doing over the course of the study.	
I understand that several sections of the group sessions will be audio recorded for quality checks.	
I am happy for the researcher to send me daily text messages to measure my parental targets of stress, with Page One Janet Txt messaging service.	

I am happy for my computer webcam/camera to be switched on during the exit interview.	
I understand that I am free to ask questions at any time. I am free to withdraw or discuss our concerns with the researcher (Olivia Hughes) or the research supervisor (Professor Andrew Thompson).	
I understand that I can pause the exit interview by requesting a break without giving a reason or end my participation without explanation or consequence.	
I understand that the research data being collected will include information regarding <u>parenting a child</u> with a skin condition. I specifically consent to this information being processed for the purposes of research including using anonymous quotes from my interview for academic papers and other formal research outputs.	
I have been informed that the information I provide will be safeguarded, although may not be guaranteed if certain information is divulged.	
I understand that the research data being collected will include information regarding <u>my child's</u> skin condition. I specifically consent to this information being processed for the purposes of research including using anonymous data from my interview for academic papers and other formal research outputs.	
I understand that the personal data will be processed in accordance with GDPR regulations (see privacy statement).	
I understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.	
I give my consent to participate in this study.	
I give my consent for my child to participate in this study	

There is likely to be an additional part to this research study, which will involve testing an online resource for children with skin conditions, if you would be happy for

the researcher to keep your contact details, and be re-contacted to take part in this next stage, please give your consent by initialling in the box below:

I give permission for the researcher to contact me and my child in future with related studies following on from this research, and I am happy for the researcher to keep our contact information.	
--	--

In the next section, you will be asked for your permission to be audio and video recorded for the purposes of data analysis. All recorded data will be stored securely and will only be accessed by the researchers and the research supervisors.

<b>Audio and video recording for the purposes of data analysis</b>	<b>Please Initial</b>
I give my permission to have my exit interview video recorded using Zoom software.	
I give my permission to have sections of our mindfulness group sessions audio recorded.	

Below, you are required to identify your two bespoke parental targets of stress, to be measured daily with text message reminders. Page One is a company used to send text messages to mobile phones: their 'Janet Txt' service will be used by the researchers to send messages to you (in line with the Data Protection Act, to ensure information is held safely and securely). Only the researchers will have access (password protected) to an account and to your phone number, and all data is stored securely within an account until it is deleted (no backups are kept by Page One). Page One stores data on secure servers in the UK and have information security accreditation ISO 27001 and ISO22301 for Business Continuity Management Systems (BCMS). For more information about Page One's security accreditations: <https://www.pageone.co.uk/about-us/accreditations/>

<p><b>Targets of 'parental stress' for change</b></p> <p>We would like you to identify one positive target (something you would like to</p>
---

improve) and one negative target (something you would like to reduce). For example, "if this 'stress' wasn't there what you be doing more of that you're not doing now, or what would it be like?". Once you have decided on two targets of parental stress, these will be measured daily throughout the study on a 0-100 scale to indicate severity (100% being most severe). You will be sent a text message every day from the start of baseline through to follow-up (using Page One 'Janet Txt' text messaging service). You will be asked to respond to the researcher via text message with a number from 0-100 based on your symptoms.

**Positive target:**

**Negative target:**

**Mobile number:**

**I (name)** \_\_\_\_\_

**consent to participate in the study conducted by Olivia Hughes, School of Psychology, Cardiff University with the supervision of Professor Andrew Thompson**

Date of birth \_\_\_\_\_

Signature \_\_\_\_\_

My contact email is \_\_\_\_\_

Date \_\_\_\_\_

Please provide consent below, for your child to provide data this study:

**I parent/carer (name)** \_\_\_\_\_

**consent for my child to provide data for this study conducted by Olivia Hughes, School of Psychology, Cardiff University with the supervision of Professor Andrew Thompson**

My relationship to the child \_\_\_\_\_

My child's first name is \_\_\_\_\_

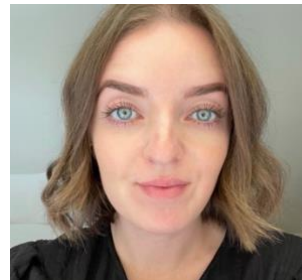
My child's last name is \_\_\_\_\_

My child's date of birth is \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

## Child Assent Form



I have some things to check with you...

**Hello!**

**My name is Olivia. I'm from Cardiff University and I'm really interested in learning about skin conditions. I would like to ask you to fill out some questions about what it's like having a skin condition. If you have any questions about this study, you can ask Olivia, or your parents/carers. If you are happy with answering some questions for Olivia, please draw a BIG tick in the box below! If you aren't happy to take part, that's ok too, just let Olivia know below.**

**Yes, I am ok with this**

**No, I am not ok with this (and do not want to take part)**

Your name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_



**Thank you!**

***Diolch!***



## Appendix E.5. Demographic questions.

### Demographic Information Form



Name:

How old are you?

How old is your child?

What type of skin condition does your child have?

How long has your child had their skin condition?

Who diagnosed your child with their skin condition?

What is your ethnic background?

What is your child's ethnic background?

What is your employment status?

What is your gender?

What is your child's gender?

What is your geographic location?

## Debrief Sheet



### **Mindfulness for Parents of Children with Ichthyosis and Other Visible Skin Conditions: A Single Group Case Series**

**Thank you very much for participating in this study, we really appreciate you giving up your time and taking part in this program**

#### **What did this study aim to find out?**

This study sought to deliver a mindfulness based program, 'Living in the Present' to parents of children with ichthyosis and other visible skin conditions, looking to reduce levels of stress associated with parenting a child with a skin condition.

**External support services:** We recommend you get in touch with your General Practitioner (GP) in the first instance if you would like additional support. Below, we have listed some website links signposting to external charities providing resources for people affected by skin conditions:

- **The British Association of Dermatologists** 'Skin Support' website has details of patient support groups <http://www.skincareaction.org.uk>. The Skin Support website also has downloadable materials to support the wellbeing of people with skin conditions, for managing stress and worry <http://www.skincareaction.org.uk/content/support-materials>
- **The Ichthyosis Support Group** has a lot of information (and a book resource) for adults and children diagnosed with the condition, including support materials for carers <https://www.ichthyosis.org.uk>
- **Togetherall** have an online community and offer mental health support on their website <https://togetherall.com/en->

gb/?gclid=CjwKCAjwjdOIBhA\_EiwAHz8xm04znkgG4UhKsjFFyYJHNYQyHG4hcD\_1XHWE633oil99f-Yt00C0sxoChoAQAvD\_BwE

- **The Samaritans** have a free, 24/7 telephone helpline, if you would like to speak to someone confidentially <https://www.samaritans.org/?nation=wales>

### **Storage and destruction of participant data**

Video and audio data has been collected and will be stored securely in compliance with GDPR. The interview has been video recorded using Zoom software for later transcription and data analysis. At this point, all identifying features including names will be anonymised, and pseudonyms will be assigned to the textual datasets. These coded, anonymised data may be stored for 7 years and could be made publicly available in accordance with open science practices, but they will not be linked to you. No names will be associated with the video recordings. The video recordings will be stored on a Cardiff University Secure Data Store. All data will be stored securely and only the main researcher, and research supervisors will have access to your data.

### **Researcher contact details:**

Researcher	Research Supervisor
Ms. Olivia Hughes School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:hughesoa@cardiff.ac.uk">hughesoa@cardiff.ac.uk</a>	Professor Andrew Thompson School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT <a href="mailto:thompsona18@cardiff.ac.uk">thompsona18@cardiff.ac.uk</a>

**What if I have concerns about this study?** If you have any concerns regarding your participation in this study, you can also directly contact the Cardiff University School of Psychology Ethics Committee: *Secretary of the Ethics Committee, School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT.*

*Tel: +44 (0) 029208 70707.*

*Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk).*



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## Appendix E.7. Evidence of NVivo analysis (NVivo 12; released March 2018).

The image displays three screenshots of the NVivo 12 software interface, illustrating the workflow from data import to analysis results.

**Top Screenshot:** Shows the 'Import' phase. The 'Data' section is active, displaying a list of imported files: Exit Interview 1 through Exit Interview 9. The main workspace shows a transcript for 'Exit Interview 1' with text from participants (Researcher and Bianca) and their responses to questions. The text is color-coded to represent different codes.

**Middle Screenshot:** Shows the 'Coding' phase. The 'Codes' section is active, displaying a list of codes created for the analysis. The codes include: Acceptability of mindfulness exercises, Bringing mindfulness into daily life, Preferences for different course components, Suggestions for future interventions, Challenges of taking part in an intervention, Pressures of time limiting ability to immerse in mindfulness, Pros and cons of a group format, Noticing the benefits of mindfulness, Healthier interactions with child, and Shifts in parental mood and attitude. A table below the codes lists the number of files, references, and creation/modification dates for each code.

Name	Files	References	Created on	Created...	Modified on	Modified by	Color
Acceptability of mindfulness exercises	0	0	3 Feb 2023 at 10:55	OH	7 Feb 2023 at 00:30	OH	Yellow
Bringing mindfulness into daily life	9	52	6 Feb 2023 at 12:02	OH	6 Feb 2023 at 13:05	OH	Orange
Preferences for different course components	7	31	6 Feb 2023 at 12:01	OH	7 Feb 2023 at 10:24	OH	Green
Suggestions for future interventions	10	34	31 Jan 2023 at 14:57	OH	7 Feb 2023 at 10:11	OH	Blue
Challenges of taking part in an intervention	0	0	6 Feb 2023 at 12:00	OH	7 Feb 2023 at 10:00	OH	Red
Pressures of time limiting ability to immerse in mindfulness	8	38	31 Jan 2023 at 14:56	OH	7 Feb 2023 at 10:17	OH	Light Blue
Pros and cons of a group format	10	26	6 Feb 2023 at 12:01	OH	7 Feb 2023 at 10:07	OH	Light Green
Noticing the benefits of mindfulness	0	0	3 Feb 2023 at 10:54	OH	6 Feb 2023 at 13:06	OH	Light Purple
Healthier interactions with child	9	70	3 Feb 2023 at 10:56	OH	6 Feb 2023 at 15:10	OH	Light Orange
Shifts in parental mood and attitude	10	64	6 Feb 2023 at 11:56	OH	7 Feb 2023 at 10:10	OH	Light Yellow

**Bottom Screenshot:** Shows the 'Analysis' phase. The 'Codes' section is active, displaying a list of codes. The main workspace shows a summary of the analysis for the code 'Challenges of taking part in an intervention'. The summary includes a reference list with coverage percentages and a detailed analysis of the code's content, discussing the difficulty of committing to the course and the challenges of attending regularly.

Files\Exit Interview (Facilitator)  
8 references coded, 16.39% coverage

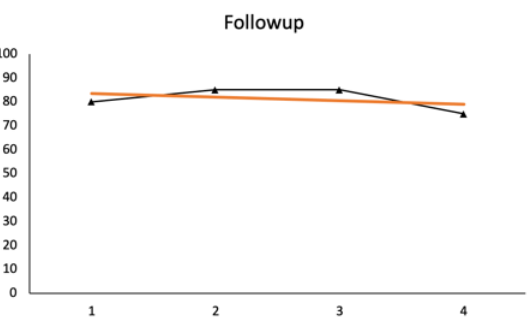
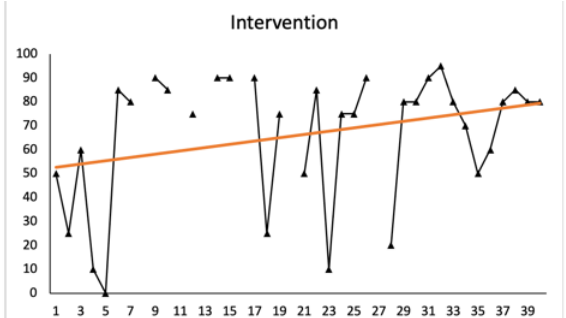
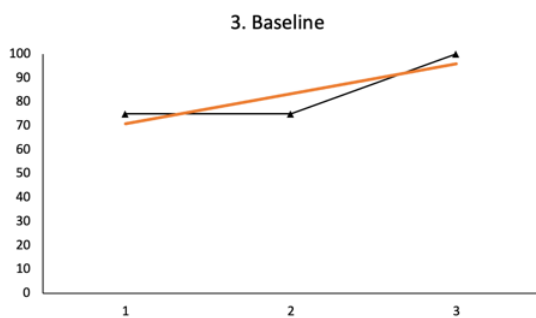
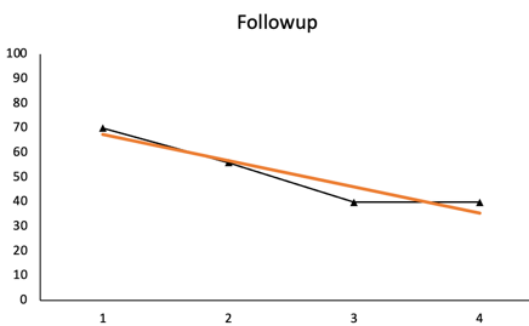
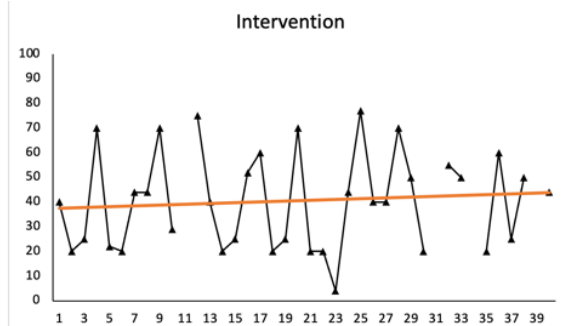
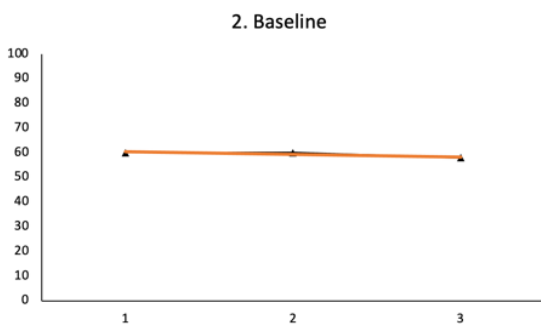
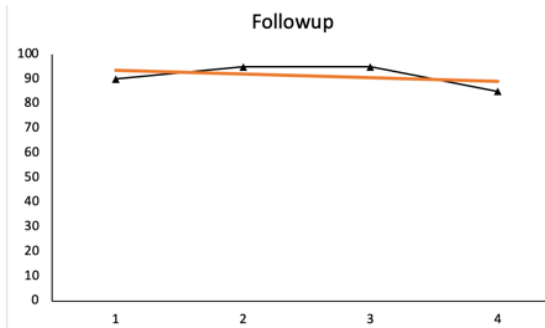
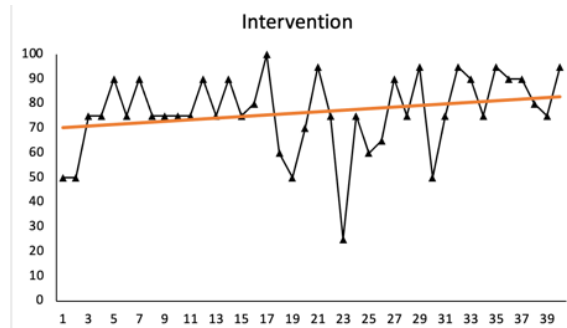
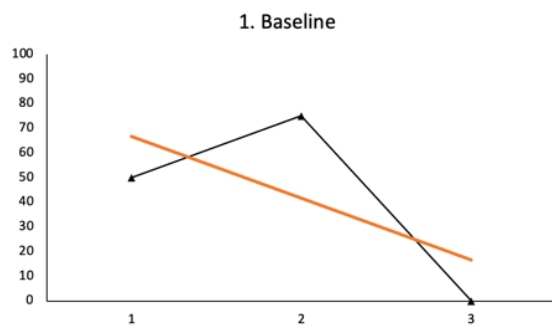
Reference 1: 2.60% coverage  
I think the obvious thing was the difficulty of committing and attending the session regularly, attendance was really patchy with this one, and even the core participants that started and stuck with it, many of them missed a number of sessions, so I think that's one of the key things is their ability to kind of commit to this, given the fact that one of the reasons why we thought this would be useful is the extra pressures and the demands and the stresses and strains in their in their context, I think that did show up through the course, even though this mindfulness course is designed to be accessible, and as minimal as possible, I wasn't convinced that many of the participants were better trying lots of activities regularly

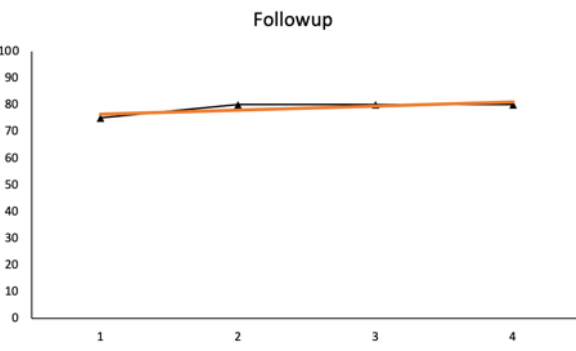
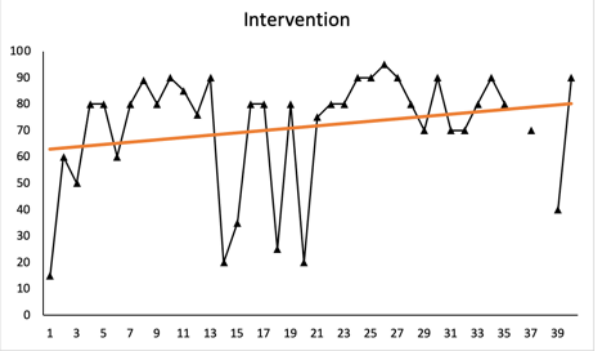
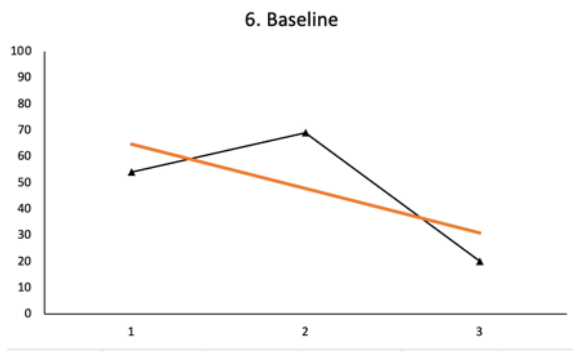
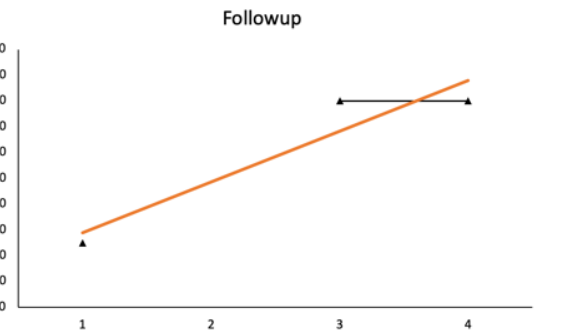
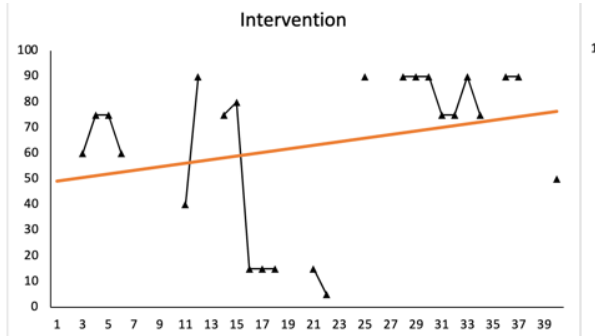
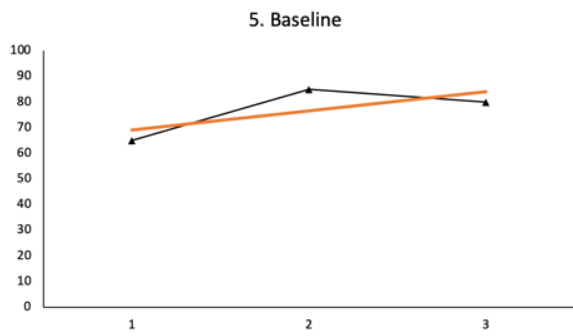
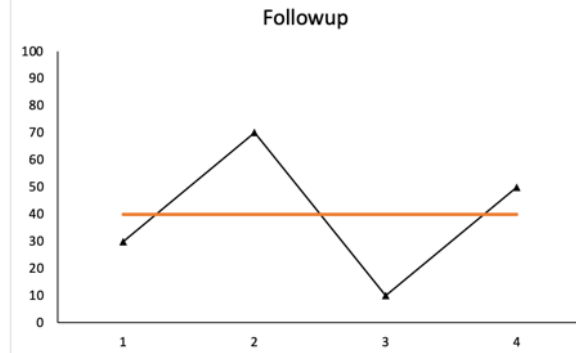
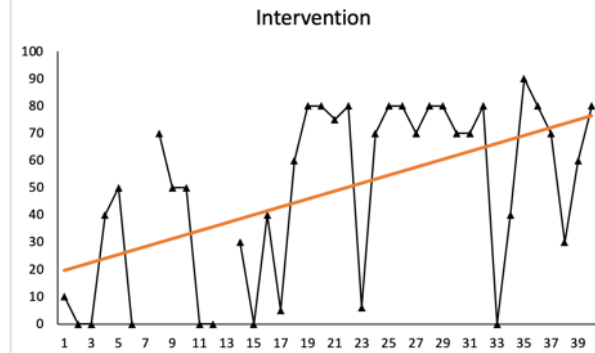
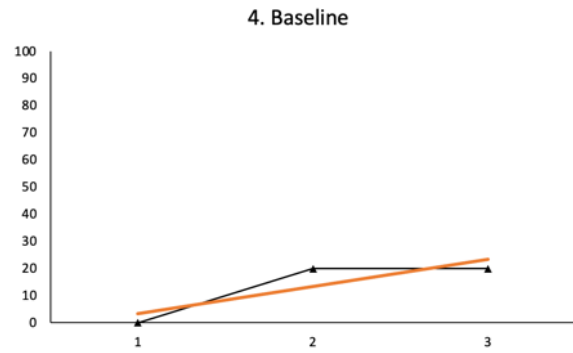
Reference 2: 0.49% coverage  
that was the kind of the biggest challenge with this group, those that stuck with it and attended regularly, they were very enthusiastic

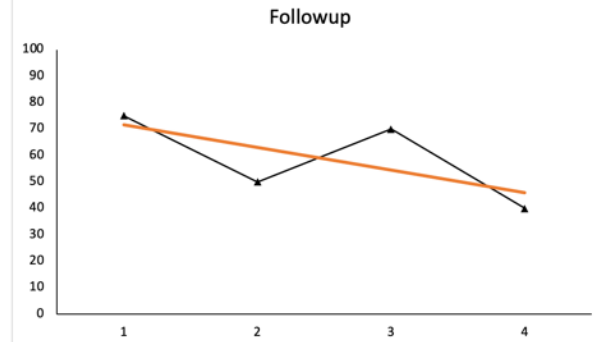
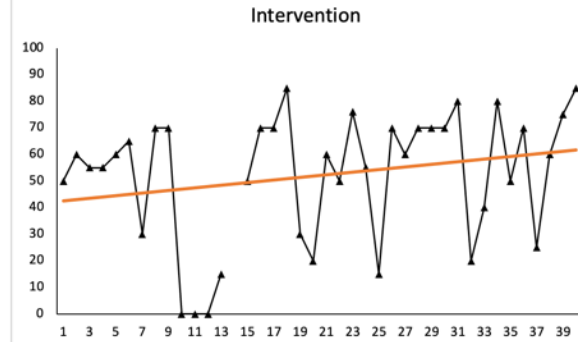
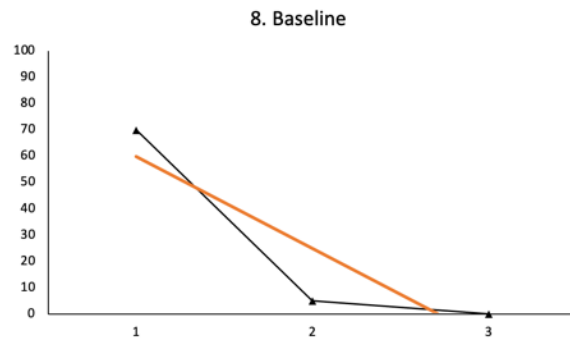
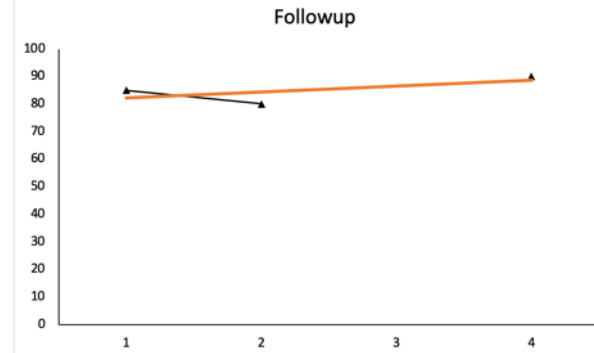
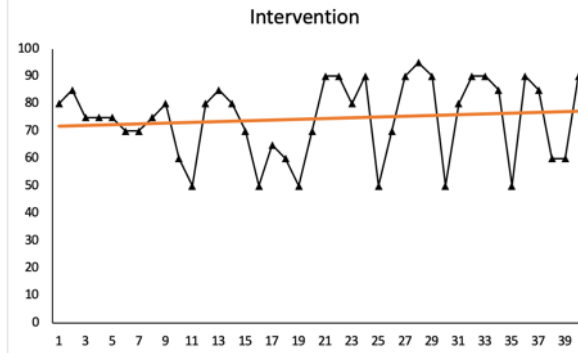
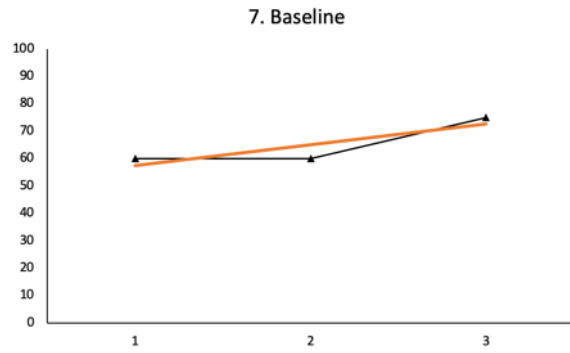
Reference 3: 1.89% coverage  
those who could commit the sessions found it very helpful and were, engaged, but I think it's the practice in-between that perhaps was more patchy, and so often there was less feedback and less to unpick from their own experiences, so we ended up speaking quite a lot about the practice in the session, or it was kind of bite-sized bits and bobs in the session, I think the course as its creative with lots of little short mindfulness activities and lots of discussions rather than directed teaching suited that style of engagement

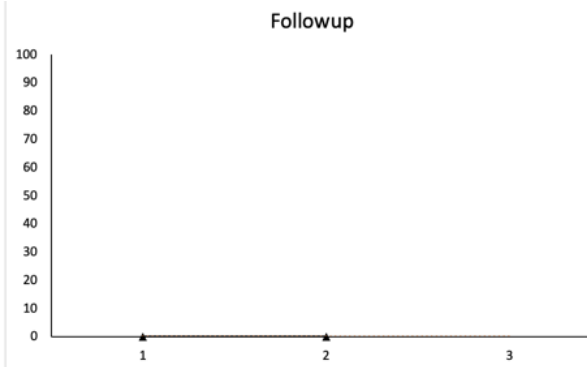
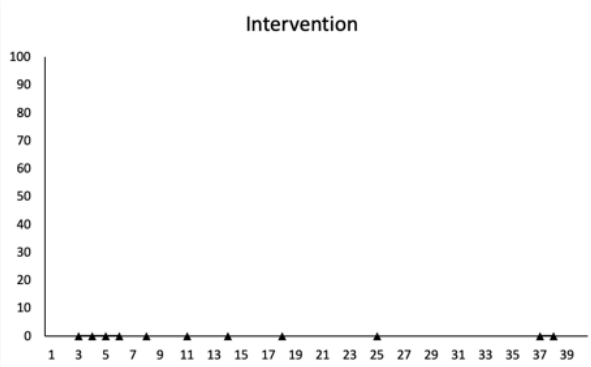
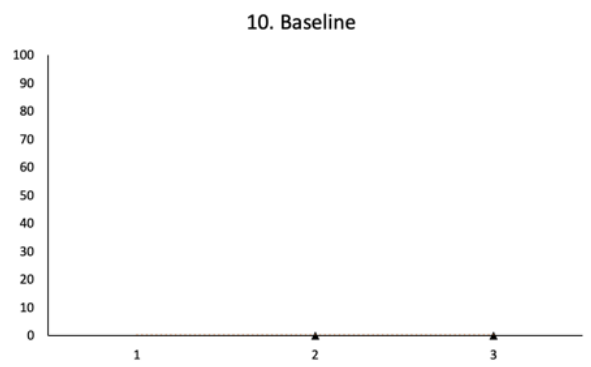
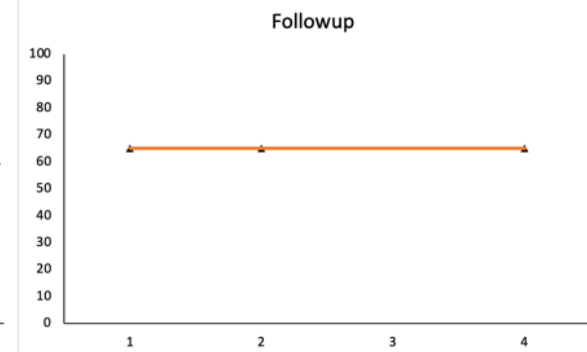
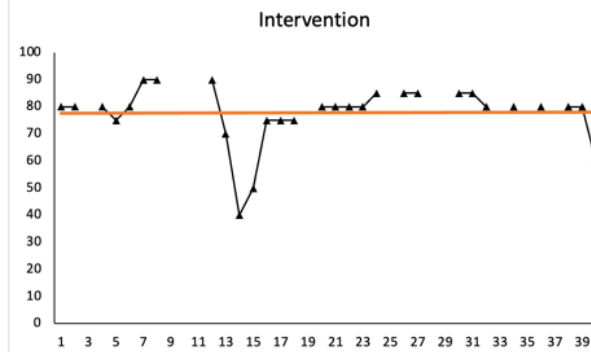
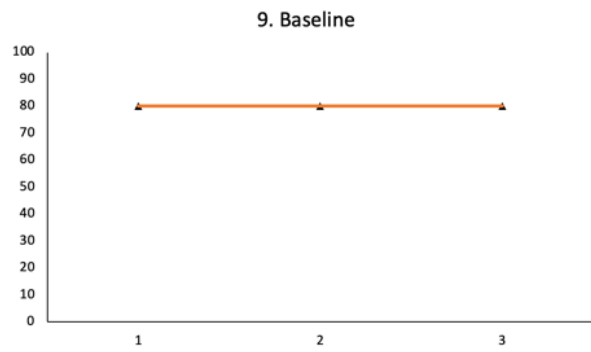
Reference 4: 3.11% coverage  
it was quite a diverse group in terms of geographical base, given that this was broad, broadly opened, but interesting, still, the majority of participants came from a similar demographic, they were all fairly articulate, white, middle-class, educated, and then there were a few participants with high powered and active roles in health, and education too, I think we saw from the registration forms, that there was quite a lot of challenge in the lives of the group, there was more than I normally would work with, I'd say, but other mindfulness practitioners in different contexts will be working with similar sort of background as these participants, most participants responded to the registration forms with quite a lot of recent and live and significant challenging

**Appendix E.8. N=10 parent positive graphs with trendlines (for visual analysis).**

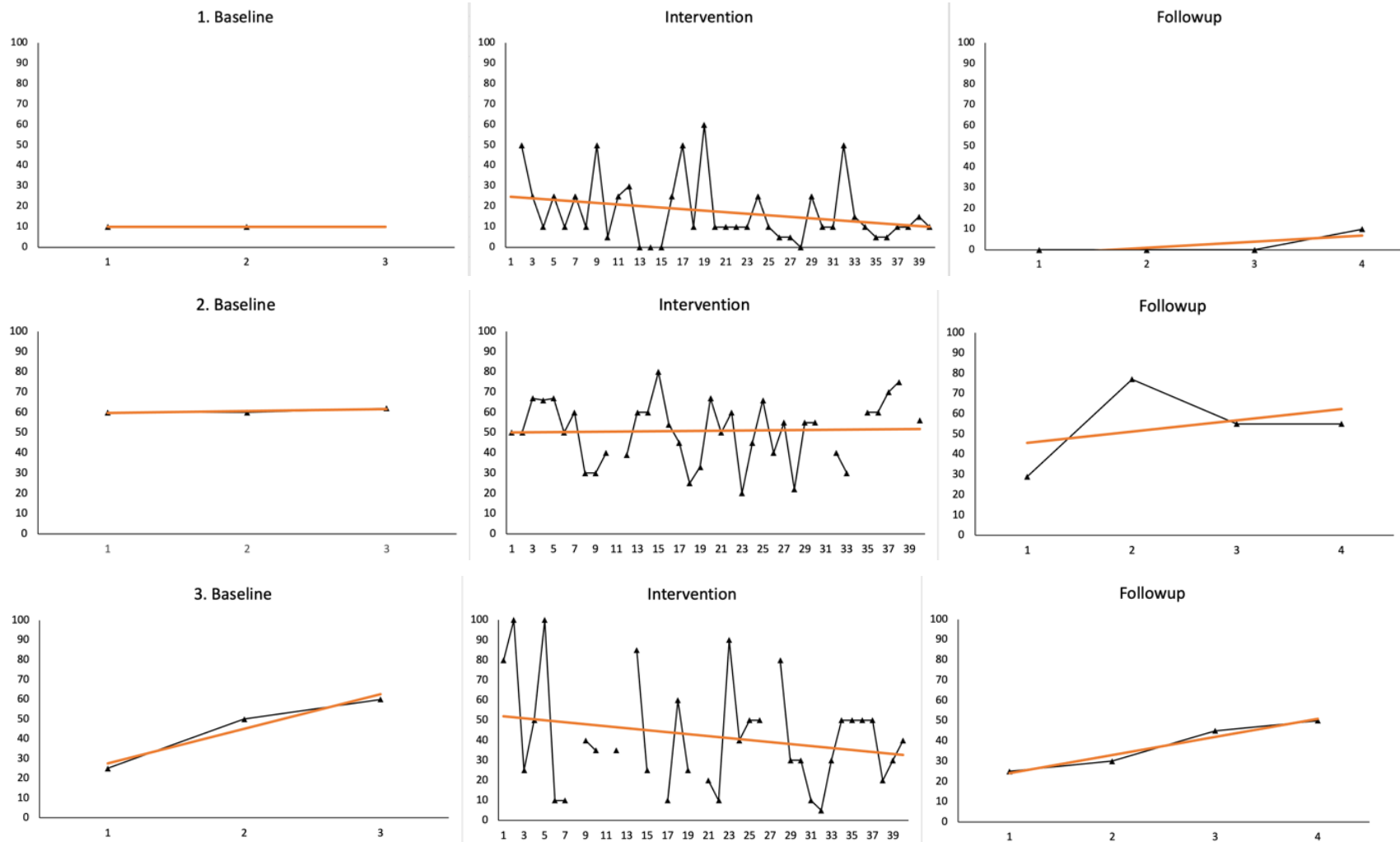


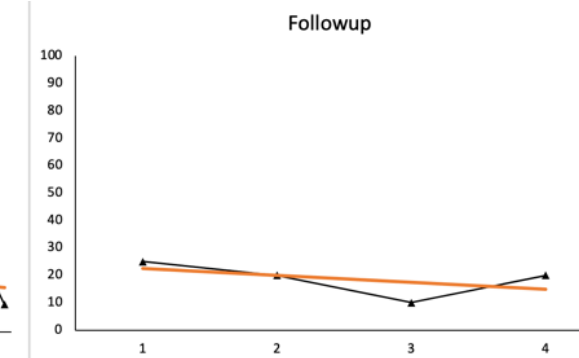
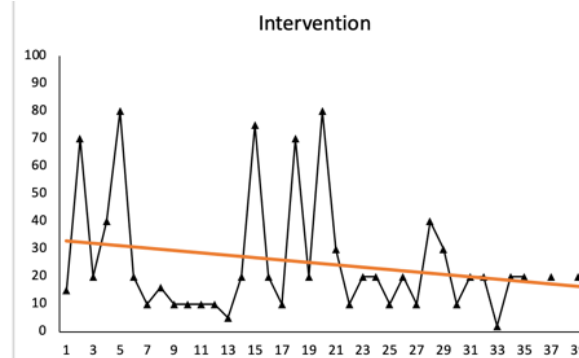
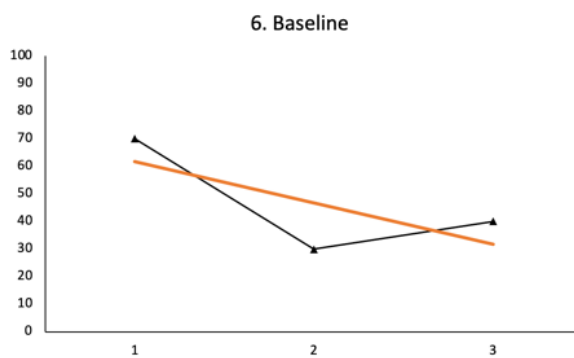
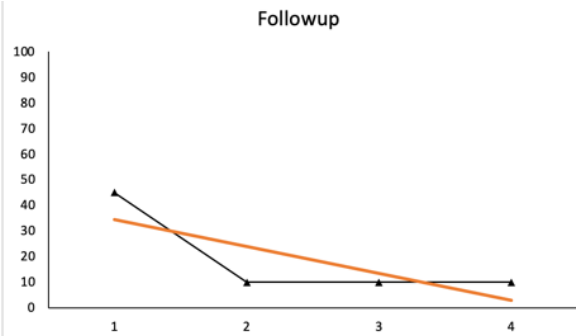
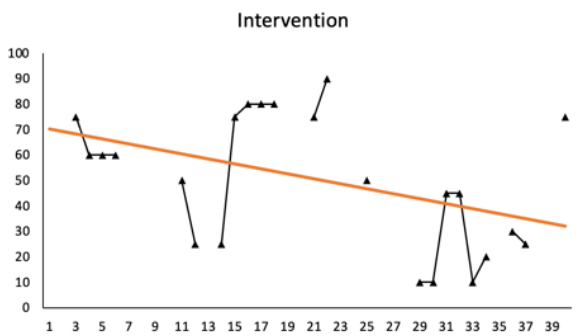
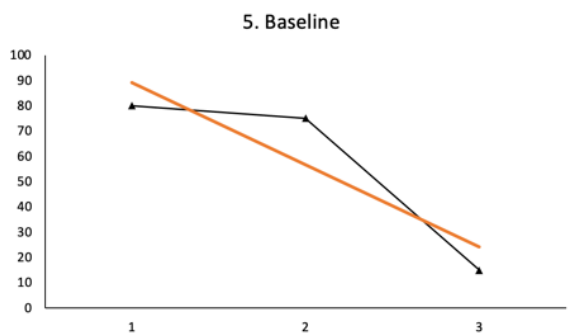
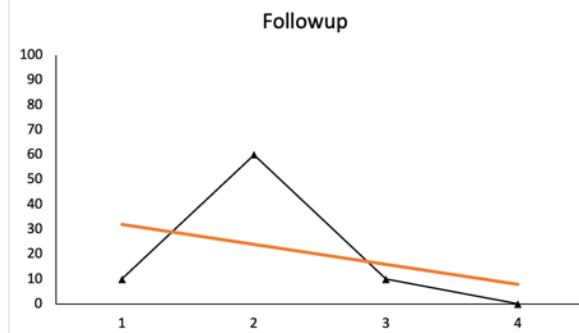
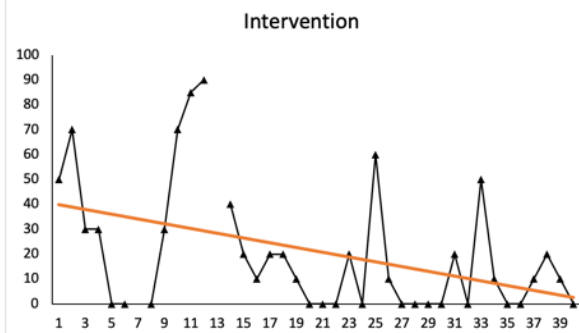
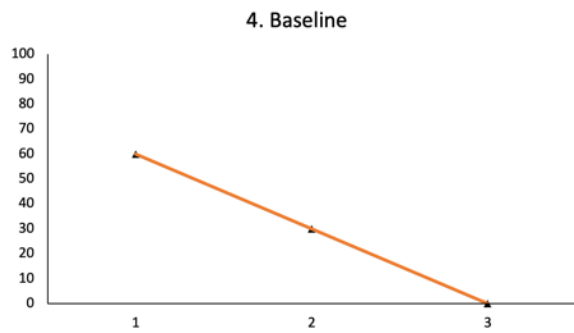




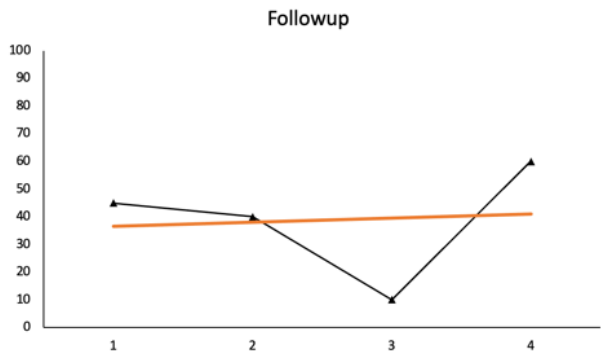
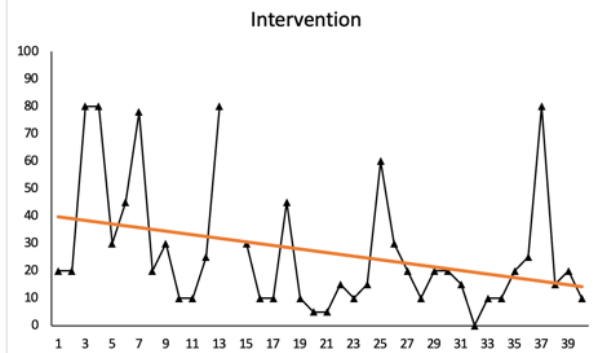
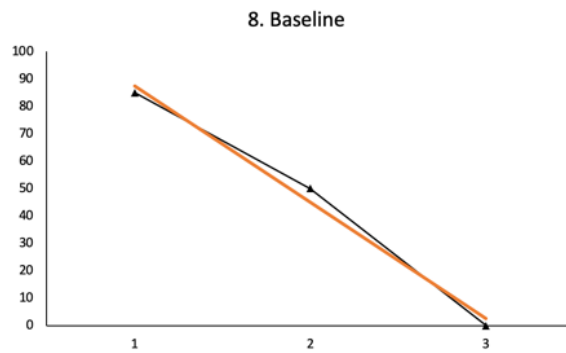
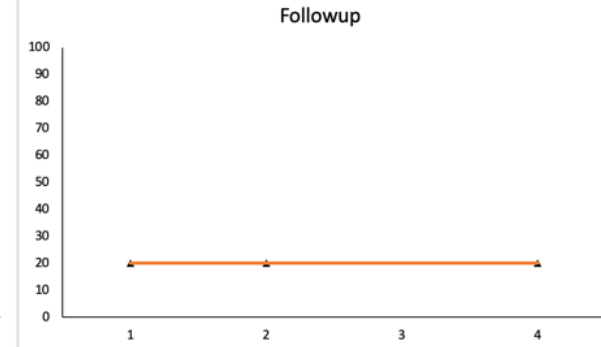
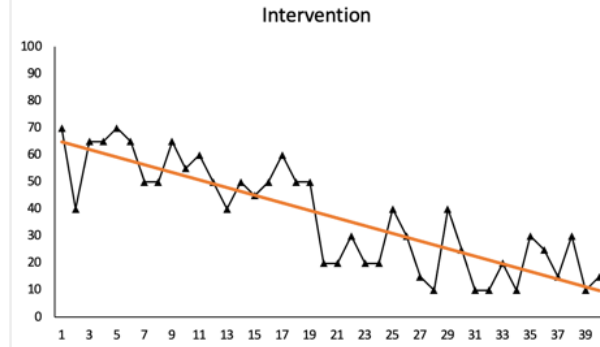
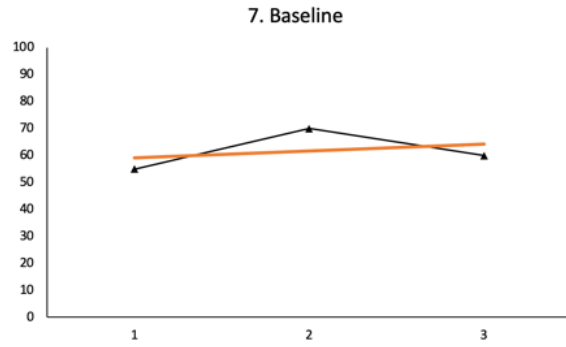


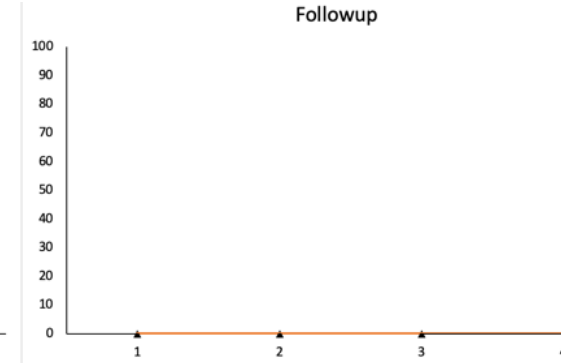
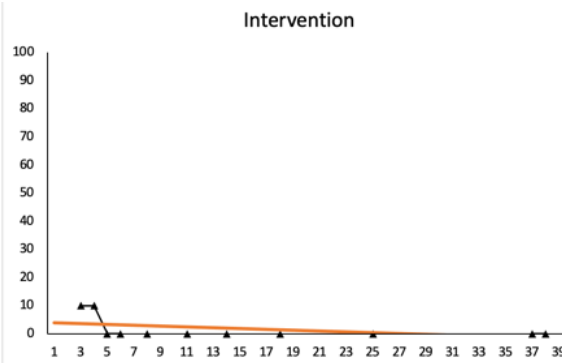
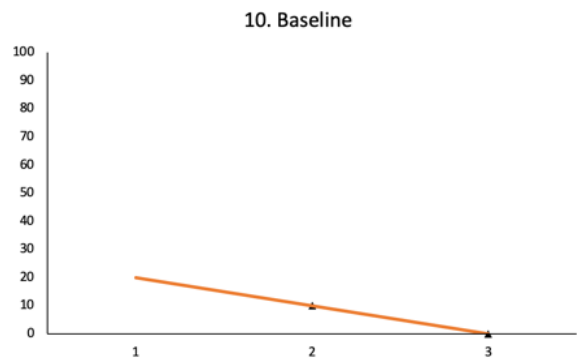
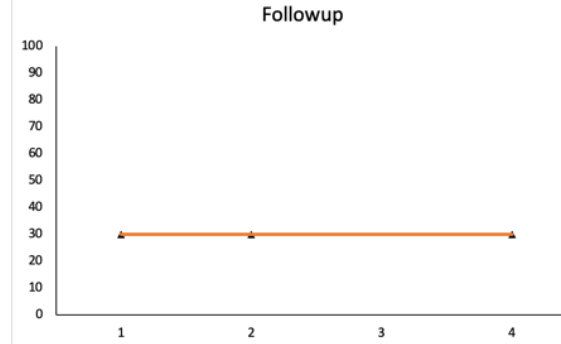
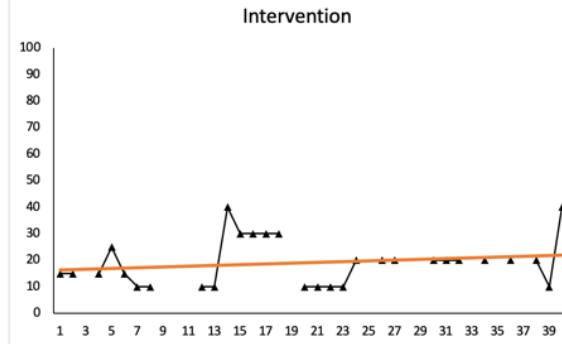
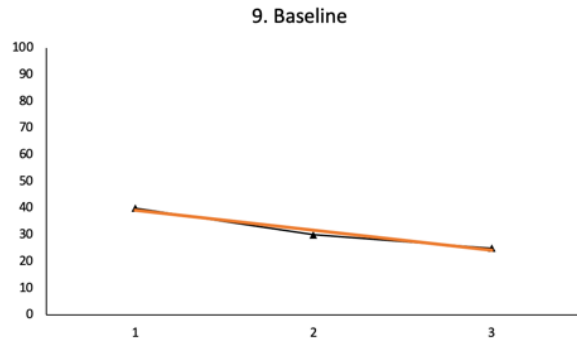
**Appendix E.9. N=10 parent negative graphs with trendlines (for visual analysis).**











### Appendix E.10. Non-baseline corrected Tau-U scores.

<b>Table 2.</b> TAU-U results for each parent participant positive success-framed target (Question 1)					
Parent ID	Comparisons	Tau	SD Tau	P	CI (90%)
1	Baseline to intervention	0.6750	0.3496	0.0535	0.100<>1
	Baseline to follow-up	1	0.4714	0.0339	0.225<>1
	Intervention to follow-up	0.6125	0.3062	0.0455	0.109<>1
2	Baseline to intervention	-0.5926	0.3514	0.0917	-1<>-0.015
	Baseline to follow-up	-0.5	0.4714	0.2888	-1<>0.275
	Intervention to follow-up	0.3056	0.3081	0.3213	-0.201<>0.812
3	Baseline to intervention	-0.2157	0.3524	0.5405	-0.795<>0.364
	Baseline to follow-up	0.1667	0.4714	0.7237	-0.609<>0.942
	Intervention to follow-up	0.2279	0.3092	0.461	-0.281<>0.737
4	Baseline to intervention	0.5877	0.3504	0.0935	0.011<>1
	Baseline to follow-up	0.6667	0.4714	0.1573	-0.109<>1
	Intervention to follow-up	-0.2105	0.3071	0.493	-0.716<>0.295
5	Baseline to intervention	-0.1250	0.3600	0.7285	-0.717<>0.467
	Baseline to follow-up	-0.3333	0.5092	0.5127	-1<>0.504
	Intervention to follow-up	0	0.36	1	-0.592<>0.592
6	Baseline to intervention	0.6842	0.3504	0.0509	0.108<>1
	Baseline to follow-up	1	0.4714	0.0339	0.225<>1
	Intervention to follow-up	0.0066	0.3071	0.9829	-0.499<>0.512
7	Baseline to intervention	0.4333	0.3496	0.2152	-0.142<>1
	Baseline to follow-up	1	0.5092	0.0495	0.162<>1
	Intervention to follow-up	0.425	0.3496	0.2241	-0.150<>1
8	Baseline to intervention	0.4359	0.3500	0.2130	-0.140<>1
	Baseline to follow-up	0.5833	0.4714	0.2159	-0.192<>1
	Intervention to follow-up	0.0962	0.3066	0.7538	-0.408<>0.601
9	Baseline to intervention	0	0.3556	1	-0.585<>0.585
	Baseline to follow-up	-1	0.5092	0.0495	-1<>-0.162

	Intervention to follow-up	-0.7778	0.3572	0.0294	-1<>-0.190
10	Baseline to intervention	0	0.4606	1	-0.758<>0.758
	Baseline to follow-up	0	0.5774	1	-0.950<>0.950
	Intervention to follow-up	0	0.3892	1	-0.640<>0.640
Weighted average	Baseline to intervention	0.1947	---	0.0911	0.0051<>0.3843
	Baseline to follow-up	0.2718	---	0.0821	-0.0346<>0.5783
	Intervention to follow-up	0.0792	---	0.4499	-0.1262<>0.2845

**Table 3.** TAU-U results for each parent participant negative stress-framed target (Question 2)

Parent ID	Comparisons	Tau	SD Tau	P	CI (90%)
1	Baseline to intervention	0.1538	0.4237	0.7165	-0.543<>0.851
	Baseline to follow-up	-0.75	0.5401	0.1649	-1<>0.138
	Intervention to follow-up	-0.7115	0.3066	0.0203	-1<>-0.207
2	Baseline to intervention	-0.4444	0.3514	0.2059	-1<>0.134
	Baseline to follow-up	-0.5	0.4714	0.2888	-1<>0.275
	Intervention to follow-up	0.0694	0.3081	0.8217	-0.437<>0.576
3	Baseline to intervention	-0.1863	0.3524	0.5971	-0.766<>0.393
	Baseline to follow-up	-0.3333	0.4714	0.4795	-1<>0.442
	Intervention to follow-up	-0.0294	0.3092	0.9242	-0.538<>0.479
4	Baseline to intervention	-0.2193	0.3504	0.5315	-0.796<>0.357
	Baseline to follow-up	-0.1667	0.4714	0.7237	-0.942<>0.609
	Intervention to follow-up	0.0132	0.3071	0.9658	-0.492<>0.518
5	Baseline to intervention	-0.1739	0.3612	0.6301	-0.768<>0.420
	Baseline to follow-up	-0.8333	0.4714	0.0771	-1<>-0.058
	Intervention to follow-up	-0.7065	0.3185	0.0265	-1<>-0.183
6	Baseline to intervention	-0.6842	0.3504	0.0509	-1<>-0.108
	Baseline to follow-up	-1	0.4714	0.0339	-1<>-0.225
	Intervention to follow-up	0.0592	0.3071	0.8471	-0.446<>0.564
7	Baseline to intervention	-0.725	0.3496	0.0381	-1<>-0.150
	Baseline to follow-up	-1	0.5092	0.0495	-1<>-0.162
	Intervention to follow-up	-0.475	0.3496	0.1742	-1<>0.100

8	Baseline to intervention	-0.2393	0.35	0.4941	-0.815<>0.336
	Baseline to follow-up	-0.1667	0.4714	0.7237	-0.942<>0.609
	Intervention to follow-up	0.3397	0.3066	0.2679	-0.165<>0.844
9	Baseline to intervention	-0.7356	0.3556	0.0386	-1<>-0.151
	Baseline to follow-up	0	0.5092	1	-0.838<>0.838
	Intervention to follow-up	0.7241	0.3556	0.0417	0.139<>1
10	Baseline to intervention	-0.3182	0.4606	0.4897	-1<>0.439
	Baseline to follow-up	-0.5	0.5774	0.3865	-1<>0.450
	Intervention to follow-up	-0.1818	0.3892	0.6404	-0.822<>0.458
Weighted average	Baseline to intervention	-0.3676	---	0.0018	-0.5984<>-0.1368
	Baseline to follow-up	-0.5229	---	0.0009	-0.8313<>-0.2144
	Intervention to follow-up	-0.0924	---	0.3716	-0.2950<>0.1103

**Appendix E.11. Parental changes for n=9 participants who completed the Elliott et al. (2001; 2008; 2012) Client Change Interview.**

Parent ID	Change noticed	Question		
		How much you <u>expected</u> it vs. were <u>surprised</u> by it?	How <u>likely</u> you think it would have been if you <u>hadn't</u> been taking part in mindfulness sessions?	How <u>important</u> or <u>significant</u> to you personally do you consider this change to be?
1	Increased patience and non-reactivity	2; somewhat expected it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	4; very important
	Feeling calmer	2; somewhat expected it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	4; very important
	Greater sense of awareness	2; somewhat expected it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	4; very important
3	Feeling more relaxed	2; somewhat expected it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	5; extremely important
4	More awareness in child	5; very much surprised by it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	4; very important
	More awareness for parent	5; very much surprised by it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	3; moderately important
5	Child is less reactive	5; very much surprised by it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	5; extremely important
	Child is more accepting	4; somewhat surprised by it	1; <u>very unlikely</u> without mindfulness (clearly would <u>not</u> have happened)	5; extremely important
	Less parental stress	4; somewhat surprised by it	2; <u>Somewhat unlikely</u> without mindfulness	5; extremely important

			(probably would <u>not</u> have happened)	
6	Greater sense of awareness	4; somewhat surprised by it	1; <u>very unlikely</u> without mindfulness (clearly would <u>not</u> have happened)	4; very important
	Less parental stress	2; somewhat expected it	1; <u>very unlikely</u> without mindfulness (clearly would <u>not</u> have happened)	5; extremely important
7	Feeling less reactive	4; somewhat surprised by it	1; <u>very unlikely</u> without mindfulness (clearly would <u>not</u> have happened)	4; very important
	Feeling more appreciative	4; somewhat surprised by it	1; <u>very unlikely</u> without mindfulness (clearly would <u>not</u> have happened)	4; very important
8	Slowing down and being more aware	2; somewhat expected it	1; <u>very unlikely</u> without mindfulness (clearly would <u>not</u> have happened)	4; very important
	Listening more	5; very much surprised by it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	5; extremely important
	Stepping back in parenting style	4; somewhat surprised by it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	5; extremely important
9	Acceptance of difficult thoughts when stressed	4; somewhat surprised by it	1; <u>very unlikely</u> without mindfulness (clearly would <u>not</u> have happened)	4; very important
10	Handling frustration better	4; somewhat surprised by it	2; <u>Somewhat unlikely</u> without mindfulness (probably would <u>not</u> have happened)	4; very important

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