Scratching the Surface: A Qualitative Study of Parents' Experience of Eczema and Support for Psychological Wellbeing

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ABSTRACT

Aims: Eczema is the most prevalent skin condition, but there is still a gap in the research regarding the impact that it has on parents, particularly regarding psychological wellbeing and the effects on parenting. The existing literature suggests that chronic health conditions impact how parents respond to their child's needs, yet there is little research investigating the impacts of eczema on this. With much of the research around being focussed on physical health, there is a need for an understanding of the psychological implications of eczema. This research aims to learn more about parent's experiences of eczema, as well as any psychological wellbeing support that they may have been offered in the context of eczema.

Method: Parents who had eczema themselves and/or had a child with eczema were interviewed about their experiences using a semi-structured interview schedule. Thematic analysis was then conducted to identify themes.

Results: Three themes were identified, including: 1) Mental health and wellbeing; 2) Relational impact, and 3) Other people's perceptions of eczema. Within these themes, ten subthemes were identified which indicated that eczema had impacted parental wellbeing and ways of parenting, as well as a need for, and uncertainty about, psychological support they could access.

Conclusion: An impact on parent's mental health and wellbeing was identified, however there is a clear gap in awareness of psychological support that may be available, with physical symptoms prioritised by professionals. There were also depictions of the relational impact of eczema. It was clear that eczema was often misunderstood which led to feelings of isolation and judgement. Future research should continue to explore how best to support families impacted by eczema.

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Firstly, and most importantly, thank you to the parents who participated in this research for lending me their valuable time and stories. I truly hope I have done justice to the strength and determination of your families. I hope that this piece of research can at least in a small way contribute to a greater understanding of what you and your families experience, and how you would like to be supported.

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This research is dedicated to everyone in the eczema community. Thank you.

Contents

1. CHAPTER ONE: INTRODUCTION

Atopic eczema is the most prevalent skin condition, affecting one in five children and one in ten adults in the United Kingdom (National Eczema Society, 2019). A large amount of previous research into eczema has been medically focussed on the physical symptoms and treatment, but there is growing interest in the psychosocial impact of the skin condition. Research into this area is still limited, particularly qualitative reports from parents who are impacted by eczema, whether this be their own or that of their child. This chapter will present a narrative review of the existing literature around the impact of chronic conditions, as well as specifically eczema, on the psychological wellbeing of parents. It will also address the theoretical underpinnings behind research into the impact of eczema on parenting, such as attachment and appraisal of needs, as well as detailing the policies that influence the direction of healthcare services in the United Kingdom. A scoping review of the relevant literature will then be presented, and the chapter will be concluded with the research rationale and questions.

1.1 Literature Review

Databases including EBSCO, SCOPUS and Google Scholar were used to review the current literature. Initial searches using various combinations of the terms “Eczema OR atopic dermatitis”, “parent OR carer”, “psychological wellbeing”, “mental health” and “appraisal of needs” was conducted. Documents published by the National Health Service (NHS) and governmental departments were also included in the review. The titles and abstracts of the articles that were presented were reviewed for their relevance to the current study. The search yielded very few pieces of relevant research, and so it was decided that a narrative review would be most appropriate, with a scoping review being conducted once there was a better understanding of the literature available.

An effort was made to use literature relevant to the United Kingdom (UK), however the searches produced many articles from the United States of America (USA), South Africa, Australia and South Korea. So as not to neglect important research, these were included when appropriate - for example, when discussing the impact eczema has on the mental health of parents. As the current study was also interested in the provision of mental health support in the context of eczema, only studies originating from the UK were included when discussing this due, to the differing health and social care systems around the world.

1.2 Terminology

Eczema is an umbrella term for a range of skin conditions. Eczema, atopic eczema, and atopic dermatitis are used interchangeably within the literature, and therefore throughout this paper. The terminology used will also depend on that which the parents themselves use, as the specific type of eczema was not specified during recruitment. It is argued that “eczema” is an imprecise label (Silverberg et al., 2017), but as this paper focuses on the experiences of the parents, their wording shall be prioritised. It is worth noting that eczema will be described as a skin condition throughout this paper. This is to align with the current understandings from medical research and the NHS (National Institute for Health and Care Excellence, 2022). That is not to dismiss or minimise the narratives that those who have experienced eczema have around the impact of eczema on aspects outside of the skin.

1.3 Medical Understanding of Eczema

1.3.1 Chronic Illness

Chronic illness is defined by the NHS as any health issue that requires ongoing management or cannot be cured (NHS Choices, 2024). The medical constructs of chronic health conditions focus on the physical pathologies and treatments for symptomology (Wellard, 1998). The World Health Organisation (WHO) defines health as being “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1948). Within the biomedical model, the motivation for research into chronic conditions comes from a desire to reduce any impact that the illness has on the body. Much of medical research into treatment aims to get those with chronic conditions to as medical stand point as close to “healthy” control individuals as possible (Wellard, 1998). This, essentially, implies that the goal point for those with chronic health conditions is to be as close to “cured” as possible. Theories such as the middle range theory of self-care of chronic illness (Riegel et al., 2012) indicate that health within a chronic illness context is maintained by processes of self-care, predominantly focussing on the monitoring of symptoms and the management of these through medication and lifestyle changes.

1.3.2 Defining Eczema

Eczema is the general term for a range of skin conditions, with the most common one being atopic dermatitis, also known as atopic eczema (National Eczema Society, 2019). Eczema is a chronic skin condition defined by inflamed, itchy skin (National Institute for Health and Care Excellence, 2022). It is the most prevalent skin condition (National Institute for Health and Care Excellence, 2022) which can occur at any point in the lifetime. Eczema most commonly presents during childhood, with around 20% of children experiencing the condition before they are five years old (Williams et al., 2008), however one in ten adults in the UK are living with eczema (National Eczema Society, 2019).

Eczema “flare-ups” are ill-defined, and often subjective (Langan et al., 2014). Commonly, they are described as the worsening of symptoms such as itchy and irritated skin. As with many chronic conditions, triggers to flare-ups can often be identified, such as exposure to allergens, hot or cold weather, and swimming (National Eczema Society, 2019), however it is contested that there is little evidence to support these commonly cited triggers (Kannenberg & Jordaan, 2014).

1.3.3 Medical Guidelines for Eczema

The National Institute for Health and Care Excellence (2022) details the medical management of eczema starting from diagnosis through to treatment guidelines. In order to receive a diagnosis, the medical professional must collect a history of the individual’s skin complaints, including a family history if possible. The guidelines stipulate different symptoms or signs dependant on age or potential eczema diagnosis. For instance, whilst adults tend to have generalised dry, itchy skin, children and adults with a long history of eczema tend to have localised areas on the backs of their elbows and knees. There are also specified signs for chronic eczema, primarily thickened, known by medical terminology as “lichenified”, skin from persistent scratching (National Institute for Health and Care Excellence, 2022). In order to receive a diagnosis of atopic eczema, three or more specific symptoms must be noted alongside self or parental report of itchy skin or scratching.

1.3.4 Eczema Treatment

Whilst there is no cure for atopic eczema, symptoms can come and go, and even disappear over time. As a chronic illness, the main function of eczema treatment is management of symptoms, in order for the individual to feel as little impact as possible. The National Institute for Health and Care Excellence (2024) guidelines outline a stepped approach treatment for the management of eczema. This entails starting treatment with the use of emollients, and then “stepping up” to stronger treatments if the approach is not effective. Following the use of emollients, topical corticosteroids (often referred to as topical steroids or steroid creams) are prescribed as the first line treatment for eczema flare-ups. Topical corticosteroids themselves are recommended to be prescribed as per a “potency ladder”, starting with the least potent and increasing if deemed necessary (National Institute for Health and Care Excellence, 2023). For cases of more “severe” eczema, where topical steroids are not effective, more intensive treatments such as phototherapy and immunosuppressants such as cyclosporin and methotrexate are prescribed (NHS, 2017). Often treatment for more “severe” eczema will require a referral to a dermatologist.

1.4 Integrated healthcare

Eczema not only has a physical health impact, but also psychosocial repercussions. To understand how the integration of mental and physical health care can effectively occur, the theoretical underpinnings of this must be explored as well as the current policies and service provisions supporting, or creating barriers to, the integration.

1.4.1 The Biopsychosocial Model of Health

The biopsychosocial model (Engel, 1977) was developed after it was noted that the medical model missed out key information about the impact of health from psychological and social perspectives. Whilst this made important advancements in understanding the relationship with health, it is argued that further developments need to be addressed in order to incorporate cultural and political aspects including how it can be applied to healthcare services (Halligan & Wade, 2017; Suls & Rothman, 2004). It is also stated that the biopsychosocial model is merely an adapted biomedical model for medical practitioners to use, which has led to its use in facilitating the continued medicalisation of illness (Pilgrim, 2015).

The THRIVE framework of coping with chronic conditions was developed by White et al. (2018). It includes six subcategories of how people cope with various aspects of their chronic illness: *Therapeutic interventions; habit and routine; relational-social; values and beliefs; emotional factors.* This framework encourages consideration of each of the subcategories, in order to understand how best to support someone with a chronic illness. This supports the notion of integrating healthcare, so as to holistically address concerns and need of people with chronic health conditions.

1.4.2 Health and Social Care Policy

Over the past couple of decades, policies and legislation have been developed to address the health and social care issues within the UK. The Health and Social Care Act 2012 stated that it was the responsibility of the NHS to create goals and meet the health and social care needs of the general public, stipulating a separate commissioning group for the NHS. The NHS Long Term Plan (NHS, 2019) committed to ensuring that a growing proportion of the NHS budget is spent of improving access to mental health care. This built upon the NHS Five Year Forward View for Mental Health (NHS England, 2016b), which stated that physical and mental health care should be integrated to ensure ease of access to all, with a focus on prevention and early intervention. It was proposed that by integrating these services there would be an overall reduction in costs due to potential decreased A&E and short stay hospital visits (NHS England, 2016a). Some issues were raised with the Five Year Forward for Mental Health plan, including difficulties with engaging front line staff, which services would be appropriate for integration, and how integration can be measured (Tracy et al., 2019).

1.4.3 COVID-19

It would be remiss to discuss the current state of health and social care in the UK without including the impact of the COVID-19 pandemic. Overall mental health in the UK was found to have deteriorated in the early months of the pandemic (Knolle et al., 2021; O'Connor et al., 2021; Pierce et al., 2020). Despite this, it was found that both mental and physical health primary care appointments reduced significantly during this time (S. Chen et al., 2020; Mansfield et al., 2021). Since the pandemic started, mental health care providers are receiving increasing referrals for individuals with more severe mental health difficulties (Royal College of Psychiatrists, 2021).

The huge impact of COVID-19 on health care services has resulted in high levels of psychological distress in healthcare staff and increased risk of post-traumatic stress disorder (PTSD) and burn-out (Petrella et al., 2021). Services have attempted to rebuild and again improve access to primary care support, however it is argued that the budget specified in the NHS Long Term Plan (2019) will no longer cover the post-pandemic necessities (NHS Reset, 2020).

1.4.4 Psychodermatology Services

The All-Party Parliamentary Group on Skin (APPGS) report (2020) found that over half of respondents with a skin condition were not aware that there were psychological support services available to them. The report stipulates that there are different services available depending on level of need, recommending that GPs be aware that they can refer those with skin conditions to primary mental health services if generalised support is most appropriate. However, it is clear that there is a need for psychological wellbeing support in the context of dermatological issues. Psychodermatology services are a relatively new concept which aims to in part address the gap between physical and mental health care. The services are set up to see patients who present with mental health difficulties in the context of dermatological issues such as skin picking disorders and body dysmorphia, or anxiety and depression as a result of a skin condition. The working party report for the British Association of Dermatologists recommended that Psychodermatology services should be available regionally, with a lead dermatologist in each services being linked to local physical and mental health care providers (British Association of Dermatologists, 2012). Whilst service provision has improved over the last few years, it is still not sufficient to cover the needs of those requiring psychodermatological support (Massoud et al., 2021).

1.4.5 Inequality and Inequity in Health Care

In 2010 a review of health care in equality within the UK was conducted, known as the Marmot Review (Marmot et al., 2010). The report found that health outcomes were associated with “social position”, with those who were deemed to be at the lower end of a social gradient having worse experiences of health and health care. The report determined that social inequalities lead to health inequalities and that universal action should be taken to address these in the form of policy change and action (Marmot et al., 2010). A decade later, a follow up report on the Marmot Review was conducted (Marmot et al., 2020) which stated that disparities in health care had increased. Of significant note was the increasing inequalities for women, with life expectancy for females declining over the decade. Regional inequalities also grew in this time, with poorer areas having the worse health outcomes. The NHS Long-Term Plan (NHS, 2019) set out aims to tackle health inequalities. This included goals to promote prevention of ill-health and prioritised risk factors such as smoking, poor diet and drug and alcohol use. The Long-Term Plan stated that NHS England would continue to fund regions with higher health inequalities with a higher share of funding and ensure that services are targeting health inequalities within their planning.

Eczema is more prevalent in Black and Asian ethnic groups than in the white population (de Lusignan et al., 2021). Despite this, a majority of dermatological research is conducted with samples from white ethnicities, meaning differences in presentations and potential treatments for non-white ethnicities are missed from the evidence base (Kaufman et al., 2018). Studies have shown that there are multiple biological and visible differences in the presentation of eczema between different races and ethnicities (Leung, 2015), meaning that primarily focussing research on white populations will undoubtedly lead to Black, Asian, and other global majority groups receiving inadequate care and support. Since the Black Lives Matter movement gained global attention in 2020, it has been suggested that academic institutions and clinical services focussing on dermatology have increased their focus on the race disparities within the specialty (Guckian et al., 2021). This has included a commitment to address structural racism in research, highlighting the need for more literature focussing on underrepresented populations, and calling out racially discriminative practice (Guckian et al., 2021). In 2021, NHS Digital conducted an audit on its inclusion of a variety of skin tones on the NHS's website pages for skin conditions (Smith, 2021). It found that only seven of the 75 pages about skin conditions included content about representative skin tones, and only three pages contained images of racialised skin tones. This is an obvious issue, as if skin conditions present differently on a variety of skin tones, then they risk going missed and untreated. Following the audit, NHS Digital conducted interviews to gather further information on how best to use inclusive language and imagery on the website (Smith, 2021). Whilst this is a step in the right direction, there is still a lot of progress to be made in closing the racial disparities in dermatology.

1.4.6 Epistemic Injustice

Inequalities in health care contribute to epistemic injustice, a concept proposed by Fricker (2007) to describe how an individual can be discriminated against in their ability to possess or present knowledge. Hermeneutical injustice describes how injustice occurs when the knower does not possess all the information necessary due to a gap in society's knowledge, whereas testimonial injustice is defined by the person presenting the knowledge being viewed as having decreased credibility by the person receiving the knowledge (Fricker, 2007). Carel & Kidd (2014) proposed that epistemic injustice is a particular risk for those with ill health. This is due to the medical model favouring third party data from empirical research over anecdotal evidence, as well as the large gaps in knowledge about certain illnesses. This is no doubt a topic of contention within the literature around eczema, where many of the studies rely on biomedical data or quantifiable outcomes rather than first hand narratives.

1.5 Relational focus

1.5.1 Appraisal Theory

Appraisal theory is the notion that our subjective interpretations of events and situations elicit differentiating emotional responses (Scherer, 1999). This helps to explain how individuals react differently in similar situations, as it is based on how these scenarios have been appraised previously. Bowlby (1969) theorised that secure attachment is based on the meeting of caregiving needs in a sensitive manner. In line with appraisal theory, this concept alongside that of the internal working model (Bowlby, 1969) suggests that if infants needs are appraised and met in a way that promotes safety and security, then this will form cognitive representations of how they can expect their future needs to be met. Here, Maslow's hierarchy of needs (Maslow, 1943, 1954) can also be drawn upon. This theory posits that to reach self-actualisation, humans must first ensure a hierarchy of needs are met, starting with *physiological needs* and moving through *safety and security*, *love and belonging*, and *self-esteem.* Infants are unable to fulfil these needs alone and therefore require a caregiver to respond to their basic needs, such as being fed, and then help them reach other tiers through safety, security, and a sense of connection. It can be assumed from the attachment and appraisal theories discussed that if these needs are not met, or are responded to in a way that feels unsafe, then this would impact on fulfilment of self-actualisation as well as the formation of future relationships. There may be various reasons that these needs cannot be fully met, such as the parents' own attachment styles, or if something such as illness means that the child's needs are not able to be responded to.

1.6 Empirical research

As discussed, much of the current research around eczema is from a medical perspective. Whilst this is crucial for creating an evidence base for a greater understanding of the condition and its treatment, it excludes much of the psychosocial aspects. There have been some studies, however, which do examine the effects that eczema has on individuals, families, and society.

1.6.1 The Impact of Chronic Illness on Families

Due to the limited research specifically focussing on the impact of eczema on families, it is worth examining the effects that chronic conditions in general may have. A study that followed up individuals from the age of 16 to 32 years old found that those with chronic health conditions were significantly more likely to have depression and lower self-esteem than "healthy" controls (Huurre & Aro, 2002). A large scale, multi-specialty study found that across different chronic conditions there were significant and yet similar effects on the quality of family life (Golics et al., 2013). This included impacts on relationships within the family, work life, social life, sleep and general health. This is supported by a study examining primary support for mothers of children with chronic health conditions in which mothers reported a range of unmet family needs, including social support (Farmer et al., 2004). Parents also felt like they were not supported by the work places when caring for a child with a long-term condition (Smith et al., 2015).

Parental chronic illness has been found to be a factor in the psychological wellbeing of children, with adolescents being more likely to internalise their difficulties if they have a parent with a chronic health condition (Kaasbøll et al., 2021). The same study found that children with parents who have a chronic illness are less likely to form secure attachments, particularly to their fathers. Distress in children of parents with physical illnesses was found to be directly linked to the emotional well-being of their ill parent (Chen & Panebianco, 2020).

There is very limited research into eczema’s impact on the appraisal of children’s needs, but the existing literature around chronic illness and pain can point to relevant areas. Maciver et al. (2010) explored parents’ experiences of caring for a child with chronic pain by conducting interviews with 12 parents. The study found that how parents responded to their child’s distress changed over time, starting with their own distress and desperation to alleviate the pain, and moving through to “taking a step back” and learning how to balance the needs of the child with their own. The parents in this study spoke about how they had to adapt their responses to their child’s needs as they learned more about how chronic pain affected them. Some parents spoke of a fear of the pain, and how that led to their own emotional responses. It could be concluded that a fear of causing pain to your child may result in less skin-to-skin contact. Skin-to-skin contact has been shown to have many positive outcomes on the psychological well-being of mothers as well as the development and health of the child (Norholt, 2020).

Wilson & Fales (2015) conducted a mixed-methods study into parenting in the context of (the parent’s) chronic pain. The study found that compared to controls, parents with chronic pain were more likely to catastrophise and react protectively when it came to their child’s experiences of pain. Despite a majority of the participants reported some positive outcomes from their chronic pain, such as responding to their child’s needs with more compassion, most of the parents also described a worry of their child developing chronic pain themselves.

Chronic pain is, of course, different to eczema in a multitude of ways, and so it cannot be assumed that the above findings can be generalised. However, it could be argued that there is a benefit to research chronic health conditions as a whole, rather than individual conditions, so as to avoid creating further gaps in research. There is certainly benefit in using previous literature to point future research in certain directions so as to see how individuals and families can be best supported, when facing a chronic health condition such as eczema.

1.6.2 The Impact of Eczema

The impact of eczema spans beyond the physical symptoms, which in themselves are often painful and at times debilitating. Studies show that there are psychosocial impacts of eczema, not just to the individual with the condition but also their loved ones and carers (Dennis et al., 2006; Howells et al., 2017; Wheeler et al., 2022). The impact on children's behaviour has also been reported (Bronkhorst et al., 2016), as well as significant effects on sleep quality (Angelhoff et al., 2018; Meltzer & Booster, 2016; Moore et al., 2006). With stress and poor sleep being a reported trigger for eczema (National Eczema Society, 2019), a cycle presents itself where symptoms lead to stressors, which exacerbate the symptoms and so forth.

1.6.3 The Psychological Impact of Eczema on Children

The impact of eczema on children's quality of life has been reported to be comparable to that of those with asthma or diabetes (Lewis-Jones, 2006). Children who have atopic diseases including eczema have been found to be more likely to have behavioural, emotional, and hyperactivity difficulties than their peers without atopic disease (Hammer-Helmich et al., 2016). This has also been reported in a study focussing on children specifically with atopic eczema, alongside increased risk of mental health difficulties such as depression and anxiety (Yaghmaie et al., 2013). The same study found a dose-dependent relationship between the severity of eczema and mental health difficulties. In a report produced for the APPGS (2020), all 27 children surveyed stated that their skin condition had a negative psychological impact, with a majority of them also reporting low self-esteem and body image. Within the same report, children with skin conditions (including, but not limited to, eczema) described feelings of depression and anxiety related to their skin APPGS, 2020).

In a recent report, 43% of children were reported to feel socially isolated due to their eczema, with two-fifths of parents stating that it negatively impacted their child's ability to make and maintain friends (National Eczema Society & LEO Pharma, 2020). A quantitative study of children with eczema and their families used establish quality of life measures to ascertain the impact of the skin condition (Lewis-Jones, 2006). It was found that there were limitations on the child's life, including socially and having to miss out on certain activities such as swimming. The same study encouraged the use of the quality-of-life measures for those affected by eczema. In an article for the British Medical Journal, Wei Chern Gavin Fong (2021) describes his experience of growing up with eczema and how he was (or was not) supported by healthcare professionals. Fong describes how the visibility of his eczema led to a significant impact on his psychological wellbeing, feeling ashamed of his appearance and leading to low mood and suicidal thoughts. Fong reflects that he would have liked to be asked about his psychological wellbeing in the context of his eczema by his doctors, and to have been signposted to support groups so that he could feel less isolated with the condition (Fong, 2021). He also discusses the importance of realistic expectations, such as not being told that he would eventually outgrow eczema, which led to much disappointment when he did not, and meant he never fully felt in control of the skin condition.

1.6.4 The Psychological Impact of Eczema on Adults

Similar findings to those of studies focussed on children, research has shown that eczema has a significant impact on the psychological wellbeing and quality of life of adults. Eczema Unmasked, a large scale survey by the National Eczema Society and Leo Pharma (National Eczema Society & LEO Pharma, 2020) asked 530 adults with eczema about their experiences. 74% reported that eczema had a negative impact on their mental health, with a majority of respondents reporting feeling embarrassed due to their eczema. Over three-quarters of the respondents reported that eczema left them with feelings of anxiety, depression and increased stress levels. The report also evidenced the social impact of eczema on adults, with two-thirds of those surveyed agreeing that it left them feeling socially isolated. The report also describes significant impact on intimacy, social life, and participation in activities, which is supported by other quantitative and qualitative studies (Howells et al., 2017; Kwak & Kim, 2017; Wheeler et al., 2022). Nearly half of the adults surveyed for the Eczema Unmasked report reported that eczema had impacted their participation in paid work.

Much of the research into adults who became parents and have eczema themselves, is focussed on the risk factors for their child developing atopic disease. There is a huge gap in the research regarding the impact that parental eczema, whether current or historical, has on both the individual and the family system. As discussed, eczema has a negative impact on psychological well-being and increases stress levels.

1.6.5 The Impact on Parents of Children with Eczema

As mentioned, eczema not only has an impact on the child, but also their parent/s or carer/s and other family members, including siblings (Filanovsky et al., 2016). Mood, financial strains and overall wellbeing are all negatively affected in parents who have a child with eczema (Bronkhorst et al., 2016), and parental stress is significantly correlated with eczema severity (Gillespie, 1996). Sleep disturbance is often reported by parents of children with eczema (Ablett & Thompson, 2016; APPGS, 2020; Meltzer & Booster, 2016).

1.6.6 Psychological Intervention for Eczema

In a survey of 544 participants with skin conditions, where 43% had eczema, it was found that there is a need for a greater understanding of the impact that eczema has, as well as more accessible services providing psychological support to cope with this (Wheeler et al., 2022). The respondents described feeling unsupported by doctors in terms of their psychological wellbeing, with most of the support being around treating the physical symptoms rather than the emotional ones. Over 86% of participants stated that they were not aware of any specialist psychological NHS services. This indicates that even if there are service provisions for the emotional wellbeing of those with eczema, a majority are not aware it exists or what it entails. Many of the participants who had received psychological support stated that they found it unhelpful or irrelevant to their needs (Wheeler et al., 2022).

Much of the literature around psychological intervention for eczema is based on its effectiveness at reducing physical symptoms. Preliminary studies into the effect of cognitive behavioural therapy on those with eczema has been shown to decrease symptoms such as scratching and increase control of the skin condition, as well as some emotional benefits such as decreased anxiety (Horne et al., 1989, 1999). Habit reversal training for eczema involves recording scratching behaviours and then finding a substitute behaviour to replace it with, which has been found in some cases break the itch-scratch cycle (Anderson, 2017; Bridgett, 2014). There have also been some preliminary studies into parental interventions to increase ability to engage with eczema treatment, which have proved initially to be effective in improving child health outcomes and treatment adherence (Morawska et al., 2016, 2017). The existing literature on psychological interventions that could potentially benefit the emotional wellbeing of those with eczema are limited, and it remains unclear what the recommendations would be.

1.6.7 Narratives of Eczema

As discussed, research is largely biased towards third party data and neglects the narratives of those with direct experience. There have, however, been some qualitative studies which explore the experiences of eczema in the words of those with skin conditions. Ghio et al. (2020) conducted a thematic analysis of interviews with 23 young aged 17 to 25 years old and elicited themes around eczema being a long-term episodic condition. The young people spoke about having to adapt to the skin condition and manage their own expectations around treatment and control of eczema, as well as having to identify triggers and make adaptations to avoid them. The study found that the young people's experiences differed depending on the information that they had available to them, particularly that eczema was a condition that they would outgrow once they reached adulthood. The study recommended that accurate information should be given to children about their eczema, as information which contradicted their own experiences led to barriers in adapting to the skin condition (Ghio et al., 2020).

McNiven & Ryan (2022) also conducted a secondary thematic analysis on interviews with 42 young people between the ages of 16 and 24 years old, who had either eczema or psoriasis. The original interviews were semi-structured and asked the young people to speak about their experiences of having a skin condition. Many of the young people spoke about their experiences of receiving a diagnosis, with some finding this distressing due to the realisation that this may shape the rest of their lives, and others describing feelings of confusion or indifference (McNiven & Ryan, 2022). The young people also described how becoming more independent with their health care led to acquiring more information and understanding about eczema, rather than there being an assumption that parents would relay this to the child. Some young people described how doctors did not give them information that they "assumed" they would know due to having the condition since childhood. The researchers recommended that health care professionals reiterate information that would have been presented at diagnosis at various stages throughout the patient's life, so as to ensure that they are fully informed (McNiven & Ryan, 2022).

1.7 Chronic health conditions, skin conditions or eczema?

As discussed, the previous literature exploring the impact that eczema has on the psychological well-being of parents is scarce. By looking into the existing literature around chronic conditions as a whole, as well as some specific chronic illnesses such as chronic pain or diabetes, it is possible to see further where the gaps in the literature and evidence base around eczema lie. There is temptation to add to the growing research around chronic illness, but it comes with the risk of implying that chronic illnesses are a homogenous group. This could also be said for contributing to research on "skin conditions" as a singular group. The term "skin condition" covers a wide range of ailments, including (but not limited to) acne, rosacea, vitiligo and warts (NHS Inform, 2023). Just a brief look at the symptoms of these skin conditions can show the vast differences in how they present and how they could possibly affect those diagnosed. It is still a generalisation to focus research on "eczema". As mentioned, eczema is an umbrella term for a range of dermatological conditions which, whilst they all share some commonalities such as itchiness, do differ still in presentation.

Previous research, including the Eczema Unmasked report (National Eczema Society & LEO Pharma, 2020), recommends future research exploring the experiences of those with eczema, especially through their own words. The aforementioned studies show that provision for those with eczema is often difficult to access, and any future research into this may help to inform services and policy makers on how best those affected can be supported. Considering that eczema is the most prevalent skin condition (National Institute for Health and Care Excellence, 2022), it is apparent that the psychosocial effects on parents and carers are incredibly under-researched compared to other chronic health conditions, or chronic illness as a homogenous group.

1.8 Scoping review

The search of the databases, using the terms previously mentioned, yielded very few relevant results specific to the experiences of parents impacted by eczema. Many of the results were excluded from the scoping review due to a focus on the child's experience, medical symptomology, or a focus on other skin conditions or chronic health conditions as a whole. Papers focussed on the parent's adherence to their child's eczema treatment were also excluded. The search also seemed to yield no results that explored parents' experiences of *having* eczema. There were, however, some relevant pieces of literature that discussed parents' experiences of eczema. The search highlighted three main areas of focus – the psychological wellbeing of parents, how eczema impacts parenting, and experiences of support. The Eczema Unmasked report (National Eczema Society & LEO Pharma, 2020) explored aspects across all three of these domains and so will be discussed in each section rather than as a separate piece of literature.

1.8.1 The Psychological Wellbeing of Parents

Gillespie (1996) conducted a quantitative analysis of stress levels in parents of children with atopic eczema. 38 parents scored the Parenting Stress Index (Abidin, 1983) and compare against norms from previous data. The analysis found that stress was significantly positively correlated with reported severity of illness, with scratching being a particularly stress-inducing symptom. Within the study, a rating scale consisting of three subscales (environmental sensitivity, psychological sensitivity, negative coping and positive coping) was developed which allowed parents to note links between increased scratching and situational variables. Parenting stress was found to positively correlate with the negative coping subscale. As this study also found that parental stress is significantly positively correlated with increased eczema symptoms and scratching, it is possible that illness severity is also linked with negative coping. It should be noted that this research was conducted just under three decades ago and discusses gaps in literature around eczema, similar to that which is still present today.

Gillespie's findings are supported by a study conducted by Faught et al. (2007) which compared stress levels of parents of children with eczema to levels of parents of children with other chronic illnesses. This study used the long-form version of the Parenting Stress Index with parents of children who attended outpatient and inpatient hospital appointments. The study found that maternal stress and eczema severity were significantly positively associated, with variability in eczema severity predicting around 20% of variance in the stress scores. The stress levels reported by the mothers of children with eczema were comparable or greater than those of mothers of children with other chronic conditions such as diabetes and deafness, as well as being a similar level to mothers of children with particular disabilities.

Chong et al. (2023) investigated the impact of psychological flexibility and self-compassion on quality of life and mental health symptoms in parents caring for children with eczema. The findings indicated that a higher level of psychological flexibility was associated with greater quality of life scores and a reduction in mental health symptoms including stress, depression and anxiety. Self-compassion was found to be associated with all mental health symptoms but not quality of life. This is supported by previous studies including one by Heapy et al. (2021) which measured parental dispositional mindfulness, stress, psychological distress and quality of life in parents of children with eczema and psoriasis. The study found that increased dispositional mindfulness in parents was associated with better parental wellbeing, and implied mindfulness intervention as appropriate support for parents of children with eczema. However, the findings also indicated that the relationship between parental wellbeing and dispositional mindfulness was not moderated by presence of a skin condition. Further supporting studies include Warschburger et al. (2003) who investigated factors which influence quality of life in parents of children with eczema. One hundred and eighty-seven parents of children in an inpatient rehabilitation unit completed outcome measures relating to psychological distress, family functioning, parental wellbeing, and eczema severity. The findings indicated that increased eczema severity was associated with higher levels of impact on family functioning. Recommendations from the study include psychological support for parents of children with eczema, particularly as part of a disease management programme.

Moore et al. (2006) conducted a quantitative study comparing sleep loss of parents of children with eczema to those with asthma. This study also looked at the association between the sleep loss and parental anxiety and depression levels. The researchers found that mothers of children with eczema lost a median of 39 minutes of sleep a night, with fathers losing a median of 45 minutes per night. Sleep disturbance was found to directly correlate with paternal anxiety and maternal depression and anxiety.

The National Eczema Society and Leo Pharma collaborated to produce a survey of 530 adults with eczema and 524 parents of children with eczema, which they used to create the Eczema Unmasked report (National Eczema Society & LEO Pharma, 2020). The surveys asked about a range of experiences in the context of eczema, including symptomology, emotional impact, and experiences of support. 61% of the adults surveyed said they had trouble sleeping due to their eczema at least weekly, with 29% saying it happened most nights. Around three-quarters of the adult eczema respondents reported that eczema has negatively affected their mental health and 61% said it impacted their social life, with two-thirds saying they felt lonely or isolated.

1.8.2 The Impact on Parenting

Penny Titman's book, *Understanding Childhood Eczema* (2003) explores the impact the eczema has on the family, as well as providing information and advice for families that have been affected by eczema. Titman's knowledge stems from her experience working with children with skin conditions as a consultant clinical psychologist, and she also has her own lived experience as a parent of a child with severe eczema. Titman discusses how eczema can have an impact on the parental relationship with their child, with parents finding it difficult to keep up with the demands of care. This includes having to manage the upkeep of treatment when the child goes to school and assessing the environment continuously to reduce risk of flare-ups. Titman also explores parents' concerns about being over-attentive with their child, and family members and friends who do not understand the full impact that living with eczema can have, which may result in loss of confidence in their parenting. Titman also addresses parents' worries about spending more time with their child who has eczema and feeling guilty about the time not spent with their other children. Whilst the book provides invaluable insight into the impact of eczema from a clinician who also has lived experience, it must be considered that the information is mostly anecdotal and so caution should be taken when generalising.

The Eczema Unmasked report (National Eczema Society & LEO Pharma, 2020) asked some questions about the impact of eczema on the family. Two-thirds of parents stated that maintaining a skincare regime for their child took up a significant amount of their time, and 27% of respondents had to regularly cancel activities or trips due to their child’s eczema. 22% of parents responded that their child’s eczema had a negative impact on their relationship with their other children.

1.8.3 Experiences of Support

The Eczema Unmasked report (National Eczema Society & LEO Pharma, 2020) asked respondents if they had been offered support with their emotional and psychological wellbeing in the context of eczema, by their NHS doctor. 58% of adults said that they had never been offered emotional or psychological support in the context of eczema. Of those who had been offered support, 21% had been offered counselling sessions and only 12% had been offered support by psychodermatology services.

The survey also asked parents of children with eczema about their experiences of support. 72% of respondents stated that their child would come to them for emotional and practical support around their eczema and 36% said they would go to their other parent. In terms of the opportunity to have an NHS doctor speak to their child about the emotional and psychological impact of eczema, only 34% of parents reported that this had happened, though 20% believed it was because their child was too young. Only one in ten children who had been offered support were offered access to a psychodermatology service.

1.9 Research rationale, aims & questions

The review of the limited literature demonstrates a large gap in the research around parents’ experiences of eczema, whether that be their own, their child’s, or both. Worldwide research has shown that eczema has a significant impact on the psychological wellbeing of children with the diagnosis as well as the quality of life of the family affected, but it fails to bridge the gap in the knowledge about how it affects parenting. Existing literature shows that chronic pain can impact the appraisal of the child’s needs (Maciver et al., 2010). Eczema can be a very painful condition, yet there is little-to-no research about how knowledge of this pain might impact how parents respond to their child’s needs. The Eczema Unmasked report (National Eczema Society & LEO Pharma, 2020) clearly highlights that eczema has a negative impact on not just children or adults with the skin condition, but also parents of children with eczema. It is not known, however, if and how having eczema as a parent impacts wellbeing and parenting. With the push towards integrated healthcare and the promotion of psychodermatology services APPGS, 2020), it is important to consider how these services can best support those using them.

The current proposed research study aims to start to bridge the gap in the research around parents' experiences of eczema. It will do this by hearing from parents about their personal experiences of eczema, whether it be theirs or their child's (or both), including if eczema has any effect on how they respond to their child's needs. The study will also aim to hear from parents about any psychological wellbeing support that they have/have not been offered or accessed, in the context of eczema. Due to the acknowledged disparities in health care provision, the study will also aim to hear about whether any support for psychological wellbeing accounts for individual and familial differences.

1.9.1 Research Questions

1) Does the experience of eczema impact parents' appraisal of their child's needs?
2) What is the experience of mental health support for parents affected by eczema, and does it meet their needs?

CHAPTER TWO: METHODOLOGY

This chapter firstly outlines the epistemological position of this research study and articulates the rationale for this approach, followed by coverage of my own positioning as researcher. Processes and procedures for the study will be covered, to include detail of ethical processes and issues, recruitment strategy, sampling, data collection and management, and finally the process of analysis.

2.1 Epistemology

A large amount of the research into eczema is quantitative, conducted within the positivist paradigm, and focussed on the physical health aspects of the condition. Positivism assumes that research provides us with an objective explanation for events and experiences (Willig, 2001). The positivist paradigm views the researcher as separate from the research, as the data can only be interpreted as fact (Ponterotto, 2005). As determined in the literature review for the current study, there is a gap in the research for qualitative data on the impact of eczema.

This research study will take the epistemological stance of critical realism. The research aims to elicit individual experiences and the meaning that has been made of them by conducting semi-structured interviews. The researcher is interested in how the diagnosis of eczema impacts the individual as well as the system around them, and equally how the system and individual impacts the management of eczema and its effects on psychological well-being.

The exploration of individual and systemic interpretations on the world and the experiences within it lends itself to social constructionism. However, it is argued that within a health psychology setting, critical realism is the most appropriate framework (Connelly, 2001). The existence of a diagnosis must be acknowledged when exploring the impact of health problems. If this research were to take a social constructionist stance, then it would not consider the reality of receiving a diagnosis of eczema. Critical realism argues that experiences can be understood via the interpretation of the data collected (Willig, 2001). The critical realism approach allows for the exploration of individual experiences within a realistic lens – the medical diagnosis is real, and yet there are individual and systemic experiences to be explored within the context of that.

2.2 Design

2.2.1 Recruitment

2.2.1.1 Inclusion Criteria

To be suitable for recruitment, participants needed to:

- be a parent of a child under the age of 18,
- live in the United Kingdom,
- have a diagnosis of eczema OR their child has a diagnosis of eczema OR both,
- be English speaking.

There was no specified severity of eczema for inclusion, and the diagnosis could have been made at any time throughout the lifespan.

2.2.1.2 Procedure

The study aimed to explore the impact of eczema on parents who at the time of being interviewed have children under the age of 18 years old. The recommended number of interviews before data saturation according to (Guest et al., 2006) is 12 and so this was the aim for the number of interviews conducted, though as this is contested it is merely a guideline rather than an aim. The recruitment process encouraged all parents who had been impacted by eczema to attend interviews, in order to gain perspectives from fathers, mothers, and other parents. Due to the researcher's appraisal that saturation of themes was being approached and holding in mind the time constraints inherent in the frame of a doctoral study, recruitment ended after ten participants had been interviewed (n=10).

2.2.1.3 Participant Demographics

The participants consisted of eight mothers and two fathers, all of whom had at least one child with eczema, and four of whom had experienced eczema themselves (Table 1).

Table 1

Participant Details

Participant	Parent	Number of children with eczema	Own experience of eczema
1	Mother	1	No
2	Father	1	No
3	Mother	1	Yes
4	Father	1	Yes
5	Mother	1	No
6	Mother	1	Yes
7	Mother	1	No
8	Mother	1	No
9	Mother	2	Yes
10	Mother	1	No

2.2.1.4 Sampling

The participants for this study were recruited via snowball sampling from the general population rather than via health care services, to ensure breadth and diversity within the participant group sample. The researcher partnered with an eczema charity to help with recruitment and consulted with them prior to and during the recruitment process. The charity featured the flyer in their monthly newsletter and informed parents about the study during routine phone calls. The flyer was also posted on social media including Facebook, Instagram and LinkedIn by the researcher to reach the wider population. These posts were shared by and within the “eczema community” on social media. Once interest had been expressed by those who had responded to the flyer via email, the potential participants were contacted with an information sheet (Appendix A) about the study and for those deemed appropriate to be included within the study they were requested to sign the consent form (Appendix B)

2.2.2 Developing the interview schedule

A semi-structured interview schedule (Appendix C) was created in collaboration with the research supervisor and in consultation with the eczema charity. The questions were guided by the aims of the study and sought to address gaps in current research by exploring the impact of eczema on parents including preferred approaches to soothing the needs of their children, attachment, and psychological well-being. The questions also aimed to explore experiences of support for psychological well-being, as well as any differences in treatment and the individual's meaning making of these differences.

Once the draft questions were developed, by way of a pilot process and to enhance ecological validity of the interview schedule, the questions were piloted on those who had expressed an interest in the study but were not eligible, to help refine the accessibility and wording used within the interview schedule. This pilot sample included parents who had experienced eczema but whose children were over the age of 18 at the time of the study, and those who had experienced eczema but were not parents themselves. This stage was included in recognition of the National Institute for Health Research (2021) who champion a consultation phases pre-commencement of research studies as a means of improving research quality and relevance as well as providing a different perspective. The participants within the consultation were explicitly asked if there was anything they would change about or add to the existing questions and if they thought the questions asked would be relevant and helpful in capturing and eliciting information relating specifically to parenting in the context of eczema as well as experiences of support with psychological wellbeing. This crucially helped refine and finalise the interview schedule and led to inclusion of relevant prompts for discussion during the interviews.

2.2.3 Semi-structured interviews

All ten interviews were conducted remotely via Microsoft Teams and allowed for approximately one hour of discussion, ranging from 13 minutes to 57 minutes. Parents were invited to interview and urged to bring the second parent if they were a part of the family system. This was to ensure the research covered as many perspectives as possible with the intent of avoiding any gender bias.

2.2.4 Transcriptions

Microsoft Teams was utilised for recording and transcribing the interviews, transcriptions were subsequently checked for accuracy by the researcher and edited for accuracy (Appendix D). The interviews were revisited and replayed multiple times during the transcription process in order to ensure accuracy when capturing the data. Transcription was conducted using the ‘Jefferson Lite’ scheme (Potter & Wetherell, 1987). This scheme was felt to elicit enough detail from the interviews, including the full questions from the interviewer and subsequent answers, without having the time consuming process of transcribing the full information on other aspects of the interview, such as tone and length of pauses; as demonstrated by Heritage & Atkinson (1984) in a full Jefferson transcription. As the transcription was conducted as part of thematic analysis, then this more basic transcription theme was appropriate rather than a more complex scheme which would be more suitable for conversation analysis.

2.2.5 Thematic Analysis

Thematic analysis (TA) was conducted as per the process described by Braun and Clarke (2006). A “inductive reflexive” approach (Braun & Clarke, 2021b) to TA was adopted, meaning that the interviewer was responsible for interpreting the information data from the interviews to draw out themes. This is in line with the Big Q TA, as defined by Kidder & Fine (1987) as an approach which allows researcher reflexivity. Whilst using a reflexive approach could risk the interviewer placing their own biases and inferences upon the data analysis, if care is taken then it can result in subjective reflections upon current context including sociocultural and political context. This can therefore result in richer evaluation and discussion of the final themes. Due to limited prior research into the experiences of parents impacted by eczema, it was decided it was inappropriate to use a more structured approach (such as the use of a codebook) as this may miss out codes that “don’t fit”. Emerging themes were noted during the transcription process, though care was taken to ensure that this did not impact or limit the awareness of new themes emerging, as the transcription progressed.

2.3 Ethical Approval

Ethical approval (Appendix D) was obtained from the University of East London School of Psychology Ethics Committee prior to commencing the study. All participants provided written consent to take part in the study, including agreeing to the process of the researcher recording and transcribing the interviews via Microsoft Teams. Participants were informed that the recordings and identifying data would be kept for three weeks in case they should choose to withdraw their data, but after this time all identifying data would be removed and included within the study data pool. All transcriptions were pseudonymised.

2.4 Analysis

2.4.1 Thematic Analysis

The five phases of TA outlined by Braun & Clarke (2006, 2021) were carried out.

Familiarisation of the data: The researcher familiarised themselves with the data by reviewing and transcribing the video recordings of the interviews, and then reviewing the transcriptions to ensure they were thorough and accurate. This included making margin notes to keep track of any codes that emerged during this process and links to wider context. The interviews were transcribed using the ‘Jefferson Lite’ scheme (Potter & Wetherell, 1987) as described in the previous section.

Generation of Initial Codes: Initial codes were generated used a “top down” inductive approach (i.e. not using pre-determined codes or themes as a guide). Codes were generated by highlighting data which was relevant to answering the study aims (Appendix E). These were then recorded onto a document and colour coded according to general themes. Following on from coding, these data was then sorted into initial groups based on similarity in meaning, as per the colour codes. They were then reviewed and initial themes were determined.

Generating Themes: The initial themes were then reviewed, which included determining which themes could be amalgamated or discarded and ensuring that extracts accurately reflected the theme group. A thematic map (Appendix F) was created which assisted in viewing the themes in the context of each other and how they may be connected.

Reviewing Themes: Once the themes were generated, they were reviewed and finalised.

Defining and Naming Themes: A final review of the completed themes ensured that the themes distilled from the data accurately captured the information provided in the interviews, and quotes representing these themes were chosen accordingly.

2.5 Reflexivity

When reflecting upon the development of reflexive TA, Braun and Clarke (Braun & Clarke, 2019, p. 594) argued that the “researcher’s role in knowledge production is at the heart of the approach”. The researcher must be aware of, and consistently reflecting upon, the theoretical underpinnings of the research, as well as the epistemological stance taken. When undertaking reflexive TA, the researcher is unable to be separated from the research findings as they are key in the analysis and interpretation of the data. As argued by Gough & Madill (2012), researcher subjectivity is not a problem within research, rather a valuable resource. This can be exampled through the “generation” of themes by the researcher, rather than the “identification” of themes which already exist in the data (Braun & Clarke, 2023).

2.5.1 Researcher Reflexivity

My interest in and commitment to conducting research in this field is in no small part influenced by my own lived experience of having eczema for my entire life. I have a first-hand insight into how eczema impacts not only the individual with the condition, but also those closest to them.

I have been acutely aware of how my own values and experiences may influence how I approach this research. My own significant and continuing journey with eczema, means that I have both conscious and unconscious bias in relation to the management and treatment of eczema, as well as the support that is available to those impacted.

As a trainee clinical psychologist working within the NHS, I am used to adopting various roles and responsibilities within my job. Whilst conducting the interviews, I felt pulled towards the “therapist” role of a clinical psychologist and had to be mindful not to advise or signpost within the interviews. I was able to manage this with the knowledge that I was providing a full debrief at the end of the interview, as detailed in the debrief form (Appendix G), which contained details of organisations that could offer support if needed.

CHAPTER THREE: RESULTS

This chapter will identify and discuss the themes elicited during analysis. In total, there are three main themes with eight subthemes between them. These themes are detailed in the table below.

Table 2

Themes and Subthemes

Themes	Subthemes
Mental health and wellbeing	“It’s such an emotional thing” “I was quite clearly breaking down” “It can be so influential on everything you do”
Relational impact	“It has a huge impact on plans” “I wish I didn’t know what it’s like” “A full-on caring role” “It’s a different way of soothing”
Other peoples’ perceptions of eczema	“They don’t actually understand” “I don’t know what others think”

3.1 Theme One: Mental health and wellbeing

Mental health and wellbeing were discussed consistently throughout the interviews. There was a particular focus on eczema related stressors, and uncertainty about how to access mental health support in the context of eczema.

3.1.1 Subtheme One: “It’s Such an Emotional Thing”

Many parents discussed the impact that caring for their child who has eczema has on their own wellbeing, particularly their mental health.

[…] and it does take that toll that you feel it's quite a burden in a way. I don't mean to call him a burden or anything, but it is. It's a toll that's on you […] to make it better for him.

Parent 1

It's kind of this horrible feeling where suddenly you realise your mental health and how you feel is based on basically how good your child's skin is.

Parent 2

As evidenced in the below quotes, parents felt there is a increase in mental load when caring for a child with eczema, particularly in relation to having to remember and keep on top of skin care routines, and having to explain this to others such as family members who may be caring for the child.

Then if I'm learning that, I'm teaching it to the other people that look after him, like - so to the nursery and to my mum and his dad and to try and make sure that we're all doing it the same, which then again goes back to that mental load on me and that's a burden.

Parent 1

It’s really - it's been, first of all, exhausting and - like going through so many different creams. I am weekly up at my doctor's picking up prescriptions, putting prescriptions in.

Parent 3

Parents who themselves currently or previously had eczema, such as Parent 4, spoke of how their child’s eczema would trigger anxiety or trauma responses in them.

There's so much anxiety with being a parent anyway, but when [eczema is] to that extent, and I think I had a lot of trauma from my own skin to even seeing [child] scratching - I got very angry very quickly because I knew that the consequences of him itching would be down to me.

Parent 4

Some of these parents, such as those in the quotes below, spoke of the guilt they felt due to the hereditary nature of eczema.

It's just heart breaking. It's just really heart breaking because you know they feel self-conscious. You feel a bit like ‘Ohh no. Somehow I've given this to them even though, you know, what can you do?’

Parent 7

It's really difficult because it's such an emotional thing and - and especially when you know it's so hereditary. You can't help but think, well, that's my fault. That's my fault. He's got that.

Parent 6

Tiredness and lack of sleep were mentioned as the result of caring for a child with eczema.

When he was younger, he'd be up all night in the night a lot. Scratching. And so you'd have sleepless nights and then you'd have to function the next day. You go to work or, like, care for my other little boy as well. It's really exhausting.

Parent 3

Sleep deprivation is a killer, isn't it? Really. And you just think that it's only gonna be for a little while. Couple of years or so and then they. But it's just been going on for such a long time and it affects everybody in the house […] You're waking up in the night numerous times having to do numerous things, showering, creaming like fans, changing the bed sheets or whatever very specific requirements my daughter has about her bedding. Um, But then I'm really tired. The next day. She's really tired, you know. Nobody's in a good mood. It affects my work. It affects probably how I am towards my son.

Parent 7

As well as impacts on their own mental health, parents also reported negative effects on their child’s mental health.

I feel like if she didn't have eczema. And then I'm sure there would be some other things. Don't get me wrong, but I'm sure if if she didn't have eczema, that maybe she wouldn't have some of these worries and anxieties and all this sort of self esteem stuff.

Parent 7

For some parents, such as Parent 2 in the quote below, this, in turn an effect on their own psychological wellbeing.

He said "Ohh, don't worry like eczema just chose me - it doesn't matter." He said that "if it stings, I'll just put cream on!". You're kind of like, "ohh God, you seem to be coping better than than, than me."

Parent 2

The concept of feeling isolated as a parent who is impacted by eczema was also explored by parents such are Parent 1 below.

It's quite isolating as well. It's a little bit like the food allergies. So none of his friends have eczema that I know of. So there's no one else to talk to about it with and I think that's really difficult.

Parent 1

Parent 2 spoke about removing themselves from social media as it was distressing to see families who didn't visibly have eczema, leading to further isolation.

I actually stopped following any of my friends with kids on Instagram. Yeah. No, I remember feeling quite bad about that cause they are friends. I just thought - I was thinking in my head, just thinking, like, you know, "fuck, fuck off".

Parent 2

Some parents also implied that their experiences with eczema had led to positive impacts on their well-being, such as learning to be more in tune with their body.

And I feel I'm trying to look at my own patterns, whether it's our PMS stuff, etcetera. So it definitely does impact you cause you also feel, I'm quite a result- quite goal orientated as well as an individual.

Parent 1

3.1.2 Subtheme Two: “I Was Quite Clearly Breaking Down”

There were difficulties reported with accessing both mental health and physical health treatment. Some parents spoke of the continuous cycle of treatment which did not lead to long-term successful management of symptoms, as illustrated below.

It doesn't end. There's no endpoint to. You know, if you have a child that's ill, it's never nice. But if you think, OK, […] if they have chicken pox for example […] they're better and then it doesn't come back again a week later or two weeks later. […] Whereas with this it's like – Ohh well it's summer. So there might be sweating, or the sun cream, but then it's autumn and it might be, ohh, cause there's leaf mould and it's winter so the air’s dry and you kind of like “Okay. So what? Where? When won't he have it?”

Parent 2

Parents including Parent 7 reported that access to a dermatologist, particularly via the NHS, was often very difficult to obtain.

It takes a really long time to get to see anybody that really specialises in skin. That is my experience.

Parent 7

This led to some parents seeking private dermatological support in order to get the relevant expertise and/or avoid waiting times, as described by the parents in the following quotes.

And we've been in a privileged situation to be able to go privately for some of her treatment, which we've needed to do. Because the doctors just keep giving you the same cream and it's not working. We need something else. We need this to change. So yeah, we were privileged to be able to do that.

Parent 9

We saw a private dermatologist and for a few years we seem to be able to get on top of it. It practically disappeared.

Parent 10

Parent 7 described having to advocate for their child or themselves in order to get the physical health support that they needed.

And finally I came to breaking point where I phoned the GP in floods of tears and said "she even has eczema on her vulva area and she can't wear knickers because it's painful. What the hell?" I and- and I went to the NICE guidelines and I did all my research and I phoned the GP and I said "I think you'll find, you know, that this says that if it's having a significant impact on their mental health and psychological wellbeing and absences from school..." And I did the probably really annoying person that's read it all up. But I just thought" no, this is no- this is no good".

Parent 7

This self-advocacy also applied to seeking mental health support for them and their children.

So, it's just insane to me that, you know, these things you have to go through just to fight your corner. And like I said, try and know everything more than they do. Which is ridiculous because they spend like five years training.

Parent 4

We did go through dermatology services for about a year last year and, you know, there's there was no mention of any kind of support, all the support that I've had, I have sourced for myself.

Parent 7

Parents with their own eczema, such as Parent 5, spoke about mental health support not being a priority when they sought treatment.

Whenever I've gone to the doctors about my eczema, I've never gone to a doctor, said "look, my skin's awful and it's really doing my nut". You know, I- I go there and say "Skin's awful. Give me some steroids", you know. So maybe if I, you know, I- I feel it's like, you kind of have to- I presume you have to ask for it.

Parent 5

Many of the parents stated that mental health was not discussed in their eczema appointments, for both parents and children. This is illustrated in the quotes below.

I was like quite clearly breaking down to a doctor, I mean you can, you know, even talking about- about it now it's got, bit upsetting, but no one [offered mental health support].

Parent 2

I was in A&E, and they made me wait for seven hours. Um. And they just said to me "you're just gonna have to wait for your derm appointment". And they knew I was suicidal. They didn't get a mental health team to talk to me. Nothing.

Parent 4

You know, when we go to the doctor and when we go to the dermatologist, you know, nobody asks "How you doing? How- how are you coping?" It's- it's all just "Oh, I'll just sign another cream off and off you go", kind of thing.

Parent 8

When mental health impact was explored in medical appointments, it was often targeted at the children and not the parents, as described by Parent 3.

I don't think it has to be honest. I know. Like with [child], they'll often do, like little questionnaires for us to fill out about experiences of other people, um, on themselves, but he's still too young, really, I think to take it in, but nothing for us as parents. […] But no, no support or help for us, just lots of leaflets about eczema and that's about it really.

Parent 3

Some parents, including Parent 2 and Parent 5, stated that they were uncertain about what mental health support could be beneficial to them.

I think it's hard when it's like, I don't even know how you would treat if you feel like you do have some mental health. Because I did- I've done CBT. […] I'm not worried about something that hasn't happened. […] Like, I'm gonna come home from work and he's gonna be covered in covered in, like, you know, skin… doesn't work.

Parent 2

The issue of trust in professionals was also evident in the analysis.

I'm not even convinced the GPs believe it when they tell me as well.

Parent 5

It was implied that the impact of eczema on parents' mental health had a lasting effect, whether it was their own eczema or their child's, as described in the quotes from Parent 2, Parent 5 and Parent 6.

Almost like that PTSD of like […] You know you remembering bits of how it, how horrible it was that you can easily project that into - well, it could happen, that could happen again.

Parent 2

People will say something and you're like, "ohh yeah, I I I do still really care about the way it looks" and, and you think that you've grown out of that, but it does just like - I can still remember. […] I would have been like 7 and a kid saying that he didn't wanna hold my hand in country dancing cause he was gonna catch something and that was 30 years ago and I still remember who it was. […] And it's still a core memory that will be there forever.

Parent 6

Some parents, including Parent 6 and Parent 10, found that eczema created a barrier to accessing their own techniques for improving their mental health.

There's a lot of things that I don't do that I know would help my mental health as well. Like, I don't really exercise. Because obviously exercise equals getting hot equals getting sweaty or foot eczema.

Parent 6

I'm just too tired and also with his cream, with his kind of evening, the fact that he's more comfortable in the evening, the fact that he struggles to go to sleep, I feel it's hard to go out to do a class, for example, it's better to be at home and around umm so it's impacted on the activities I would do to benefit my well-being.

Parent 10

3.1.3 Subtheme Three: "It Can Be So Influential on Everything You Do"

Parents spoke about how they made meaning of eczema, including how they believed that eczema was a key influence in how positively or negatively they viewed not only their day-to-day lives but their entire existence. This is demonstrated in the quotes below.

Something that can takeover- control your life, like you try to do so much to manage it and make it better. And it can be so influential on everything that you're doing, and it can be so up and down as well. And sometimes it can be brilliant. You think you've cracked then and then all of a sudden with no explanation, it's horrendous again.

Parent 1

You know, you wake up and it's good and you think, "OK, I can have a good day", and you get home from work and it's still good and you think "Ohh great. You still got good skin." That comes a point where it's almost like that's all you're focused on.

Parent 2

Some parents implied that eczema was something which they could fail or succeed at, as described by Parent 2.

Because if his skin is good, then you feel like he's okay and you haven't like, you know, almost failed at something that you can't, you can't control.

Parent 2

Some parents also reflected how their child's skin is "telling a story", and that they view eczema as an indicator of what is currently happening or things to come.

His skin is telling us the story, and I always think that with [child], so he's got a little red mark on his face that always comes up. And then, like, "right in a couple of days, we're gonna have a bad night" or "you're gonna come down with something because it's like an infection marker". And I do feel like his skin tells a story.

Parent 1

His skin is an external manifestation of a whole system. Dysregulation and inflammation basically, but that's maybe me interpreting it symbolically and kind of more widely than just the skin. But I just think the skin is our interface between us and the world and it says a lot for someone to suddenly - everywhere he has eczema.

Parent 10

Parent 2 explored the idea that children feel eczema is something that can be wished away was brought up.

The day before his 5th birthday, he said, "will I have it tomorrow because the doctor said when I'm older, I won't have it." And obviously in his head he's thinking that or - he even blew out his candles on his cake. And I said, "Ohh, what did you, you know, what you wish for?". And you know, he said "Ohh, that I didn't have eczema".

Parent 2

Parents also spoke about viewing eczema as a disability, and how other's not sharing this view can exacerbate the impact, as demonstrated in the quotes below from Parent 7 and Parent 2.

You know in this hot weather last week and she had to wear a blazer and I was like you she she needs to not wear a blazer and you know you just got to think of it almost as a disability. If somebody had a wheelchair, you wouldn't try and make them stand up, would you? So she if she gets hot and if her skin gets into a flare, it's very difficult to rectify that. So what we need to do is prevent the flare. And that takes, you know, everybody involved in their lives to have an understanding, but they don't.

Parent 7

To me and my wife, that is how I felt like - that I've got child that's quite badly disabled, cause I didn't feel like I could do normal things with him and I felt like it was a real problem, but no one else around me, I think, sort of thought that or saw that.

Parent 2

3.2 Theme Two: Relational impact

It was clear across most of the interviews that eczema has a distinct impact on a multitude of aspects of family life. This includes day-to-day family functioning and activities, differing parenting styles, as well as an overlap with the previous theme of mental health and well-being, with parents discussing how eczema impacts their own perceived ability to parent and the effect this has on any siblings without eczema. This theme also covers how adaptations may be made to soothe and appraise needs when eczema is in the picture.

3.2.1 Subtheme One: “It Has a Huge Impact On Plans”

In the quotes below, we see parents reflecting that their child’s eczema has led to them making changes to family life, such as not doing activities together.

And it just has a huge impact on […] you know, if you've got plans, you don't wanna keep the plans. Can I be bothered to go shopping? Food shopping. Ohh, you know, I'll just get takeaway or I'd just can't go to work because I'm so tired.

Parent 7

Her eczema's been worse than anything we've ever known with my eldest. It's been really constant and angry and it's taken over like the entire family life of dealing with it. It's it's really, really stressful.

Parent 9

Swimming was mentioned throughout multiple interviews as an activity which the child has missed out on, examples of which can be found in the quotes below.

We don't go swimming very much because it affects his skin. He used to scream, going in the water and he doesn't always like to have a bath and because of these things, so it worries about those are social settings and if he goes out and spends it with other people.

Parent 1

He had to stop swimming at school. He was - cuz they do swimming at school and he did a couple and then he had to stop because it started making his skin worse.

Parent 10

The parents also discussed how much time is taken up by eczema management, such as applying creams and washing bedsheets. This was often linked to the tiredness that was discussed in the previous theme, as described by Parent 10 and Parent 8:

As for us as a family to carry on functioning, and also there's so much to remember in terms of his treatment plan. Like you need to put this cream on and then you need to leave this cream on half an hour before you put the next one on and you need to, *you know, if he has a shower he can't rob, he needs to just pat and so constantly having to be present is, umm, it's exhausting.*

Parent 10

She takes – it takes so much time our time – to cream her. You know, this summer she had a major flare and you know the dermatologist was like, you need to put steroid on twice a day. Cream her five more times a day. Then she developed her some really bad sores in her head. So that was another type of cream to apply on the head. And it was just the physical time that that took.

Parent 8

The below quotes describe how attempting to avoid flare-ups of eczema is a process that takes up a lot of the families' time. This also contributed to the concept that eczema was something that the parents were consistently thinking about.

Like I do sort of always think about the activities we're doing and then have his skin in the back of my mind thinking "oh I don't know" and I know you shouldn't limit them and you should try everything and we do try it. But it does have an impact like day-to-day activities. I do have to double think over and like plan for.

Parent 3

You're constantly monitoring yourself to see what's gonna flare next or what's feeling a bit rough or feeling bit dodgy next.

Parent 5

The impact that eczema was having on siblings was also highlighted, including eczema care disrupting activities or sleep schedules, as described by Parent 6 and Parent 1:

Like, on days that I'm off with both the kids. [Sibling] wants to go swimming and I just say "Sorry, we can't go swimming. I can't take [Child]".

Parent 6

They'll get their own rooms, and I can't wait for that because I think going in and soothing [Child] affects [Sibling] and wakes him up. And so then you've got a double *edge sword of juggling the two of them up or they’re both up at different times in the night.*

Parent 1

In the quotes below, the financial impact of eczema was brought up, with some differences due to geographical location being highlighted.

So we have to buy cotton sheets and we've bought all the anti-allergy and eczema appropriate sort of mattress protectors? And we've bought all the zipped pillow protectors and everything. So that's quite a cost, and cotton jammies, and cotton clothes, and also so we’re very, very fortunately here in Scotland - we have prescriptions for free. But I can go through a tub of a big tub of dermal in a week and I think they're about 10-11 pound.

Parent 1

So even things like his school uniform, I've got to go to John Lewis cause it's all 100% cotton. So like, I've paid extra just to try and make him as comfortable as I can.

Parent 3

Some parents, such as Parent 7 in the below quote, spoke about how their child has missed school due to the pain and lack of sleep associated with eczema.

[…] school absences that they have because they're in pain, or because they haven't slept. Sometimes it was just that she hadn't really had any sleep, and so I just say, well, she's not coming to school or her skin so bad. She's not coming to school today.

Parent 7

3.2.2 Subtheme Two: “I Wish I Didn’t Know What It’s Like”

Throughout the interviews, parents discussed the different levels and ways of understanding eczema within their inner and wider families. This included parents and children understanding each other’s experiences of eczema, siblings being involved in eczema care, and wider family members role in relation to eczema.

Feelings of guilt were expressed through the interviews, with some parents voicing how difficult they found being the one to implement eczema treatment for their child, as demonstrated in the quotes from Parent 3 and Parent 7.

So it's a lot of guilt because for one, you can just do things straight away. Getting him dressed. The one who doesn't have eczema. Not a problem. Whereas my one who does. You've got a cream and wait 20 minutes. Steroid, then getting dressed. Think about what clothes to put on him, gotta be cotton. Long sleeved. I'm just always double thinking of this condition as well as him.

Parent 3

I tried really hard to kind of instil good beliefs about consent and things like that. And she's screaming "no" at me and I'm having to do it anyway, you know, and it's that's really hard for me […] and it's really hard because I have to carry on, you know, you have to put that cream on her and it is really - that's the hardest thing, I think, kind of constantly having to do something that I know is not very nice for her.

Parent 7

Some of the parents also spoke about how siblings of children with eczema were involved with treatment. Parent 1 explained this in the below quote:

[Sibling] likes to help put the cream on. And so he likes to put the cream on to [Child] - in all the wrong places - but that's fine. At least he's trying.

Parent 1

Parents who had experienced eczema themselves spoke of an understanding of how their child must be feeling which elicits feelings of empathy.

Whenever you see them uncomfortable or in pain, it's so much harder because you know how that feels like. I know exactly how painful that is. I know how uncomfortable that is. I know how annoying it is to have people go, don't scratch, don't scratch, don't scratch. And you're like, I didn't even know I was doing it.

Parent 6

There's definitely a big understanding that I get that that itch, it's uncontrollable. So when you're being told to stop scratching. […] Once you've broken that skin at the *end of that scratching, I get that and I know it and I understand it […] But yeah, I think I definitely have much more of, kind of, yeah, closeness with that and understand why she needs to scratch. What relief it gives her.*

Parent 9

Whilst parents with eczema had more of an understanding of how their child felt due to the condition, some felt this made it harder for them to manage as they knew the pain that their child was experiencing. Parent 6 spoke about this:

I see a lot of these parents on a lot of the eczema groups and stuff saying like, "ohh, I don't know what to do for my child and now it just looks so painful and I just, I don't. I don't know what to do because I've never experienced it" and I sort of wanna say like "I wish I didn't know what it was like."

Parent 6

As described in the quotes below, the role of the wider family was also discussed in the interviews, with grandparents often being a source of support despite differing levels of understanding of eczema.

My dad's very familiar with eczema and obviously so is my mum because they grew up with me so they know what it's all about, so they're quite good with stuff like that. They're quite sort of conscious of making sure that he gets moisturiser on all that, all that kind of stuff. But my in-laws are probably not quite as familiar and I always find it really difficult.

Parent 6

So my friends and family do try and support and I have often left - If I did leave her, she went to my mum's or something. There would often be quite a long list of instructions about her creams […] She might need this or that, they're all - you know they try. They try. But I feel like, as is often the case with lots of conditions, unless you've really experienced it, you can't really then truly understand what it's like.

Parent 7

3.2.3 Subtheme Three: “A Full on Caring Role”

Many aspects of parenting were explored during the interviews. This included gender differences in parenting, differing soothing styles for the child with eczema, and how eczema impacted the parent-child attachment.

For some parents there was a sense of concern about their child’s independence as they heavily relied on their parent for aspects of the eczema care, which is discussed by Parent 7 here:

Because it's a very full on, you know, caring role that you have to take on, particularly when they're young and they can't do all the creams and the care and stuff for themselves and they don't have any understanding of what you're trying to get them to do and why. And I think it's had an impact in the sense that she's very dependent still on me because I've done loads for her.

Parent 7

Some mothers interviewed, such as Parent 1 and Parent 3, expressed how they perceived the majority of the care for their child with eczema fell to them.

I think as well, with all credit to my husband, it all falls on the mother - or at least in our case it does. I'm the one that's always been at the doctor's appointment. I'm the one that's pushing it for him. I'm the one that's comforting him at night. I'm the one that's learning which creams and […] all the different ointments that you can get in different types and learning it all.

Parent 1

He's been there all the appointments and he knows all about creams. But I'll be the one to be like, "Right. Can you put this cream on?"

Parent 3

Some of these mothers implied that they felt a lack of control when leaving the care to their partner, and so felt more comfortable taking the lead. Parent 10 discusses this here:

But then I also have to supervise my partner to make sure that he's doing it right because it's - I feel it's really important we get it right and so then I get impatient *sometimes if something goes wrong because I feel like I put so much energy into trying to manage his skin and then if something goes wrong, it's like it almost feels like a kick in the face.*

Parent 10

It was brought up that much of the discourse around parenting a child with eczema was targeted at the female caregiver which left fathers feeling unwelcome in the space. Parent 2 spoke on this:

It seems to be the mum- aimed at the mum […] it's "eczema mums" or the blog is like "what to do if you're an eczema mum", "10 things you can't live without being an eczema mum". I guess. You know, maybe they are doing the most. But you do sort of feel. I think like, you know I am putting cream on him three times a day. I'm up at 6am with him, when he's scratching…

Parent 2

This highlighted how parents may differ in their approach to seeking support, such as use of social media.

Ohh, men do it too, but you know you might feel like even more isolated, you know, like I said, I don't have Facebook. I'm not on Facebook. But I did have a look through and actually all the posts are mums on that Facebook group as well. So you know, perhaps generally they are taking more of the burden, I think, yeah, perhaps if you're a single dad with a child with it might be even harder to find somewhere to chat or to speak to someone.

Parent 2

Parent 2 also spoke about how one parent taking the lead in attending medical appointments can lead to differences in how they approach caring for their child due to different levels of understanding.

I think uh, you know, if you're treating in a child with your partner, you might have different ideas on what you should be doing […] Especially during covid, only one of you went to the doctors, so the other would have to relay it back […] And then you might say, "okay, did you ask about this?" And "ohh no, I didn't". And then you sort of think "ohh, that's our appointment done like you should have asked why".

Parent 2

Parents with eczema also spoke about the difficulties of having to balance their own care with caring for their child. This is demonstrated in the following quotes from three of the parents.

You're trying to find a balance between looking after yourself because you can't be a good parent if you're in pain or uncomfortable or whatever - and you do need to manage your own medical condition - but then also going, well, I still need to make sure that I'm prioritising my kids as well. It's hard, really.

Parent 6

The idea of helplessness arose in the interviews, in particular how parents felt as though they were unable to take away the pain and inconvenience of eczema.

The thing is the not knowing and the feeling helpless and I think, yeah, on your own.

Parent 2

[Child says] "Why? Why me? Why am I having to have cream five times a day? Why do I have to stop playing with my brother and have to come back upstairs and get undressed and have my cream put back on? Why is it constantly me?". And yeah, it's really hard because I don't know why? [...] I can't take it away. I can't take it off her. I can't make it any better, you know, I say to her, if I could wave a magic wand, I would do. And so that kind of powerlessness - it's really hard.

Parent 8

3.2.4 Subtheme Four: "It's a Different Way of Soothing"

Differing ways of soothing and appraising the needs of their child were explored by the parents. This included the use of ice packs and application of creams for physical comfort.

If he has a flare up […] getting ice packs like the fridge, and I'm sitting on the sofa with ice packs all round them, just sat next to him, sort of watching his favourite programme or something like that. It is a different way of soothing them compared to my other one definitely.

Parent 3

She often doesn't really want to be touched and cuddled, but she will want me to, you know, can you put the cream on and then "can you rub my back?" […] I feel that maybe the action of putting cream on her skin is probably quite reassuring for her?

Parent 7

Some parents compared how they cared for a child who did not have eczema to the child who does. In the following quotes the differing ways of soothing are described.

I remember a lot of when she's trying to go to sleep, just kind of holding her still until she's asleep. And then she'd be all right. But yeah, my youngest was a different kettle of fish and has tested us from the start. Yeah, her eczema - It was more aggressive, more angry, harder to deal with. We'd never get respite from it. And I was having to swaddle her in one of those big muslin, like metre square muslins until she was too literally too strong and could weasel her way out of it.

Parent 9

With [sibling] you can pick him up, you can cuddle him, squeeze him like you don't even think twice. But then with [child], of course I do.

Parent 3

Some of the parents who had a child with eczema and another without acknowledged the disparities in the amount of time spent with each child when trying to soothe them. They also spoke about how they may be more lenient towards their child with eczema in an attempt to soothe them, as illustrated in by Parent 2:

If it takes him an hour and a half to go to bed, then I'll be on his floor for an hour and a half at night because maybe with like an earphone and listen to a podcast, whereas [sibling], we put in his cot and then if he cries, you think, "well, no, it's bedtime." Whereas [child] starts to play up and I'm thinking "No, no, no. You know, I don't want you to. I don't want you to get hot or stressed". So you know there is that difference. I think that I'm still […] "ohh you can you can do whatever you want and have whatever you want." But I know, it's like, I can stop him crying by letting him have another ice pole. You know I just - I don't care. I think with [sibling] I might tell him "you've already had one today".

Parent 2

Participants who had eczema themselves discussed how this impacted their ability to soothe their child through touch, including difficulties with breastfeeding due to soreness of skin. This led to discussion about the impact this had on bonding with their child. Parent 3, Parent 4 and Parent 6 shared their concerns about breastfeeding:

I would really struggle in the summer because you'd get so hot - sweat triggers your eczema. You'd be so uncomfortable, you'd be so conscious of your skin, wanting to cuddle them […] having a nap on you and stuff like that was really difficult and it was a real battle between like, "this is a really nice bonding thing to do with my child" and "oh my God, this makes me want to rip my skin off because I'm so hot" and having a little hot baby on you.

Parent 3

I was also scared I wouldn't be able to breastfeed if I couldn't do skin on skin and all that kind of thing. And even when he came out and they have that white stuff on them, can't remember what it's called. But I even thought about "Ohh do I want that on my skin? Is that gonna irritate me?", like it's just horrible to have to think about all these things when people without skin condition would never even think of it.

Parent 4

I was on steroid creams and stuff and I was breastfeeding and one of the areas that I struggled as I was on my chest and I was like, well, what do I do? Do I breastfeed and not use steroid creams because I don't want it to transfer onto like his face. Or do I say, well, I shouldn't breastfeed because then my skin's really terrible.

Parent 6

3.3 Theme Three: Other People's Perceptions of Eczema

Parents spoke about the impact of other people's perceptions of eczema. They discussed how unsolicited advice, whilst well-meaning, can be unhelpful overall, and how lack of understanding of eczema can lead to difficult situations and feelings. Parents of children with eczema also felt worried about how other people might view how they care for their child.

3.3.1 Subtheme One: "They Don't Actually Understand"

Many parents spoke about how others often offered advice around eczema, such as recommendations for treatment. This advice on the whole was felt to be unhelpful and feelings of frustration were implied, particularly when it was perceived that those giving the advice had limited understanding of eczema and its treatment, as described in the quotes below:

The woman said “Ohh, you know, we used E45!” and [...] I didn't say anything. I was trying to be nice but you think like “he's on the drug they used to treat cancer - like obviously a smaller dose - so it's kind of like “we've tried E45 cream”.

Parent 2

Especially from family members, like they think it's helpful and they're being helpful, but I think it really needs to be reiterated that just saying “I'm here if you need me is” much better than saying “have you tried this cream? Have you tried this? Have you tried this?” Because although they think that that's helpful – it feels like you're being undermined and they don't actually understand the implication of trying a cream that could send you into like the worst flare, and there's just so much attached to it.

Parent 4

It was acknowledged that whilst the advice was often given with good intentions, it drew attention to the eczema which could be distressing, as described below.

Other people, they think they're being really sympathetic, being kind and they're being, sort of, empathising with you and you kinda just wanna scream at them. Like, “stop reminding me that he's in pain. Stop me that he's got this thing that everyone can see and everyone notices”.

Parent 6

The lack of understanding around eczema being a chronic condition for some and comparison with short-term childhood eczema also led to frustration.

"Ohh I had it when [they] were a child", or their kids had it, or they had it. And "ohh I remember having it on, you know, my elbows or behind my knees" and I'm kind of like "Okay. Well, he's got it from his head to his toe and he can't walk."

Parent 2

I'm not sure if other people understand it as much and take it as seriously. I think they hear eczema and just think it's a bit of dry skin.

Parent 3

The lack of understanding around eczema from those who have not had personal experience led to parents having to educate others who care for their child, including school. Parent 7 spoke about how eczema having to ensure school catered to their chlid's needs.

People don't think the eczema is like a medical condition, so I always - in all my communications to schools and things over the years - I'm like, you know, "this is a medical condition and you need to make these reasonable adjustments to her school day to support her health".

Parent 7

Parents who had their own diagnosis of eczema spoke about how much other's understanding of eczema can have an impact on their own thoughts and feelings around the condition and its treatment, including how positively or negatively perceived interactions can influence future interactions with those with eczema.

When I was younger, people would go "oh, that looks so painful" and "oh, you poor thing" and "oh, that looks so sore". And my mum and dad don't do it because they knew that it's actually a lot worse for someone to keep saying that, and especially when someone says it about your child and they go "Oh, God, poor thing" and "he looks so sore" and you're like, "yeah, I know, I know he does. I know it looks really painful. And thanks for bringing it up and reminding me that he's in pain". So my mum and dad don't do it, because they know that that's how it feels when someone's constantly telling you that your child looks like they're in pain, but other people don't know that.

Parent 6

3.3.2 Subtheme Two: "I Don't Know What Others Think"

Concern about how those outside of the parent-child relationship may perceive various aspects of the impact of eczema was also mentioned throughout the interviews. This included worry about how avoiding certain triggers for an eczema flare may be viewed. Parent 2 described worries about what their family thought of them:

I don't know what other family members think when we're, like, round there, a list of things and food you can't eat.

Parent 2

Parents who had made a choice to avoid using certain methods of treatment for their child spoke of worries about how this may be perceived by others. This included those who wanted to avoid use of topical steroid creams due to their own experiences or stories of other people's experiences of negative the consequences of the treatment, as explained in the quotes below.

It's different when you're at home and […] there's no judgement from anyone, or assumed judgement, where he's scratching and just people knowing that I'm not using medication that perhaps they would think that I should be using on him to give him relief.

Parent 4

They will tell me to put steroid cream all over him again […] but there's lots of talks about steroids.

Parent 2

Parents who are caring for a child with eczema may feel like they are conscious of other people's perceptions than their child are.

It's me, frankly. He rarely mentions it, but I just worry about the future and other children. What other people say when they see him as well.

Parent 3

Parents described how this has led to worries about socialising when trying to manage eczema:

But he will want to go for sleepovers and he will want to spend time with our parents who will learn to look after him. And I do worry about that aspect. Like what parent is going to put on all the multiples of cream that he needs in an evening and what parent is going to accept that he, like, if he goes and stays one night and he's up *through the night scratching, how are they going to comfort and support him? How are they going to have him back if they're like, he's a horrendous sleeper?*

Parent 1

It's also worrying about him. So, when he goes to play group and also, he starts school soon as well, it's sort of meeting extra with school to tell them about him and just not - it's hard letting go of him really cause I know everything I do for him, his routines and his treatments. I'm not sure if other people understand it as much and take it as seriously.

Parent 3

The concern about how well other people understand eczema impacted the likelihood that those affected by it would speak to others about the experience, as explained by Parent 3:

I can't even face going into it with people. Cause I think sometimes they think it's me and I'm being too dramatic or something like that. And it's like "no, his skin, can't tolerate anything like that. It has to be just what he's prescribed".

Parent 3

Parents reflected on their own experiences of being the ones to pass judgement on those impacted by eczema.

I remember we were looking at that and thinking, like "Jesus. Like if- thank goodness, he's not like that". And now, the last year, we're at the point we're thinking we're now one of those pictures where we used to think "these poor kids".

Parent 2

CHAPTER FOUR: DISCUSSION

The current study aimed to gather the experiences of parents who have been impacted by eczema, whether that be their own diagnosis or that of their child(ren). Due to the identified lack of research into the area, the impact of eczema on the parents' mental health was of particular interest. The research also set out to determine what mental health support the parents were aware of, in the context of eczema, and if and how they were able to access this. The hope was that this research could inform service provision to improve eczema related well-being.

This section will discuss the findings of the study and further explore them with reference to current literature, including what has been elicited with regards to the research questions. The limitations of the study will also be explored, as well as the implications of the research for future research and potential clinical service development.

4.1 Main Findings

1) Does the experience of eczema impact parents' appraisal of their child's needs?

Within the first theme there are depictions of how the impact of eczema on parent's psychological wellbeing can in turn affect parenting. Many of the parents described exhaustion from eczema care, whether their own or their child's, both from following a routine and having to collect prescribed treatment, and from disturbed sleep due to itchy and uncomfortable skin. Moore et al. (2006) demonstrated how increased sleep disturbance correlated with a significant increase in maternal depression and anxiety and paternal depression for parents of children with eczema. The results of the current study indicate that lack of sleep has an impact on how well parents can function day-to-day, such as at work, but also how well they are then able to respond to the demands of parenting. Previous research (Faught et al., 2007; Muller et al., 2021) corroborates the parents' experiences of their child's eczema having an impact on their own psychological wellbeing.

Parents described how their experiences of eczema added to the stress of caring for a child. This is supported by current literature which also indicates that severity of eczema positively correlates with parental stress levels (Gillespie, 1996). Faught et al. (2007) suggested that parenting a child with eczema should be viewed in the same respect as parenting a child with a severe physical or developmental disability. This was touched upon in the interviews, with parents believing that their concerns would be taken more seriously if eczema was conceptualised as a disability.

It was apparent that many of the parents felt that their experiences with eczema had a negative impact on their mental health. This appeared to be a culmination of numerous factors, including lack of sleep, the mental load of managing eczema, the isolating experience of having eczema, and feelings of helplessness and hopelessness. Previous research supports the suggestion that eczema negatively impacts on the quality-of-life of families whether as a carer of someone with eczema (Bronkhorst et al., 2016; Lewis-Jones, 2006; Marciniak et al., 2017) or as a parent who has eczema themselves (Howells et al., 2017). It can be reasonably deduced from these findings that the effect on parents' wellbeing will have an impact on how well they feel able to function day-to-day, not only with parenting duties but at work and socially. Dennis et al. (2006) suggested that children with eczema whose parents reported good mental wellbeing were predicted to display less internalising behaviours, such as social withdrawal and depression.

The second theme presented explored the relational impact of eczema. For parents who had one child with eczema and another without, lack of sleep and increased stress levels impacted on how they responded to either child's needs. Parents described feelings of guilt with regards to how they may treat each child differently, such as spending less time with the child without eczema, or the time spent with the child with eczema mainly being focussed on unpleasant eczema care. They also indicated that siblings may be involved in eczema care through enabling distraction of their sibling. Whilst parents may feel like giving siblings caring responsibilities is unfair, there is literature that suggests that siblings who are involved in care for children with chronic illnesses report lower anxiety levels and greater problem focussed coping, among other psychosocial benefits (Kelada et al., 2022). The same study, however, found that these siblings would also benefit from increased levels of affection from parents, as this was perceived to be lower than that received by the child with a chronic illness.

Differing ways of soothing in the context of eczema were mentioned in the interviews. Some parents spoke about how they soothed their child who had eczema in more practical ways than their child who did not have a skin condition. This included the use of ice packs and applying creams. They described how they may avoid comforting their child with eczema through touch, such as hugging, due to the pain or overheating that this may cause, whereas this would be something they would do for their child without eczema. Parents who themselves had eczema described a similar experience where they would avoid skin-to-skin contact with their child in order to avoid discomfort for themselves. Skin-to-skin contact between a parent and child has been theorised to have numerous positive outcomes, including improved developmental and health factors for the child, and decreased depression symptoms for mothers (Norholt, 2020).

Mothers who had eczema themselves discussed their difficulties or reluctancies regarding breastfeeding. These mothers may have chosen to avoid breastfeeding in order to prevent their own pain or a flare up on their eczema symptoms. This resulted in some concern about how other’s may view their decision not to breastfeed. There is very limited previous research regarding the impact of eczema on the decision of whether to breastfeed, with more research being focussed on whether breastfeeding is a protective factor against developing childhood eczema (Flohr et al., 2011; Wang et al., 2017). There is also a small amount of literature discussing the management of nipple eczema with the aim to prevent “prematurely” ceasing breastfeeding (Barankin & Gross, 2004; Reynaert et al., 2023).

The parents spoke more of the distress they experienced at not being able to physically comfort or breastfeed their child and did not imply that there had been any noticeable impact on how close they felt to their child. Early attachment theory as presented by (M. S. Ainsworth & Bowlby, 1991) implies that attachments are formed through caregivers responding to basic needs such as feeding and protecting from danger. It could be argued that whilst the parents are concerned about not being able to hold their child, as they may have expected to do to form attachments, by responding to their needs in the form of eczema care they are fulfilling requirements enabling the formation of positive attachments with their child.

The concept of gender differences in parenting was discussed during the interviews. Mothers spoke about taking on the majority of the eczema care for their child, including attending appointments, collecting prescriptions, and learning treatment routines. They voiced feelings ranging from frustration to upset about the level of responsibility they felt regarding this, compared to their child’s father. There is very limited research regarding the differences between mothers and fathers when caring for a child with eczema, though it appears that a majority of the research conducted is focussed on mothers, or had a majority of their participants as mothers (Faught et al., 2007; Howells et al., 2017; Simsek et al., 2016). The current study is not an exception to this, with 80% of the participants identifying as mothers. Taking into account previous research by Swallow et al. (2009) mothers may be focussing more on the immediate issues of care, such as attending medical appointments and following a treatment regimen, whereas fathers may tend to think more about the future implications of illness.

Some mothers spoke about their desire to feel “in control” of their child’s eczema care, and whilst they felt frustration at being the primary carer, they did not feel confident in allowing other people (including partners) take sole responsibility. This has also been described by parents in previous studies (Angelhoff et al., 2018). This may contribute to the amount of stress and mental load described by the mothers, as they feel they cannot let go of the primary caring role.

Fathers may find it difficult to know where they “fit” within eczema care for their child, as it was implied in the current findings that a substantial amount of care advice is targeted at mothers. They described searching for ways to help their child but feeling as though they were not welcomed into these spaces as they had been seemingly created for mothers. This is not unique to families affected by eczema, as previous literature reports that fathers feel there is less psychosocial support for them than mothers and some feeling actively excluded from discussions around child care (Ives, 2014; Kowlessar et al., 2015). There is evidence to suggest that relational difficulties can be improved by including fathers and mothers equally in support around being a parent (Schober, 2012). This should be further explored to ascertain how support can be best offered and accessed to all parents.

2) What is the experience of mental health support for parents affected by eczema and does it their meet needs?

It was apparent throughout the interviews that despite the clear impact eczema has on the psychological wellbeing of parents, mental health support is not routinely offered or discussed. Many parents described how the impact of eczema on mental health was not brought up during physical health appointments, and that they felt it was not a priority for the medical professionals they encountered. The current findings support those of Wheeler et al.'s (2022) study, which concluded that mental health was not deemed by patients to be a priority for dermatologists, and psychological support was not offered by the GP to the majority of patients. Many of the parents in the current study discussed how physical health treatments were often the priority in medical appointments, with it being implied that this affected how some of the parents approached the appointments, feeling like they were not able to discuss the psychological impact of eczema. Some spoke of how they were not offered any mental health support in the context of eczema and instead found that this was offered by the services supporting them with other issues such as allergies. The Eczema Unmasked report (National Eczema Society & LEO Pharma, 2020), found that only 43% of participants with eczema had been asked by their NHS doctor about their mental health, and 42% had been offered psychological support for this.

The first theme contained explorations of whether parents were able to access mental health support if they felt this was necessary. There were many discussions of need to advocate for themselves, such as having to approach their GP or dermatologist multiple times in order for this to progress. Previous research indicates that patients appreciate when they are asked about how they are feeling during appointments which does not happen routinely (De Vere Hunt et al., 2021). Medical professionals asking patients and parents or carers how they are feeling, could lead to a conversation around how eczema may have impacted their mental health, which could hopefully elicit avenues of support. The difficulties in accessing eczema-related mental health support also indicates that more healthcare professionals should be aware of the NICE guidelines for the treatment of eczema (National Institute for Health and Care Excellence, 2024). However, this states that once eczema is “controlled” and psychological wellbeing “has not improved” that a referral to a clinical psychologist should be made. The parents in the current study spoke about the significant impact on their mental health during and after eczema flares, and discussed the continuous cycle of managing eczema symptoms and how this impacts their wellbeing. It should be considered, as a clinical recommendation, that mental health support be offered at any point where it is deemed that eczema is having a negative impact on an individual or family's psychological wellbeing. This would mean the difficulties can be addressed and the patient or parent/carer be supported appropriately. It could be argued that by addressing mental health difficulties, then daily activities and responsibilities may feel more manageable. This could include the physical health treatment of eczema.

When mental health support was offered by the GP, it was not always deemed to be helpful. This included being offered cognitive behavioural therapy (CBT), which was felt by the parents not to be appropriate as their anxieties were around their child's eczema. This indicates a need for professionals involved in the treatment of eczema to have a clearer understanding of what psychological interventions may be most appropriate to support those affected. Some of the parents stated that they were not sure what mental health support would be beneficial for them. Whilst there are no official recommendations by the NHS for what psychological support should look like for those impacted by eczema, it has been shown that psychological therapies alongside medical treatment can improve outcomes of both mental and physical health for individuals with the skin condition (Oska & Nakamura, 2022). There is very limited research into eczema and psychological therapies, though studies into appearance related difficulties and other skin conditions such as psoriasis indicate that psychological interventions support overall positive outcomes (Chouliara, 2021) and reduce overall treatment costs (Vlăduţ & Kállay, 2010).

In a similar way to seeking private dermatology appointments due to NHS waiting lists, the parents spoke about accessing mental health services through alternative routes such as their employment. Whilst this was felt to be beneficial, it was not a privilege that was afforded to the majority of participants, and therefore is not a guarantee for all those in the population affected by eczema. Another downfall of this is the distance then created between the eczema treatment and the mental health treatment when it is clear from the interviews that they are intrinsically linked. Psychodermatology services are a relatively new concept, but they provide patients with a space to access treatment for psychological distress within the context of dermatological conditions such as eczema (Marshall et al., 2016). A report by the British Association of Dermatologists (Bewley et al., 2013) proposes that these services should be available regionally, whilst also suggesting that dermatology services should have a named clinician who is aware of local mental health services that can be signposted to if it is felt support from them is most appropriate.

Wellbeing support is not only accessed through professionals, but also through family and social circles. Many of the parents discussed how a large amount of support came from their close family members, most notably their own parents. Whilst some parents were concerned about letting their family members care for their child with eczema, they mostly appreciated emotional support from them. Those with eczema themselves also received emotional and practical support from family members. Previous studies show that whilst grandparents are a valuable source of support in families with a child with a chronic or severe physical illness, they often do not have sufficient knowledge about the illness (Gantner et al., 2023; Priboi et al., 2022). It is reasonable to suggest that psychoeducation around eczema targeted at family members such as grandparents may be extremely valuable in helping to relieve some of the mental load from parents. Research indicates that family support predicts improved mental health outcomes for parents of children with eczema (Dennis et al., 2006).

The parents spoke about how it can be difficult to speak to their peers who have not been affected by eczema about what they are experiencing. A lack of understanding about eczema was a large contributor to this, with some parents expressing that it was easier to not have these conversations rather than be misunderstood. It is known from previous research (Mizara et al., 2012; Treudler et al., 2020) as well as the current study that those who experience eczema feel socially isolated, and so this will only be compounded by feeling unable to speak to their friends and family about what they are going through. The need for spaces for those with similar experiences to share their stories then presents itself. Further research into the potential for support groups for those affected by eczema, whether that be as a parent or carer, or someone who has their own diagnosis, should be conducted.

The interviews elicited some differences in how parents access support and advice in the context of eczema. It appeared that fathers used social media less to access social support, however due to the small number of fathers who participated in the study, caution should be taken when making any generalisation. Research suggests that mothers are significantly more likely to seek advice around their own and child's health through social media, as well as using it to link up with other parents (Haslam et al., 2017). Another study into fatherhood and social media use (Ammari & Schoenebeck, 2015) counters this with their findings, which indicate that fathers will use various social media platforms depending on factors such as relationship and employment status to seek advice and social support. This suggests that social media can be used to create specific spaces for fathers to seek support and advice, and the curation of these spaces should be encouraged in order to reach fathers who may initially feel like they are not welcomed into all parenthood support spaces.

The third theme explored how the input from others and the way this is perceived impacts parents who have experienced eczema, whether for their child or their own. Parents spoke about how whilst they acknowledged much of what others had to say was well-meaning, it often added to their feelings of being judged and/or misunderstood. Much of the advice given was based on other people's experiences of mild eczema, often from childhood. The parents described their frustrations at people's misunderstandings of how much eczema can impact daily life, as well as suggestions about treatments which they had already tried. It can be concluded from this research's findings that parents would appreciate spaces to speak to others who have been through similar experiences as opposed to those who may be closer to them but have less of an understanding.

4.2 A Note on Topical Steroid Withdrawal

In order to do justice to the narratives that I heard, it is important to mention an additional set of reflections regarding treatment commonly used within eczema treatment. Topical steroid withdrawal (TSW) is not formally recognised by the NHS or a majority of dermatology services, though with growing anecdotal evidence from those who are experiencing the condition it is starting to be acknowledged as an issue. This is significant, as it has been putting people off utilising the treatment, as demonstrated by some of the quotes within the results section (p. 59, parent 2, parent 4). This study also heard from a parent who identified with going through TSW and spoke on the significant impact that TSW has had on their physical and mental health. The narratives around TSW in the current study were not found to be a elicit a theme or subtheme, and so it has not been included as a part of the results. However, I feel it is important to speak to as something to further be explored by future researchers.

4.3 Critical Review

4.3.1 Epistemological Reflexivity

The use of reflexivity within a critical realism lens is not to ensure complete objectivity, as in positivism, but rather to encourage critical interpretation of the experiences described by the participants (Willis, 2023). The formulation of the research questions will have been influenced by the epistemological stance of critical realism. The literature review included studies from medical research, which is often aligned with positivism and third person, evidence based data (White & Willis, 2002). Reviewing this alongside psychological perspectives allowed the drawing together of the reality of medical diagnoses and the interpretations of how these impact individuals and families. The conclusions drawn from the findings will have been shaped by the critical realism lens from which the research has been framed. This will have been influenced by the researcher's own personal experience of eczema and the perceived gap between physical health and mental health treatment.

4.3.2 Reflexive Thematic Analysis

It is important not to completely disregard the researcher's subjectivity in analysing the data. This is an integral part of reflective thematic analysis, as described by Braun & Clarke (2021a). They suggest that the themes cannot exist without the researcher, and they are created through analysis informed by the researcher's own experiences. The researcher ensured that throughout the analysis she was aware of her own experiences, perspectives, expertise, and blind spots which may be informing her interpretation. Rather than doing this in an attempt to eliminate any biases, as this is not fully possible (Braun & Clarke, 2019), this allowed the researcher to acknowledge the impact that this might be having on the identification of the codes and creation of themes.

4.3.3 Researcher Reflexivity

Braun & Clarke (2006, 2019) indicate the importance of researcher reflexivity and how it informs the thematic analysis and conclusions drawn. Despite attempts to ensure analysis was not significantly skewed towards my own perspectives, my own experiences of eczema cannot be completely separated from the findings. My personal experience has been a large factor in my interest in this research and so will have influenced the construction of the research questions. I kept a reflexive diary from the outset of the study in order to understand and park my own feelings about throughout the process, and how these may impact the analysis of the findings. I brought these reflections to conversations with my supervisors who had their own insights into chronic health conditions and the impact on family. I also considered how my own experiences of working within, as well as using as a patient, health care systems may influence my interpretation of the findings. Similarly, my views on the current political climate will have had an impact on my motivation to complete this research and conclusions which can be drawn from the findings.

4.3.4 Quality of Research

The process of thematic analysis as described by (Braun & Clarke, 2006b) was followed from the outset of the study, bearing in mind the recommendations for inductive, reflexive thematic analysis (Braun & Clarke, 2021b). Positivist research can be assessed on reliability via standardisation of data collection tools in order to produce replicable results (Long & Johnson, 2000). As explained by Braun & Clarke (2023), reflexive thematic analysis cannot be standardised even with a process being followed as coding and creation of themes relies on the interpretation of the researcher. Braun & Clarke (2023) outlined twenty questions for reviewers of thematic analytic research to ask to test quality. These questions fell under two sections, first examining the methods and methodology and then secondly addressing analysis. Whilst it is not possible to demonstrate this within the constraints of the thesis, the researcher addressed each of these questions in relation to the methodology and analysis of the current study to try to ensure the quality of the research.

As there are many different paradigms within which qualitative research exists, it is argued that a framework to assess quality may not be appropriate (Rolfe, 2006). Yardley (2000) developed a framework to assess qualitative health research quality which considered four key areas which are detailed below.

Sensitivity to Context: The context of the study was formulation throughout, from the literature review through to the analysis of the results. The previous literature discussed what is currently being discussed with regards to chronic health conditions, parenting, and psychological well-being. The review of this literature drew together context from a range of disciplines, increasing the breadth of knowledge about the experiences of eczema. The interviews themselves added to the context, with parents sharing their own stories, which were reported in their own words. The researcher brought in their own context through reflexivity.

Commitment and Rigour: The commitment to the study process began well before data collection or even development of the research questions. The researcher's own experiences meant that commitment to the topic was present throughout the lifespan and influenced the dedication and motivation in conducting the study. The literature review was conducted to thoroughly immerse oneself in the topic. Experts by experience were consulted when developing the semi-structured interview schedule to ensure relevance. As discussed, rigour was ensured by following the (reflexive) thematic analysis and quality assurance guidelines (Braun & Clarke, 2006b, 2021b).

Transparency and Coherence: The researcher has ensured transparency throughout, with each stage of the research process being clearly discussed, including researcher reflexivity. The study has shown coherence throughout as health psychology lends itself to critical realism, as does thematic analysis. The study stayed true to hearing from parents about their experiences of eczema, and after some thought it was decided that professionals such as psychodermatologists were not involved in the consultation process detailed in Section 2, as this would conflate the experiences of professionals with those of the parents.

Impact and Importance: The literature review identified a clear gap in the research regarding the impact of eczema on psychological wellbeing of parents, the support they receive for this, and the effect that this has on appraising the needs of their child. There are quantitative studies addressing the impact of eczema on well-being (Gillespie, 1996; Moore et al., 2006; National Eczema Society & LEO Pharma, 2020), and qualitative studies around experiences of health care provision for those with eczema (De Vere Hunt et al., 2021). The current study begins to bridge the gap between the discussions around medical, physical symptomology and treatment of eczema and the impact that this has on the wellbeing of parents. The study has several implications for clinical practice, service development, and policy, which will be further discussed later in this chapter.

4.4 Strengths

Limited research has been conducted to date on eczema's impact on parenting, especially qualitative studies. This study has provided an opportunity for parents to speak about what they feel is most important for others to know about the impact of eczema in their own words. As highlighted by the parents, the vast majority of the focus around eczema is on physical health symptoms and treatment, and this research supports more recent research findings that the skin condition also has a significant impact on the mental health and wellbeing of not only the individual with the diagnosis, but also their parents and carers. The findings also add to the literature around how chronic health conditions impact various aspects of parenting, and how and which adaptations may have to be made when appraising the needs of a child when there is a chronic health condition in family.

Parents who had experienced eczema but were ineligible for the study (e.g. their children were now adults) were consulted with when creating the interview schedule. This ensured that the study remained true to eliciting the experiences of parents impacted by eczema as the questions were deemed to be appropriate and relevant and informed-by these experiences. Their involvement in creating the semi-structured interview schedule, ensured relevant both relevant questions were asked, and the semi-structured nature enabled the research to avoid the rigidity that a more structured interview may bring.

The sample included parents who had their own diagnosis of eczema, and/or had a child with the skin condition, meaning there was a wide range of experiences and perspectives on the impact of eczema. Whilst geographical demographics were not collected, the use of remote interviews meant that location of the participant was not a limiting factor in recruitment. Many of the parents had multiple children which meant they were able to compare their experiences of parenting a child with and without a diagnosis of eczema.

The advert for the study stated that the researcher had their own experiences of eczema. This potentially led to an openness during the interviews due to an assumed level of understanding about their experiences. The researcher was also able to use and understand language around eczema which those who had less experience with the skin condition may have struggled with. This meant there could be more time and space to allow to the parents speak in their own words.

4.5 Limitations

Despite the perceived strengths of the study, there are of course some limitations. For one, the population diversity was limited. Whilst specific demographics were not collected, a large majority of the sample were white British. This means that the findings are not generalisable to the wider population, especially as studies show that eczema may be more common in Black and Asian ethnic groups than white groups (Ban et al., 2018; de Lusignan et al., 2021). It is also known that racialised populations experience more barriers to physical and mental health support (Grey et al., 2013), and so whatever difficulties are reported by white parents cannot be assumed to be the same across populations. The study sample was also 80% mothers and 20% fathers, and so the majority of the data was from a mother's perspective. This study has therefore added to the already evident paucity of data around the experience of fathers and of racialised people.

The study was advertised via social media and through the eczema specialist charity, utilising a volunteer sampling method. It should be considered that this will have only reached people who are already using these mediums to seek support, and so will have missed those who may either be seeking support elsewhere, or those not accessing these avenues. Therefore, the findings may not be representative of everyone in the eczema community's experience of support.

It should also be noted that the participants were not asked about any existing or pre-existing mental or physical health comorbidities. Therefore, it would not be possible to say that any difficulties that they described were solely due to the impact of eczema. Similarly, the inclusion criteria did not stipulate the severity of eczema, only that they had received a diagnosis of the skin condition. This means that it is not possible to determine whether the issues raised by the parents are able to be generalised to all severities of eczema, or if certain severities have differing experiences. The inclusion criteria specified that the participants must be parents of children under the age of eighteen which means that the experiences of parents with babies were conflated with those who had older children and teenagers and therefore may not be an accurate representation.

The study also did not address the potential impact that the Covid-19 pandemic had on health care and how this may have affected the support sought by, or offered to, parents of children with eczema. It is therefore difficult to determine whether the reported lack of mental health care in the context of eczema is specific to the condition, or whether it is reflective of the overall current state of psychological support provision in the UK.

4.6 Implications

4.6.1 Future Research

As there is a significant gap in the literature regarding the impact that eczema has on parenting and the psychological wellbeing of parents, the current study has identified many areas where future research would be beneficial. As this research is skewed towards the mother's perspective, it cannot be generalised to all parents and therefore a follow-up study with a more gender diverse population is imperative. It is also crucial that follow-up studies ensure that a breadth of ethnicities are included so as to hear of experiences from a representative, inclusive sample.

The confusion from the parents of where to seek psychological wellbeing support in the context of eczema appeared to be echoed by the medical professionals that they spoke to. Future research should investigate how best this can be addressed, including whether psychological intervention is necessary, and, if so, which intervention would be most effective. Research could also ascertain how best to approach parents about these concerns.

Further research into the impact of eczema on parenting and appraisal of the child's needs would help to inform how best parents can be supported. Parents also spoke about how this impacted siblings who do not have eczema, and so future research into the implications eczema has on "healthy" siblings would, again, advise how they can be supported. Research already shows how siblings of children with chronic health conditions are affected (Kelada et al., 2022), but this should not be generalised to all conditions, and eczema specific studies would be desirable.

4.6.2 Clinical Implications

There is a clear implication from this research that families who have been impacted by eczema would appreciate a clear, accessible pathway to mental health support services. Previous literature supports that eczema significantly impacts the well-being of the individual with the diagnosis as well as that of any parents and carers they may have. The current study shows that those impacted are not routinely asked by their health care provider, such as GP or dermatologist, about their psychological well-being and feel that physical health is significantly prioritised in treatment. It also indicates that parents do not always trust that their doctor will know when, how or where to refer to mental health support. This study along with current literature and any future research should inform considerations into how to address the gap in mental health support in the context of eczema.

The parents in the current study reported increased levels of stress, depression and anxiety, and many implied that whilst they would appreciate psychological support, they were unsure of what could be helpful. The findings also indicated that the parents didn't feel that the healthcare professionals they encountered regarding eczema treatment were informed about potential support for psychological wellbeing. Psychological interventions that could be beneficial in supporting parents of children with eczema could draw upon current studies indicating the benefits of mindfulness (Heapy et al., 2021). With mindfulness as one of its core principles, Acceptance and Commitment Therapy (ACT; Hayes et al., 2011) could be an appropriate intervention to offer the parents affected by eczema. ACT draws upon theories of psychological flexibility, which has been shown to have positive associations with parental wellbeing for parents of children with eczema (Chong et al., 2023). Though there is very limited research into the efficacy of this, Akhouri et al. (2020) found that mindfulness and acceptance therapies were effective in improving psychosocial difficulties in adolescents who had a diagnosis of eczema.

4.6.3 Service Level Implications

Parents stated that despite eczema having a significant impact on their psychological wellbeing, they felt that there are not currently sufficient and effective spaces to discuss and address this. GP and dermatology appointments are often focussed on physical symptoms, meaning that discussions around medical treatments often overshadow any opportunities that parents may have to bring up their mental health.

Some of the parents noted that this was not the case when they met with allergy services. This poses the question: what are allergy teams doing differently so that parents feel their psychological wellbeing is being taken into consideration? Some of the responses demonstrated that children were asked about how eczema impacts their mental health, but parents were not afforded the same opportunity.

Facilitation of discussions around mental health and wellbeing in eczema appointments is just one of the steps. Professionals should be aware of what to do when a parent presents with mental health difficulties in the context of eczema. This displays the need for clear pathways between physical and mental health professionals. As discussed, combining physical and mental health care can save time and decrease treatment costs. Psychodermatology services can address the gap between these services and ensure more holistic care, but referrals to these services need to be made in the first place, and they may not be available locally. GP and dermatology services, along with future research, should consider how these pathways can be created so that the efficient and holistic care of eczema patients and their families can be provided.

The current study focusses on the specific skin condition of eczema, whereas psychodermatology services are designed to treat those affected by a range of skin conditions. The recommendations from this study should be taken tentatively when exploring the development of psychodermatology services, as the findings cannot be generalised to skin conditions outside of eczema. Future research should explore the similarities and differences in the experiences of various skin conditions so as to appropriately allocate funding and service provisions.

Implications for Charities/Support Services

There are also implications for the charities set up to support those experiencing eczema, including the one partnered with for this research. The dissemination of the data produced in this study would be an important step in helping parents experiencing eczema to feel less alone, an issue which arose from the data. The charities also tend to have links with statutory services such as the NHS and policy makers, which means that they are well placed to raise awareness of the difficulties that those impacted by eczema experience. By disseminating the findings of this study they can raise awareness of the mental health difficulties and challenges that parents experience due to eczema.

4.6.4 Implications Across Disciplines

The question of where the responsibility to assess and respond to the mental health of carers of those with chronic health conditions is posed. There are various barriers to GPs being able to facilitate discussions around mental health and emotional well-being (Parker et al., 2020). GPs also have significant time pressures and may be inclined to focus on the immediate presenting symptoms, such as itchy, sore skin. Whilst mental health services may be more suited to address emotional well-being, there may not be the understanding of the chronic illness specifics, such as the physical symptoms and the impact of treatment. Parents may be able to access specialist support if they are under a dermatology team, but, as presented in the findings, referrals to a dermatology service are hard to get and can take a very long time to progress. Health visitors are well placed to have conversations with parents about emotional well-being in the early stages of the post-natal period, but as presented in the results, the impact of eczema is long-lasting and in many cases continues well into childhood. It should be clearly determined where responsibility for management of emotional well-being of parents of children with eczema, and parents who have eczema themselves should fall. The current data suggests that parents experiencing eczema are extremely busy trying to manage family life alongside treatment regimens, collecting prescriptions and attending medical appointments. This would suggest that additional appointments around emotional wellbeing may be difficult to accommodate, and that perhaps initial conversations need to be held within existing appointments which would currently focus mostly on physical symptoms and treatment.

4.6.5 Implications for Policy

The APPGS (2020) reported the evidence that skin conditions including eczema have a significant impact on mental health. It also details the need for services to acknowledge the service gaps in delivering support for those whose wellbeing has been affected and suggest that a portion of funding to clinical commissioning groups be allocated to address this. The current study supports these recommendations, with parents reporting that their wellbeing is not being addressed in medical appointments and the focus on physical symptoms being insufficient in delivering overall care.

4.6.6 Social Implications

The parents detailed how they also did not feel supported within social circles, including by friends and childcare providers such as school and nursery who do not understand the significance of eczema. This in turn adds to the negative impact on the parents' mental health, for instance due to social isolation and the frustrations of not being able to share the mental load and of feeling misunderstood. This highlights the need for social groups for parents having similar experiences, as well as spaces for education of childcare providers around the impact of eczema and the importance of treatment adherence.

4.6.7 Implications for Parenting Support

Whilst many of the implications revolve around the themes relevant to mental health, the impact on parenting is also of importance. The parents spoke about how they had to adapt their ways of appraising their child's needs, such as applying creams to soothe upset, and giving in to demands as they did not want to cause further distress. Parents with eczema themselves spoke about how they may avoid skin-to-skin contact and breastfeeding due to their own sore skin. The parents also spoke about how exhaustion from lack of sleep and the constant cycle of treatment had a significant impact on day-to-day life, including parenting. Professionals involved in supporting parents, such as health visitors, midwives and GPS, should be aware of these added difficulties for parents who are affected by eczema. Further research should address how best to support these parents.

4.7 Conclusion

This research aimed to address the gap in the literature by providing parents' experiences of eczema and how it impacts their psychological wellbeing and approaches to parenting. Despite a range of experience, themes emerged that indicated some commonalities.

The interviews and analysis elicited a range of accounts about parents' experiences of eczema, whether it be their own or their child's. The parents described a significant impact on their psychological well-being, citing eczema as a large contributor to their stress levels, as well as having a negative effect on their sleep and ability to function day-to-day. Parents who had eczema themselves described how their child's eczema can trigger anxiety or trauma responses around their own experiences. These parents also spoke of feelings of guilt about the hereditary nature of eczema, and therefore beliefs that they may be the cause for their child's illness.

Despite the clear impact on psychological wellbeing, it was reported that this was often not discussed in medical appointments for eczema, with there being a focus on treatment of physical symptoms. Some parents reported that their mental health difficulties had even been dismissed due to the physical health context. It was found that parents were on the whole unaware of any emotional wellbeing support that might be available to them, though some were making use of charities and social media groups to receive advice.

The relational impact of eczema was also represented in the findings. Parents found themselves making adaptations to how they responded to their child's needs. Where there was a sibling without eczema in the family, there were concerns about that sibling's experience. Support from others was reported to be problematic at times, with a lack of understanding from family members and friends who were not aware of the full impact of eczema. Parents often felt isolated and misunderstood with regards to the care they were giving their child.

This research is missing the experiences of racialised parents, and doesn't do enough to contribute towards research about experiences of fathers. Future research should consider how these groups can be prioritised so that their experiences can be included and research can be representative of the population.

There are implications for clinical practice and policy, as well as future research from this study. This study only begins to fill the gap in research about parents' experiences of eczema. Further research into how best these families can be supported is needed, especially in the context of the integration of physical and mental health care. Services should consider where this support is best placed and how they can meet the needs of families impacted by eczema, crucially by centring the voices of those who are affected.

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APPENDIX A: Participant Information Sheet

Version: 1

Date: 24/02/2023

PARTICIPANT INFORMATION SHEET

Exploring Parents' Experiences of Eczema

Contact person: Lauren Waples

Email: u2195641@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

My name is Lauren Waples. I am a Doctorate of Clinical Psychology student in the School of Psychology at the University of East London (UEL). As part of my studies, I am conducting the research that you are being invited to participate in.

What is the purpose of the research?

It is known that both having eczema yourself and being a parent or carer of someone with eczema has an impact on psychological wellbeing, quality of life, social functioning, and family relationships. This research study aims to explore the impact of a diagnosis of eczema on parents, whether it is the parent, child, or both who have the diagnosis. The study hopes to understand how eczema impacts areas such as soothing styles, attachment, and mental health and wellbeing, as well as exploring the support parents are offered and if it meets their needs.

Why have I been invited to take part?

To address the study aims, I am inviting parents who have an experience of eczema (whether it be their own diagnosis or the diagnosis of a child) to take part in my research. If you are a parent of a child who is under 18 years old, and either you or your child has eczema, then you would be suitable for this study. It is entirely up to you whether you take part or not, participation is voluntary.

What will I be asked to do if I agree to take part?

If you agree to take part, you will be asked to participate in an interview. These interviews will take up to one hour, with the option of breaks during, and will be held via Microsoft Teams. The interviews will be recorded and stored securely. You may withdraw from the interview at any time. There is no follow up from the interview.

Can I change my mind?

Yes, you can change your mind at any time and withdraw without explanation, disadvantage or consequence. If you would like to withdraw from the study or interview, you can do so by letting me know at any time before, during, or after the interview. If you withdraw, your data will not be used as part of the research. You can withdraw from the study until up to three weeks after the interview has taken place.

Are there any disadvantages to taking part?

- The interviews will cover some personal topics, including how eczema has impacted your life including your wellbeing and your role as a parent. This can be difficult to talk about, and if you have any questions or concerns then please do raise them with me either during or after the interview. Support resources will also be provided.
- The interviews will be held over Microsoft Teams. Some people may find it difficult to be in front of a computer screen for a longer period, and so breaks are allowed at any point during the interview.

How will the information I provide be kept secure and confidential?

The interview will be transcribed and pseudonymised, and the initial interview recording will be deleted. The transcriptions will be able to be identified for three weeks, in case you decide that you no longer want us to use your answers. After this time, the identifying data will be deleted to ensure confidentiality.

The data will be seen by myself, my supervisor, and the examiner. Other than this, it will not be shared with anyone. Confidentiality only may be broken if during the interview you disclose something which indicates you or someone else are at risk. If this is the case, you would be spoken to about this before the information is shared with relevant organisations.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the ‘public task’ condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as ‘special category data’ in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL’s online Repository. Findings may also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) who may be interested such as article for the charity, conferences, and journal articles. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally.

Anonymised research data will be securely stored by Dr Paula Corredor-Lopez for a maximum of 3 years, following which all data will be deleted.

Who has reviewed the research?

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee’s evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?

If you would like support with eczema, please reach out to the following charities:

Eczema Outreach Support - https://eos.org.uk/

National Eczema Society - https://eczema.org/

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Lauren Waples (Trainee Clinical Psychologist)

University of East London

U2195641@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Paula Corredor Lopez. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: P.Corredor-lopez@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: t.patel@uel.ac.uk)

Thank you for taking the time to read this information sheet

APPENDIX B: Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Exploring Parents' Experiences of Eczema

Contact person: Lauren Waples

Email: u2195641@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using Microsoft Teams	
I understand that my personal information and data, including audio/video recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant’s Name (BLOCK CAPITALS)

....
....

Participant’s Signature

....
....

Researcher’s Name (BLOCK CAPITALS)

....
....

Researcher’s Signature

....
....

Date

....
....

APPENDIX C: Semi-structured Interview

Semi Structured Interview Schedule

The following questions are drafts, which will be discussed as part of the consultation process and so are subject to change on this basis.

1) Please could you tell me about your experience of eczema? (Prompts: How long have you/your child had it? Has your experience changed over time?)

2) Please could you tell me about your experience parenting whilst experiencing eczema? (Prompts: see question 1. How have you found managing the symptoms? Impact on soothing/Management and supporting of child’s needs?)

3) Have you found that eczema has had an impact on your mental health and wellbeing as a parent? (prompts: stress levels, work, attachment with child, stigma)

4) Have you accessed support for mental health and wellbeing (in the context of eczema?) If so, please could you tell me about your experiences?

5) Is there anything else you would like to mention that we haven’t discussed?

APPENDIX D: Ethical Approval

University of East London

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in blue | **Student:** Please complete/read sections in orange

Details

Reviewer:	**Tom Mackay**
Supervisor:	**Paula Corredor Lopez**
Student:	**Lauren Waples**
Course:	**Doctorate of Clinical Psychology**
Title of proposed study:	**Scratching the Surface: A Qualitative Study of Parents' Experience of Eczema and Support for Psychological Wellbeing**

Checklist

(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐

Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher’s personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options	
APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study	
Please indicate the decision:	**APPROVED**

Minor amendments
Please clearly detail the amendments the student is required to make

Major amendments
Please clearly detail the amendments the student is required to make

Assessment of risk to researcher		
Has an adequate risk assessment been offered in the application form?	**YES** ☒	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	
If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐
LOW	Approve and if necessary, include any recommendations in the below box.	☒
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature

Reviewer: (Typed name to act as signature)	**Tom MacKay**
Date:	**17/04/2023**

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

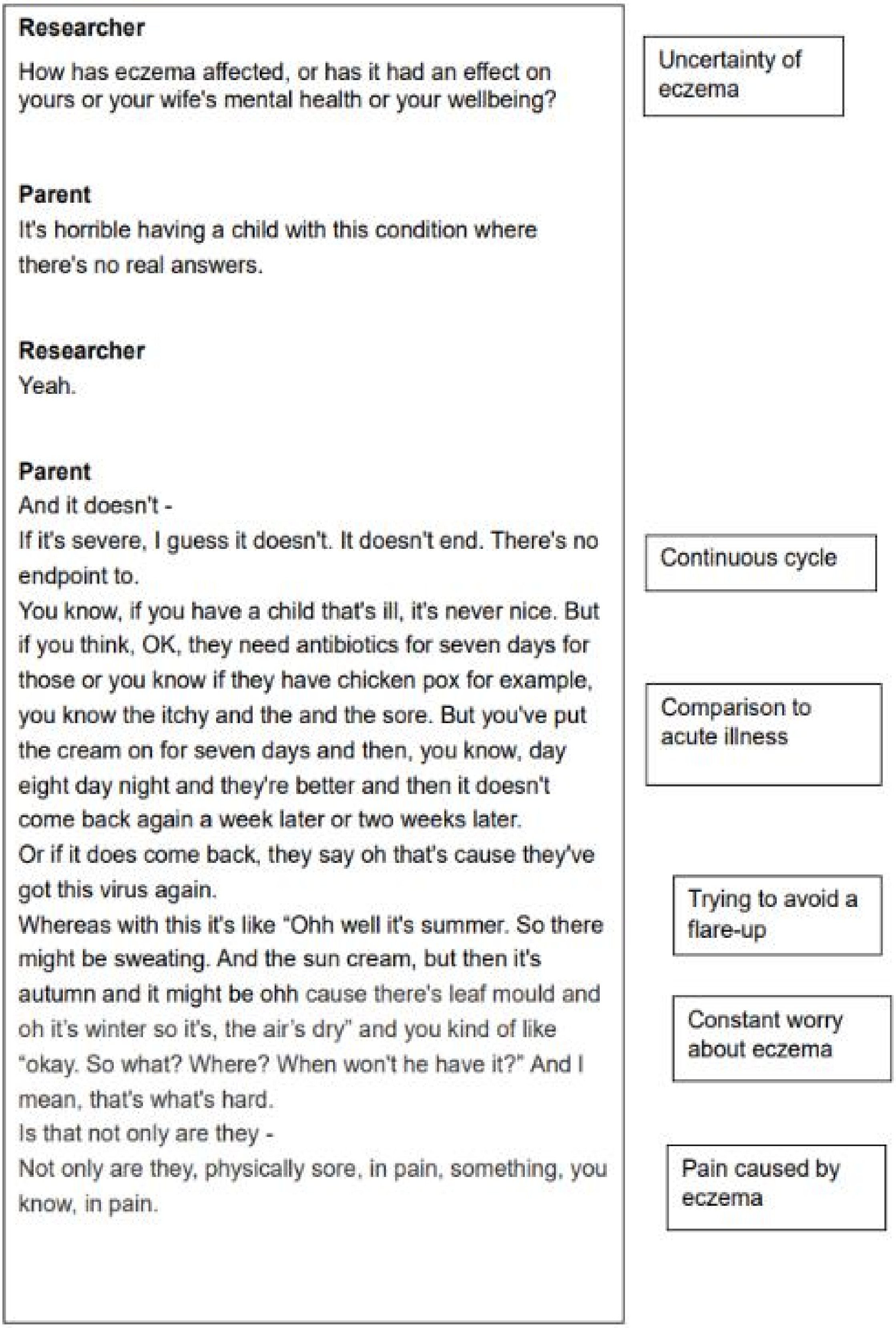
(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data

Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a date

Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required

APPENDIX E: Transciption and Coding Sample



Researcher

How has eczema affected, or has it had an effect on yours or your wife's mental health or your wellbeing?

Parent

It's horrible having a child with this condition where there's no real answers.

Researcher

Yeah.

Parent

And it doesn't -

If it's severe, I guess it doesn't. It doesn't end. There's no endpoint to.

You know, if you have a child that's ill, it's never nice. But if you think, OK, they need antibiotics for seven days for those or you know if they have chicken pox for example, you know the itchy and the and the sore. But you've put the cream on for seven days and then, you know, day eight day night and they're better and then it doesn't come back again a week later or two weeks later.

Or if it does come back, they say oh that's cause they've got this virus again.

Whereas with this it's like "Ohh well it's summer. So there might be sweating. And the sun cream, but then it's autumn and it might be ohh cause there's leaf mould and oh it's winter so it's, the air's dry" and you kind of like "okay. So what? Where? When won't he have it?" And I mean, that's what's hard.

Is that not only are they -

Not only are they, physically sore, in pain, something, you know, in pain.

Uncertainty of eczema

Continuous cycle

Comparison to acute illness

Trying to avoid a flare-up

Constant worry about eczema

Pain caused by eczema

Researcher
Hmm.

Parent
They also look awful they look like your child looks ill, like they are covered in. It's not like they've scratched themselves in some brambles and go back. They are covered in red and it doesn't like. I know like, you know, follow quite a lot of different people and things on Instagram and, you know, there's lots of people who are against, like, nothing will work. I've tried [brand of cream], I tried. And you, you and then? I think what is hard is all this because there's not a "You've got this, so you need this." You know, got this the doctor, it doesn't properly work. So then you, you start to, I guess, almost, you know, look for what might help, and I think that's where the where the issues are that you don't really know what to do.

Parent concern of impact on child appearance

Social media for advice

Helplessness of parent

Researcher
Yeah.

Parent
And there's so you know, the two extremes really of. Of, of to leave it and do you know? Don't you never use steroids? Just leave it will. It will get better. But then you know I had him without steroids and he was head to toe covered in it. So then.

Treatment uncertainty

Researcher
Yeah.

Parent
That's why we tried methotrexate, but then the doctor said "no, you need to use it", and you're sort of like, I don't really know what to do.

Uncertain whether treatment is the right thing to do

Researcher
Yeah.

Parent: I don't really know. I probably know.
You know, I reckon I'm pretty know quite a lot about eczema now and the treatments of it, but still, I think it just comes back and you've you've you've worked so hard and you've done so much stuff. And you spent so much money.

Time consuming

Comes back after hard work to control symptoms

Financial impact

Researcher

Yeah.

Parent

To try and sort it and spend so much of your time and.
It doesn't seem to you thinking does nothing seems to be doing anything like. Is this like a bit of a joke like? And all this advice that you're given. Um, and especially when I think you see a dermatologist and the first thing that you read about is like avoid your allergens and it's not a standard thing to go and see an allergist when you have eczema.

Conflicting advice and practice

Researcher

Yeah.

Parent

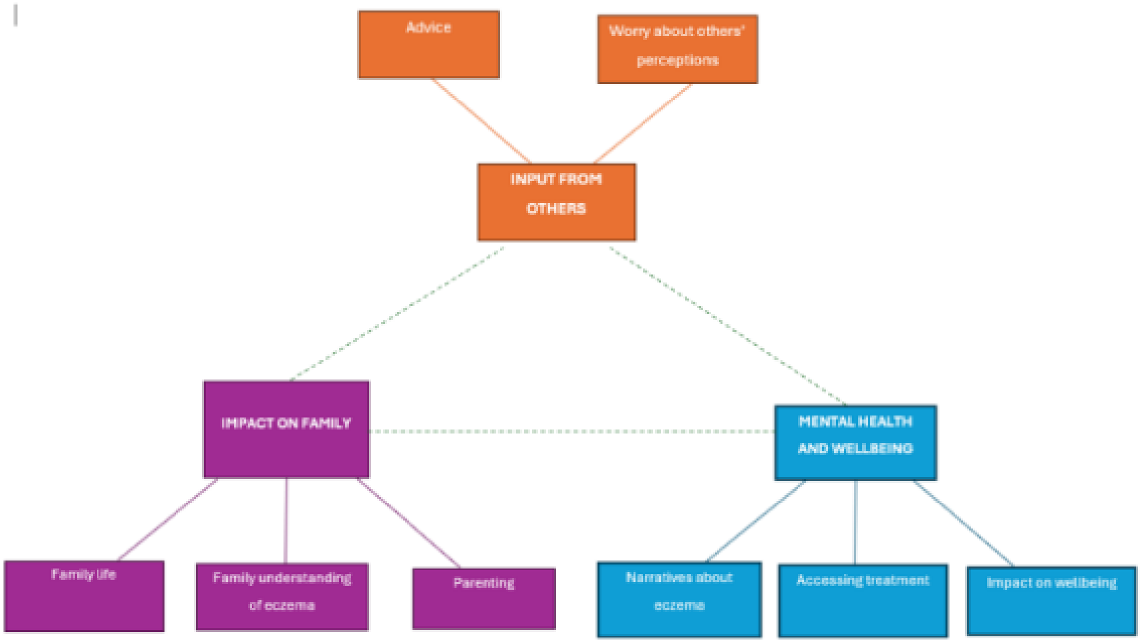
So you'll say to the dermatologist like ohh how do we find out what might be causing it? And it's kind of like "you've just got it.
So when it comes use this medicine. But as soon as you stop using it, you'll have it again."
Um, that's what makes it really hard and I think the lack of sleep.

Symptoms keep reoccuring

Advice but no certainty

Lack of sleep

APPENDIX F: Thematic Map



APPENDIX G: Participant Debrief Sheet

University of East London

PARTICIPANT DEBRIEF SHEET

Exploring Parents' Experiences of Eczema

Thank you for participating in my research study on the impact of eczema on parents. This document offers information that may be relevant in light of you having now taken part.

How will my data be managed?
The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

What will happen to the results of the research?
The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. Findings may also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles and conference presentations. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by Dr Paula Corredor-Lopez for a maximum of 3 years, following which all data will be deleted.

What if I been adversely affected by taking part?
It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of

those ways, you may find the following resources/services helpful in relation to obtaining information and support:

Eczema Outreach Support - https://eos.org.uk/
National Eczema Society - https://eczema.org/

Who can I contact if I have any questions/concerns?
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Lauren Waples (Trainee Clinical Psychologist)
University of East London
U2195641@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Paula Corredor Lopez. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: P.Corredor-lopez@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking part in my study