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## REVIEW ARTICLE

# Patient Education in Chronic Skin Diseases: A Systematic Review

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**The negative impact of skin disease on quality of life (QoL) has been described in many studies. Patient education as an adjunct to treatment, with the aim of improving QoL and reducing disease severity, is a relatively new technique in dermatology. The objective of this article is to analyse and summarise evidence concerning the effects of patient education on QoL and disease severity in patients with chronic skin diseases. All source material was identified through searches in MEDLINE and Embase. The CONSORT statement was used to assess the quality of reported randomised controlled studies. Ten of 254 studies met the inclusion criteria. In five of them, statistically significant improvements in QoL were reported. The severity of skin disease significantly improved in three studies. In conclusion, patient education appears to be effective in improving QoL and in reducing the perceived severity of skin disease. Key words: patient education; skin diseases; quality of life.**

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Patient education can be defined as the provision of information in a clinical setting with the aim of empowering patients and carers to solve problems arising from chronic diseases (1). Health-related quality of life (QoL) is a multidimensional concept, reflecting patients' evaluation of the effects of disease on their physical, psychological and social functioning and wellbeing (2). The negative impact of skin disease on QoL has been described in many studies (3, 4). Chronic skin diseases, such as psoriasis and atopic dermatitis (AD), can have a particularly profound, negative impact on QoL. This impact can result from impairment caused by symptoms – such as itch and pain – long-term and/or invasive dermatological treatments, and psychosocial issues linked to the visibility of the disease. Besides disease severity, QoL is generally considered to be an important, secondary outcome measure in the treatment of skin diseases. For many patients with chronic skin diseases, it is the primary outcome measure (5, 6).

Patient education as an adjunct to treatment, whose aims are to improve QoL and to reduce disease severity,

represents a relatively new approach to enhancing overall health perception. Most studies on patient education have focused on diabetes or pulmonary diseases (7, 8). To our knowledge, only a few studies on this subject relate to dermatology.

An understanding of 1) the specific disease and 2) its self-management (the patient's treatment of his/her skin condition), as well as improving coping behaviour (a psychological way of dealing with the skin condition), are expected to improve QoL and disease control. Developing a good understanding of the disease takes time, which is at a premium in healthcare. Efficiently informing patients through education, e.g., by a nurse, may complement standard care. The objective of the present review is to analyse and summarise the evidence concerning the effects of patient education on QoL and disease severity in patients with chronic skin diseases.

## METHODS

### *Inclusion and exclusion criteria*

Studies were assessed for eligibility. Included were studies which (i) were randomised controlled trials (RCTs), (ii) concerned patients with skin diseases who received patient education, and (iii) reported the outcomes of patient education, at least in terms of QoL. Excluded were studies whose primary focus was the prevention of skin diseases, the education of specialists, students or residents, or teledermatology.

### *Literature search*

A literature search was carried out in August and September 2008 in MEDLINE and Embase using MeSH words (Table S1 (<http://adv.medicaljournals.se/article/abstract/10.2340.00015555-1022>)). The search was restricted to studies reported in English, German or Dutch. No limit was placed on the date of publication. References cited in published articles were screened in order to identify additional relevant articles.

### *Study selection*

All articles with titles and abstracts covering skin disease, patient education and QoL were selected based on their relevance by one reviewer, and assessed in full. Eligibility criteria were taken into account when performing these assessments.

### *Assessment of methodological quality*

Each included study was independently critically appraised by two reviewers using the CONSORT statement checklist, an evidence-based, minimum set of recommendations for reporting RCTs (9).

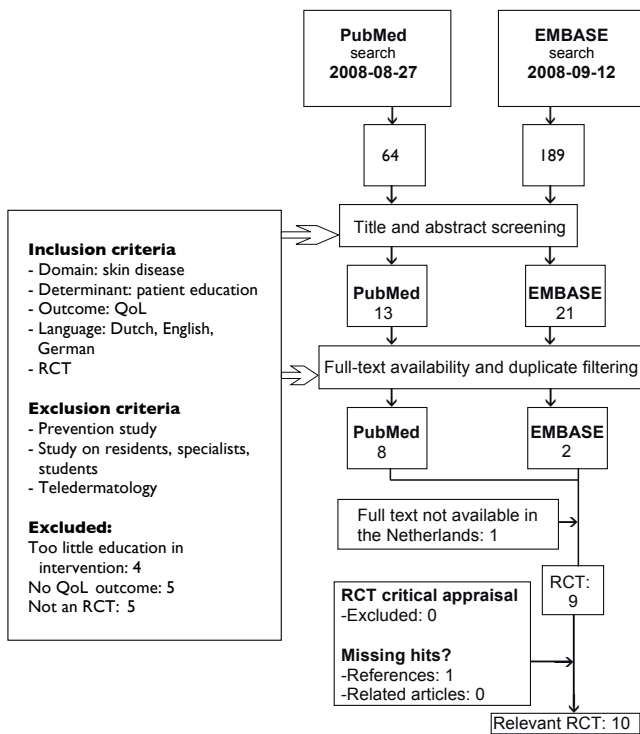


Fig. 1. Flowchart representation of the literature search process. RCT: randomised controlled trial; QoL: quality of life.

Outcome measures

The primary outcome measure of this systematic review was QoL. The secondary outcome measure was disease severity.

RESULTS

Literature search

An initial search yielded 253 articles (Fig. 1). After screening titles and abstracts for eligibility, 34 artic-

les were selected. Twenty-four of them were retained after filtering duplicates. After reading the remaining articles in full, four were excluded because their intervention was mainly non-educational (10–13), five on the grounds of absence of a QoL outcome parameter (14–18), and a further five because they turned out to be non-randomised studies (19–23). Searching the references used in a systematic review on atopic dermatitis by Errser et al. (24) yielded one additional publication (25). Ultimately, our search yielded ten articles that satisfied the inclusion criteria (25–34). The quality of the methodologies employed in the included studies was assessed using the CONSORT statement, as illustrated in Table I.

Study description

The ten included articles were published between 2000 and 2008. Eight of them focused on AD (25, 27–32, 34), and two on AD and psoriasis (26, 33).

Two studies were carried out in primary care settings (32, 33), and seven in dermatology (25–28, 30), paediatric (29) or interdisciplinary (31) outpatient clinics. In one study, the patients described were of unknown origin (34).

Patient education focused on children in six studies (27, 29–32, 34), on adults in three (25, 28, 33), and on both children and adults in one (26). All studies employed a parallel group design.

QoL in children was measured using age-specific questionnaires, such as the Children’s Dermatology Life Quality Index (CDLQI) (35) and the Infant Dermatitis Quality of Life Questionnaire (IDQoL) (36). The QoL questionnaires used in adults were the Dermatology Life Quality Index (DLQI) (37), the Short-Form Health Status Survey (SF-36) (38), the Marburger Neurodermitis

Table I. Assessment of study quality using the CONSORT statement (refs 25–34)

Authors (ref)	Relevance			Validity										
	Domain: skin disease	Determinant: patient education	Outcome: quality of life (QoL)	Eligibility criteria and setting	Details of intervention	Primary and secondary outcomes clearly defined	Sample size	Randomisation	Statistical method	Blinding	Loss to follow-up	Baseline characteristics	Results	Generalisability (external validity)
Chinn et al. (32)	+	+	+	+	+	+	+	+	+	+/-	+	+	+	+/-
Staab et al. (27)	+	+	+	+	+	+	+	+	+	+/-	+	+	+	+/-
Gradwell et al. (26)	+	+	+	+/-	+	+	-	+	+	-	+	+	+	+
Coenraads et al. (28)	+	+	+	+	+	+	+	-	+	+	+	+	+	+/-
Shaw et al. (29)	+	+	+	+/-	+	+	+	+	+	+/-	-	+	+	+/-
Grillo et al. (30)	+	+	+	+/-	+	+	+	+/-	+	-	+	+	+	+/-
Kernick et al. (33)	+	+	+	+	+/-	+/-	+	+/-	+	+/-	-	+	+	+/-
Staab et al. (31)	+	+	+	+	+	+	-	-	+	-	-	+	+	+/-
Jaspers et al. (25)	+	+	+	+	+	+	-	-	+	-	+	-	+/-	+/-
Blessman-Weber et al. (34)	+	+	+	+/-	+/-	+/-	-	-	+	-	+/-	+	+	+/-

++Excellent; +Sufficient; +/-Moderate; -Insufficient.

Questionnaire (MND/MNF) (39) and the EuroQol (40). Parent QoL was measured using two questionnaires: 'Quality of life in parents of children with atopic dermatitis' (41) and 'Daily life' (42). For further information on these questionnaires refer to the legend accompanying Table II. Disease severity was measured according to the Scoring of Atopic Dermatitis Scale (SCORAD) (43), using 'Skin Detective' (44), and based on clinical scores (45).

### Outcomes

*Quality of life.* Five studies demonstrated a statistically significant improvement in QoL as a result of patient education in patients with chronic skin diseases ( $p < 0.004$ – $0.04$ ) (25, 27, 28, 30, 34). The remaining five studies found no significant improvement in QoL (26, 29, 31–33). The intervention of Jaspers et al. (25) consisted of a ten-day intensive day-care program (6 h/day), led by a multidisciplinary team that supplied information about AD and delivered training in appropriate skin care. In addition, the program promoted active coping with AD. MNF scores improved significantly after only 10 weeks, the median score being  $-9$  in the intervention group (range  $-20.0$  to  $-1.0$ ), compared with  $0.0$  in the control group (range  $-13.75$  to  $2.75$ ) ( $p = 0.04$ ). After 40 weeks, the median score in the intervention group had fallen to  $-16$  (range  $-28.25$  to  $-4.7$ ), while that in the control group was  $-3$  (range  $-17.0$  to  $5.5$ ) ( $p = 0.03$ ) (25).

The interventions of Staab et al. (27, 31) comprised once-weekly 2-h sessions during a 6-week period. During each session, the parents of affected children received education by a multidisciplinary team of dermatologists or paediatricians, psychologists and dieticians. The sessions covered information on medical, nutritional and psychological issues, the sharing of personal experiences and ways of helping children to improve their skills. In their 2006 study, Staab et al. reported statistically significant improvements in the QoL of parents of children aged three months to seven years ( $p = 0.04$ ) and eight to twelve years ( $p < 0.031$ ) (27).

Intervention in a study performed by Coenraads et al. (28) consisted of group participation in a ten-day program comprising daily 6-h meetings, during which a multidisciplinary team gave information and discussed various dermatology-related topics. MND scores improved both in the short term (10 weeks) and long term (40 weeks). After 10 weeks of follow up the median score being  $-9$  in the intervention group (range  $-20$  to  $-1$ ), compared with  $0$  in the control group (range  $-13.7$  to  $2.7$ ) ( $p = 0.04$ ). After 40 weeks of follow-up: the mean score in the intervention group was  $-16$  (range  $-28.2$  to  $-4.7$ ), versus  $-3$  in the control group (range  $-17$  to  $5.5$ ).

Patient education in the study performed by Grillo et al. (30) was aimed at children diagnosed with AD and

consisted of a 2-h workshop on trigger factors, skin care and treatment, and a practical session. This intervention resulted in a statistically significant (78%) improvement in CDLQI score at week 12 in the intervention group, compared to a 27% improvement in the control group ( $p = 0.004$ ). Blessman-Weber et al. (34) held a 90-min group meeting for AD children and their parents, in which a child psychiatrist and a volunteer medical student participated. The consultation started with the children being allowed to play and relax. Thereafter, the educational theme – disease and treatment – was briefly introduced to the children, and then discussed with their parents. Finally, the children participated in a structured playful activity, in which they performed a task related to the educational theme. They then presented the results of this task to the parents. In the mean time, the parents received further explanations of the educational theme, before engaging in a group discussion. The intervention resulted in a statistically significant improvement in QoL as assessed using the CDLQI questionnaire ( $p < 0.01$ ).

The five studies in which no statistically significant improvement in QoL was achieved employed a range of different interventions. Gradwell et al. (26) offered a 20-min interview with a dermatology nurse in addition to regular consultations with a dermatologist. In a study by Shaw et al. (29), AD patients received medication and behavioural instructions from a trained medical student for 15 min. In their 2002 study, Staab et al. (31) used the same intervention as they successfully employed four years later (27), without achieving a significant improvement (31). Chinn et al. (32) introduced an intervention consisting of a demonstration of how to apply medications, together with advice and education, in a single 30-minute session led by a trained dermatology nurse. In a study by Kernick et al. (33), patients with AD and psoriasis were offered as many consultations as they required with a trained nurse within a four-month period.

### Disease severity

Subjective or objective severity of patients' skin disease was significantly decreased as a result of patient education in three studies (27, 30, 33). Staab et al. (27) demonstrated a statistically significant decrease in disease severity in the intervention group, compared to the control group (scores improved 5 to 14 points in different age groups ( $p < 0.03$ )). Elsewhere, Grillo et al. (30) found that, by week 4, SCORAD scores had improved in 45% of patients in the intervention group, but only 7% of control group patients. At week 12, they had improved in 53% and 16% of patients in the intervention and control groups, respectively ( $p < 0.005$ ). Kernick et al. (33), meanwhile, reported significant improvements in clinical scores in intervention group

Table II. Results of the included studies (refs 25–34)

Article	Design	Setting	Patient, n Diagnosis	Age	Education	Scoring	Outcome
Chinn et al. (32)	Parallel group	Primary care	235 Atopic dermatitis	6 month–16 year	30-min demonstration, advice on techniques, education	IDQOL CDLQI	QoL: no significant effects.
Gradwell et al. (26)	Parallel group	Dermatology outpatient clinic	66 Atopic dermatitis psoriasis	≥14 year	20-min interview with a specialist dermatology nurse in addition to an initial consultation with the dermatologist	DLQI	QoL: no significant effects
Staab et al. 2006 (27)	Parallel group	Dermatology outpatient clinic	823 Atopic dermatitis	3 month–18 year	6 weekly group sessions, each lasting 2 h	'Skin Detective' 'QoL in parents of children with AD' SCORAD	QoL: Skin Detective scores significantly improved ( $p < 0.0022$ ) QoL in parents: significantly improved ( $p < 0.004$ and $p < 0.031$ ) Severity: significantly improved ( $p < 0.005$ )
Coenraads et al. (28)	Parallel group	Dermatology outpatient clinic	54 Atopic dermatitis	18–35 year	10-day education programme	MND SF-36 SCORAD	QoL: MND scores significantly improved after 10 and 40 weeks ( $p = 0.03$ ) Severity: no significant effects
Shaw et al. (29)	Parallel group	Pediatric outpatient clinic	106 Atopic dermatitis	0–18 year	15 min education from an AD educator (medical student)	IDQoL CDLQI SCORAD	QoL: no significant effects Severity: no significant effects
Jaspers et al. (25)	Parallel group	Dermatology outpatient clinic	53 Atopic dermatitis	18–35 year	10-day intensive course, 6 h/day	MNF SF-36 SCORAD	QoL: MND scores significantly improved after 10 ( $p = 0.04$ ) and 40 weeks ( $p = 0.03$ ) Severity: not assessed
Grillo et al. (30)	Parallel group	Dermatology outpatient clinic	58 Atopic dermatitis	4 month–13 year	2-h workshop	IDQoL CDQoL SCORAD	QoL: CDLQI scores significantly improved only at 12 weeks ( $p = 0.004$ ) Severity: significant improvement ( $p < 0.0005$ )
Staab et al. (31)	Parallel group	Interdisciplinary clinic	204 Atopic dermatitis	Mean age 3.1 year	6 weekly group sessions, each lasting 2 h	'QoL in parents of children with AD' Daily Life SCORAD	QoL: no significant effects Severity: no significant effects
Kernick et al. (33)	Parallel group	Primary care	100 Atopic dermatitis psoriasis	18–65 year	4 months, as many consultations by the nurse as necessary	DLQI EuroQoL Clinical score	QoL: no significant effects Severity: significantly improved ( $p < 0.05$ )
Blessman-Weber et al. (34)	Parallel group	Unknown	32 Atopic dermatitis	2–16 year	Children: 90 min 'play, education, task' Parents: subject explanation, discussion, parent reports	CDLQI	QoL: CDLQI scores significantly improved ( $p < 0.01$ )

CDLQI/CDQoL: Children's Dermatology Life Quality Index (QoL of children aged 4–16 years) (35)

IDQoL: Infant Dermatitis Quality of Life Questionnaire (QoL of children aged 6 months to 12 years) (36)

DLQI: Dermatology Life Quality Index (QoL of adults) (37)

SF-36: Dutch validated Short-Form Health Status Survey (38) (non-age-specific QoL questionnaire)

MND/MNF: Marburger Neurodermitis Questionnaire (disease-specific functioning of patients) (39)

EuroQoL: Visual analogue QoL scale measuring disease-specific clinical data (40)

'Quality of life in parents of children with atopic dermatitis': Comprising 26 subjects, divided into five subscales: psychosomatic wellbeing, effects on social life, confidence in medical treatment, emotional coping and acceptance of the disease (41)

Daily life: Generic QoL instrument (42)

SCORAD: Scoring of Atopic Dermatitis Scale for monitoring the severity of eczema (mild <15, moderate 15–40, severe >40) (43)

Clinical Score: Specification of up to three features of a skin condition (scaling, redness, itching, pustules, swelling, dryness, extent of rash, thickness of rash), scored from 1–5; the sum of these scores gives a clinical score from 3 (best) to 15 (worst) (33)

Skin Detective: Subjective severity score, generated by parents comparing the morphology of their child's lesion with those of illustrations evaluated by experts (44)

patients compared to control patients ( $p < 0.05$ ). Three studies failed to demonstrate a statistically significant improvement (28, 29, 31); disease severity was not assessed in the remaining four studies (25, 26, 32, 34).

#### *Additional outcomes measures*

Some of the studies describe additional outcomes measures that are worth mentioning. Gradwell et al. (26) found that 33% of follow-up appointments with the dermatologist were cancelled in the intervention group, compared with 0% in the non-intervention group, suggesting that patients did not require extra information from the dermatologist after an interview with the nurse. In the primary care group, 11% of patients in the intervention group felt the need for a follow-up appointment with their general practitioner (GP) compared to 39% in the control group ( $p = 0.01$ ). In the study by Coenraads et al. (28), no significant difference in consultation frequency at the dermatology outpatient clinic was seen, but the consultations involving intervention group patients were shorter than those involving controls.

## DISCUSSION

In this review we analysed studies describing patient education in relation to skin diseases. Patient education appeared to be effective in improving QoL and decreasing the severity of skin diseases, even in the long-term management of chronic skin diseases (25, 27, 28, 30, 33, 34).

Important limitations of this study and the studies presented merit attention: (i) Only RCTs were assessed in this review. (ii) Although most interventions were directed at secondary care patients (in dermatology outpatient clinics), two were directed at primary care patients (32, 33). Primary care patients commonly have lower disease severity than secondary care patients, which may influence the outcomes. Moreover, child patients and their parents will react differently to adult patients at educational interventions. With most interventions focusing on the parents rather than the child, one needs to consider whether it is appropriate to utilise child-centred outcomes when trying to achieve internal validity. (iii) Improvements in SCORAD scores may, in part, be due to seasonal factors that influence skin diseases. (iv) All studies, except those reported by Staab et al. (27, 31) and Chinn et al. (32) used small samples. (v) Jaspers et al. (25) and Coenraads et al. (28) used the SF-36 (38) questionnaire to assess QoL. This questionnaire has been shown to be too non-specific to be effectively applied to dermatology (45). (vi) Sample size varied greatly – from 32 in Blessman-Weber et al. (34) to 823 in Staab et al. (27) – and so thus did statistical power, which was low in studies with small sample si-

zes. Sample sizes were reported in Coenraads et al. (28), Chinn et al. (32), Staab et al. (27), Grillo et al. (30) and Kernick et al. (33) with a power of at least 80%. Shaw et al. (29) reported 30% loss to follow-up, which left their study with a sample size smaller than was needed for a power of 90%. (vii) Finally, the studies employed different methodologies, as illustrated in Table I. It was therefore difficult to compare outcomes.

Future studies on patient education programs are needed to further evaluate their cost-effectiveness and suitability for dermatological practice. Development of standard (multidisciplinary) education models for various skin diseases should be pursued in order to enhance their applicability to all patients. The quality of the employed methodologies and statistical power needed should be considered when designing such studies. To improve comparability, more patient education studies should be performed in adult patients.

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