



Review article

Parental, child, and adolescent experience of chronic skin conditions: A meta-ethnography and review of the qualitative literature



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ABSTRACT

Childhood skin conditions can affect the quality of life of children, adolescents, and families. As such, paediatric dermatological conditions have been the focus of a number of qualitative studies and there is now a need to integrate the findings. A meta-ethnography was carried out with the existing 12 studies, which included nine studies examining parental experiences and three studies of child experiences. Meta-ethnographic analysis of the studies identified themes focused on the child's sense of stigmatisation and the challenges for families that arose from this. Common experiences across studies were feelings of difference relating to the appearance of the skin. The results highlight that children and adolescents can experience negative social reactions and that parents may struggle with some aspects of the physical management of the condition. The studies indicate the need to examine in more detail the psychosocial aspects of childhood skin conditions and the role played by stigmatisation.

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Introduction

Skin conditions such as eczema, psoriasis, and acne are common in childhood and adolescence. For example, eczema affects over 20% of children under the age of 5 (Williams, Stewart, von Mutius, Cookson, & Anderson, 2008). Skin conditions may be evident from birth or can develop during childhood or adolescence. Some conditions may be highly visible (i.e., on the face or hands) and others may be more 'hidden'. It is relatively unusual for the majority of childhood skin condition to be life threatening, nevertheless there are life threatening skin diseases, such as toxic epidermal necrolysis, as well as life limiting conditions, such as in some cases of epidermolysis bullosa. Indeed, even a typically non-life threatening condition such as atopic dermatitis can via neglect or inappropriate treatment become life threatening (Smith, Stephens, Werren, & Fischer, 2013). Consequently understanding the experience of children, adolescents, and their parents is important not only in informing the management of distress and the improvement of quality of life, but also in potentially aiding the understanding of the pressures that might contribute to the development of serious complications or even harm to children living with skin conditions.

The impact of the skin condition is likely to vary according to the child's developmental stage (Titman, 2005). Initially, early parent-child interactions or attachment may be affected. For example, skin conditions may cause pain or itching that could mean that touch is not experienced as comforting and this could affect bonding (Chamlin, 2006). However this has not been borne out in the research and a study by Daud, Garralda, and David (1993) highlighted that babies with eczema were not at an increased risk of developing an insecure attachment with their primary caregiver. Nevertheless, some studies have shown an increased level of behavioural difficulties in children with skin conditions. For example Chamlin (2006) reported that young children with dermatitis show increased levels of restlessness, hyperactivity, and sleep difficulties. These factors might result in increased demands on parents and lead them to feel exhausted and/or frustrated (Rumsey & Harcourt, 2007). This could affect their relationship as parents may struggle to be emotionally containing for their child. However, little research has examined child and parent relationships in the context of a child living with a skin condition.

Skin conditions can be highly visible and require frequent applications of treatment and as such might be expected to have an impact on emerging body image (Thompson, 2011). Body image awareness in the general is thought to start developing as early as 3 years of age (Gilbert & Thompson, 2002) and is likely to be influenced by family, cultural, and social representations about the value of appearance (Kearney-Cooke, 2002). However, it is probably not until around the age of 6 years that the self-evaluative aspects of appearance schemas develop (Smolak, 2011). In relation to childhood skin diseases it has been posited that children are likely to internalize negative skin based reactions from others, whilst at the same time being influenced by socio-cultural values and stereotypes associated with the appearance of the skin, and as a consequence they might be at a particular risk of developing body-image related distress (Thompson, 2011, 2012; Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999).

Unsurprisingly, for children and adolescents with visible skin conditions, the condition might well be expected to have some degree of impact on wider psychological functioning and self-esteem (e.g., Papadopoulos, Walker, Aitken, & Bor, 2000). Some survey studies have found higher rates of psychological difficulty for young people with skin conditions in comparison to 'healthy' peers (e.g., Smithard, Glazebrook, & Williams, 2001). A recent review indicates that the majority of studies have investigated quality of life, and there is a dearth of research that has investigated body image and self-esteem issues in children and adolescents with visible skin conditions (Nguyen, Koo, & Cordoro, 2016). In addition, the majority of body image research with children drawn from the general population has focused on weight and shape and tended to ignore concerns about the appearance of the skin (Smolak, 2011).

As the research into the psychosocial understanding of childhood skin conditions is in its infancy, it is important for qualitative studies to be conducted in order to identify individuals' experiences without rushing to impose theoretical frameworks on this experience. This is particular important in conducting research with children whose 'voice' within research might otherwise be lost and there has been a number of qualitative studies conducted over the past two decades, but as yet these have not been synthesised.

The aim of this review is to systematically evaluate and synthesise the peer-reviewed literature in order to understand the impact of skin conditions on children and young people and their families. An updated Cochrane review (Ersner et al., 2013) examining the educational and psychological interventions available for children with eczema has highlighted that there are only a limited number of interventions available and this mirrors the case with adults who fare little better (Lavda, Webb, & Thompson, 2012). The present review therefore also has an important role to play in contributing to the identification of areas that require consideration in future psychological intervention research.

A meta-ethnographic approach (Noblit & Hare, 1988) was used which began with systematic identification of the available literature. Novel themes were generated by working with 'data' extracted from the existing studies, that was then subject to a rigorous analytical process. This method of meta-synthesis has been widely used to aid the understanding of wider aspects of the experience of living with other physical health conditions such as diabetes (e.g., Campbell et al., 2003), and has also been used in relation to synthesising studies relating to some areas pertaining specifically to body image experience (e.g., Watson, Fuller-Tyszkiewicz, Broadbent, & Skouteris, 2015).

Method

Search Strategy

A search of the Cochrane Library revealed no current reviews on this topic. A search of the peer-reviewed literature was conducted in three databases: PsycINFO, Medline, and CINAHL. The journals '*Dermatology*' and '*The British Journal of Dermatology*' were hand searched, but did not reveal any additional studies. Citation and ancestry searches were completed on the studies selected for inclusion.

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