Systematic review of self-management interventions for people with eczema*

M.J. Ridd, A.J.L. King, E. Le Roux, A. Waldecker and A.L. Huntley

School of Social and Community Medicine, University of Bristol, Bristol, U.K.

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Summary

Eczema is a common long-term condition, but inadequate support and information can lead to poor adherence and treatment failure. We have reviewed the international literature of interventions designed to promote self-management in adults and children with eczema. MEDLINE, MEDLINE in process, Embase, CINAHL and the Global Resource for Eczema Trials database were searched from their inception to August 2016, for randomized controlled trials. Two authors independently applied eligibility criteria, assessed risk of bias for all included studies and extracted data. Twenty studies (3028 participants) conducted in 11 different countries were included. The majority (n = 18) were based in secondary care and most (n = 16) targeted children with eczema. Reporting of studies, including descriptions of the interventions and the outcomes themselves, was generally poor. Thirteen studies were face-to-face educational interventions, five were delivered online and two were studies of written action plans. Follow-up in most studies (n = 12) was short term (up to 12 weeks). Only six trials specified a single primary outcome. There was limited evidence of effectiveness. Only three studies collected and reported outcomes related to cost and just one study undertook any formal cost-effectiveness analysis. In summary, we have identified a general absence of well-conducted and well-reported randomized controlled trials with a strong theoretical basis. Therefore, there is still uncertainty about how best to support self-management of eczema in a clinically effective and cost-effective way. Recommendations on design and conduct of future trials are presented.

What’s already known about this topic?

- Eczema requires a high degree of self-management by patients.
- Adherence to eczema treatments, and hence control of symptoms, can be poor.
- There is uncertainty about how best to support self-management in a clinically effective and cost-effective way.

What does this study add?

- A wide range of interventions designed to promote self-management have been evaluated in 20 studies across 11 different countries.
- Reporting of the design and conduct of these studies is generally poor, and explicit theory describing how interventions are expected to improve care is uncommon.
- What works best for people with eczema and whether it is cost-effective is unknown.
- Recommendations for future trials are made.

Eczema is a long-term condition that usually begins in infancy and can have a significant impact on patient quality of life. Also referred to as atopic dermatitis and atopic eczema, the World Allergy Organization suggests that the phenotype of ‘atopic eczema’ should be simply called ‘eczema’ unless specific IgE antibodies are demonstrated.1 Eczema is common and
its prevalence is increasing. Approximately 20% of children in industrialized countries have eczema, and in developing countries the prevalence is heading towards this figure. In adults, population studies report an overall prevalence of 2–18%. It is also a condition for which a high degree of self-care is needed.

Recently, there has been a policy shift in the U.K. towards self-management for long-term conditions. Interventions to improve patient (or carer) self-management of long-term conditions are broadly designed to ‘increase the capacity, confidence and efficacy of the individual’ to manage their health on a day-to-day basis. Improved self-management has been identified as key in improving disease outcomes and promoting quality of life for people with long-term conditions. Effective treatment of eczema demands good self-management, which, if established early on, could lead to considerable improvement in quality of life. However, families of children with eczema state that they do not receive adequate support and information about symptom management. A lack of education about therapy can lead to poor adherence (patients/carers not using creams effectively) and treatment failure.

In view of this, we sought to review the evidence on the effectiveness of interventions designed to promote self-management for children, their caregivers and adults with eczema. In particular, we wanted to answer the following questions: What evidence is there that interventions designed to promote self-management of atopic eczema are clinically effective and cost-effective? What have the interventions evaluated to date comprised? Has previous research established the contribution of the different components of self-management interventions to the outcomes assessed?

Materials and methods

We followed Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines and the protocol was prospectively registered with PROSPERO (PROSPERO 2015: CRD42015025314).

Information sources and search strategy

We searched relevant databases (MEDLINE, MEDLINE In Process, Embase, CINAHL and Global Resource for Eczema Trials, from inception to August 2016) for randomized controlled trials (RCTs) of interventions (delivered to children with eczema, caregivers of children with eczema and adults with eczema) that promote self-management. With the aid of a medical information scientist, a search strategy was developed that included the following terms: eczema (and its synonyms atopic eczema and atopic dermatitis), self-care, self-management, education, patient education, action plan, treatment plan and management plan (Appendix S1; see Supporting Information). Authors were contacted regarding further trial publications and any unpublished studies and/or unpublished data. Forward and backward searching was also conducted within the reference lists of all included studies.

References from the searches were downloaded into Endnote (Endnote X7, Thomson Reuters, New York, NY, U.S.A.). Two people independently screened all titles and abstracts using the eligibility criteria. All included studies were accessed in full and were screened by two reviewers independently. The reasons for exclusion of all full-text trials were recorded and any disagreements were resolved by the research team.

Eligibility criteria

We restricted our search to RCTs of interventions that promote patient/carer self-management in children (and/or their caregivers, including parents) and adults with atopic eczema/atopic dermatitis, compared with no intervention, usual care, or an alternative intervention. The outcomes of primary interest were effects on eczema severity and quality of life.

There is no agreed definition of self-management. Therefore, based on the relevant literature, we defined a self-management intervention as one that included one or more of the features listed in Table 1. If a trial included patients with other skin diseases, and the data for eczema could not be analysed separately, it was excluded. As our main outcomes of interest were eczema severity and quality of life, we excluded trials that did not include these outcomes.

Data extraction and risk of bias

A data extraction tool was developed and piloted. Data on study design, description of intervention/comparison components and outcomes were extracted independently, and in duplicate, by two reviewers (A.J.L.K./E.L.R. and M.J.R.). Authors were contacted to confirm missing data. Risk of bias was conducted by two blinded reviewers (A.J.L.K./E.L.R.) and checked by a third (M.J.R.), using the Cochrane Collaboration’s risk of bias tool and Review Manager software (version 5.3, Informer Technologies Inc., Roseau, Dominica).

Results

Study selection

After deduplication, 1895 titles and abstracts were screened for eligibility and 33 full-text papers were assessed for

| Table 1 Definition of interventions that promote patient/carer self-management |
|---------------------------------------------------------------|
| • Imparts knowledge of the condition and/or its management |
| • Supports people in managing the social, emotional or physical impacts of their conditions |
| • Involves patients/carers in decision-making |
| • Motivates people to self-manage (using targeted approaches and/or structured support) |
| • Helps people to monitor their symptoms and know when to take appropriate action, for example through the use of written action plans |
eligibility (Fig. 1). After the exclusion of 10 papers, we included 23 articles16–38 that described 20 RCTs. Two studies were published in German25,27 and were translated for the purpose of this review. Two articles were published as research letters.23,32

**Design, setting and participant recruitment**

Participants were individually randomized in all 20 studies, which included a total of 3028 participants (Tables 2 and 3). The majority of studies were conducted in Europe (n = 14) and the U.S.A. (n = 4). Most (n = 18) were set in secondary care with participants recruited via dermatology16,17,20,23–28,30,32,38 and paediatric outpatient clinics.22,31,34,35

The exception of two three-group trials,27,29 most studies comprised two groups (intervention and comparison groups). Only five studies27,29,34,35,37 gave details of any theoretical framework that underpinned intervention development or possible mechanisms of effect.

**Characteristics of participants**

In the majority of studies (n = 16), the participants with eczema were children, but two studies were of adults with eczema,16,19 and two were of adults and children with eczema.32,38 One study included participants with eczema, psoriasis and other chronic skin diseases.19

Regarding inclusion criteria (Table 2), two studies stated that participants had to be diagnosed for at least 3 months,28,35 and two studies specified 1 year.29,37 Twelve studies did not specify any diagnostic criteria,23 and seven studies included only participants with moderate38 or moderate-to-severe eczema,17,22,25,28,34,35 although how this was determined was not clear in three studies.17,22,38 In most studies of children, the caregivers were parents (three studies specify mothers),22,27,37 but in six studies the ‘caregiver’ was not further described.23,29–32,35 Broberg et al.20 did not report participant baseline characteristics.

**Interventions and comparison groups**

Of the studies aiming to improve the self-management of eczema in children, only the caregivers of children with eczema were the recipients of the intervention in eight studies,17,22,23,26–29,31,34,37 while eight studies included children with eczema and their caregiver.20,21,24,25,30,35 However, this distinction was often not very well described.

The majority of interventions (13 studies) were face-to-face educational interventions.19–22,24–28,30,31,34,35 Seven face-to-face educational interventions were delivered to groups,19,20,22,24,28,34,35 four were delivered to individuals,21,25,30,31 and two to a mixture of individuals and groups.16,27 In one study, three different variations of intervention were delivered according to the age of the child (3 months to 7 years, 8–12 years and 13–18 years).35 The duration and intensity of interventions varied from a one-off 15-min educational session,31 to 12 weekly 2-h sessions.19

Interventions were delivered by between one and four health professionals including dermatologists, specialist dermatology nurses, nurse practitioners and interdisciplinary teams. Eighteen studies gave details on the type of health professional delivering the intervention,16,17,19–22,25–32,34,35,37,38 three stated the level of staff training,16,21,31 and 13 studies16,19–22,26,28–31,34,35,38 stated the number of health professionals that were involved in delivering the intervention. Most studies of face-to-face education (n = 11) compared their intervention with ‘usual care’,16,17,19–22,25–32,34,35,37 although this was often not made explicit and/or the specific details of usual care were unclear.

Five studies were delivered via the internet,16,17,29,37,38 of which three studies compared their intervention with ‘usual care’.17,29,38 These varied from simple online videos16 and educational modules29,37 to online consultations.17,38

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*Fig 1. Flowchart showing the flow of studies through the systematic review.*
Table 2 Summary of included studies

| Characteristic                        | Number of studies | Study (First author, year)                                                                                                                                 |
|--------------------------------------|-------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country                              |                   |                                                                                                                                                          |
| U.S.A.                               | 4                 | Armstrong et al. 2011, Shaw et al. 2008, Shi et al. 2013, Gilliam et al. 2016                                                                          |
| Germany                              | 4                 | Kardorff et al. 2003, Niebel et al. 2000, Staab et al. 2002, Staab et al. 2006                                                                         |
| U.K.                                 | 2                 | Chinn et al. 2002, Santer et al. 2014                                                                                                                    |
| The Netherlands                      | 2                 | Schutteelaar et al. 2009, van Os-Medendorp et al. 2012                                                                                                 |
| Australia                            | 2                 | Grillo et al. 2006, Moore et al. 2009                                                                                                                    |
| Norway                               | 1                 | Bergmo et al. 2008                                                                                                                                         |
| Belgium                              | 1                 | Bostoen et al. 2012                                                                                                                                          |
| Croatia                              | 1                 | Pustišek et al. 2016                                                                                                                                         |
| Sweden                               | 1                 | Broberg et al. 1990                                                                                                                                         |
| Japan                                | 1                 | Futamura et al. 2013                                                                                                                                         |
| Republic of Korea                    | 1                 | Son et al. 2014                                                                                                                                                |
| Setting                              |                   |                                                                                                                                                          |
| Secondary care                       | 18                | Armstrong et al. 2011, Bergmo et al. 2008, Bostoen et al. 2012, Broberg et al. 1990, Futamura et al. 2013, Gilliam et al. 2016, Grillo et al. 2006, Kardorff et al. 2003, Moore et al. 2009, Niebel et al. 2000, Pustišek et al. 2016, Schutteelaar et al. 2009, Shaw et al. 2008, Shi et al. 2013, Staab et al. 2002, Staab et al. 2006, Son et al. 2014, van Os-Medendorp et al. 2012 |
| Primary care                         | 2                 | Chinn et al. 2002, Santer et al. 2014                                                                                                                    |
| Participants                         |                   |                                                                                                                                                          |
| Children only                        | 16                | Bergmo et al. 2008, Broberg et al. 1990, Chinn et al. 2002, Futamura et al. 2013, Gilliam et al. 2006, Grillo et al. 2006, Kardorff et al. 2003, Moore et al. 2009, Niebel et al. 2000, Pustišek et al. 2016, Schutteelaar et al. 2009, Shaw et al. 2008, Shi et al. 2013, Staab et al. 2002, Son et al. 2014, van Os-Medendorp et al. 2012 |
| Adults only                          | 2                 | Armstrong et al. 2011, Bostoen et al. 2012                                                                                                                   |
| Adults and children                  | 2                 | Shi et al. 2013, van Os-Medendorp et al. 2012                                                                                                                  |
| Inclusion criteria                   |                   |                                                                                                                                                          |
| Eczema diagnosis                     |                   |                                                                                                                                                          |
| Not stated                           | 12                | Armstrong et al. 2011, Bostoen et al. 2012, Futamura et al. 2013, Gilliam et al. 2016, Grillo et al. 2006, Kardorff et al. 2003, Moore et al. 2009, Niebel et al. 2000, Pustišek et al. 2016, Schutteelaar et al. 2009, Shaw et al. 2008, Shi et al. 2013, Son et al. 2014, van Os-Medendorp et al. 2012 |
| Hanifin and Rajka                    | 5                 | Armstrong et al. 2011, Broberg et al. 1990, Pustišek et al. 2016, Staab et al. 2002, Staab et al. 2006                                                                 |
| U.K. diagnostic criteria             | 2                 | Chinn et al. 2002, Schutteelaar et al. 2009                                                                                                                  |
| Clinical (GP diagnosis)              | 1                 | Santer et al. 2014                                                                                                                                             |
| Minimum eczema severity              |                   |                                                                                                                                                          |
| None                                 | 13                | Armstrong et al. 2011, Bostoen et al. 2012, Broberg et al. 1990, Chinn et al. 2002, Gilliam et al. 2016, Grillo et al. 2006, Kardorff et al. 2003, Moore et al. 2009, Niebel et al. 2000, Santer et al. 2014, Schutteelaar et al. 2009, Shaw et al. 2008, Shi et al. 2013, Son et al. 2014, van Os-Medendorp et al. 2012 |
| Moderate                             | 1                 | van Os-Medendorp et al. 2012 (not defined)                                                                                                              |
| Moderate-to-severe                   | 6                 | Bergmo et al. 2008 (not defined), Futamura et al. 2013 (not defined), Kardorff et al. 2003 (SCORAD of between 25 and 50), Pustišek et al. 2016 (SCORAD > 25), Staab et al. 2002 ([SCORAD > 20] for at least 4 months), Staab et al. 2006 (SCORAD ≥ 20) |
| Duration of follow-up                |                   |                                                                                                                                                          |
| Not stated                           | 1                 | Shi et al. 2013                                                                                                                                                |
| 2 weeks                              | 1                 | Son et al. 2014                                                                                                                                               |
| 4 weeks                              | 1                 | Moore et al. 2009                                                                                                                                             |
| 6 weeks                              | 1                 | Kardorff et al. 2003                                                                                                                                          |
| 1–3 months                           | 1                 | Shaw et al. 2008                                                                                                                                              |
| 2 months                             | 1                 | Pustišek et al. 2016                                                                                                                                          |
| 12 weeks/3 months                    | 6                 | Armstrong et al. 2011, Broberg et al. 1990, Chinn et al. 2002, Gilliam et al. 2016, Grillo et al. 2006, Santer et al. 2014                                                                 |
| 3–4 months                           | 1                 | Niebel et al. 2000                                                                                                                                            |
| 6 months                             | 1                 | Futamura et al. 2013                                                                                                                                           |
| 9 months                             | 1                 | Bostoen et al. 2012                                                                                                                                            |
| 12 months                            | 5                 | Bergmo et al. 2008, Schutteelaar et al. 2009, Staab et al. 2002, Staab et al. 2006, van Os-Medendorp et al. 2012                                                                 |

(continued)
Duration of follow-up and collection of outcomes

Follow-up in most studies was between 2 weeks and 12 weeks.16,20,21,23,24,26,28,29,31,37,39 Seven studies included longer follow-up periods of 6 months,22 9 months23 and 12 months,17,30,34,35,38 One study did not state the duration of follow-up32 and two studies27,31 stated varying follow-up intervals.

Outcomes

Only six of the 20 trials specified a single primary outcome (Table 2).16,22,24,26,29,30 The studies by Staab et al. (2006),31 van Os-Medendorp et al.38 Pustišek et al.38 and Bostoen et al.19 specified two, three, four and five primary outcomes, respectively. No primary outcome was specified in the other 10 studies.17,20,21,23,25,27,31,32,34,37

A wide range of other/secondary outcomes were also collected, often using modified versions of published questionnaires, or unpublished and unvalidated scales. Only the following three studies collected and reported any outcomes related to cost: Staab et al. (2002)34 reported direct costs of treatment; Bergmo et al.17 reported loss of employment; Bergmo et al.17 and Bostoen et al.19 reported cost of contact with healthcare professionals and prescription costs; and van Os-Medendorp38 reported direct and indirect participant costs. Only Bostoen et al.19 reported undertaking a formal cost-effectiveness (cost-utility) analysis, and simply concluded that their intervention (2-h group-based educational sessions per week for 12 weeks) was not cost-effective at 6 months. It does not appear that separate analyses were done for the 21 of 59 participants with atopic eczema in this study.

We did not attempt to perform a meta-analysis because there were not at least three similar studies with a low risk of bias. In addition, data on outcomes (e.g. means, SDs) on eczema severity and quality-of-life outcomes were often not reported (a complete list is presented in Appendix S2 and Appendix S3; see Supporting Information). We have summarized the findings graphically in Figure 2 for these outcomes where reported by two or more studies.

The available evidence suggests that the interventions developed and evaluated to date may improve both patient-reported and objective measures of eczema severity but not quality of life. The three web-based studies16,29,37 report changes in Patient-Oriented Eczema Measure scores at 4–12 weeks near or greater than the published minimal clinically important difference (MCID) of 3.40 However, the studies themselves are quite different. Armstrong et al.16 compared an educational video with an information leaflet for adults recruited from a U.S. dermatology clinic; Santer et al.29 compared an educational website (with or without healthcare professional support) with usual U.K. primary care for caregivers of children under 5 years and Son et al.37 recruited parents of children in Korea under 3 years of age via a paediatric clinic to use a...
| Study no. | First author, year | Country | Setting | Total number of participants | Participants | Intervention | Comparison | Outcomes |
|-----------|--------------------|---------|---------|-----------------------------|-------------|-------------|------------|----------|
| 1         | Armstrong 2011     | U.S.A.  | Secondary care | 80 | Adults with atopic dermatitis | Online video-based patient education that aims to improve atopic dermatitis knowledge and disease severity | Identical information in written pamphlet form | Primary: POEM Secondary: knowledge of atopic dermatitis and skincare for atopic dermatitis questionnaire; satisfaction with education material Primary outcome not specified Self-management behaviour – number/frequency of skincare treatments performed by parent/carer Eczema severity (SCORAD) Resource use (self-report of number of general practitioner visits, outpatient consultations, emergency visits, hospital admissions, visits to complementary therapists) Personal expenses and loss of employment Family costs |
| 2         | Bergmo 2009        | Norway | Secondary care | 98 | Parents of children with atopic eczema | Web-based consultations for parents of children with atopic dermatitis | Usual care (seek treatment through general practitioner visits and hospital care) |
| 3         | Bostoen 2012       | Belgium | Secondary care and patient advocacy groups | 50 | Adults with atopic dermatitis or psoriasis | Educational programme (described in Lambert et al. 2011) 18 h twice weekly for 12 weeks Multidisciplinary educational programme delivered by a dermatologist, dermatology nurse, pharmacist, psychiatrist, psychologist, dietician, philosopher, mindfulness and yoga teacher Content of programme: specific information on skin diseases; stress-reduction techniques; information sessions on lifestyle factors and psychodermatology | Not stated | Primary outcomes: SCORAD, EASI, DLQI, Skindex-29 and QoLIAD Secondary outcomes: Beck Depression Inventory, smoking behaviour, physical activity and everyday problem checklist (stress), EQ5-D Costs: topical (corticosteroids, calcineurin inhibitors, hydration) and systemic therapy; medication and doctor visits related to skin disease |

(continued)
| Study no. | First author, year | Country | Setting | Total number of participants | Participants | Intervention | Comparison | Outcomes |
|----------|--------------------|---------|---------|------------------------------|-------------|--------------|------------|---------|
| 4        | Broberg et al. 1990 | Sweden  | Secondary care | 50 | Children with atopic eczema | 'Eczema school', health education intervention aimed at parents of children with atopic eczema. This was run for patients by a trained nurse who offered practical training on management of atopic eczema | Control group received routine information given by the physician during a medical visit | Primary outcome not specified. Physician-assessed 'Eczema score' of 0–96 (based on type, intensity and distribution of lesions), itch score (0 = none to 4 = severe); topical steroid use (by weight) |
| 5        | Chinn 2002         | U.K.    | Primary care | 240 | Children with atopic eczema | Patient education provided by a primary care nurse in a single (30 min) consultation | Usual care | Primary outcome not specified Quality of life (IDQOL or CDLQI; Family Dermatitis Index) |
| 6        | Futamura 2013      | Japan   | Secondary care | 59 | Children with atopic eczema and their parents | 2-day Parental Education Programme on managing childhood eczema. Parents received this along with a booklet on atopic dermatitis | Parents were given a booklet about atopic dermatitis and received usual care | Primary: SCORAD Secondary: objective SCORAD; symptom scores (0–10) for pruritus and sleeplessness; corticosteroid cream use (total weight estimated by counting no tubes used), Dermatitis Family Impact questionnaire, parental anxiety about topical corticosteroid use |
| 7        | Gilliam 2016       | U.S.A.  | Secondary care | 88 | Parents of children with atopic eczema | Eczema Action Plan | Standard clinical care/education | Childhood Eczema Study Questionnaire score (derived from Childhood AD Impact Score, Chamlin et al.) |
| 8        | Grillo 2006        | Australia | Secondary care | 61 | Children with atopic eczema and their parents | 2-h group workshop | Usual care (routine education, medical consultation and management) | Primary outcome not specified. Eczema severity (SCORAD); Quality of life: CDLQI, IDQoL and Dermatitis Family Impact questionnaire |
| Study no. | First author, year | Country | Setting | Total number of participants | Participants | Intervention | Comparison | Outcomes |
|----------|--------------------|---------|---------|------------------------------|-------------|-------------|------------|----------|
| 9        | Kardorff 2003      | Germany | Secondary care | 30 | Caregivers (parents) of children with atopic eczema | 10-min consultation with a dermatologist including routine explanation of diagnosis and treatment plus ‘Hautmodell’ (skin model) – a 3D educational tool, developed by the study authors, which demonstrated to children and their parents the rationale behind regular emollient use | 10-min consultation with a dermatologist including routine explanation of diagnosis and treatment plus verbal instruction on emollient application (as per routine dermatological practice) | Eczema severity of children (SCORAD) Change in emollient use by parents |
| 10       | Moore 2009         | Australia | Secondary care | 165 | Children and adolescents with atopic eczema | Nurse-led eczema workshop | A dermatologist-led clinic (registrar or consultant) | Primary outcome: SCORAD Secondary outcome: comparison of eczema treatments used by patients in the eczema workshop and in the dermatologist-led clinic |
| 11       | Niebel 2000        | Germany | Secondary care | 47 | Children with eczema and their mothers | Behaviour-based parental education (direct parent education, 10 sessions) or video education at home | Usual care | Skin condition Symptomatic behaviour of the children with atopic eczema Problems faced by mothers and the burden they experience |
| 12       | Pustišek 2016      | Croatia | Secondary care | 134 | Parents of children with atopic eczema | 2-h structured educational programme comprising a lecture by dermatologist and nurse, written material including educational booklet and a diary of corticosteroid use | Usual care | SCORAD, PO-SCORAD, pruritus symptoms score, sleeplessness symptoms score, Perceived Stress Scale, State Trait Anxiety Inventory, Croatian version of Family Dermatology Life Quality Index, use of topical corticosteroids (not clear how collected) |
| 13       | Saner 2014         | U.K.    | Primary care | 143 | Children with eczema and their parents/carers | Website intervention only or website plus healthcare professional support | Usual care | Primary outcome: Eczema severity (POEM) Secondary outcome: Quality of life (DFI, DQoL and CDLQI, Secondary outcome: adherence to interventions (Problematic Experiences of Therapy Scale) |
| Study no. | First author, year | Country | Setting | Total number of participants | Participants | Intervention | Comparison | Outcomes |
|----------|--------------------|---------|---------|-----------------------------|-------------|--------------|------------|----------|
| 14       | Schuttelaar 2010   | The Netherlands | Secondary care | 160 | Children with eczema | Nurse practitioner (NP) routinely followed up 2 weeks after the first visit. Thereafter, the visits depended on the severity of the eczema and the needs of the parents. Average visit length: first, 30 min, second 10 min (telephone) or 20 min (clinic). It was possible to contact the NP for feedback, support or tips by mail and telephone daily. The NP was supervised by an independent dermatologist if necessary. Parents were also provided with a Written Eczema Action Plan. Information and instruction were offered during the treatment visits or in a 2-h group session comprising a maximum of eight parents. 5-min individual face-to-face education session with an atopic dermatitis educator. Usual care, an individual treatment plan for each child was verbally explained to the family with some written notes given if deemed necessary. Primary outcomes: change in quality of life at 12 months (IDQOL) for children under 4 years and CDLQI for children aged 4-16 years. Secondary outcomes: changes in IDQOL and CDLQI at 4 and 8 months postintervention. Family impact of eczema (Dermatitis Family Impact Questionnaire), eczema severity (SCORAD). |
| 15       | Shaw 2008          | U.S.A. | Secondary care | 151 | Children with eczema | Usual care (dermatologist). Number and interval between the treatment visits depended on the severity of the eczema. Average visit length: first 20 min, second 10 min, ± 5-min telephone call for laboratory results on allergy tests. Patients received no education from the nurse. Primary outcome: eczema severity (SCORAD). Secondary outcome: change in infant's quality of life (IDQOL). Change in children’s quality of life (CDLQI). |
| Study no. | First author, year | Country | Setting | Total number of participants | Participants | Intervention | Comparison | Outcomes |
|----------|--------------------|---------|---------|-------------------------------|--------------|--------------|------------|----------|
| 16       | Shi 2013           | U.S.A.  | Secondary care | 37 Adults and children with atopic eczema | Eczema Action Plan | Verbal instruction only | Participants’ understanding of their individualized treatment plan, benefits and risks of the prescribed medication, anatomic location of medication use, duration of treatment, recognizing exacerbating factors, adjusting treatment based on disease severity, comfort about their treatment plan, anxiety about caring for atopic eczema at home, understanding of atopic eczema and ability to recognize disease remission |
| 17       | Staab 2002         | Germany | Secondary care | 204 Children with eczema | Structured parental training programme on managing atopic dermatitis in children (six group sessions, 2 h each) | Usual care (routine information from the physician during a medical visit). The control group could participate in the parental training programme 1 year after the randomized controlled trial | Primary outcome not specified. Eczema severity (SCORAD), treatment behaviours, treatment costs, quality of life (disease specific (quality of life in parents of children with atopic dermatitis) and generic (‘daily life’)) and coping strategies (The Trier Scales of Coping) |
| 18       | Staab 2006         | Germany | Secondary care | 992 Children (aged 3 months to 7 years, 8–12 years) and adolescents (13–18 years) with eczema | Parent/patient education sessions, different for each of the three age groups | Usual care | Primary outcomes: eczema severity (SCORAD) and parents’ quality of life (‘quality of life in parents of children with atopic dermatitis’). Secondary outcomes: subjective severity score (skin detective), itch (catastrophization and coping, measured using JUCKKI and JUCKJU) |
| Study no. | First author, year | Country          | Setting        | Total number of participants | Participants | Intervention                                                                 | Comparison | Outcomes                                                                 |
|-----------|--------------------|------------------|----------------|-----------------------------|--------------|-------------------------------------------------------------------------------|------------|--------------------------------------------------------------------------|
| 19        | Son 2014          | Republic of Korea| Secondary care | 40                          | Parents of children with atopic eczema | Web-Based Educational Programme                                               | Not stated | Primary outcome not specified                                            |
|           |                    |                  |                |                             |              |                                                                                |            | Parent-reported global eczema severity, area of lesion and treatment method. |
|           |                    |                  |                |                             |              |                                                                                |            | Korean language versions of POEM, IDQoL, and Child Eczema Management          |
|           |                    |                  |                |                             |              |                                                                                |            | Questionnaire                                                              |
|           |                    |                  |                |                             |              |                                                                                |            | Mothers’ self-efficacy                                                     |
| 20        | van Os-Medendorp 2012 | The Netherlands  | Secondary care | 199                         | Adults and children with atopic dermatitis | Dermatologist and dermatology nurse outpatient appointment followed by dermatologist appointment 6 weeks later and no further scheduled appointments. An internet-guided monitoring and online self-management training intervention, which included patient-initiated access to an eczema portal. Face-to-face visits to the dermatology nurse or dermatologist were possible in individual cases where e-health was inadequate or when requested by the patients | Dermatologist and dermatology nurse outpatient appointment. After that, usual care (five scheduled follow-up visits to the dermatologist, and at least one visit to a dermatology nurse for self-management training depending on disease severity) | Primary outcomes: quality of life (DLQI for adults and IDQoL for infants), eczema severity Secondary outcomes: direct and indirect costs of care, costs of e-health service, outpatient visits and days taken off work by adult patients and parents of children with atopic dermatitis |
website, but did not describe what participants in their control group received.

The face-to-face interventions trialled by Futamura et al.,22 Grillo et al.,24 Kardorff et al.,25 Pustisiek et al.,28 and Staab et al.,25 all seem to decrease disease severity assessed by SCORing Atopic Dermatitis (SCORAD) and, with the exception of Kardorff et al. and the participants aged 13–18 years in the trial reported by Staab et al., exceeded the published SCORAD MCID of 8.7.31 While all of these studies were set in secondary care and examined interventions for children with eczema, the interventions were different in their nature/intensity (skin model,25 2-h workshop/education programme,24,28 2-day education programme,22 six 2-h education sessions),35 comparator groups (usual care,24,25,28,35 booklet)22 and had different durations of follow-up (from 6 weeks to 12 months).

Risk of bias

Assessments regarding risk of bias in the included studies are summarized graphically in Figure 3. These judgements were difficult to make owing to the generally poor standard of reporting. In trials of self-management interventions, it is not possible to blind participants to their allocation. Therefore, the majority of trials were graded as ‘high risk’ for this domain.

Six study authors did not state the funding source of their study.16,17,20,25–27 When specified, the trials were mainly funded by public bodies, with one funded by pharmaceutical companies.19 Ten papers declared no conflict of interest,16,19,22,23,28–30,32,35,38 nine did not state any conflict of interest17,20,21,25–27,31,34,42 and the one ‘conflict of interest’ declared stated that the study was from an unpublished PhD thesis.37

Discussion

We identified 20 RCTs of interventions that promote self-management in people with eczema. Most studies had been conducted in Europe or the U.S.A., were based in a hospital setting and targeted children with eczema. The most common type of intervention was face-to-face education, but there were wide variations in the nature of these sessions, both in terms of how they were delivered (individually, in groups, or a mixture of both), who delivered them (from one ‘eczema educator’ through to multidisciplinary teams) and their intensity (from 15 min to a total of 24 h). Papers published more recently have focused on interventions delivered via the internet, but again the nature of these interventions varied significantly. All interventions included information on symptom and medication management.

Reporting was generally poor, making it difficult to interpret the findings. Many studies did not specify any criteria for eczema diagnosis. It was often not clear who the ‘caregiver’ was and the methods used to randomize patients were not stated. Interventions or usual care were often described poorly or not at all and it was uncommon for any rationale or formal theory to be given regarding the means by which interventions were expected to effect change. The timing and means of outcome data collection, where specified, were unclear; unpublished or unvalidated measures were frequently employed. Follow-up was generally short term (12 weeks or less). The absence of any substantial evaluation of cost-effectiveness is also notable.

We have conducted this review in accordance with current recommendations, have published the review protocol with PROSPERO9 and followed PRISMA guidelines for the reporting of reviews evaluating randomized trials.8 All screening, data extraction and risk of bias assessments were done by two reviewers independently.

While it is still possible that we may have missed a relevant study, we think this is unlikely because we independently identified relevant studies cited by other related reviews (see below). In the absence of any agreed definition of self-management, we developed and applied our own criteria based on our reading of the literature. However, given the lack of detail often provided by authors on the content of the different interventions trialled, we consider this to be the safest approach.

Our review complements and extends a number of related reviews that have recently been published, which examine the effect of psychological and educational interventions for eczema on treatment adherence, disease severity and quality of life.43–45 Our broader remit (all interventions designed to promote self-management), strong critique of the methods and reporting, and the inclusion of recently published trials will help clinicians, researchers and commissioners better understand what we know about interventions that might help patients with eczema. However, unfortunately, we are in agreement that there is still uncertainty about whether educational interventions are effective in improving quality of life for people with eczema;46 most studies of parental education for eczema have been small and of poor quality;44 and it is unknown which particular components are clinically effective and cost-effective in different clinical settings.47

We are not alone in noting the ‘preponderance of small, poorly reported and poorly conducted trials’,47 which is an issue not confined to just this area of dermatology research. McLean et al.48 have highlighted the problem specifically with respect to statistical reporting. In keeping with the findings of Alvarez et al.,49 we found that the standard of reporting was generally better in papers published more recently. However, uncertainty regarding the effectiveness of different interventions to promote self-management will only be reduced by better designed trials of adequate size reported in line with guidance such as CONSORT50 and Statistical Analyses and Methods in the Published Literature.51

In addition to improving the reporting of trials (Table 4), researchers should recognize that all interventions to promote self-management are complex, and their development, description and evaluation should follow an appropriate framework.52 Furthermore, interventions should be
underpinned by an explicit theory regarding the mechanism of action and preferably accompanied by a process evaluation. Future studies should seek to evaluate interventions that are pragmatic and tailored to the context and needs of the recipients. In particular, research to date does not reflect the fact that the majority of people with eczema have mild-to-

(a) Online-only education

Outcome: eczema severity (POEM)

| Study or Subgroup | Intervention Mean | SD | Total | Comparator Mean | SD | Total | Mean difference | IV, Random, 95% CI |
|-------------------|------------------|----|-------|----------------|----|-------|----------------|-------------------|
| Armstrong 12 weeks| 5.73             | 3.71| 37    | 7.6            | 3.83| 35    | –1.87          | [–3.61, –0.13]     |
| Santer Web only 12 weeks| 7.6 | 6.1 | 44 | 7.1 | 6.6 | 49 | 0.50 | [–2.08, 3.08] |
| Santer Web+HCP 12 weeks| 8.7 | 7.0 | 50 | 7.1 | 6.6 | 49 | 1.60 | [–1.08, 4.28] |
| Son 4 weeks       | 9.9 | 2.31| 20   | 17.7          | 7.06| 20    | –7.80          | [–11.06, –4.54]    |

(b) Face-to-face education

Outcome: eczema severity (SCORAD)

| Study or Subgroup | Intervention Mean | SD | Total | Comparator Mean | SD | Total | Mean difference | IV, Random, 95% CI |
|-------------------|------------------|----|-------|----------------|----|-------|----------------|-------------------|
| Bostoen 36 weeks  | 33.91            | 16.9| 8     | 34.47          | 17.45| 8     | –0.56          | [–17.39, 16.27]    |
| Futamura 26 weeks | 15.4             | 7.6 | 28    | 27.8           | 10.8 | 28    | –12.40         | [–17.29, –7.51]    |
| Grillo 12 weeks   | 23.52            | 16.53| 30    | 40.21          | 22.9 | 28    | –16.69         | [–27.03, –6.35]    |
| Kardorf 6 weeks   | 14.1             | 4.3 | 15    | 19.8           | 5.9  | 15    | –5.70          | [–9.38, –2.01]     |
| Niebel 3–4 months| 36.91            | 25.95| 15    | 32.33          | 17.75| 14    | 4.58           | [–11.51, 20.67]    |
| Pustisek 2 months | 23.08            | 15.19| 64    | 36.44          | 16.76| 64    | –13.36         | [–18.90, –7.82]    |
| Staab (13–18 years) 52 weeks | 23.4 | 12.6 | 70    | 35.2           | 15.2 | 50    | –11.80         | [–16.94, –6.66]    |
| Staab (3 months–7 years) 52 weeks | 23.7 | 16.7 | 274   | 28.4           | 16.5 | 244   | –4.70          | [–7.56, –1.84]     |
| Staab (8–12 years) 52 weeks | 25.8 | 17.7 | 102   | 32.6           | 16.5 | 83    | –6.80          | [–11.74, –1.86]    |

Outcome: quality of life

| Study or Subgroup | Intervention Mean | SD | Total | Comparator Mean | SD | Total | Mean difference | IV, Random, 95% CI |
|-------------------|------------------|----|-------|----------------|----|-------|----------------|-------------------|
| 5.1.1 IDQOL       | 6.91             | 5.3 | 30    | 5.33           | 3.02| 28    | 1.58           | [–0.53, 3.69]     |
| Schuttelaar 52 weeks | 5.7  | 5.4 | 37    | 5.6            | 3.9 | 34    | 0.10           | [–2.08, 2.28]     |

| Study or Subgroup | Intervention Mean | SD | Total | Comparator Mean | SD | Total | Mean difference | IV, Random, 95% CI |
|-------------------|------------------|----|-------|----------------|----|-------|----------------|-------------------|
| 5.1.2 CDLQI       | 1.75             | 1.16| 30    | 7.08           | 4.52| 28    | –5.33          | [–7.05, –3.61]    |
| Schuttelaar 52 weeks | 4.9  | 3.5 | 35    | 5.6            | 4.2 | 35    | –0.70          | [–2.51, 1.11]     |

| Study or Subgroup | Intervention Mean | SD | Total | Comparator Mean | SD | Total | Mean difference | IV, Random, 95% CI |
|-------------------|------------------|----|-------|----------------|----|-------|----------------|-------------------|
| 5.1.3 DFI         | 3.9              | 3.7 | 28    | 5.1            | 4.8 | 28    | –1.20          | [–3.44, 1.04]     |
| Grillo 12 weeks   | 7.47             | 5.79| 30    | 7.69           | 5.85| 28    | –0.42          | [–3.42, 2.58]     |
| Schuttelaar 52 weeks | 4.8  | 4.8 | 74    | 5.1            | 5.5 | 71    | –1.10          | [–2.78, 0.58]     |

Fig 2. Forest plot of outcomes by intervention type. (a) Online-only education. (b) Face-to-face education. POEM, Patient-Oriented Eczema Measure; CI, confidence interval; HCP, healthcare professional; SCORAD, SCORing Atopic Dermatitis; IDQOL, Infant’s Dermatitis Quality of Life Index; CDLQI, Children’s Dermatology Life Quality Index; DFI, Dermatitis Family Impact Questionnaire.
moderate disease and are managed in primary care. For example, the needs and likely cost-effectiveness of an intervention for preschool-age children is likely to be very different from an intervention for adults with life-long disease. Despite being

Table 4 Recommendations to improve conduct and reporting of trials of interventions to promote self-management in people with eczema

| Recommendations                                           |
|-----------------------------------------------------------|
| All trials should be prospectively registered, with a trial identifier and a protocol that conforms with CONSORT guidelines published prior to completing participant recruitment |
| Authors should specify which, if any, eczema diagnostic criteria was used and by whom these were administered |
| Studies should clarify which population groups are participating in their trial and at whom the intervention is targeted (children with eczema, caregivers of children with eczema, adults with eczema) and the mechanism by which the authors expect their intervention to work (e.g. improved caregiver knowledge and confidence in use of topical treatments, or improved adherence to treatment in adults with eczema). Studies should state who in the family or otherwise are the main caregivers of children with eczema |
| The type, timing and intensity of the intervention should be described in sufficient detail to enable its replication in clinical practice, observing checklists such as TIDieR |
| The content of control and comparison groups needs to be described in detail, even if the comparison group is “usual care” because this will vary between settings and countries |
| Primary outcomes within studies need to be specified. Studies should be adequately powered in relation to this. Key outcomes need to be appropriate and relevant to adults and children with eczema and/or their caregivers |
| Outcomes should include core outcomes (symptoms, signs, quality of life, long-term control) as per Harmonizing Outcomes Measures for Eczema (HOME) recommendations, to enable comparisons across studies and the combination of data in future systematic reviews |
| The timing and method of collection of all outcomes should be stated |
| To reduce detection bias, researchers should give serious consideration to collection of outcomes by an observer blinded to allocation |
| All trials should include an economic evaluation and where appropriate, nested qualitative work and/or a process evaluation |

TIDieR, template for intervention description and replication.

Fig 3. Risk of bias summary. Review authors’ judgements about each risk of bias item for each included study.

recommended by guidelines, the evidence base for written action plans is almost negligible\(^5\) and, as a potentially low-cost intervention, warrants particular attention.

While our search and focus was on RCT evidence, the lack of reference to, or use of, qualitative methods in intervention development and evaluation was stark. One encouraging exception to this was the pilot trial by Santer et al.,\(^19\) whose study was supported by both a strong theoretical framework (PRECEDE-PROCEED) and prior qualitative research. Future trials should also include robust evaluations of the cost-effectiveness of interventions.

What should clinicians draw from this review? Both internet-based and face-to-face approaches probably improve self-management and outcomes for patients, but the optimum means of delivering support in a cost-effective way has yet to be determined.
To return to our original questions, a mixture of different interventions that might promote self-management have been evaluated and there is evidence that some may be clinically effective. However, it is unknown which components of these interventions (e.g. patient–clinician relationship, use of written action plan) are the most important and cost-effectiveness has yet to be determined.

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Author contributions

M.J.R. proposed the review question, obtained funding, wrote the protocol, helped develop the literature search, read all of the full-text articles, designed the data-extraction tool, undertook data extraction/risk of bias assessments for all included studies, drafted the content of the paper, reworked the first draft and produced the final version, and reworked the response to peer review comments/the manuscript. A.J.L.K. searched the wider literature, researched definitions of self-management, developed and ran the literature search strategy, deduplicated, applied eligibility criteria and screened 1651 papers, extracted data/underwent risk of bias assessments of 18 of the included studies, drafted the first version of the paper and commented on subsequent redrafts and drafted an initial response to peer review comments. A.L.H. provided methodological expertise and hands-on guidance in developing, running and importing the results of the literature search strategy as well as the approach to data extraction, interpretation and reporting and contributed to the structure/commented on all versions of the paper. E.L.R. updated the literature search, deduplicated and screened 244 papers, extracted data/underwent risk of bias assessments of two of the included studies, and commented on drafts of the paper. A.W. second screened 1651 papers, translated the two German language papers and commented on drafts of the paper and created the Forest plots.

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Supporting Information

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

Appendix S1. Search strategy employed in MEDLINE, MEDLINE in process, Embase and CINAHL databases.

Appendix S2. Eczema severity outcomes by study and time point.

Appendix S3. Quality-of-life outcomes by study and time point.

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