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

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

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.

Keywords. meta-ethnography; skin conditions; paediatric dermatology; psycho-dermatology; appearance concern; qualitative research.

Research highlights

- Children and adolescents with skin conditions frequently report feeling different.
- High levels of teasing suggest a need for skin specific school interventions.
- Interventions need to tackle the effects of skin related teasing.
- Behavioural interventions should be used support parents managing physical care.
- Further qualitative dermatology research with children is needed.

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 et al., 1999; Thompson, 2011, 2012).

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 particularly 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.

Search terms were generated to indicate the context in question (living with a dermatological condition), the population required (children), and the method of research (qualitative). Synonyms and various concepts were derived from a Google Scholar search of literature in the area. Truncation (*) was used in order to explore variations and wildcards (?) helped to capture variations in spelling.

Databases were initially searched in January 2014 using the following terms and combined using Boolean operators: (skin condition* OR skin disorder* OR vitiligo OR eczema OR atopic dermatitis OR psoriasis OR rosacea OR ichthyosis OR urticaria OR port wine stain* OR acne* OR visible difference* OR disfigure*) AND (p?ediatric* OR child* OR adolesce* OR young person) AND (qualitative* OR Grounded Theory OR Interpretative Phenomenological Analysis OR Discourse Analysis OR interview). The following Medical Subject Headings (MeSH) terms were also used in PsycINFO and Medline: Skin Disorders, Dermatitis, Physical Disfigurement, Pediatrics, Qualitative Research, and Grounded Theory. The search was repeated in November 2015 and August 2016 and no new studies were identified.

Screening

Entering the search terms into the selected databases resulted in a total of 140 studies. Following removal of duplicates, titles and abstracts were screened according to the inclusion/exclusion criteria in Table 1. The first author largely conducted this screening, and where there was any degree of uncertainty about inclusion of papers they were also screened by the second author. The remaining 24 articles were accessed in full-text form. Twelve studies

published since 1997 were eventually included (Figure 1). Papers were excluded at the final stage for a variety of reasons, as noted in Figure 1. For example, two studies of patients with dermatological conditions included both adolescent and adult participants but did not conduct separate analysis for adolescent participants (Magin, Adams, Heading, Pond, & Smith, 2008; Magin, Adams, Heading, & Pond (2009).

The studies explored experiences of three childhood skin conditions: eczema, psoriasis, and epidermolysis bullosa (EB). The majority (9 studies) reported the impact on parents, while the other three involved children or adolescents as participants. Two studies used the same set of parent participants (Santer et al., 2012, 2013) but drew out different themes so both were included in the analysis. Where reported, ethnicity was predominantly white, although one study was conducted specifically with Chinese mothers and others included some participants of Asian, Afro-Caribbean, or Hispanic origin. See Table 2 for further details of the studies and their participants.

Quality Rating

Making judgements about the quality of qualitative literature is a contentious issue and still in its infancy compared with methods for reviewing quantitative studies. The Critical Appraisal Skills Programme (CASP, 2013) guidelines for qualitative research were used as a checklist for rating quality, due to their utility in previous reviews (e.g., Campbell et al., 2003). The twelve studies deemed appropriate for inclusion were rated on key features (such as a clear explanation of the participant recruitment process and rigorousness of data analysis) and given a score out of 18 (see Table 2: The full rating for each study is available online in a Supplementary Materials document linked to this article). An independent second rater reviewed three studies with a single-point difference being found on overall score for two of the papers. This was discussed and an agreement reached.

The most frequent reason for studies to lose points was not adequately considering (or stating) the relationship between researcher and participants. The quality rating process did not result in the exclusion of any studies as all were of sufficient quality.

Process of Data Synthesis

Noblit and Hare (1988) described meta-ethnography as akin to meta-analysis, in that it involves a systematic combining of studies in order to allow for the development of new interpretations and conceptual insights. Following Noblit and Hare's (1988) directions, all 12 included studies were read in chronological order. First and second order constructs were noted for each study, with first order being the participants' direct accounts and second being the authors' interpretations of the participants' accounts (or 'themes'). Tables were generated to map the links between first- and second-order constructs, so that the review would remain close to the original data.

Following this, the 12 studies were separated into those that focused on parents' views and those that were child or adolescent focused. All studies were read again and their second order constructs were compared with each other (within the parent or child and young person subset and then together). This involved 'reciprocal translation' whereby a search for themes or patterns that occurred across the studies was conducted, and 'refutational analysis' in which themes that refuted these patterns were also actively sought. Finally, the use of a 'line of argument' method resulted in the development of a set of third order constructs that "completely expresses the emerging patterns across the included studies" (Downe, 2008, p. 7). Separate themes were identified for child/adolescent and adult perspectives, followed by overall themes, which were common to both.

Results

The majority of papers that explored parental perspective utilised semi-structured interviewing as the data collection method, with several methods of analysis having been used

(content analysis, thematic analysis, constant comparative approach, IPA, and grounded theory). The two studies that did not employ interview techniques used written accounts of mothers' experiences or focus groups. These two studies were both analysed using content analysis. Throughout the results section the word "parents" is used to denote parent-participants. It must be noted that four studies included mothers only, with the others also including fathers. Where both participants were both mothers and fathers, the analysis did not explicitly separate their views according to gender. The three studies exploring child and adolescent perspective all used different analysis methods: grounded theory, content analysis, and IPA; with two of these conducting interviews and one study using focus groups. The fact that such a wide range of methodologies and analyses were used across the twelve studies should be kept in mind when reading the following results.

Parental Perspective

Skin conditions get in the way of a 'normal' family life. For many families, having a child or adolescent with a skin condition affected a number of areas of life. Treatments were often time consuming to administer (e.g., Santer et al., 2013) and this led to a lack of time to spend with spouses or other members of the family (e.g., Elliot & Luker, 1997). In some instances, problems were exacerbated by differing opinions on how to manage the condition (Cheung & Lee, 2012) and in more extreme cases this had led to the breakdown of relationships (van Scheppingen, Lettinga, Duipmans, Maathuis, & Jonkman, 2008a).

The impact of the child or young person's skin condition was such for some parents that they had actively chosen not to have any more children (Chamlin, Frieden, Williams, & Chren, 2004; Cheung & Lee, 2012). This was due, in part, to not wanting future children to suffer in the same way but also to avoid adding to the existing family burden. The burden of caring for a child with a chronic skin condition was frequently reported as including extra housework. For example, many children and adolescents scratched and bled and therefore

required frequent bedding or clothing changes (e.g., Elliot & Luker, 1997). Families also reported a need to plan and prepare more extensively for trips away from the home (Cheung & Lee, 2012).

The demands on parents were such that for some there was an impact upon work, for example some parents reported choosing certain jobs due to their flexibility or choosing not to work at all (Cheung & Lee, 2012). Similarly, some parents reported having reduced or changed their leisure activities (van Scheppingen et al., 2008a). The resultant impact on parental mental health and wellbeing appeared to be low mood and a sense of isolation.

Alongside the impact on themselves, parents reported that their child or adolescent occasionally were unable to participate in everyday activities and consequently were at risk of not having a 'typical' childhood. For example, some parents in the extant papers described restricting the activities their child took part in, such as going swimming or playing outside (Chamlin et al., 2004; Santer et al., 2012). Children also had to endure difficult bath times and had different routines to their siblings or peers due to the need for treatments or the potential for pain (e.g., Elliot & Luker, 1997).

What hurts you hurts me. Whilst the skin condition belonged to the child or adolescent, parents often felt as though they took on the associated stresses. A key example was sleep disturbance. Many skin conditions, including all of those covered in this review, can lead to an intense itch and desire to scratch. Parents across the studies reviewed reported that night-time scratching when there were fewer distractions and no adults were present. Parents then spent time checking that scratching was not occurring or resorted to keeping their child in bed with them to monitor and attempt to prevent scratching (Chamlin et al., 2004). Night-time for some parents also included the need for cleaning and soothing children who had woken up distressed (Santer et al., 2012). This was likely to result in exhausted parents who then had the

added burden of needing to care for their children during the day as well (Smith, Hong, Fearn, Blaszczynski, & Fischer, 2010).

Further to this, parents experienced a psychological ‘burden’ of the skin condition, both for themselves and on behalf of their children (Cheung & Lee, 2012). Many parents reported feeling upset when strangers made comments or asked questions about their child, including if the parent became aware that their son or daughter was also upset by this (e.g., Chamlin et al., 2004). An additional psychological strain was that of the feelings elicited when having to treat the skin condition, as this often resulted in the child being unhappy or even in pain (e.g., van Scheppingen et al., 2008a).

Perhaps due to the young age of many of the children included in the studies reviewed, parents reported worries about the future for their child. The skin conditions in the studies can be unpredictable and may have an uncertain course. This led to anxieties about the potential for the conditions getting worse in the future or worries about when flare ups might occur (e.g., van Scheppingen et al., 2008a). In those cases where the condition was visible, some parents feared appearance-related teasing in the future or felt concerned that their child or adolescent might struggle to make friends (e.g., Chamlin et al., 2004).

Making or breaking: The relationship between parent and child. Parenting a child with a skin condition often required different interactions than would be expected with a child without a skin condition. This may have impacted on the way the relationship developed. Parents often needed to apply treatments (creams; bandages etc.) that the child disliked. This sometimes resulted in a sense of battling or needing to ‘coerce’ the child (e.g., Santer et al., 2013; Smith et al., 2010). In some cases, parents felt they had to hold their child very still in order to administer treatment (Gore, Johnson, Caress, Woodcock, & Custovic, 2005). In other cases, parents had to cause the child a certain degree of pain in order to treat the skin condition (van Scheppingen et al., 2008a).

Children with skin conditions sometimes exhibit behavioural difficulties, including fussiness, irritability, and ‘bad tempered’, which might be as a result of pain or itch caused by their condition (e.g., Cheung & Lee, 2012). Parenting children who exhibit these behaviours could be difficult or tiring and lead to difficulties with the relationship, due to a sense of frustration (e.g., Chamlin et al., 2004).

In contrast, the level of care and supervision parents gave their child with a skin condition might have resulted in a strengthened bond. Many parents spent a great deal of time focusing on or supervising the child (e.g., Alanne, Laitinen, Soderlund, & Paavilainen, 2011). In one study parents reported feeling compelled to keep their child ‘entertained’ as a preventative measure (Elliot & Luker, 1997). The need to hold a baby or young child with a skin condition more regularly to prevent them from scratching (e.g., Chamlin et al., 2004) might have fostered a deeper sense of closeness with that child.

We’re not good enough parents vs. becoming experts. Unhelpful input from a number of individuals (including medical professionals and relatives) had led some parents to feel blamed for either causing or not managing to prevent their child’s skin condition and any associated behaviour problems (e.g., Smith et al., 2010). Some mothers developed theories that something they did or did not do in pregnancy had caused the condition and others felt guilty due to the belief that their child had inherited the condition from them or their partner (e.g., Chamlin et al., 2004). A sense of guilt was experienced very strongly by mothers who believed that their child’s skin condition had been affected by their breast milk (Alanne et al., 2011). In extreme cases, blaming manifested as a suggestion that the condition had been caused by maternal negligence (Cheung & Lee, 2012). Some parents felt a sense of guilt at not spending enough time with their other children (van Scheppingen et al., 2008a). The study by Cheung and Lee (2012) with Chinese mothers highlighted a large amount of blaming, which might

suggest that there are cultural differences or localised myths influencing how parents experience their child's condition.

In contrast, parents felt as though they had gained a number of specialist skills due to having a child with a skin condition. They became experts in delivering treatment effectively to their child, for example through certain games or with the use of distraction (Santer et al., 2013). Further to this, through necessity, they had developed a wide knowledge of medical interventions and spent time monitoring new treatments (e.g., Cheung & Lee, 2012; Gore et al., 2005). However, with this level of expertise came an added burden. Parents were often reluctant to leave their child with other adults, as they did not feel they would be able to provide adequate care (e.g., Alanne et al., 2011; Elliott & Luker, 1997). Also, if the child's condition was not highly visible, other people did not seem to understand or appreciate how difficult it must be for the child or parent (van Scheppingen et al., 2008a).

Feeling the need to go our own way. Many parents were distrustful of medical advice, particularly when they received contradictory messages from different professionals. Although emollients are reported as a 'mainstay' of eczema treatment, parents felt confused about using them. This was particularly the case if the emollients did not appear to be having any beneficial effects (Santer et al., 2012). Parents were also frequently anxious about the potential for serious side effects following regular use of another common treatment (cortisone/ corticosteroids) and did not feel the future impact was adequately addressed (e.g., Chamlin et al., 2004; Smith et al., 2010). Some felt "fobbed off or dismissed" by medical professionals. This was commonly reported by parents of children with eczema, with some doctors being reported as simply suggesting that their child would grow out of the condition; thus not appreciating the current level of need or difficulty being experienced by the parent or child (Santer et al., 2012).

In one study, a key finding was that parents found it difficult to accept the advice that their child's skin condition needed to be 'controlled' and was unlikely to ever be 'cured'

(Smith et al., 2010). Many parents across the parent-perspective studies strived for answers and explored methods not suggested by medics in an attempt to avoid flare ups or rid the child of the condition altogether. For example, several attempted to modify their child's diet, despite there not being any medical evidence to support this (e.g., Elliot & Luker, 1997).

Child and Adolescent Perspective

The three studies that have investigated young people's experience of their skin condition included participants with psoriasis or EB. As noted in Table 2, they ranged in age from 6 to 17 years at the time of the study. In two of the studies, the gender mix and ethnicities of participants were not stated. In the third, 6 out of the 11 participants were male, with a predominantly White British sample. Two studies involved the use of interviews, whilst the third used online focus groups.

Wanting to be normal versus needing to be different. Young people with skin conditions are reported in the studies as holding a sense of difference from others as a result of their condition. In some cases, they only began to develop an awareness of this difference from the comments made by others, having previously felt 'normal' (van Scheppingen, Lettinga, Duipmans, Maathuis, & Jonkman, 2008b). Some young people were teased for their appearance and there was a sense that not having a visible skin condition would reduce or avoid negative attention (Fox, Rumsey, & Morris, 2007). The skin condition and people's reactions sometimes resulted in feelings of isolation (Williams, Gannon, & Soon, 2011).

Whilst developing a sense of being different affected young people's self esteem and wellbeing, they also acknowledged the need for things to be different due to their skin condition. For some there were physical limitations due to their restricted movement and choices had to be made about 'joining in' but risking potential pain (van Scheppingen et al., 2008b). Some adolescents felt that they needed to be different by avoiding certain activities

due to embarrassment about their appearance, for example engaging in intimate behaviours (Fox et al., 2007).

The importance of others understanding. When the young person's skin condition was not immediately obvious (i.e., visible on the hands or face) they reported that others did not understand or appreciate the impact of the condition or the difficulties they were facing (van Scheppingen et al., 2008b; Williams et al., 2011). Furthermore, young people sometimes felt the need to educate others due a lack of sympathy, or when misunderstandings occurred, such as beliefs about the condition being contagious (Williams et al., 2011). Sometimes the misunderstandings occurred with medical professionals, for example if they underestimated the impact of the condition or did not offer appropriate support (Fox et al., 2007).

Powerlessness. Children and adolescents are inherently in a lower position of power to adults. However, this appears to be exaggerated by having a skin condition. For example, strangers sometimes openly asked about their condition (Williams et al., 2011), which would perhaps be less likely to occur for adults. Discrimination or name-calling was commonly described (e.g., Fox et al., 2007), which was in some studies reported as effecting young people's self-esteem. Indeed, for some teasing was the worst aspect of their experience of living with a skin condition.

It is to be expected that adults make some decisions on behalf of all children and adolescents, but this seemed particularly salient and detrimental for the young people in these studies. For example, some were deemed to have 'special needs' at school in relation to their physical limitations (Williams et al., 2011). Being labelled or separated out in this way led to high levels of distress and reduced self-esteem. Further to this, at home there was a sense that some parents spent a large amount of time 'policing' how their children handled their skin condition (van Scheppingen et al., 2008b).

Overall Family Impact

Drawing together results from the 12 studies, there were some similar themes for children and young people and their parents as well as some differences. Both groups reported a variety of ways in which the skin condition meant that their lives were not (and perhaps could not be) 'normal'. There was also common ground regarding development of expertise in understanding and managing the condition. A key difference between the themes raised by children and adolescents and parents was what effect they expressed most concern about.

Not being normal. Young people with skin conditions often felt as though they were different from their peers (Williams et al., 2011) and in some cases needed to do things differently, such as avoiding physical activity (van Scheppingen et al., 2008b). The impact of the condition and its subsequent treatment led to many aspects of parents' lives being different, for example the requirement of extra house work (Elliot & Luker, 1997), affected choice of leisure activities (van Scheppingen et al., 2008a) and time needed to apply creams and bandages (Santer et al., 2013). Anxiety about potential negative consequences (e.g., teasing; pain) led parents to promote - and children and adolescents to choose - avoidance as a way of coping, which resulted in further difference.

Rising to the challenge. Both parents and children and adolescents described a sense of becoming experts in understanding the skin condition and ways of managing it. Many parents felt they had a higher level of medical knowledge (e.g., Gore et al., 2005) or had developed extra skills in comforting or distracting their child (e.g., Santer et al., 2013). Young people in one study described that having psoriasis meant that they were more mature and had a greater level of coping skills than their healthy peers (Fox et al., 2007).

In many cases, however, it seemed that developing knowledge or skills was a requirement of having the condition and perhaps an added burden rather than a positive 'side effect'. For example, children and adolescents in some studies described feeling the need to educate others in order to reduce negative social interactions (Williams et al., 2011) and

parents did not feel comfortable leaving their child with some care providers due to their lack of knowledge (e.g., Alanne et al., 2011). Both parents and children and adolescents reported some difficulties with medical professionals not appreciating the impact of the skin condition on their life and felt that they had to demand treatment or support (Fox et al., 2007; Santer et al., 2012).

The greatest difficulty. There appeared to be a difference in emphasis between young people and parents regarding which factors relating to the skin condition were most distressing. Children and young people predominantly highlighted difficulties with feelings about their appearance and stigmatisation, whereas for the parents, burden of care or/and the physical impact seemed to be the most commonly reported theme, although they were aware of the risk of ‘teasing’. One of the papers that reported young people’s perspectives (van Scheppingen et al., 2008b) demonstrated an equal balance between both appearance concerns and physical burden yet clearly the existing research indicates that young people are experiencing body image related concerns and these seem related on occasion to actual receipt of negative comments from others or fears of receiving such comments.

Methodological Limitations

Studies in this review were all of a satisfactory quality according to the CASP rating tool (2013: see Supplementary Materials). However, there were some methodological flaws that should be held in mind when interpreting the results reported above. For several studies the ethnicity of the participants was not stated. Where it was, participants were predominantly white and the majority of the studies were conducted with those from Western societies. Findings may therefore not apply to non-Western cultures, for example where there is a greater emphasis on family as support or differences in how medical conditions are understood.

For some of the studies, the authors had not clearly outlined the process of analysis or included many/any quotes to support their findings. In some cases this made it difficult to

ascertain the exact meaning behind the themes chosen and this in turn affected the meta-ethnography conducted for this review. Also, the majority of studies did not report how reflexivity had been considered. Whilst this is not always crucial in qualitative research (e.g., when results are drawn straight from content without any explicit interpretation), the researchers' knowledge and background may have shaped the focus of interviews and therefore the findings and future studies should be more transparent in their description of consideration of reflexivity.

Discussion

The current review is, to the author's knowledge, the first meta-ethnography that draws together the qualitative studies that have sought to understand the impact of childhood skin conditions on children and adolescents and their parents. The review included studies that either focused on the experiences of parents or of the young person themselves. Parents reported a number of issues relating to their child's skin condition that impacted on their family's ability to live a normal life. The condition also impacted on the relationship with their child and on the parent's wellbeing. Many parents developed a number of skills in response to the condition but were somewhat distrustful of medical advice. Young people experienced their skin condition as meaning that they were not 'normal', but also in some instances they reported having benefitting from adapting to this experience. The skin condition often resulted in a sense of powerlessness. Young people were often more positive if others understood their condition and people appreciated the potential difficulties they might have. Finally, common themes across both parent and studies with young people included feelings of a lack of 'normality' and the development of expertise. Differences were evident in what parents and children and adolescents found the most difficult aspect of the skin condition to cope with.

The findings of this review corroborate a number of previous results in quantitative studies. For example, Moore, David, Murray, Child, and Arkwright (2006) found elevated

levels of depression and anxiety in parents of children with eczema. Mood difficulties were significantly correlated with poorer sleep, which was a commonly reported burden across the qualitative parental literature reviewed here. Furthermore, in their development of a tool to measure impact of skin conditions on family members, Basra, Sue-Ho, and Finlay (2007) highlighted a number of factors that parents found difficult and were also seen in the current review. Examples included effect on social life or leisure activities, burden of care, and problems due to other people's attitudes.

It is important to note that not all quantitative studies have found difficulties for parents. For example, two studies looking at eczema and port wine stains respectively showed levels of parental distress to be comparative to that of norms (Daud et al, 1993; Miller, Pit-Ten, Watson, & Geronemus, 1999). Whilst this could reflect a counter-argument to many of the findings of this review (i.e., suggesting that parenting a child with a skin condition does not result in any additional burden or concern) it must be held in mind that many quantitative studies have used tightly defined measures that might not have adequately captured parents experience, and such may have lacked the sensitivity to locate specific parental difficulties.

The parental theme regarding difficulty in maintaining a 'normal' life due to physical and lifestyle-related burdens has similarities with research into other chronic health conditions. For example, Silver, Westbrook, and Stein (1998) investigated the impact of chronic childhood illness (e.g., asthma; diabetes) on parental adaptation. Their results highlighted that parents were more likely to experience a significantly greater level of stress than parents of children without skin conditions, but only if the condition resulted in an impairment of functioning. This included requiring extra support for activities of daily living, which is a commonly described feature in the current review (i.e., administering treatments).

Some qualitative studies with children with visible differences (i.e., Cleft lip/palate) have suggested that parental adaptation seems to be an even greater challenge when the chronic

health problem results in a disfigurement. This might be as a result of distress relating to negative social feedback (Johansson & Ringsberg, 2004) or worries about their child's self-esteem (Klein, Pope, & Tan, 2010). This finding was mirrored in the current review with many parents highlighting the feeling that what hurt their child also hurt them.

The skin conditions described across the 12 studies in this review are commonly present from birth or early infancy, therefore may be around at an early stage in relationship development. A number of features resulting from the child's condition and described by parents in this review might impact this development. There is a paucity of research into the impact of childhood skin conditions on the attachment process. Previous research has failed to reach a consensus (e.g., Daud et al., 1993; Whittkower & Hulnt, 1958). A study regarding children with Cleft lip/palate indicated that children with a more severe disfigurement were more securely attached to their primary caregiver (Clements & Barnett, 2002). This finding corresponds with the suggestion in the current review that an increased amount of time-spent with/holding a child could increase bonding. Clearly, the impact of skin conditions on attachment requires further investigation.

Findings across the child and adolescent-perspective studies in this review somewhat support previous research indicating that the process of managing a chronic health condition could challenge a young person's ability to complete certain developmental tasks. Importantly, this may include consolidation of positive self image (Fritz & McQuaid, 2000), as seen in the young person's desires to appear 'normal' in order to feel good about themselves.

Quantitative studies have highlighted greater rates of psychological difficulty in children with skin conditions, in comparison to 'healthy' peers. Gupta, Johnson, and Gupta (1998) found a reduction in quality of life for adolescents with acne due to the negative social impact of the condition. The experience of negative encounters was described by many of the

young people in the current review and was commonly linked to a lack of others' understanding, for example believing the skin condition to be contagious.

A number of factors might have impacted on the difference in focus across the child and adolescent and the parent-based studies. All skin conditions in the review resulted in some degree of itch/pain, which might explain the parents' heightened focus on physical care. This focus could also be due to the age of the child for whom the parents were looking after. Most of the children being described in the parent-based studies were under the age of five and so would have required a greater level of physical support. Age may also have affected the focus on appearance as a concern, with this being heightened for older children. It might be the case that studies including samples made up entirely of parents with adolescent children would have more of a shared concern about image and appearance. Finally, it is important to note that differences could have been due to the focus of questions asked in the research or parents not feeling comfortable to discuss appearance concerns.

The predominance across all studies was for discussion of difficulties, however, a few studies also included accounts of positive experience, for example young people feeling as though they were more mature due to having to cope with the condition (Fox et al., 2007). In Elliott and Luker's (1997) research, two mothers reported that their child's skin condition resulted in no burden for them. The focus on negative aspects might have been due to the questions asked by the researchers or could reflect a bias in the sample of individuals who chose to take part and discuss their experiences. This bias may also have been generated by the sampling method, for example, in both studies by Santer and colleagues (2012, 2013) participants were only included if they expressed that their child's skin condition was currently causing them difficulties.

Limitations of Current Review

Firstly, it must be recognised that the themes presented in this review are based on the authors understanding of the material presented in the studies. There is the potential for an element of error due to the distance from the original data and also for bias, although this risk was reduced by close adherence to Noblit and Hare's (1988) description of meta-ethnography.

Across the reviewed literature the number of skin conditions researched was limited. While this might have made synthesis easier due to homogeneity, it will mean that the themes might not be transferable to all childhood skin conditions. Further to this, there were only three studies that looked at the children's and adolescent's experience. Synthesising the findings from such a small number of studies might have compromised the degree to which nuanced themes could be generated.

Finally, a difficulty in synthesising any literature is the requirement to compare studies, which have used a range of methodologies. Whilst there were some similarities, different data collection, and analysis types were included across the studies. For example, those that used Interpretative Phenomenological Analysis generated interpretative themes, whereas other methods drew themes directly from the participants' words. Authors chose to present their findings in different ways, with some including minimal raw data and others only reporting a few of their key themes due to word limits for publication.

Implications for Clinical and Educational Practice

From a psychological perspective, parents might benefit from therapeutic support regarding managing their future fears for their child or current concerns regarding management of negative social interactions. Relationship support might also be helpful, particularly in situations where there are strong differences in opinion regarding how to care for a child, or if the burden of caring is resulting in relationship breakdown. Parents could be offered support to explore their feelings of guilt and desire to cure rather than control the condition. Although there is currently limited evidence for the effectiveness of psychological interventions for

children with skin conditions, psychological interventions with children with other forms of conditions affecting appearance suggest that interventions aimed at raising social confidence might be useful (Kapp-Simon, McGuire, Long, & Simon, 2005), and behavioural interventions to manage problems such as scratching and difficulty sleeping could be more widely available (Ersser et al., 2013).

Prior to any support being offered the psychosocial issues present need to be identified and it is therefore essential that dermatologists routinely conduct holistic assessments to ascertain the psychosocial impact of skin conditions on children and families (Westphal & Malik, 2014). Further, this study particularly highlights the importance of specifically assessing subjective concerns about the appearance of the skin and the use of validated measures such as the Cutaneous Body Image Scale (Gupta, Gupta, & Johnson, 2004) could be more widely used. Further research is needed to examine the utility of this construct and of other approaches to the assessment of skin related body image in children and adolescents (for a review see Hill, 2011). The Children's Dermatology Life Quality Index (CDLQI: Lewis-Jones & Finlay, 1995) also contains items relating to embarrassment and self-consciousness, and relationship with friends that are validated and might be more widely used to screen for body image related distress.

Young people and children could benefit from support groups, including those online (with close adult moderation) in order to share and normalise their experiences. This might reduce feelings of difference and isolation. However, as receipt of negative appearance related feedback was commonly reported within the studies reviewed, this indicates that educators should also be alert to teasing and harassment that children and adolescents with skin conditions might encounter. This is particularly important given that there is evidence from a number of studies that social harassment plays an important role in the later development of both body dissatisfaction and mood disturbance (Menzel et al., 2010). For example, the

association between cleft visibility and appearance satisfaction in adolescent girls has been found to be mediated by prior experience of intrusive comments from peers (Feragen & Borge, 2010). Indeed, Feragen and Stock (2016) recently conducted a longitudinal study with children with a range of conditions affecting the appearance of the face, and found that perception of social harassment at the age of 10 predicted appearance dissatisfaction and mood disturbance in their female sample at the age of 16 years. It appears from our review that this relationship warrants investigation in children living with a visible skin condition and educational programmes might be developed for use in schools in order to develop greater peer understanding and tolerance of skin conditions (Frances, 2003), and the charity Changing Faces produces a number of resources for this purpose (<https://www.changingfaces.org.uk/resources/education>).

Implications for Future Research

The majority of studies in this review focused on the negative impact of childhood skin conditions on families. However, there has been a recent focus in the appearance-related literature, with studies exploring protective factors and positive adjustment or coping (e.g., Feragen, Borge, & Rumsey, 2009; Strauss & Fenson, 2005). Whilst not taking away from the difficulties and burden that childhood skin conditions could have on families, it is important for future qualitative research to investigate resilience and naturalistic coping strategies.

Further qualitative research is needed into the wider range of dermatological conditions that can affect children, as only a very small number of conditions were covered in the studies reported within this review. It may be important to focus on skin conditions that do not result in such physical difficulties (e.g., vitiligo or port wine stains) to explore the impact of a more ‘pure’ visible difference. It would also be useful for future research to examine longitudinal effects, as difficulties are likely to vary according to the age of the child and how long the family have been coping with the condition. Longitudinal studies are also needed to

specifically investigate the role played by key factors such as appearance related social harassment, teasing, and exclusion.

Conclusion

This is the first meta-ethnography examining the experience of childhood skin conditions. The findings highlight that parents experience social, psychological, and practical burdens as a result of caring for their child. Furthermore, a child's skin condition may impact the parent-child relationship. Young people had difficulties with negative social experiences and feeling as though they did not fit in. The results highlight the need for clear medical advice and practical or emotional support for parents.

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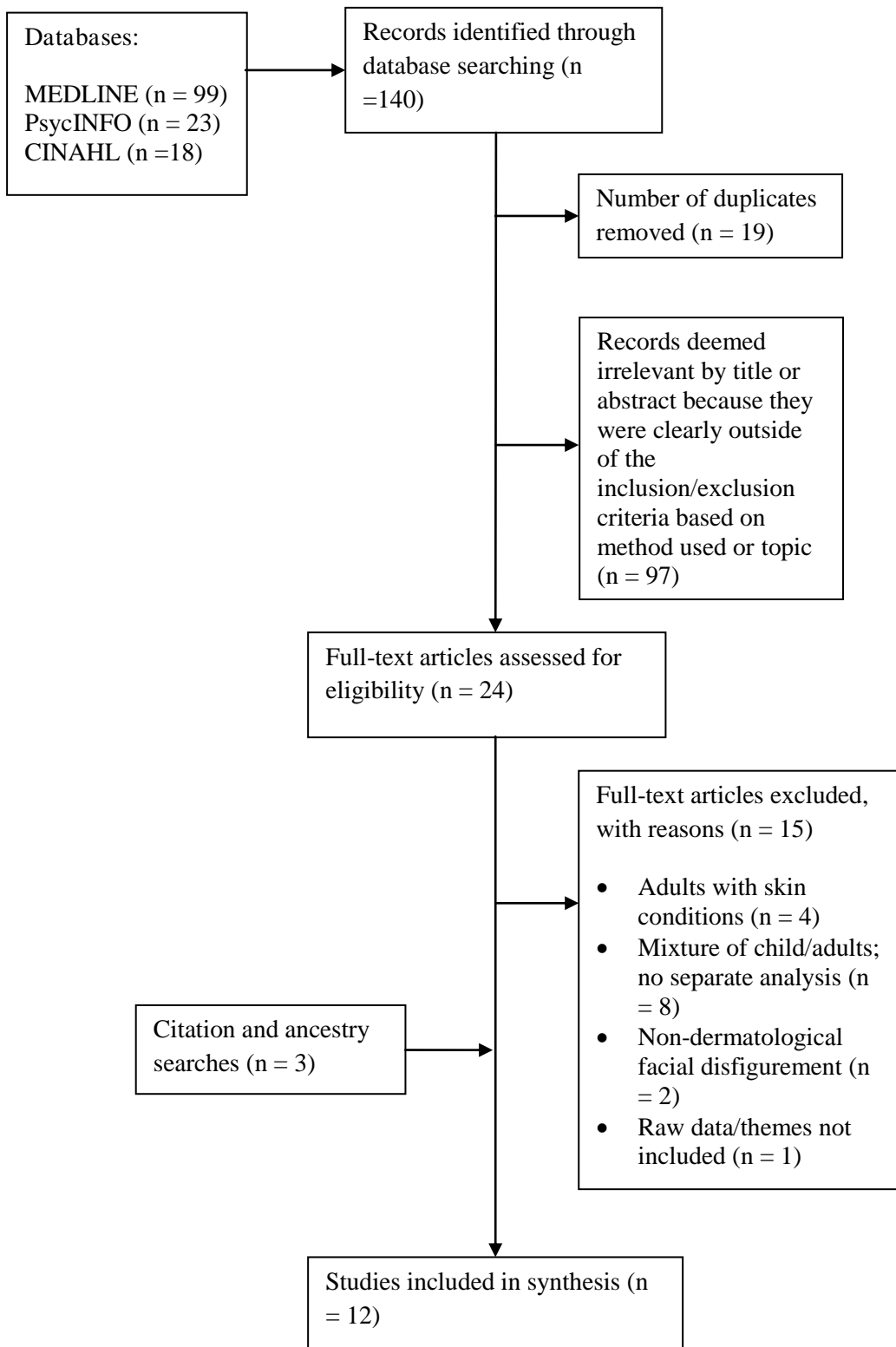


Figure 1. Flow diagram of the selection procedure

Table 1 Inclusion and Exclusion Criteria

Inclusion	Exclusion
Written summary of empirical study; peer-reviewed	Book chapters, Reviews
Experience of a skin condition	Experience of an alternative disfiguring condition: acquired (e.g. burn) or congenital (e.g. Cleft lip/palate)
The individual with the skin condition was under 18	Studies about skin conditions in adults or mixed child/adult with no separation of analyses
Qualitative research	Quantitative studies; Mixed methods research where no qualitative raw data was presented

Table 2 Details of Studies Included in the meta-ethnography

No.	Study and country of origin	Aim	Sampling	Skin Condition	Participants	C/YP	Data Collection	Analysis Method	CASP score (out of 18)
1	Elliott & Luker (1997) UK	To contribute an understanding of pressures imposed on family life when caring for a child with severe eczema	Purposive-through consultant paediatrician	Eczema	Mothers of children under 5 years with severe eczema	No data	Written accounts	Latent content analysis	13
2	Chamlin, Frieden, Williams, & Chren (2004) San Francisco, USA	To document the effects of atopic dermatitis on young children and their families	Purposive-through dermatology clinic	Eczema	Parents of 26 young children with eczema and 6 dermatologists	Mean age 23 months, range 3-69 months. 10 female, 58% Asian, 19% white, 19% black, 4% Hispanic	Focus sessions: 23 with the 26 parents, interviews with 'experts' 14-45 minutes, mean 27 minutes	Method not explicitly stated	14
3	Gore, Johnson, Caress, Woodcock, & Custovic (2005) UK	To explore the information needs and decisional role-preferences of parents caring for infants with eczema	Purposive-Recruited from ongoing study in paediatric allergy clinic	Eczema	31 mothers (age 21-40 years, mean 32 years). 29 WB, 1 Afro-Caribbean, 1 Chinese	Infants 3-12 months	Focused conversational-style interviews	Thematic analysis	16

No.	Study and country of origin	Aim	Sampling	Skin Condition	Participants	C/YP	Data Collection	Analysis Method	CASP score (out of 18)
4	Fox, Rumsey, & Morris (2007) UK	To explore the experiences of young people with psoriasis	Purposive-adverts on websites of psoriasis-related organisations	Psoriasis	8 individuals 11-18 years, had psoriasis for at least 1 year	C/YP are participants (see previous column)	3 Online focus groups, moderated by researcher, lasting on average 1 hour	Grounded theory	17
5	van Scheppingen, Lettinga, Duipmans, Maathuis, & Jonkman (2008a) The Netherlands	To gain an understanding of problems that children with EB have to deal with. (1. What problems are the most difficult? 2. Do the differences depend on severity?)	Purposive-via Medical Centre	EB	11 families with one or more child with EB- 5 mothers, 6 mother/father pairs	C/YP aged 2-19 years	Semi-structured interviews (1-1.5 hours)	Content analysis	15
6	van Scheppingen, Lettinga, Duipmans, Maathuis, & Jonkman (2008b) The Netherlands	To gain an in depth understanding of the problems that children with EB have to deal with. (1. What problems are the most difficult? 2. What is the impact on daily life? 3. Are there differences depending on EB severity?)	Purposive-via Medical Centre	EB	9 C/YP (aged 6-17 years)	C/YP are participants (see previous column)	Semi-structured interviews	Content analysis	17

7	Smith, Hong, Fearn, Blaszczyński, & Fischer (2010) Sydney, Australia	To explore parental attitudes to the use of corticosteroids and the associated desire for natural therapy for eczema.	Purposive-recruited via paediatric dermatology clinic	Eczema	16 parents, aged 34-49 years. 15 female	No data	3 focus groups, 1.5-2 hours long	Grounded theory style. Open-, axial- and selective-coding procedures	16
8	Alanne, Laitinen, Soderlund, & Paavilainen (2011) Finland	To identify mothers' perceptions of the supporting or straining factors involved in motherhood generally and in relation to child's eczema and food allergy at the age of one and two years	Convenience-Women who were part of ongoing mother-infant study were invited by authors	Eczema	8 mothers with 'healthy' children, 13 mothers with 'allergic' children. 11 repeat interviews of allergy mothers	13 children with eczema and/or food allergy aged 1 year old. Repeat interviews when 2 years	Semi-structured Interviews	Deductive content analysis	16
9	Williams, Gannon, & Soon (2011) UK	To explore the experiences of young people with EB	Purposive-recruited via centre where received medical treatment	EB	11 participants aged 10-14 years, median 12 years. 6 male. 1 Black British, 2 British Asian, 8 WB	C/YP are participants (see previous column)	Semi-structured interviews (15-70 minutes)	IPA	16

No.	Study and country of origin	Aim	Sampling	Skin Condition	Participants	Children	Data Collection	Analysis Method	CASP score (out of 18)
10	Cheung & Lee (2012) Hong Kong, China	To describe Chinese mothers' experiences of caring for their children who are living with eczema	Purposive	Eczema	9 Chinese mothers aged 30-45 years. Cantonese speakers	Aged 2-14 years	Semi-structured interviews (45-90 minutes)	IPA	16
11	Santer et al. (2012) UK	To explore parents' and carers' views of childhood eczema and its treatment	Purposive-invited by primary care staff	Eczema	27 mothers, 4 fathers. Age median 36 years, range 26-46 years. 25 WB, 3 black/Asian British, 2 white non British, one mixed heritage British	Aged 7 months- 5 years	Semi-structured interviews (30-60 minutes)	Constant comparative approach	15
12	Santer et al. (2013) UK	To explore parents' and carers' experiences of barriers and facilitators to treatment adherence in childhood eczema	As above	Eczema	As above	As above	Semi-structured interviews (30-60 minutes)	Content analysis using a constant comparative approach	16

Note. C/YP, children and young people; ASP, Critical Appraisal Skills Programme Checklist; WB, White British; EB, epidermolysis bullosa; IPA, Interpretative Phenomenological Analysis; Shaded studies, from child perspective

Supplementary materials showing CASP rating for each paper

Paper	1. Was there a clear statement of the aims of the research?	2. Is qualitative method appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	Score out of 18
Elliott & Luker (1997)	Yes	Yes	Yes	Yes: Purposive	Partly: written accounts*	Not explicitly stated	Not stated	Yes	Yes	13
Chamlin et al. (2004)	Yes	Yes	Yes	Yes: Purposive	Yes: clear outline of questions	Not explicitly stated	Partly: regarding consent but not ethical approval	Yes	Yes—but only effects mentioned by 20%+ families reported	14
Gore et al. (2005)	Yes	Yes	Yes	Yes: Purposive	Yes	Not explicitly stated	Yes	Yes	Yes	16
Fox et al. (2007)	Yes	Yes	Yes	Yes	Yes: online focus groups justified and explained	Not explicitly stated	Yes	Yes	Yes	16

van Scheppingen et al. (2008a)	Yes	Yes	Yes	Yes: Purposive	Yes: clear outline of interview schedule development	1.Partly- Notes made on interviewer-child interaction*	Yes	Yes	Yes	17
van Scheppingen et al. (2008b)	Yes	Yes	Yes	Yes: Purposive	Yes: clear outline of interview schedule development	1.Partly- Notes made on interviewer-parent interaction	Yes	Yes	Yes	17
Smith et al. (2010)	Yes	Yes	Yes	Yes- Purposive, although ?group composition	Yes: outline of questions asked in focus group	Not explicitly stated	Yes	1.Included use of 2nd coder, although no raw data included	Yes	15
Alanne et al. (2011)	Yes	Yes	Yes	Yes-described as convenience, but purposive sampling of 'allergic' children	1. Very brief outline of questions	1.Partly- researcher kept reflexive log, but no explanation of how reflections were used	Yes	Yes	Yes	16

Williams et al. (2011)	Yes	Yes	Yes	Yes: purposive	Yes- brief explanation of interview schedule preparation	Not explicitly stated	Yes- ethical approval and consent/assent use stated	Yes- in depth explanation of IPA and audit	Yes	16
Cheung & Lee (2012)	Yes	Yes	Yes	Yes: purposive	Yes- brief outline of questions used	Not explicitly stated	Yes- ethical approval stated and consent gained	Yes- in depth explanation	Yes	16
Santer et al. (2012)	Yes	Yes	Yes	Yes: purposive	Yes- very brief description of interview method	Not explicitly stated	1. Ethical approval but not about consent from participants	Yes- brief description	Yes	15
Santer et al. (2013)	Yes	Yes	Yes	Yes: purposive	Yes- outline of interview schedule although no explanation of design	Not explicitly stated	Yes	Yes- in depth, plus rigour discussion	Yes	16

* Discrepancy noted between researcher and individual conducting audit (by 1 point for each case). Agreement reached through discussion

