

Barriers that Influence Treatment Adherence for Children and Young People with Atopic Eczema:

A Literature Review

Background

Atopic eczema (AE) is a chronic, non-contagious, inflammatory skin condition, commonly starting in childhood (Nottingham Eczema 2019; British Skin Foundation 2021; Singleton et al. 2021). One in five children in the UK is affected by eczema, and the prevalence is increasing (Nankervis et al. 2016; British Skin Foundation 2021). The aetiology of AE is unknown, but it is thought to be multifactorial involving genetics, immunologic and environmental factors (Nutten 2015; Nottingham Eczema 2019; National Institute of Health and Care Excellence (NICE) 2021a).

Current management and treatment involves the use of medications used in conjunction with psychological and educational interventions (Singleton et al. 2021). In relation to medication, standard treatment is designed to avoid trigger/irritant and encourage regular application of emollients and topical steroids/calcineurin inhibitors (Wollenberg 2020), necessitating adherence to complex and invasive regimes. The NICE Clinical Guidelines (2021) recommend a stepped approach:

- for mild eczema use: moisturisers (emollients) and mild topical corticosteroids,
- for moderate eczema use: moisturisers, moderate topical corticosteroids, bandages
- for severe eczema use: moisturisers, stronger topical corticosteroids, topical tacrolimus ointment, bandages, and phototherapy (UV light).

One of the most common causes of treatment failure in AE is non-adherence, particularly to topical treatments (Teasdale 2021a). Several definitions of non-adherence have been proposed (Hugtenburg et al. 2013; Santer et al. 2014; Chappell 2015). One that works well with the relapsing nature of AE is that patients may be non-

adherent during different stages of their treatment (Hugtenburg et al. 2013). These children often endure complex skincare regimes which when effectively managed can keep the condition under control (Powell et al. 2018a; Nottingham Eczema 2019). Non-adherence to long-term treatments for eczema is a barrier to effective management. When prescribed medications and emollients are not used consistently, the child's skin can become inflamed and this leads to irritation and pruritus. Scratching can affect the integrity of the skin barrier and thicken the dermis making it more difficult for the skin to absorb creams and breaks in the skin increase the incidence of infection (Schut et al. 2015). Hence this paper aims to locate and examine studies that investigate the barriers to treatment adherence for children and young people with AE, and make subsequent recommendations for practice.

Method

The Sample, Phenomena of Interest, Design, Evaluation and Research (SPIDER) framework (Cooke et al. 2012) was used to develop and structure the research question for this literature review, as follows: Sample- Children and Young People, Phenomena of Interest- Atopic Eczema, Design- Interviews, questionnaires, Evaluation – Barriers that in Evaluation- Barriers that influence treatment and Research- Qualitative or Quantitative. The search string used was: eczema OR “atopic dermatitis” OR “atopic eczema” AND child* OR infant OR young people AND “treatment n2 adherence” OR compliance AND factors OR causes OR influences OR barriers, via four databases (Medline, Cinahl, Psycinfo and Science Direct) (Figure 1).

Figure 1 Prisma Diagram

Studies were included if they had: participants aged younger than 18 years, peer reviewed articles written in English and published between 2011 and 2021. Articles focussing on hand eczema, allergies, or other dermatological diseases were excluded. The remaining six research papers were subjected to the critical appraisal skills programme (CASP 2021) using the relevant tools for qualitative and quantitative papers. The CASP tool was used to rigorously assess the reliability and validity of the

identified papers (Long et al. 2020). All studies were deemed to be of acceptable quality as per the criteria within the CASP (2021) checklists. Thematic synthesis was used to group the findings and identify the main themes drawn from the papers (Maguire and Delahunt 2017).

Findings

Table 1 provides a summary of the studies included in the review. All papers related to patients being treated by general practitioners in primary care. Children within the selected research papers were <12 years of age.

Table 1 Summary of findings

Three common themes were identified: relationships, medication concerns and information deficits. Thematic analysis identified links between themes and subthemes demonstrating their interdependence (Figure 2).

Figure 2 Thematic Analysis

Relationships

Two subthemes emerged in this area: parent/professional relationships and personal relationships. These described the ways in which marriage, parent-child relationships, and children's friendships influenced treatment adherence. All papers identified the relationship with HCPs as a barrier to adherence to treatment. Some papers explicitly reported suboptimal relationships with doctors (Cheung and Lee 2011; Santer et al. 2012, 2016). Whereas the Teasdale et al. (2021a) paper examined limitations in school environments and described them as 'disempowering' for children.

Some parents felt they were being criticised for the way they cared for their child and were seen as responsible for causing their child's AE (Cheung and Lee 2011), whilst

Santer et al. (2012) found similar negative emotions as parents expressed their feelings of not being taken seriously. This was typified by doctors being dismissive and asserting that their child would "grow out of eczema". This did not encourage parents to seek advice and support. A need for good communication was a common theme in each of the papers for improving care, optimal medication adherence and establishing trust with HCPs.

Personal relationships were identified as a barrier to treatment compliance. Friendship difficulties were also acknowledged, with poor self-image stemming from "unwanted comments" and "teasing" from classmates (Cheung and Lee 2011; Teasdale et al. 2021a). This demonstrates that stigma and the opinions of peers can influence uptake of treatment in children and young people as they typically want to fit in and strive for 'normality'. Difficulties in forming and maintaining friendships was found to be a result of the side effects of topical treatments (Cheung and Lee 2011; Santer et al. 2013). Children endured damaging comments such as "greasy" and "oily boy" because of the appearance caused by emollients (Cheung and Lee 2011; Teasdale et al. 2001a).

The effects of caring for a child with eczema on relationship dynamics between parents and also parent and child have been emphasised across the studies (Cheung and Lee 2011; Santer et al. 2013; Teasdale et al. 2021a). Cheung and Lee (2011) focused on mothers and the ways in which their attitude and personality influenced the treatment for their child's AE. Emotional guilt, criticism, and accusations from spouses were key factors. Time taken to apply treatments before school, were also seen to effect quality of life (Santer et al. 2013). One mother reported giving up her spare time to focus on caring for her child's skin regime, others described having to give up their jobs and social life to "cope with the demands" (Cheung and Lee 2011).

Medication concerns

Two subthemes emerged for medication concerns: the side effects of topical treatments and the potential side effects of steroids. Parents were wary about the chemicals in the creams, and many favoured more natural products (Cheung and Lee

2011; Santer et al. 2013, 2016). Children also shared their views on topical treatments being time-consuming and excessively greasy (Teasdale et al. 2021a). However, one child noted that she was happy to have the cream applied as it made her skin slippery making it more difficult for her to scratch. The most common side effect was 'stinging' on application which led to questions from parents about the effectiveness of the medication, and question the choice and frequency of the prescribed treatment, this was raised in all of the studies.

Unease about taking steroids was explicitly mentioned by Cheung and Lee (2011); Santer et al. (2012, 2016) and Teasdale et al. (2021a). The most extensive study described serious concerns over general side effects of topical treatments (Capozza and Schwartz 2020). In contrast, in Santer et al.'s (2016) paper a mother talked positively about steroids finding that 'leave-on emollients' were uncomfortable for her daughter, choosing instead to rely on topical corticosteroids.

Information Deficits

The final theme described the ways in which the lack of AE education impacted adherence to treatment regimens (Cheung and Lee 2011; Santer et al. 2012, 2016; Capozza and Schwartz 2020; Teasdale et al. 2021a). The primary cause was a paucity of education for parents. Parents described gaining control over their child's AE as a lengthy process (Santer et al. 2012). Mothers updated themselves through the internet, constantly looking for advanced treatments to help their children's AE and ultimately they became "the expert" (Cheung and Lee (2011). However, through becoming "the expert", there is a risk of consulting unreliable sources, which can increase anxiety surrounding steroids and side effects. Santer et al. (2016) showed that, parents were at times, confused, frustrated, and overwhelmed by the range of topical products available. Despite these negative remarks, there was a strong desire for information about treatments, safety profiles, benefits, and rationales to assist parents/carers in making informed decisions regarding their child (Capozza and Schwartz (2020). Furthermore, it was recognised in Teasdale et al. (2021a) that the under-researched area of parent/child co-management could act as a treatment facilitator if children are included in treatment options early on.

Discussion

This paper aimed to uncover the barriers that influence treatment adherence in children and young people with AE. The barriers were categorised into themes and subthemes, which were consistent with the wider literature relating to AE and non-adherence with treatment plans (Hugtenburg et al. 2013; Powell et al. 2018a, 2018b; Teasdale et al. 2021b; Muller et al. 2021; Singleton et al. 2021).

In relation to the first theme, relationships between family and HCP, the context is of relevance. Although the research papers focused on general practitioners in primary care, the findings may be transferable and generalisable to nurses, including those working in general practice, specialist roles and dermatology. This paper revealed the implications of unfavourable dynamics between parents and HCPs. The results suggested this was an area for improvement. The psychological effects of childhood eczema have also been highlighted by Ersser et al. (2014) and Singleton et al. (2022), who advocated psychological interventions for children to compliment educational interventions and usual care for AE.

Additionally, the relationship between the HCP and the parents of children with AE appears to be a key factor for treatment adherence (Heath and Feldman 2019). Therefore, it is reasonable to argue that suboptimal relationships with HCPs can create other barriers. Current literature (Powell et al. 2018a, 2018b; Brimble and Mcnee 2021) confirmed that mothers' feelings resonated with reports of feeling unsupported and not being taken seriously leading them feeling stressed and fatigued, potentially leading to the reduction in adherence to treatment to avoid child refusals and constant bribery. The time taken to apply topical treatments meant less time was spent on family activities and siblings often missed out on quality time with their parents due to the "demands" of skin care regimes (Powell et al. 2018a; Brimble and Mcnee 2021). This could be exacerbated if the child's behaviour was difficult to manage.

With regard to the theme identifying medication concerns, despite apprehensions among many parents, topical corticosteroids were described as a “necessary evil” (Teasdale et al. 2021b). These negative connotations are not surprising when looking at the large number of emollients available in the UK on prescription (NICE 2021a). Lack of confidence in this mode of treatment may have led to the possibility of reading sources unsubstantiated by research and the purchase of products based on commercial advertising, rather than reliable evidence (Powell et al. 2018a; Muller et al. 2021). This confirms the need for high-quality, accessible educational interventions.

The theme “information gap” showed that information about eczema was variable. More child and family focused research is needed to provide information about AE treatment approaches which assist parents/carers in making informed decisions. A good example of an evidence based resource is the Nottingham Support Group for Carers of Children with Eczema (NSGCCE 2022) website. It is a collaboration between carers of children with eczema and NHS Dermatology healthcare professionals, thus ensuring it is not only evidence based but also an authentic source of information for families. Further research is needed to understand how school nurses can facilitate empowerment through health promotion and education in children in order to help them gain control of their AE.

One limitation of this review is that the six studies only focused on children <12 years of age and do not represent adolescents with AE, who may experience different barriers to younger children who primarily rely on parents to apply topical treatments. Another limitation is that the papers focused on the mothers views about caring for children with eczema, considering fathers views could add to the depth to these findings. In order to try to improve the trustworthiness and authenticity (Guba and Lincoln 1994) of this paper PRISMA and CASP tools were used to enhance transparent reporting and replicability of the method.

Implications for practice

As a result of the findings of this paper, HCPs should seek to optimise relationships with children and parents/carers, actively listening and responding to individual needs wherever possible. Families need to feel that what they tell a HCP will be valued and taken seriously in order for mutual trust to be established. Quality of life and psychosocial wellbeing should be discussed more regularly so that advice can be targeted appropriately and specialist referrals can be arranged as required (NICE (2021b)). Parents/carers should be offered support if they feel unable to cope with the child's behaviour, as behaviour management may aid optimal treatment adherence.

HCPs should sign post children and families to AE education including websites and apps. Giving parents time to ask questions about steroids and reassuring their fears with facts and information about charities and other reliable sources will better prepare them to care for their child. It would be valuable to spend more time discussing common side effects, such as 'stinging' on application, and more time reviewing the efficacy of the treatment along with the child and family's experiences of their treatment schedule.

AE has consequences for the entire household, so it is important for nurses and other HCPs to be aware of this and work with the family to develop a realistic treatment plan. Ideally they should involve the wider family unit in the discussion, so that everyone is educated about the condition and can understand the reasons for topical treatments. HCPs should plan for parent/child co-management as this could facilitate if children are included in treatment options from the start. This may also benefit children as they transition to adolescents and may result in improved adherence. A HCP could recommend a lighter cream, or adjusted frequency of application, if that would be more acceptable for that child.

The findings of this paper are not only limited to GP's in primary care but also apply to all nurses caring for children with AE. Therefore, nurses should receive training in AE, as well as the challenges faced by children and families. Nurses must ensure

children's voices are heard during consultations, ensuring an individualised, humanised approach by designing nursing care around the specific barriers to AE treatment adherence (NMC 2018).

Conclusion

This paper explored the barriers that influence treatment adherence in children and young people with AE. One of the main findings of this review was the need to foster optimal relationships between parents and HCPs. HCPs, including children's nurses, can help to bridge the information gap and allay medication concerns by providing and signposting to timely and regular education to children and families. Everyone involved in the child's care plays a role in promoting AE treatment adherence. This paper has also emphasised the importance of advocating for the child and hearing their voice, this is key to adherence with effective management of childhood eczema.

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