Views and experiences of managing eczema

DOI:
10.1111/bjd.19299

Document Version
Final published version

WILEY

Janssen-Sponsored Satellite Symposium at the 30th EADV Virtual Congress 2021

The art of joint forces: crafting psoriatic arthritis care for dermatologists

This virtual satellite symposium will focus on the necessity for practicing dermatologists to understand the burden of psoriatic arthritis in patients with psoriasis. It will emphasize how important it is that dermatologists detect early signals of psoriatic arthritis in patients with psoriasis and also understand why targeting IL-23 directly can be effective in treating and potentially also preventing the development of psoriatic arthritis for their psoriasis patients

Janssen Immunology

PHARMACEUTICAL COMPANIES OF Johnson & Johnson

CP-255722

SYSTEMATIC REVIEW

BJD
British Journal of Dermatology

Views and experiences of managing eczema: systematic review and thematic synthesis of qualitative studies*

E. Teasdale[1] I. Muller,[1] K. Sivyer,[2] D. Ghio,[1] K. Greenwell,[2] S. Wilczynska,[1] A. Roberts,[3] M.J. Ridd,[4] N. Francis,[1] L. Yardley,[2,5] K.S. Thomas[6] and M. Santer[1]

[1]Department of Primary Care, Population Science and Medical Education, Faculty of Medicine and [2]Centre for Clinical and Community Applications of Health Psychology, University of Southampton, Southampton, UK
[3]Patient and Public Contributor, Nottingham, UK
[4]Department of Population Health Sciences and [5]School of Experimental Psychology, University of Bristol, Bristol, UK
[6]Centre for Evidence Based Dermatology, University of Nottingham, Nottingham, UK

Linked Comment: Capozza. Br J Dermatol 2021; **184**:587–588.

Summary

Background The number of qualitative studies on eczema has increased rapidly in recent years. Systematically reviewing these can provide greater understandings of people's perceptions of eczema and eczema treatments.
Objectives We sought to systematically review and thematically synthesize qualitative studies exploring views and experiences of people with eczema and parents/carers of children with eczema.
Methods We searched MEDLINE, EMBASE, PsycINFO and CINAHL from the earliest date available to February 2019. We selected papers focusing on views and experiences of eczema and eczema treatments, and barriers/facilitators to eczema self-management. We excluded papers focusing on health service provision models or health professionals' views.
Results We synthesized 39 papers (reporting 32 studies) from 13 countries. We developed four analytical themes: (1) Eczema not viewed as a long-term condition; (2) Significant psychosocial impact not acknowledged by others; (3) Hesitancy (patient/carer uncertainty) about eczema treatments; and (4) Insufficient information and advice. Our findings suggest that people with eczema and their carers experience frustration at having to manage a condition that is often seen by others as mundane but has significant psychosocial impact and is difficult to manage due to concerns about, and burden of, treatment. This frustration can be exacerbated by experiences of conflicting and/or insufficient information and advice from health professionals, family and others.
Conclusions Effective self-management of eczema could be supported by addressing beliefs and concerns about treatments; seeking positive ways to promote a 'control not cure' message; acknowledging psychosocial impacts of eczema and treatment burden; and providing clear consistent advice or signposting towards reliable information.

What is already known about this topic?

- Eczema is a common skin condition that can have a substantial impact on quality of life.
- One of the most common causes of treatment failure in mild-to-moderate eczema is the underuse of topical treatments.
- Increasingly, qualitative approaches have been adopted to understand people's views and experiences of eczema and eczema treatment, which can help to address common barriers and support effective self-management.

Correspondence
Emma Teasdale.
Email: e.j.teasdale@soton.ac.uk

Accepted for publication
3 June 2020

Funding sources
This study presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research programme (grant ref. no. RP-PG-0216-20007). M.J.R. was funded by a Post-Doctoral Research Fellowship from the NIHR (PDF-2014-07-013). The views expressed are those of the authors and not necessarily those of the National Health Service, the NIHR or the Department of Health and Social Care.

Conflicts of interest
The authors declare they have no conflicts of interest.

Review registration
The protocol for this systematic review was registered on PROSPERO (CRD42018110496) on 21 September 2018.

*Plain language summary available online

DOI 10.1111/bjd.19299

What does this study add?

- We found a large volume of qualitative studies giving valuable insights into people's perceptions of eczema.
- Synthesizing these studies highlights many recurring themes and adds further insights, for instance different perceptions between adults with eczema and parents of children with eczema on its long-term nature.
- Eczema can be difficult to manage due to treatment hesitancy and burden and misperceptions about the long-term nature of eczema.
- Hesitancy or concern about eczema treatments is made worse by insufficient and inconsistent information and advice.

What are the clinical implications of the work?

- Health professionals need to address common treatment beliefs and concerns and seek positive ways to promote a 'control not cure' message to support effective ongoing self-management.
- Acknowledging the significant psychosocial impacts of eczema and burdensome nature of treatment and providing clear consistent information and advice or signposting towards credible information may address people's concerns that distress caused by the condition is not taken seriously.

Eczema is common and can have substantial impact on quality of life due to itch and sleep disturbance.[1] Eczema management involves applying topical treatments and avoiding triggers (e.g. soap).[2] National Institute for Health and Care Excellence guidance[2] suggests the main cause of treatment failure is due to the underuse of topical treatments.[3] Treatment usage is related to people's understanding of their condition and its treatment, as well as their perceived need for treatments and concerns about any negative effects.[4] Surveys have found that people with eczema worry about using topical corticosteroids,[5,6] yet relatively little is known about the reasons behind this.

Qualitative research seeks to gain a comprehensive understanding of people's lived experiences of a condition. Greater understanding of their perspectives on treatments may help to promote a 'shared understanding' and identify narratives that could mitigate against increasingly polarized views about eczema treatments that have emerged between patients/carers and health professionals.[7,8]

Synthesizing the results from existing qualitative research studies helps to generate new valuable insights into people's beliefs and concerns, and their support and information needs.[9,10] We aimed to synthesize existing qualitative studies exploring the views and experiences of eczema and eczema management among people with eczema and parents/carers of children with eczema.

Methods

Thematic synthesis was used to synthesize the review findings.[11] We followed the ENTREQ statement[12] to facilitate reporting.

Selection criteria and search strategy

We included papers that focused primarily on the views and experiences of eczema and eczema treatments, and barriers/facilitators to eczema self-management. To be eligible for inclusion, studies must have used qualitative data collection and analysis methods. Mixed methods studies were included if they had a substantive qualitative component. Papers that focused solely on health service provision models or the views/experiences of health professionals were excluded (Table 1).

Five electronic databases were searched using a comprehensive search strategy (Table S1; see Supporting Information): MEDLINE (1946 to week 2 of February 2019); EMBASE (1980 to 27 February 2019); PsycINFO (1887 to week 3 of February 2019) and CINAHL (1982 to week 4 of February 2019). The last search was conducted on 27 February 2019. There were no language or date restrictions. We reviewed the references of each included paper, conducted forward citation tracking and contacted experts in the field to identify other eligible papers. Multiple papers from a single study were included if each presented unique data. Two eligible studies (published in German and Korean) were translated into English by a professional translator. Three authors independently screened all titles and abstracts against the inclusion criteria (E.T., N.F. plus either S.W. or I.M.).

Comprehensiveness of reporting

Two authors (E.T., D.G.) and two student research assistants (N.W., L.S.) independently extracted data and appraised the reporting quality of identified studies. We used the COREQ (Consolidated Criteria for Reporting Qualitative Research)[13]

Table 1 Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Population of interest	Children with eczema Young people with eczema Parents/carers of children with eczema Adults with eczema	Health professionals' views only
Exposure of interest	*Eczema and eczema self-care* • Eczema • Emollient use • Topical corticosteroid use • Topical calcineurin inhibitor use • Avoidance of triggers • Emotional/stress management • Reducing scratching • Psychosocial impact of eczema only • Accessing health services, treatment, dealing with healthcare professionals	Models of health service provision
Outcome of interest	Patients and parent/carers' beliefs, views, concerns, understandings and experiences	
Study design	Qualitative (including ethnography, grounded theory, phenomenology, focus groups, interviews and participant observation) Mixed methods	Quantitative Reviews Not primary research

checklist to systematically examine the comprehensiveness of reporting to judge the trustworthiness and transferability of the studies. Any discrepancies were resolved by consensus. No studies were excluded on grounds of quality.

Thematic synthesis

We imported the findings from each paper (including participants' data and author interpretation of findings) into NVivo version 12. Thematic synthesis[11] comprises three distinct stages: line-by-line coding, developing descriptive themes from initial codes and generating analytic themes that 'go beyond' the descriptive themes. One author (E.T.) conducted line by line coding then compared and categorized initial codes to create a set of descriptive themes that represented the content and meaning of the individual studies. A detailed coding manual ensured transparent and systematic data coding. Coding, descriptive themes and subthemes were discussed with, and iteratively developed by, coauthors (M.S., A.R., M.J.R., K.S.T., L.Y., K.S., D.G., K.G.) to offer diverse inferences and interpretation of the data, and to facilitate the generation of analytic themes.

Results

Our searches yielded 2241 records (1569 after duplicates removed). Eligibility screening identified 39 papers reporting 32 studies for inclusion (Figure 1).

Study characteristics and comprehensiveness of reporting

The included studies explored the views and experiences of 1007 participants including 405 parents/carers of children with eczema, 252 people with eczema and 350 online forum users. Study characteristics are presented in Table S2 (see Supporting Information).[14–52] The comprehensiveness of reporting was mixed. Participant selection, setting, data analysis and findings were well reported, while interviewer characteristics and relationship with participants were poorly reported (Table S3; see Supporting Information).[14–52]

Synthesis of findings

Our synthesis identified four overarching analytical themes: (1) Eczema not viewed as a long-term condition; (2) Significant psychosocial impact of eczema not acknowledged by others; (3) Hesitancy (patient/carer uncertainty) about eczema treatments; and (4) Insufficient information and advice about eczema (Figure 2). Table 2 presents quotes from study participants to illustrate each theme and subtheme.[18,20,21,27,28,30,32,33,37,39–42,50,51] Further theme tables are provided in Table S4 (see Supporting Information).[14–52]

Eczema not viewed as a long-term condition

A common perception highlighted in the synthesis was that people with eczema often do not view eczema as a chronic condition requiring long-term treatment. Research with parents and children identified hopes of outgrowing eczema and/or experiences of being told they would outgrow eczema. Participants hoped to discover an underlying cause of eczema to 'cure' eczema, which further contributed to a perception of eczema as short term. This had implications for the perceived necessity of long-term treatment and was linked with frustration at the perceived 'simplicity' of eczema management in targeting symptom control rather than underlying causes.

Desire to seek an underlying cause and potential 'cure' for eczema

A diverse range of beliefs about underlying causes of eczema was reported, including exogenous factors (dietary allergens, chemicals, medication and water type) and endogenous factors (genetic disposition, stress/psychological factors). A common belief among families was that dietary avoidance might represent a potential 'cure'; many described having tried this and described frustration with healthcare professionals' perceived lack of interest in exploring dietary causes.[14,18,21–23,26,28,31,32,41,50–52]

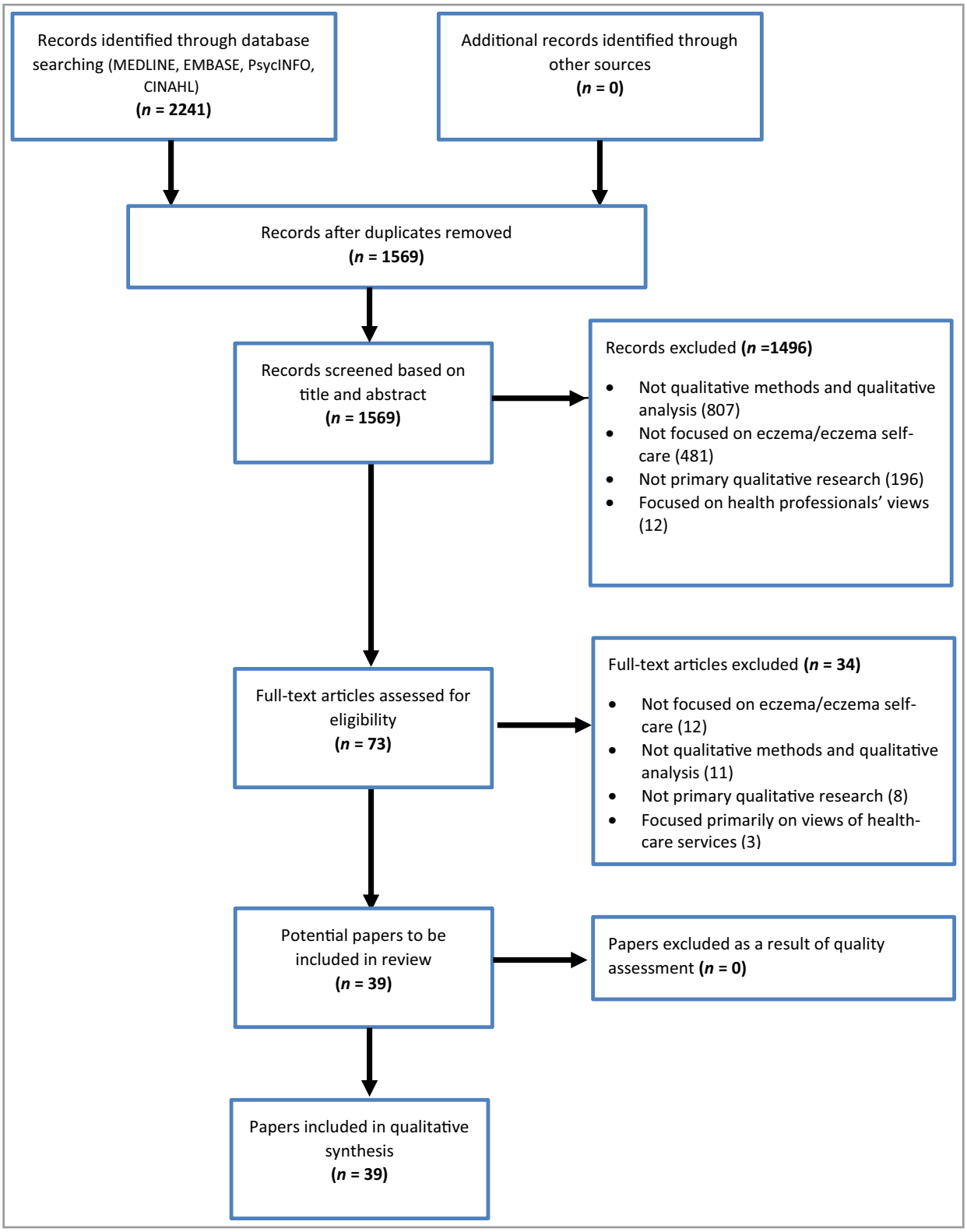

Figure 1 PRISMA flowchart for systematic review and qualitative synthesis.

Frustration at perceived simplicity of eczema treatment

Frustrations were identified with treatments viewed as only 'controlling' eczema rather than providing a 'cure'.[27,31,33,37,40] One study[37] outlined a paradox of complexity and simplicity, whereby living with eczema is experienced as complex in terms of impact and treatment burden, but people perceive that they are offered only simple 'Band-Aid' solutions that do not treat

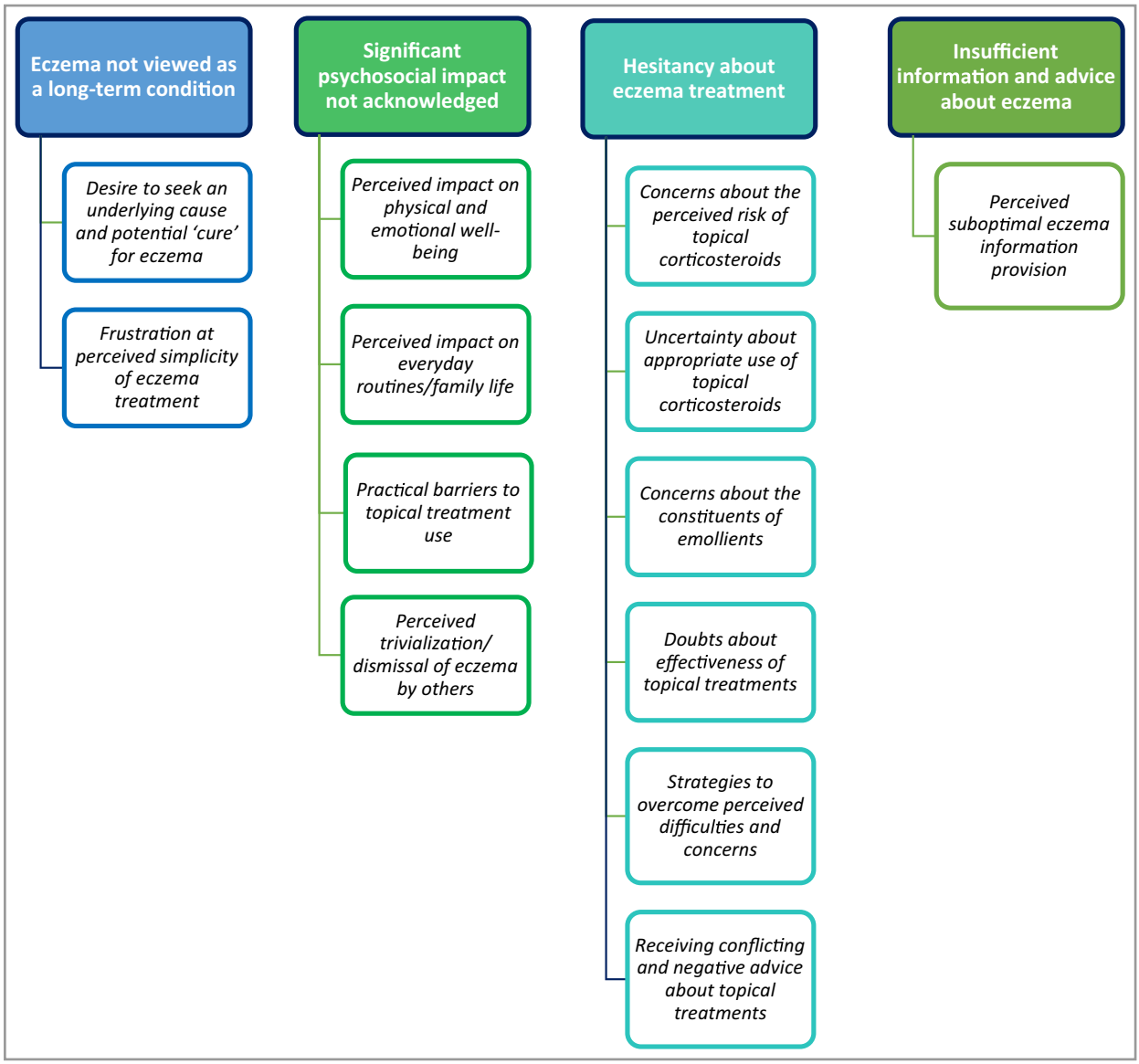

Figure 2 Components of key themes.

the underlying cause. Such beliefs represent potential challenges to adherence to long-term eczema treatments.

Significant psychosocial impact of eczema not acknowledged by others

People across studies were frustrated at the lack of recognition and acknowledgment by both health professionals and wider society of the significant physical and emotional impacts of eczema on people with eczema and their families.

Perceived impact on physical and emotional wellbeing

Physical impacts of eczema commonly described across studies were persistent itch, pain and discomfort due to dry skin, chronic sleep disruption for people with eczema, and parental exhaustion from attending to their child's needs at night.

Significant emotional impacts of eczema were experiencing distress, low mood and self-esteem due to feeling stigmatized and self-conscious about their appearance and feeling that they do not fit a societal ideal of 'perfect' skin, and the resultant effect this can have on relationships. Studies also highlighted the negative effect of dealing with others' perceptions and distress experienced in response to intrusive comments or reactions by strangers to visible eczema, such as fear of contagion. A sense of blame, guilt and worry were common, especially parental feelings of inadequacy in their ability to prevent the eczema, envy of other parents with perceived 'normal' children and fears and concerns about the impact on their child's self-esteem and social interactions.[16–18,21,23,26–28,33,36,38,41,42,44,45,47–51]

Table 2 Illustrative quotes by theme

Theme and subtheme	Representative quotes
Eczema not viewed as a long-term condition	
Desire to seek an underlying cause and potential 'cure' for eczema	'The condition of my AE child is getting worse. I try my best to relieve his suffering. Some mothers have told me that the chlorine in the water supply and the water pipes affects AE. So, I replaced the water pipes and use a filter, and his condition is getting better now.'[18]
	'I just, I wanted to know really why was she getting it, was it diet orientated because it seemed to crop up at the same time as I was weaning her, and I thought she might have an allergy to milk or, you know that milk I was using, or perhaps some of the, the fabric conditioners or, you know, or the baby bath I was using, something like that.'[21]
Frustration at perceived simplicity of eczema treatment	'The frustrating thing with TCs [topical corticosteroids] is that they don't really treat the disease. They provide relief but they don't heal.'[40]
	'I don't like that it only treats the symptoms and not the cause of the problem.'[33]
Significant psychosocial impact of eczema not acknowledged by others	
Perceived impact on physical and emotional wellbeing	'She hardly got any sleep, she scratched herself, and she was at a point where she couldn't keep up at school. She was totally exhausted, which affected her mood.'[42]
	'I sometimes feel so ugly when everything is stuck together, I am like a monster. I don't want anybody to see me and I don't want to go out.'[51]
Perceived impact on everyday routines/family life	'There are many things which you have to give up. That is, I liked knitting and I liked to cook and make pickles and jam. I was very, you know, active with my hands. I don't bother to do these things anymore because it's far too troublesome.'[37]
	'The very fact the she does not sleep means that we very rarely go out. The few occasions we do go out K's grandma will baby-sit, but this [is] extremely tiring for her and therefore we do not ask often'[19]
Practical barriers to topical treatment use — Child resistance — Time-intensive nature of eczema treatment — Difficulties of using topical treatments outside of home environment	'It is very difficult to apply the cream to my son as he always fights with me and runs away from me when I am trying very hard to keep his skin moist. Sometimes I have to wait and apply the cream at 2 am when he is asleep.'[18]
	'If I was having a bad day and it would take 2 hours in the morning just to cream her up and to get the routine done, it was just . . . I was so exhausted and you've still got to do everything else and life and fit it all in. It could be quite hard. . .'[28]
	'I think [the daycare providers are] limited on what they can and can't do for a child with eczema during the day. . . . That's one of the most problems I have . . . to keep shine to her, you have to apply lubrication all day.'[20]
	In spite of relevant precautions at work, one participant had an eruption, interpreted as work-related, from touching a door handle where a colleague could have left residue of the allergen. 'One can't control other people's actions [. . .] no matter how many labels you read [. . .].'[37]
Perceived trivialization/dismissal of eczema by others	'There's nobody else and they don't understand how it is [. . .] They don't even believe before they see it, my coach thought I was exaggerating.'[51]
	[Health professionals say] 'No, no it's just dry skin', 'Oh, it's just eczema'. I don't think they realize how much children can suffer from it.'[21]
	'And then it got to the point where my mother actually took her in because I was getting nowhere with the doctor, he kept on fobbing me off with rubbish, you know, "She'll grow out of it", yeah but that doesn't help now.'[27]
Hesitancy about eczema treatment	
Concerns about the perceived risk of topical corticosteroids	'It makes your skin wither . . . Will they tell you later on that you shouldn't use D . . . fear that in a few years it could give you something . . . that we don't know about for now . . . medicine evolves.'[40]
	'My baby started getting eczema over the last month or so. My GP suggested [leave-on emollient] and I am using loads of it, but I don't think it's doing anything. I asked the GP if there's anything else I can try because I thought it might be worth trying a mild steroid cream, but my doctor advised against it because the risks (skin thinning) outweigh the benefits.'[32]
Uncertainty about appropriate use of topical corticosteroids	'I did ask once what exactly is a thin layer?'[33]
	'I guess the question is when to use steroids. The doctors always said to only use them for a few days at a time. When a patch flares up the steroids generally help within a few days, but then we find that another small patch has flared up somewhere else on his body so we end up using the cream for ages but in different places if that makes sense.'[32]

(continued)

Table 2 (continued)

Theme and subtheme	Representative quotes
Concerns about the constituents of emollients	'My son uses emulsifying ointment as a protective layer for his skin. My approach would be different if it were made of a different substance. Some are made from natural materials but some are chemical products. I can distinguish between the two just by smelling!'[18] '... I'm not into kind of putting loads of chemicals on them if I can possibly avoid it, which is why I think in the end my solution was if it's really bad I'll use the cream but otherwise I'll just stay away from anything I put on his skin and look at diet first and then kind of consider that.'[27] 'Sometimes it's annoying, especially in the morning, because greasy spots appear in my trouser due to the creams.'[50] '... the other creams, we had a couple, I think it was E [ointment], I'm not sure, but it was really thick, like Vaseline [ointment], they were quite difficult – they're really thick, greasy, really hard to apply, 'cos that ruined loads of clothes, so you had to wash things. That was quite hard work at the beginning, I'd say.'[30]
Doubts about effectiveness of topical treatments	'Sometimes we are advised to use steroids for x long ... then as soon as it stops everything flares up again. Not a long-term solution really.'[41] 'At this moment, I feel like the effect is becoming weaker. Because as soon as I start to reduce the amount, it comes straight back.'[33]
Strategies to overcome perceived difficulties and concerns — Distraction, disguising treatment — Establishing a daily routine — Personal adjustment of treatment regimes	'I usually rub it on and let it dry for 2 seconds. [...] rub it on sort of like in a car wash. Apply polish and dry.'[39] 'Well, not everyone feels like this, right. I think it's a habit, but with the mobile phone you can set more than one alarm. I have begun to set it thrice a day. At least in the evening, because then the phone hoots even if you have gone to bed. Well – put on the cream and the gloves.'[37] 'I don't apply it until my comfort threshold has been exceeded and I'm all red and it itches all over.'[40]
Receiving conflicting and negative advice about topical treatments	'I saw this one doctor who said that we should use the [mild topical corticosteroid] on red inflamed skin and that we should use [potent topical corticosteroid] anywhere where the skin is actually broken. But then I saw another GP who told me not to use [potent topical corticosteroid] unless it is really bad because it is so strong and it would damage the skin. Could anyone please give me a clear answer about when I should use an emollient, or a mild steroid or a stronger steroid?'[32] 'I was disappointed when the paediatrician said, "It's nothing serious, but unfortunately, we'll have to use cortisone." When he said "unfortunately"...'[40]
Insufficient information and advice about eczema	
Perceived suboptimal eczema information provision	'I just wish that the GP at the beginning had recognized it more quickly and explained more about the importance of emulsifying and, erm, proper use of the hydrocortisone really, that's the one thing that stands out.'[21] 'It would be good if they showed you how to apply the cream, when collecting it for the first time.'[50] 'I kind of feel that ... it's not come back in, say, 2 months' time and we'll review whether it's making a difference or not ... I have felt some of the time that I'm making it up as I go along ...'[27]

GP, general practitioner

Perceived impact on everyday routines/family life

Participants commonly reported changing behaviours and modifying everyday routines in response to eczema symptoms, in a desire to avoid potential irritants and adhere to treatment regimes.[14–20,23,34,37,51] Studies highlighted participants' experiences of restricting social activities, work activities or career choices to prevent flare-ups. In contrast, a desire to live an 'ordinary' life and not let eczema impact on routines or behaviours was evident in some studies.

As well as restricting or giving up certain activities, a common impact among parents was dealing with the extra burden on daily life of caring for a child with eczema.[14–20,23,34] Many parents described carrying out extra tasks to manage their child's eczema, e.g. applying topical treatments, extra washing and cleaning, buying particular clothing.

Practical barriers to topical treatment use

Treatment burden and its impact on people with eczema and family life was apparent along with a sense that this burden was not acknowledged by others.[14,15,18,20,28,37,41,49,50] A dominant experience was around perceived difficulties in applying topical treatments, particularly due to its time-intensive nature and

among parents of younger children, the challenge of child resistance due to discomfort/pain/stinging or 'just being a toddler'. Some studies found that the burden of treatment related more broadly to additional activities needed to manage eczema: 'just something else you have to remember to do', e.g. always being alert to avoiding possible triggers. These were viewed as energy- or time-consuming, resulting in less attention given to other children and/or family members. Parents also found it difficult to maintain treatment routines outside the home as they felt that their childcare or school was ill-equipped to manage treatment routines and avoid triggers.

Perceived trivialization/dismissal of eczema by others

A dominant belief was that eczema is misunderstood or dismissed as trivial by health professionals, friends, family and wider society as 'just a bit of dry skin'.[16–18,21–23,25–27,31,43–49,51] Some studies highlighted how parents felt that family and friends normalized sleep loss as being a normal part of parenting, failing to recognize chronic sleep loss as related to eczema. Others highlighted the perception that eczema is viewed in society as a mundane, insignificant condition, common in childhood (i.e. most people know a child who has it mildly) and as such it is something that people should 'cope' with. This was linked to accounts of family, friends or strangers giving unsolicited advice about eczema.

Hesitancy (patient/carer uncertainty) about eczema treatments

Many studies reported common concerns, doubts and perceived difficulties around eczema treatment, reflecting an implicit caution and uncertainty about topical treatments, particularly topical corticosteroids, and a general hesitancy towards regular or long-term treatment. This hesitancy seemed to be exacerbated by having received negative or conflicting advice about topical treatments from health professionals and significant others.

Concerns about the perceived risk of topical corticosteroids

A dominant concern was that using topical corticosteroids can lead to skin damage, particularly skin thinning and possibly other long-term negative effects, e.g. weakened bones, weight gain and delayed growth. These seemed to be influenced by a shared belief or social discourse that topical corticosteroids should be treated with caution and apprehension.[20,27,31–33,38,40] Some studies highlighted how participants felt their concerns had been reinforced by negative attitudes of health professionals and significant others delivering messages such as the 'risks of topical corticosteroid use outweigh the benefits'. Despite such concerns, some studies found that while people were concerned about potential risks, they found topical corticosteroids helpful/effective in managing their eczema and saw them as a 'necessary evil'.

Uncertainty about appropriate use of topical corticosteroids

Participants reported a lack of confidence and low self-efficacy in applying topical corticosteroids. This was related to uncertainty and confusion about the appropriate use of topical corticosteroids in terms of dosage (e.g. strength/potency of different preparations), where to apply, when to use, duration of use and what constitutes a 'thin layer'.[27,31–33,40]

Concerns about the constituents of emollients

Some studies highlighted people's concerns about the constituents of emollients, the unpleasant feel (thick, greasy, messy) and odour of emollients and their uncertainty/confusion about the range and choice of different emollients.[14,15,18,20,26–28,30,32,33,37,39,41,42,49,50] Some participants felt that emollients are unnatural products containing chemicals and expressed a desire for more 'natural' creams that they deemed to be safer, or other treatments for eczema such as special clothing. Other studies identified people's mixed feelings towards the range of different emollients creams and resultant process of 'trial and error' in finding the 'right' cream.

Doubts about effectiveness of topical treatments

Many participants expressed doubts about topical treatments as being 'just some creams' and perceived them as ineffective or even that they make the eczema worse. Some studies highlighted a belief around becoming 'resistant' to both emollients and topical corticosteroids if used regularly or over the long term (i.e. skin becomes 'used to' treatment and treatments lose effectiveness). Topical corticosteroids were frequently viewed as effective only in the short term. A common frustration was that once you stop using them, the eczema just flares up again, causing some to worry about 'dependency'. In contrast, some studies highlighted the perceived effectiveness of topical corticosteroids in terms of symptom relief and the belief that topical corticosteroids are safe and effective if used correctly and that uncontrolled eczema is a greater threat to skin than treatment.[26,27,31–35,37,38,41,52]

Strategies to overcome perceived difficulties and concerns

As well as highlighting perceived difficulties, some studies proposed strategies to address difficulties and help facilitate topical treatment use.[15,18,20,25,26,28,30] One study[28] described a range of responses that families adopted to overcome their child's resistance to topical treatments including involvement of the child in treatment; distraction or games; using 'bribes' and, in a few cases, force. Other studies highlighted general beliefs about what may make eczema treatment times easier, such as establishing a routine, i.e. sticking to daily treatment times to establish habits and finding the right treatment by trial and error, i.e. discovering what works for the person

with eczema in terms of effective, convenient topical treatments that fit with daily life.

Some studies found that participants tried to make personal adjustments/'do their own thing' (e.g. reducing dose) to help mitigate their concerns and uncertainty about topical treatments.[37–40,42,50–52] Modifications to treatment regimens included using creams that are less strong (or perceived to be less strong), delaying the application of topical corticosteroids for as long as possible and reducing the frequency of emollient application. Although modifying treatment regimes may lead to a sense of increased confidence and self-efficacy, it may contribute to the underutilization of topical treatments and poor eczema control.

Receiving conflicting and negative advice about topical treatments

Our synthesis revealed common experiences of receiving conflicting advice (contradictory opinions) and/or negative opinions from health professionals regarding topical treatments, especially around the safe use of topical corticosteroids.[15,20,21,26,27,29,32,33,39,40] Conflicting advice was received from different health profession specialties (e.g. primary care, paediatrics, dermatology, pharmacology), from different individuals within the same specialty (e.g. different general practitioners), or between health professionals and other sources (e.g. product information leaflets and medical websites). This seemed to exacerbate concerns and uncertainty about applying topical corticosteroids, which is likely to influence treatment use. Some studies suggested that conflicting advice can lead people to seek information and advice elsewhere, such as online, despite their doubts about the credibility of online information, which may add confusion.

Insufficient information and advice about eczema

Information and support provided by health professionals was commonly seen as suboptimal in terms of quantity, detail and timing. Our synthesis highlighted participants' desire to have more up-to-date, personalized information about treatment, identifying flare-ups, and other aspects of living well with eczema (e.g. strategies to reduce itch) as well as practical advice around applying topical treatments, including demonstrations from health professionals.[16,18,21,24–27,29–31,33–35,39,42,43,50]

Participants typically expressed a desire for patient-centred management of eczema or shared decision-making. However, one study[42] noted that in the absence of sufficient eczema information, provision and support can be experienced negatively, with participants experiencing 'involuntary autonomy', i.e. feeling 'left to your own devices' and having to self-manage by default.

Discussion

Our evidence synthesis highlights that people living with eczema, particularly young people and parents of children with eczema, often do not see eczema as a long-term condition. People are cautious about topical treatments for eczema, especially topical corticosteroids and this appears to be exacerbated by experiences of conflicting and inconsistent advice from health professionals and others. People with eczema and their carers feel frustrated when others view eczema as mundane, insignificant or 'easy', while it has significant psychosocial impact.

In terms of the strengths and weaknesses of our study, this systematic review and synthesis of qualitative studies provides a comprehensive overview of a sizeable qualitative literature on eczema and valuable insights into views and experiences of managing eczema from the perspective of children and adults with eczema, and parents/carers of children with eczema. We used rigorous systematic review methods and identified many well-reported studies from different countries. Key themes were reported across many of the papers, suggesting that our findings are robust. Valuable input from patient contributors and the multidisciplinary team enabled a comprehensive interpretation of findings.

We included only studies from peer-reviewed journals and did not search the grey literature. We did not apply any language restrictions to our search and included some non-English-language papers, but we might have missed relevant papers not recorded on English-language databases. As with other reviews, we are limited to data in the included primary studies, which were predominantly conducted in European countries. The synthesis process is inherently interpretive, and this synthesis presents one possible interpretation of the data. Our study was undertaken as part of a larger project to develop online resources to support eczema self-care, which may have influenced our interpretations. Another research team would likely generate a different interpretation.

In comparison with other studies, our findings are supported by a previous synthesis of qualitative studies of treatment adherence, which suggests that people dislike taking regular medication or treatment on a long-term basis as it reminds them of the chronicity of their illness, which many do not accept.[53] It may be that the perception of needing to limit the use of other types of medication, such as antibiotics (due to antibiotic resistance), may fuel people's general reluctance to taking medication and so clear, consistent advice about eczema treatments is needed.

It is interesting to note that it was often parents and young people who focused on a 'cure' for eczema. It is likely that adults with eczema had been living with the condition for longer and had more experience of its long-term and fluctuating nature. Commonly reported messages around 'you or your child will grow out of it' can feel like dismissal, especially when mismatched with actual experiences. Traditional clinical teaching promotes eczema as primarily a childhood condition that generally remits by 10–12 years of age.[54] However, recent research suggests that this may not be true for many.[55] Managing expectations accordingly might help to reduce disappointment for those who don't grow out of it.[56]

In conclusion, much qualitative research on eczema has focused on the views and experiences of adults and

parents/carers. Although more recent research has shed light on the impact of eczema on children,[57] further research is needed from the perspective of children and young people. There is a need for health professionals to address beliefs and concerns about eczema treatments, address the significant psychosocial impacts of eczema and burdensome nature of treatments, including practical, clear, consistent advice about treatments and strategies to overcome perceived difficulties.

Acknowledgments

We would like to thank our voluntary student research assistants, Niamh Wood and Laura Smith, for helping with the data extraction process and quality assessment. The research programme of L.Y. is partly supported by the NIHR Southampton Biomedical Research Centre.

References

1 Chamlin SL, Frieden IJ, Williams ML *et al.* Effects of atopic dermatitis on young American children and their families. *Pediatrics* 2004; **114**:607–11.
2 NICE. *Clinical Guideline 57. Atopic Eczema in under 12s: diagnosis and management*. London: National Institute for Health and Care Excellence, 2007.
3 Bass AM, Anderson KL, Feldman SR. Interventions to increase treatment adherence in pediatric atopic dermatitis: a systematic review. *J Clin Med* 2015; **4**:231–42.
4 Horne R, Chapman SC, Parham R *et al.* Understanding patients' adherence-related beliefs about medicines prescribed for long-term conditions: a meta-analytic review of the Necessity-Concerns Framework. *PLoS ONE* 2013; **8**:e80633.
5 Charman CR, Morris AD, Williams HC. Topical corticosteroid phobia in patients with atopic eczema. *Br J Dermatol* 2000; **142**:931–6.
6 Fischer G. Compliance problems in paediatric atopic eczema. *Australas J Dermatol* 1996; **37** (Suppl. 1):S10–13.
7 Santer M, Roberts A. Diverging views on eczema treatments – promoting shared understanding between doctors and patients. *The BMJ Opinion* 2019 (17 October). Available at: https://blogs.bmj.com/bmj/2019/10/17/diverging-views-on-eczema-treatments-promoting-shared-understanding-between-doctors-and-patients/ (last accessed 18 June 2020).
8 Perera K, Timms H, Heimans J. New power versus old: to beat antivaccination campaigners we need to learn from them – an essay by Kathryn Perera, Henry Timms, and Jeremy Heimans. *BMJ* 2019; **367**:l6447.
9 Ring NA, Ritchie K, Mandava L, Jepson R. *A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews*. Edinburgh: NHS Quality Improvement Scotland, 2011.
10 Seers K. What is a qualitative synthesis? *Evid Based Nurs* 2012; **15**:101.
11 Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008; **8**:45.
12 Tong A, Flemming K, McInnes E *et al.* Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012; **12**:181.
13 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; **19**:349–57.
14 Alanne S, Laitinen K, Soderlund R *et al.* Mothers' perceptions of factors affecting their abilities to care for infants with allergy. *J Clin Nurs* 2012; **21**:170–9.
15 Alanne S, Laitinen K, Paavilainen E. Living ordinary family life with an allergic child – the mother's perspective. *J Ped Nurs* 2014; **29**:679–87.
16 Angelhoff C, Askenteg H, Wikner U *et al.* 'To cope with everyday life, I need to sleep' – a phenomenographic study exploring sleep loss in parents of children with atopic dermatitis. *J Ped Nurs* 2018; **43**:e59–65.
17 Chamlin SL. The psychosocial burden of childhood atopic dermatitis. *Dermatol Ther* 2006; **19**:104–7.
18 Cheung WK, Lee RL. Children and adolescents living with atopic eczema: an interpretive phenomenological study with Chinese mothers. *J Adv Nurs* 2012; **68**:2247–55.
19 Elliott BE, Luker K. The experiences of mothers caring for a child with severe atopic eczema. *J Clin Nurs* 1997; **6**:241–7.
20 Fenerty SD, O'Neill JL, Gustafson CJ *et al.* Maternal adherence factors in the treatment of pediatric atopic dermatitis. *JAMA Dermatol* 2013; **149**:229–31.
21 Gore C, Johnson RJ, Caress AL *et al.* The information needs and preferred roles in treatment decision-making of parents caring for infants with atopic dermatitis: a qualitative study. *Allergy* 2005; **60**:938–43.
22 Halls A, Nunes D, Muller I *et al.* 'Hope you find your "Eureka" moment soon': a qualitative study of parents/carers' online discussions around allergy, allergy tests and eczema. *BMJ Open* 2018; **8**:e022861.
23 Kwen H, Shin S. Experiences of stress amongst mothers of preschoolers with atopic dermatitis. *Child Health Nurs Res* 2018; **24**:166–77.
24 Nettleton S, Burrows R, O'Malley L. The mundane realities of the everyday lay use of the Internet for health, and their consequences for media convergence. *Sociol Health Illn* 2005; **27**:972–92.
25 Powell K, Le Roux E, Banks JP *et al.* Developing a written action plan for children with eczema: a qualitative study. *Br J Gen Pract* 2018; **68**:e81–9.
26 Powell K, Le Roux E, Banks J *et al.* GP and parent dissonance about the assessment and treatment of childhood eczema in primary care: a qualitative study. *BMJ Open* 2018; **8**:e019633.
27 Santer M, Burgess H, Yardley L *et al.* Experiences of carers managing childhood eczema and their views on its treatment: a qualitative study. *Br J Gen Pract* 2012; **62**:e261–7.
28 Santer M, Burgess H, Yardley L *et al.* Managing childhood eczema: qualitative study exploring carers' experiences of barriers and facilitators to treatment adherence. *J Adv Nurs* 2013; **69**:2493–501.
29 Santer M, Muller I, Yardley L *et al.* 'You don't know which bits to believe': qualitative study exploring carers' experiences of seeking information on the internet about childhood eczema. *BMJ Open* 2015; **5**:e006339.
30 Santer M, Muller I, Yardley L *et al.* Parents' and carers' views about emollients for childhood eczema: qualitative interview study. *BMJ Open* 2016; **6**:e011887.
31 Smith SD, Hong E, Fearns S *et al.* Corticosteroid phobia and other confounders in the treatment of childhood atopic dermatitis explored using parent focus groups. *Australas J Dermatol* 2010; **51**:168–74.
32 Teasdale EJ, Muller I, Santer M. Carers' views of topical corticosteroid use in childhood eczema: a qualitative study of online discussion forums. *Br J Dermatol* 2017; **176**:1500–7.
33 Veenje S, Osinga H, Antonescu I *et al.* Focus group parental opinions regarding treatment with topical corticosteroids on children with atopic dermatitis. *Allergol Immunopathol (Madr)* 2019; **47**:166–71.
34 Bathe A, Diepgen TL, Matterne U. Subjective illness perceptions in individuals with occupational skin disease: a qualitative investigation. *Work* 2012; **43**:159–69.
35 Drixler K, Luntz E, Wiedemann R *et al.* What motivates patients with atopic diseases to search the internet – a focus group study on expectations and demands. *Hautarzt* 2018; **69**:832–38 [German].

36 Jowett S, Ryan T. Skin disease and handicap: an analysis of the impact of skin conditions. *Soc Sci Med* 1985; **20**:425–9.
37 Mollerup A, Johansen JD, Thing LF. Knowledge, attitudes and behaviour in everyday life with chronic hand eczema: a qualitative study. *Br J Dermatol* 2013; **169**:1056–65.
38 Nørreslet M, Bissell P, Traulsen JM. From consumerism to active dependence: patterns of medicines use and treatment decisions among patients with atopic dermatitis. *Health (Lond)* 2010; **14**:91–106.
39 Waernulf L, Moberg C, Henriksson EW *et al.* Patients' views on care and treatment after phototherapy for psoriasis and atopic eczema including a gender perspective. *J Dermatolog Treat* 2008; **19**:233–40.
40 Le Rhun A, Aubert Wastiaux H, Moret L *et al.* Fears regarding the use of topical corticosteroids in atopic dermatitis: looking at the coping strategies and the role of health care providers. A qualitative study. *Educ Ther Patient/Ther Patient Educ* 2015; **7**:20102.
41 Howells LM, Chalmers JR, Cowdell F *et al.* 'When it goes back to my normal I suppose': a qualitative study using online focus groups to explore perceptions of 'control' among people with eczema and parents of children with eczema in the UK. *BMJ Open* 2017; **7**:e017731.
42 Noerreslet M, Jemec GBE, Traulsen JM. Involuntary autonomy: patients' perceptions of physicians, conventional medicines and risks in the management of atopic dermatitis. *Soc Sci Med* 2009; **69**:1409–15.
43 Cowdell F. Knowledge mobilisation: an ethnographic study of the influence of lay mindlines on eczema self-management in primary care in the UK. *BMJ Open* 2018; **8**:e021498.
44 Magin PJ, Adams J, Heading GS *et al.* Complementary and alternative medicine therapies in acne, psoriasis, and atopic eczema: results of a qualitative study of patients' experiences and perceptions. *J Altern Complement Med* 2006; **12**:451–7.
45 Magin P, Adams J, Heading G *et al.* Experiences of appearance-related teasing and bullying in skin diseases and their psychological sequelae: results of a qualitative study. *Scand J Caring Sci* 2008; **22**:430–6.
46 Magin PJ, Adams J, Heading GS *et al.* Patients with skin disease and their relationships with their doctors: a qualitative study of patients with acne, psoriasis and eczema. *Med J Aust* 2009; **190**:62–4.
47 Magin P, Heading G, Adams J *et al.* Sex and the skin: a qualitative study of patients with acne, psoriasis and atopic eczema. *Psychol Health Med* 2010; **15**:454–62.
48 Magin P, Adams J, Heading G *et al.* 'Perfect skin', the media and patients with skin disease: a qualitative study of patients with acne, psoriasis and atopic eczema. *Aust J Prim Health* 2011; **17**:181–5.
49 Iio M, Hamaguchi M, Nagata M *et al.* Stressors of school-age children with allergic diseases: a qualitative study. *J Ped Nurs* 2018; **42**:e73–8.
50 Kosse RC, Bouvy ML, Daanen M *et al.* Adolescents' perspectives on atopic dermatitis treatment – experiences, preferences, and beliefs. *JAMA Dermatol* 2018; **154**:824–7.
51 Roje M, Rezo I, Flander GB. Quality of life and psychosocial needs of children suffering from chronic skin diseases. *Alcohol Psychiat Res* 2016; **52**:133–48.
52 Wake EV, Batchelor J, Lawton S *et al.* The views of children and young people on the use of silk garments for the treatment of eczema: a nested qualitative study within the CLOTHing for the relief of Eczema Symptoms (CLOTHES) randomized controlled trial. *Br J Dermatol* 2018; **178**:183–90.
53 Pound P, Britten N, Morgan M *et al.* Resisting medicines: a synthesis of qualitative studies of medicine taking. *Soc Sci Med* 2005; **61**:133–55.
54 Abuabara K, Margolis DJ. Do children really outgrow their eczema, or is there more than one eczema? *J Allergy Clin Immunol* 2013; **132**:1139–40.
55 Silverberg JI, Hanifin JM. Adult eczema prevalence and associations with asthma and other health and demographic factors: a US population-based study. *J Allergy Clin Immunol* 2013; **132**:1132–8.
56 Ghio D, Muller I, Greenwell K *et al.* 'It's like the bad guy in a movie who just doesn't die': a qualitative exploration of young people's adaptation to eczema and implications for self-care. *Br J Dermatol* 2020; **182**:112–18.
57 Xie Q-W, Chan CL, Chan CH. The wounded self – lonely in a crowd: a qualitative study of the voices of children living with atopic dermatitis in Hong Kong. *Health Soc Care Community* 2020; **28**:862–73.

Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Table S1 Comprehensive search strategies for each database: MEDLINE, EMBASE, PsycINFO and CINAHL.

Table S2 Study characteristics of papers identified for synthesis (n = 39).

Table S3 Comprehensiveness of reporting (COREQ): COREQ results.

Table S4 Themes identified in each study.

Powerpoint S1 Journal Club Slide Set.