

Patient and parent education in atopic dermatitis:

The German experience with a
structured educational program

Doris Staab
Berlin, Germany

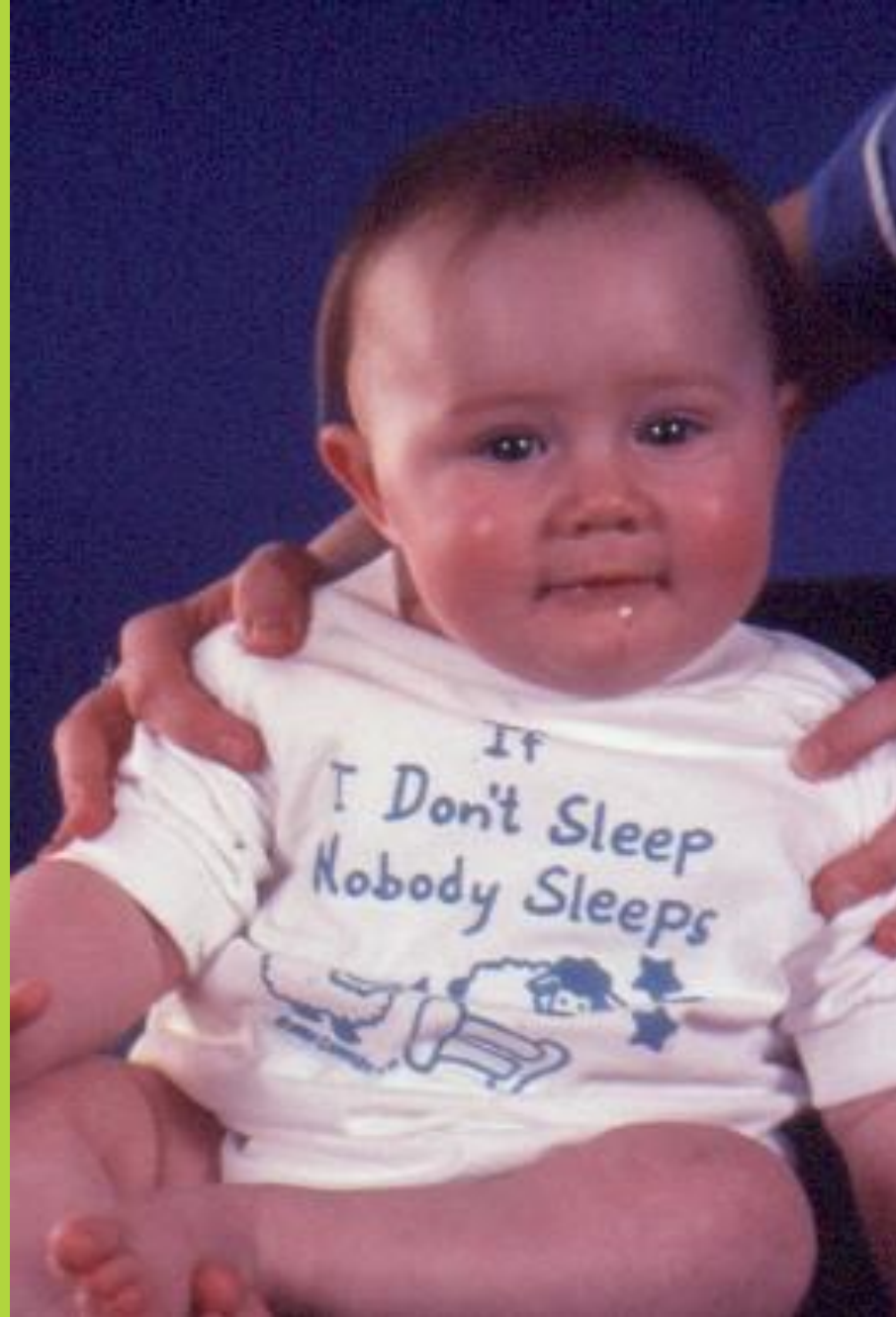


Topics

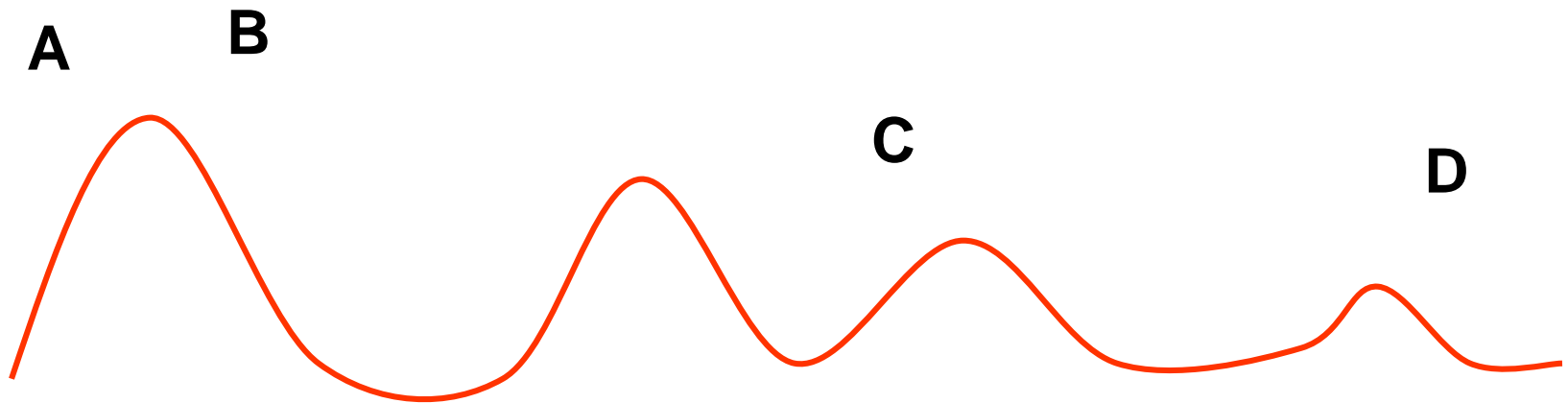
- Background and specific problems in AD
- Overview on existing programs
- The German atopic dermatitis intervention study (GADIS)
- Outlook

Specific Problems in AD

- multiple hypotheses on the genesis of the disease
- chronic recurrent course of the disease
- no causal treatment
- lack of confidence in the treatment
- fear about side effects of steroids
- Stigmatizing appearance



Problems in judging effectiveness of treatment



therapist D has cured !

4 Different Ways of Education

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4 Different Ways of Education

- Information the informed patient
- Promotion of compliance the obedient patient
- Training the capable patient
- Empowerment the responsible patient

aims of patient empowerment

Enable the patient or parent to.....

- Have realistic goals
- Enter a process of problem solving
- Accept the disease
- Seek for social support
- Enhance the own motivation for therapy

Objectives of the AD Education Program

- improve self-management skills
- promote a better outcome of the ekzema
- promote a better quality of life for the family
- reduce „doctor shopping“
- reduce costs of treatment

Early Trials

Author	Publication	n	Control group	Intervention
Williams DH	Arch Dermatol 1951	53	no	Single education
McSkimming J	Australas J Dermatol 1984	11	no	Group education
Koblenzer CS	Arch Dermatol 1988	8	no	Single education
Gieler U	Hautarzt 1992	23	no	Single education
Schmidt-Grüber C	Sozialpädiatrie 1996	102	no	Group education
Cork	Br J Dermatol 2002	51	no	Single education
Chavigny	Ann Dermatol Venereol 2002	40	no	Single and group education

Randomised Controlled Trials Cochrane Review 2014

Author	Publication	n	Control group	Intervention
Sokel	Contemporary Hypnosis 1993	44	yes	Single education
Niebel	Hautarzt 2000	47	yes	Single education (video/direct)
Staab	PAI 2002	204	yes	Group education
Chinn	Br J Dermatol 2002	240	yes	Single education
Staab	Brit Med J 2006	992	yes	Group education

Oriented Patient Education Network in Dermatology (OPENED)

- Review on Therapeutic Patient Education in Atopic dermatitis
- Questionnaire on the topics:
 - Population profile
 - Process (type of program)
 - Organization (including funding)
- 23 experts from 11 countries worldwide
 - Mainly Europe plus USA, Canada, Japan and Brazil

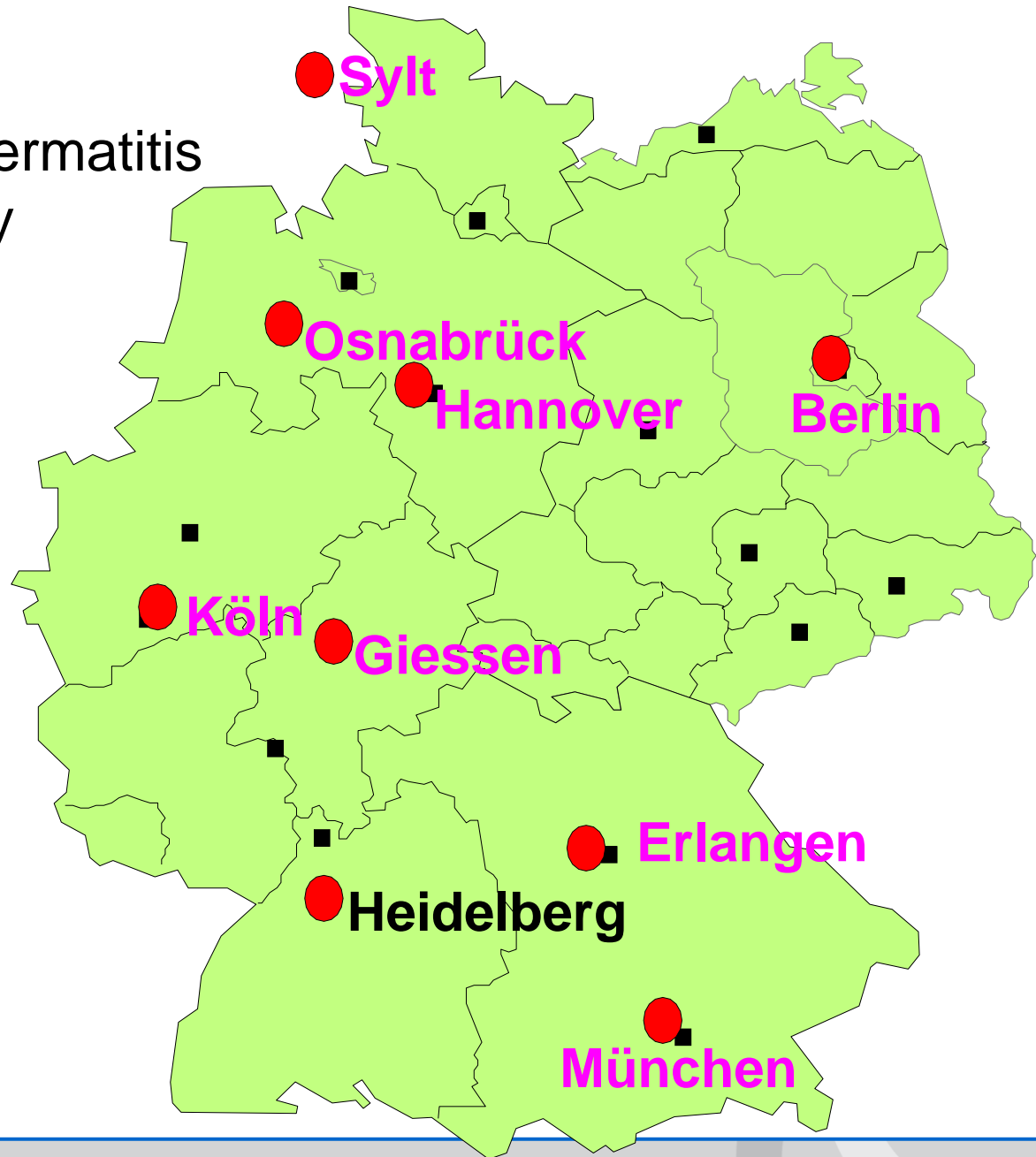
Variety of programs

- Duration: 1 hour nurse consulting – 12 hours interdisciplinary education team
- Group size: single family up to 100 patients
- Educational methods:
 - e-learning,
 - individual face-to-face counseling,
 - interactive group settings,
 - Lectures (yearly family days)

Evaluation

- They all showed to be effective
- Evaluation instruments and time differ widely
- No direct comparison possible

German Atopic Dermatitis Intervention Study (GADIS)



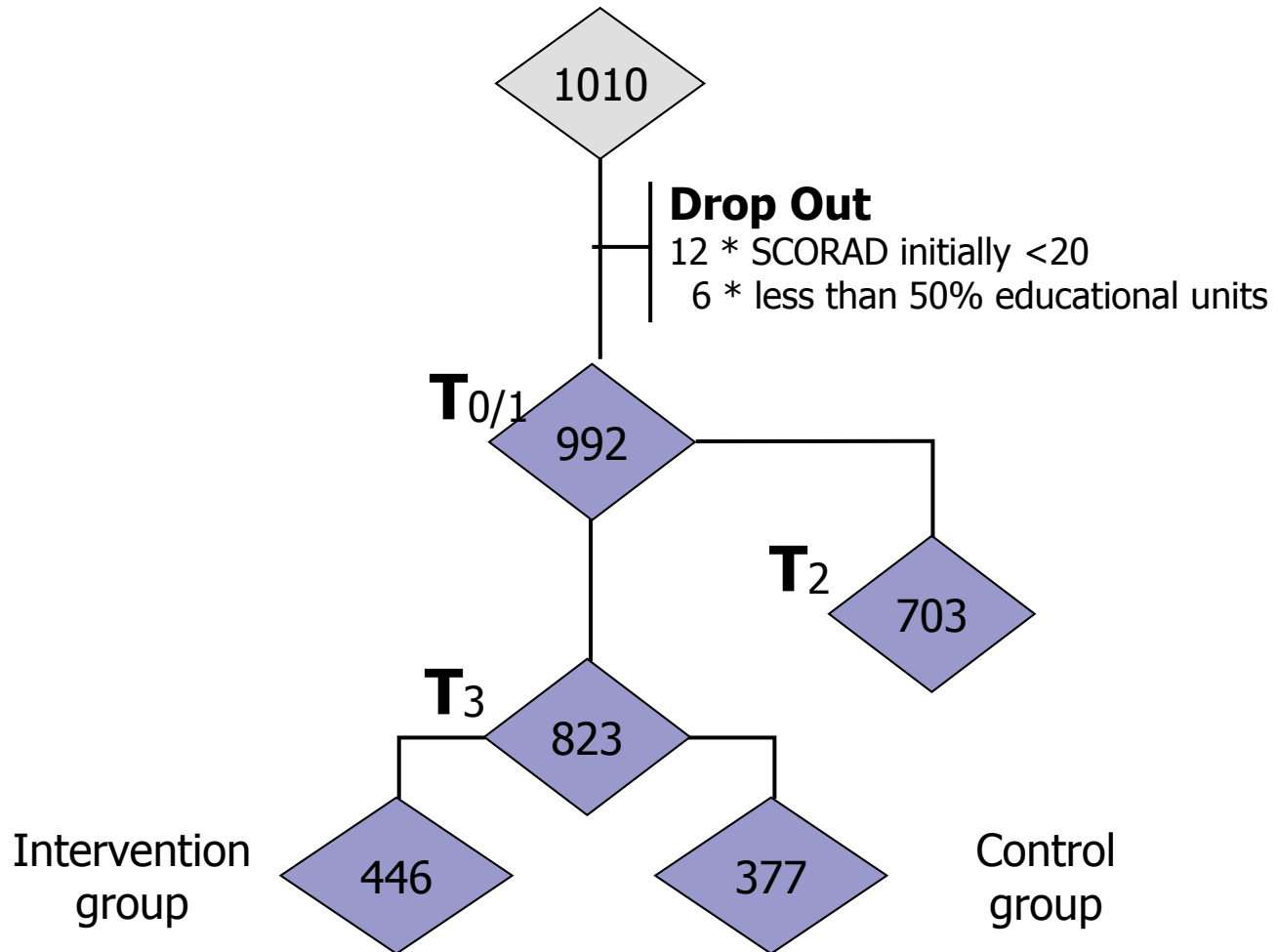
Structure of the Training Program

- 6 sessions of 2 hours each once weekly
- groups of 6 - 8 families
- interdisciplinary team of trainers
(pediatricians/dermatologists, psychologists,
nurses and dieticians)

Topics of the Sessions

1. basic medical information on pathophysiology
2. dealing with stress and itching and scratching
3. basic skin care
5. nutritional aspects
4. skin treatment
6. transfer to the daily management

Patients

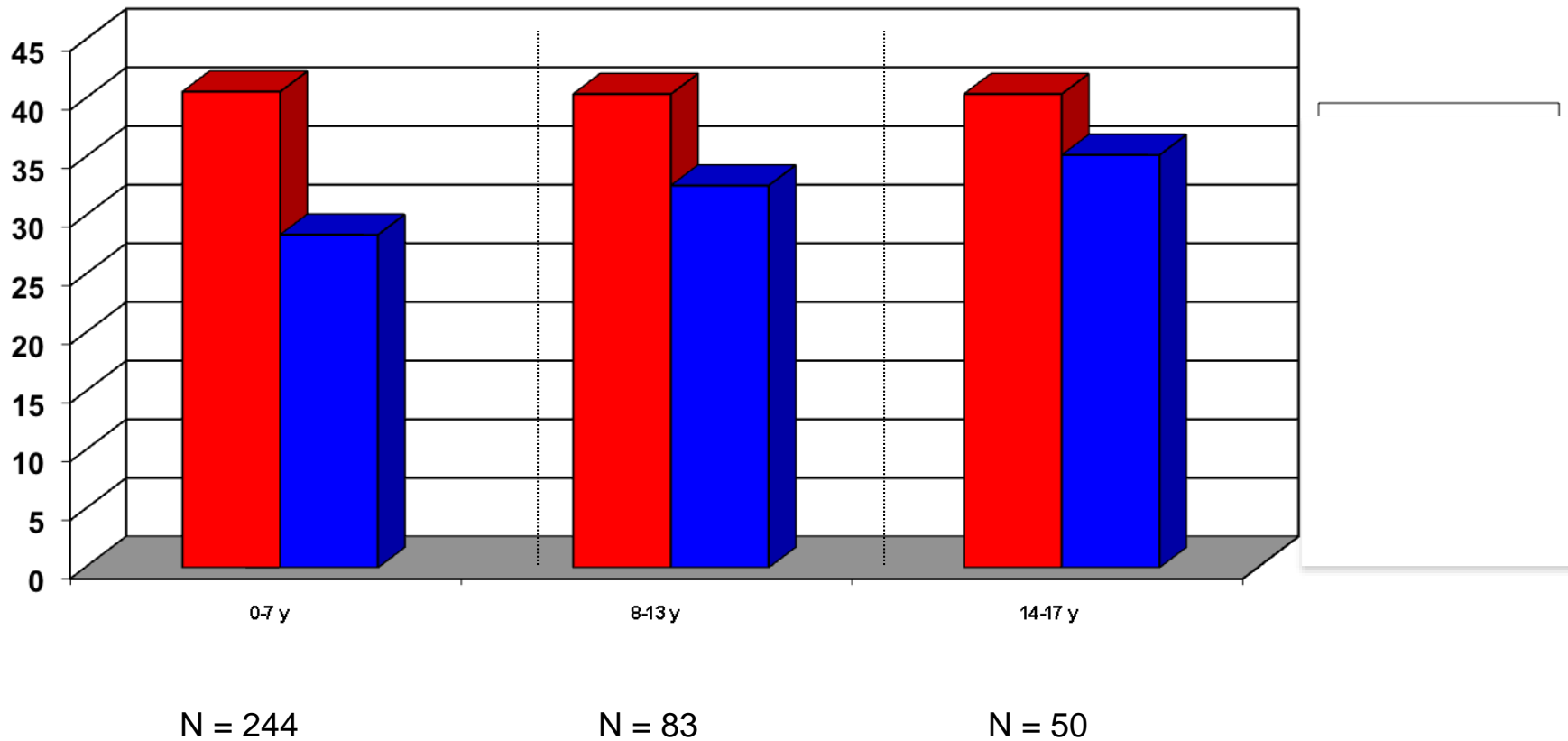


Evaluation

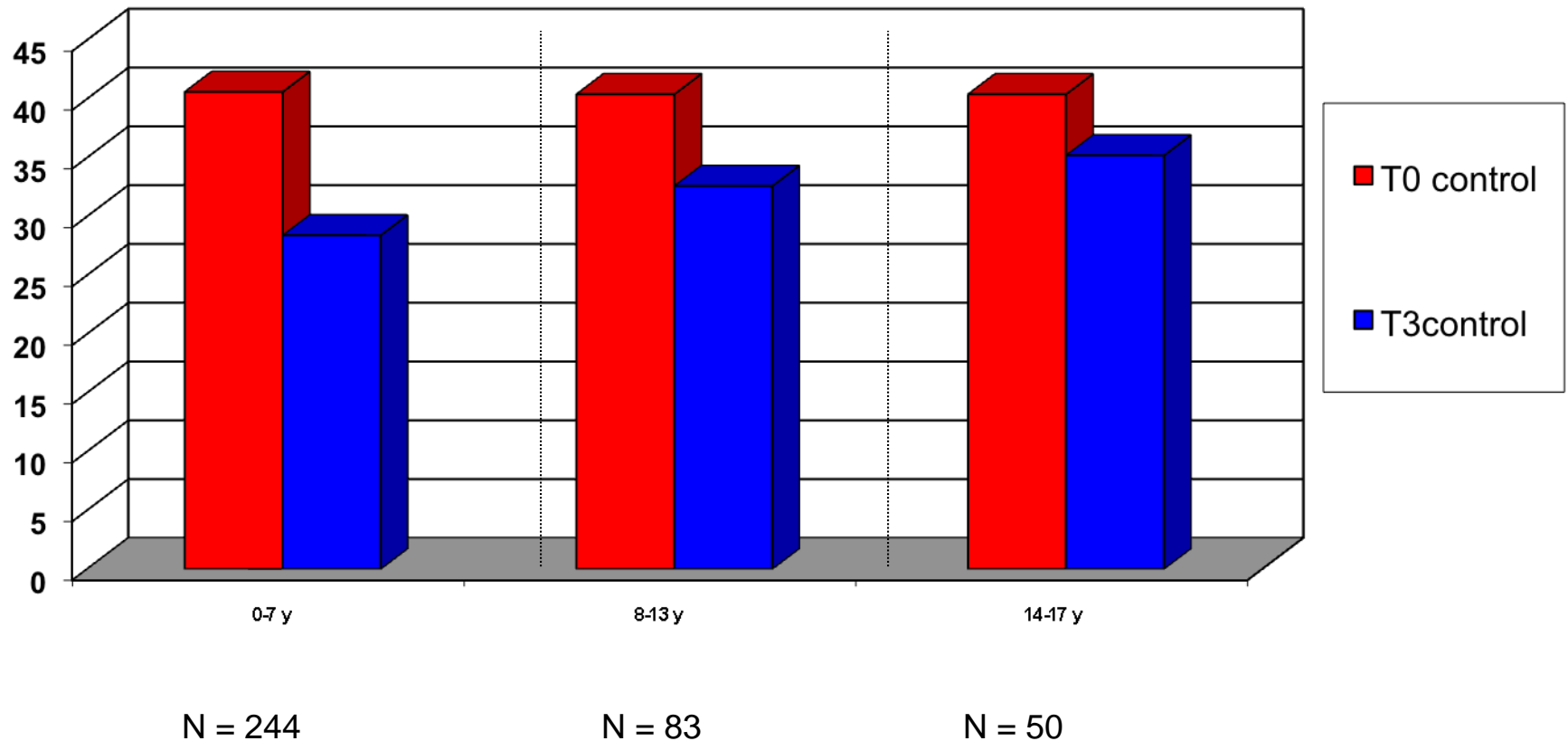
Scores and Questionnaires

- Disease Severity – objective and subjective
- Quality of Life – parents and children
- Coping – parents and children
- Itching cognitions
- Knowledge about skin inflammation and treatment

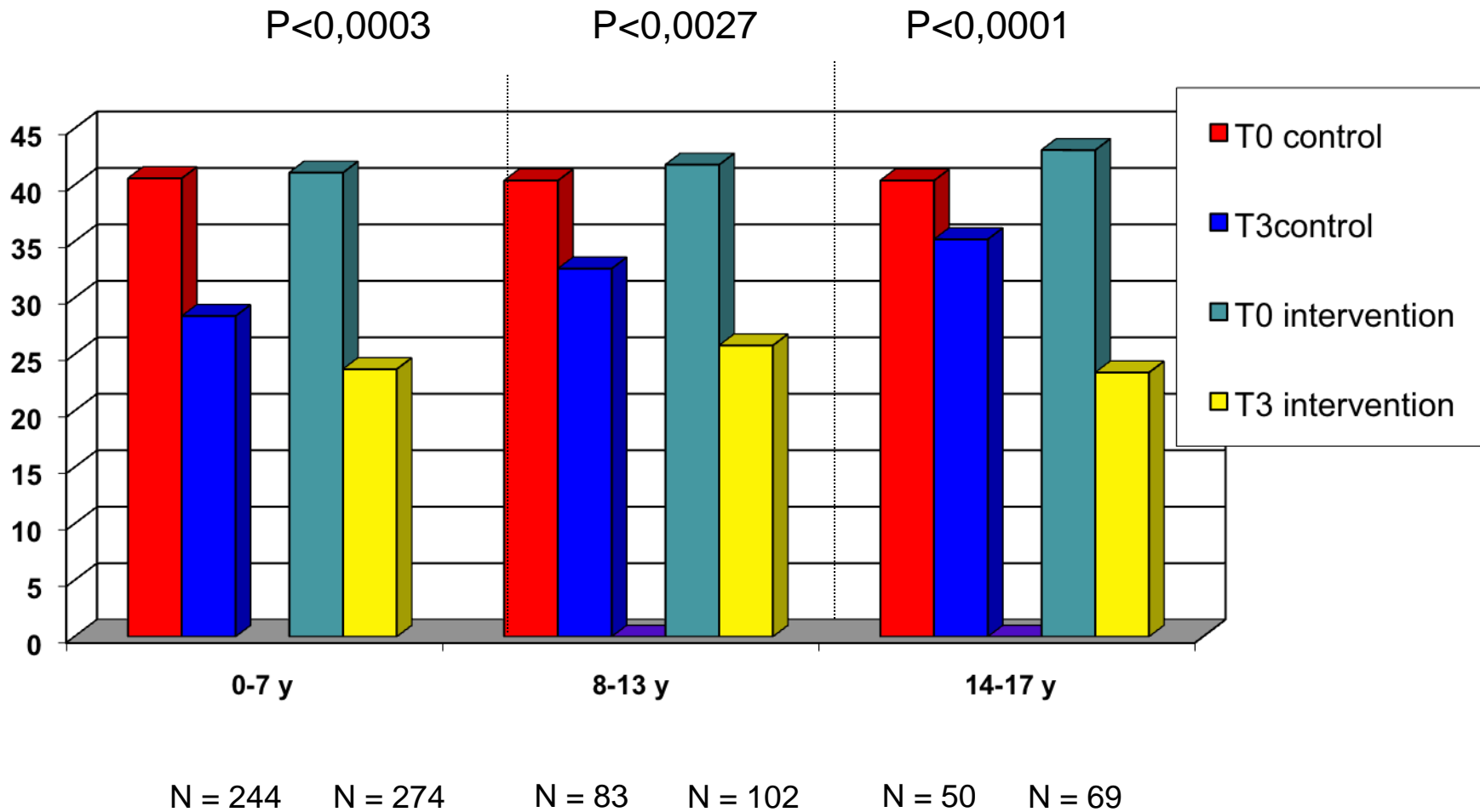
Changes in skin condition (SCORAD)



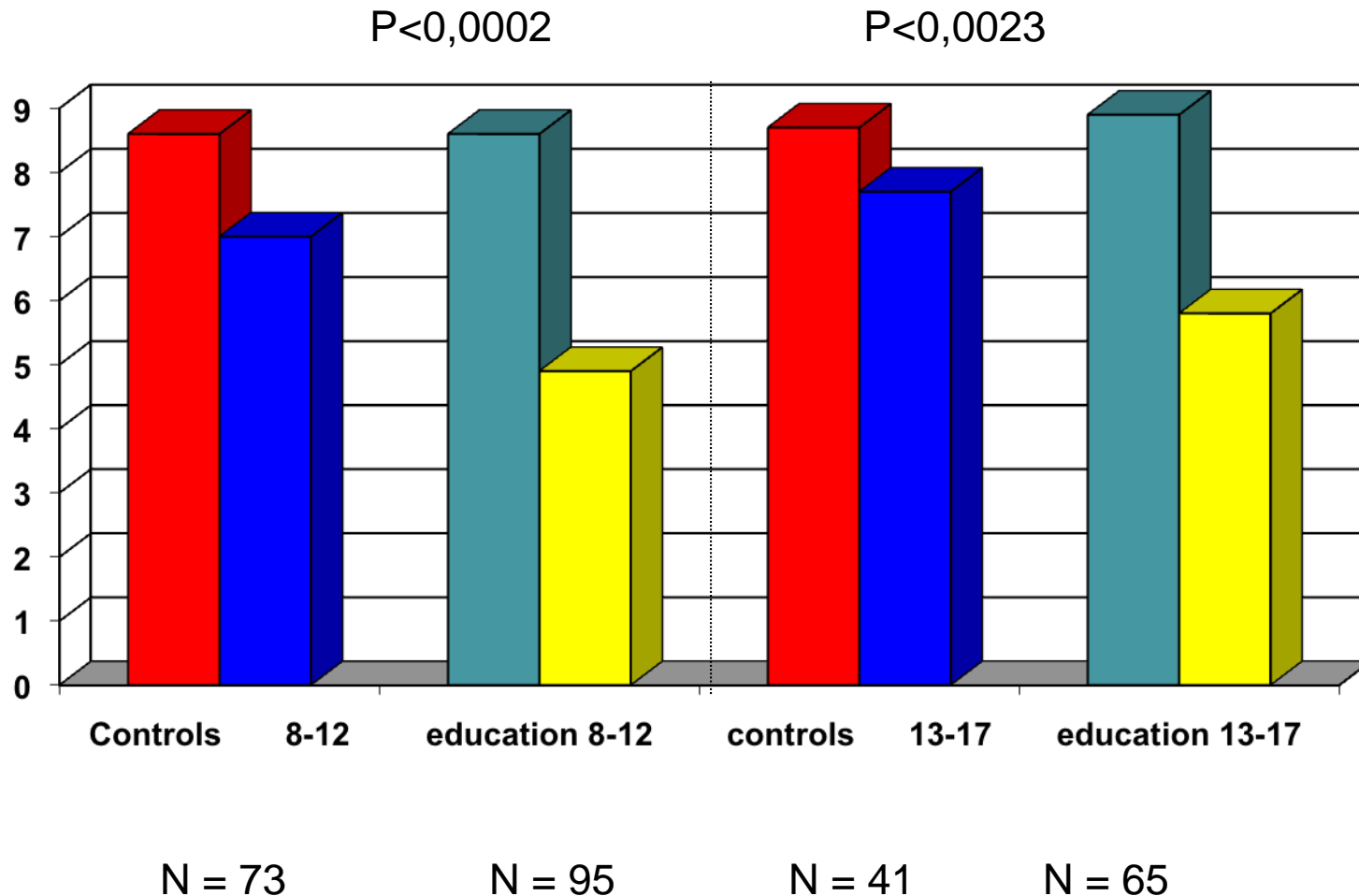
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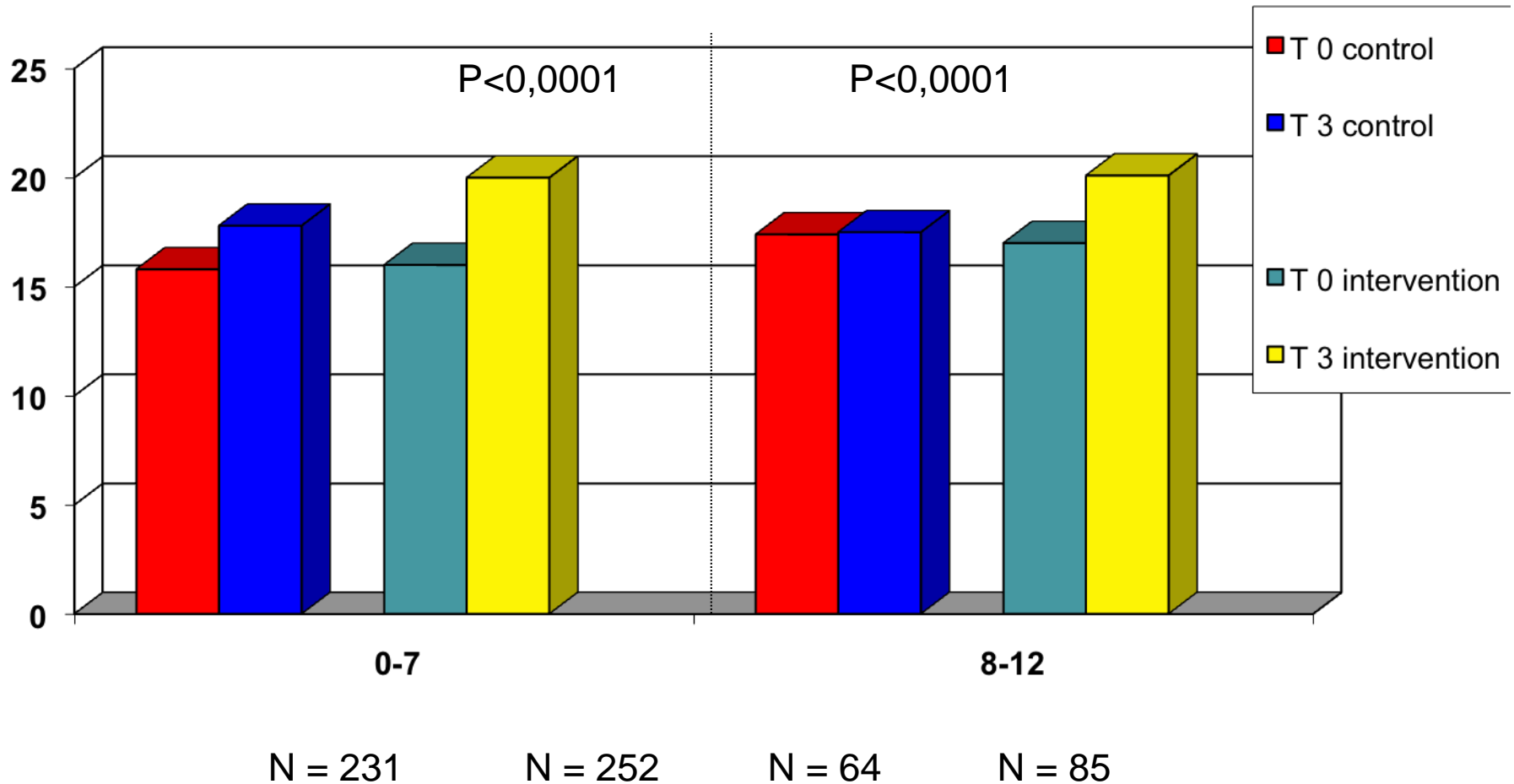


Childrens subjective severity score (skin detective)

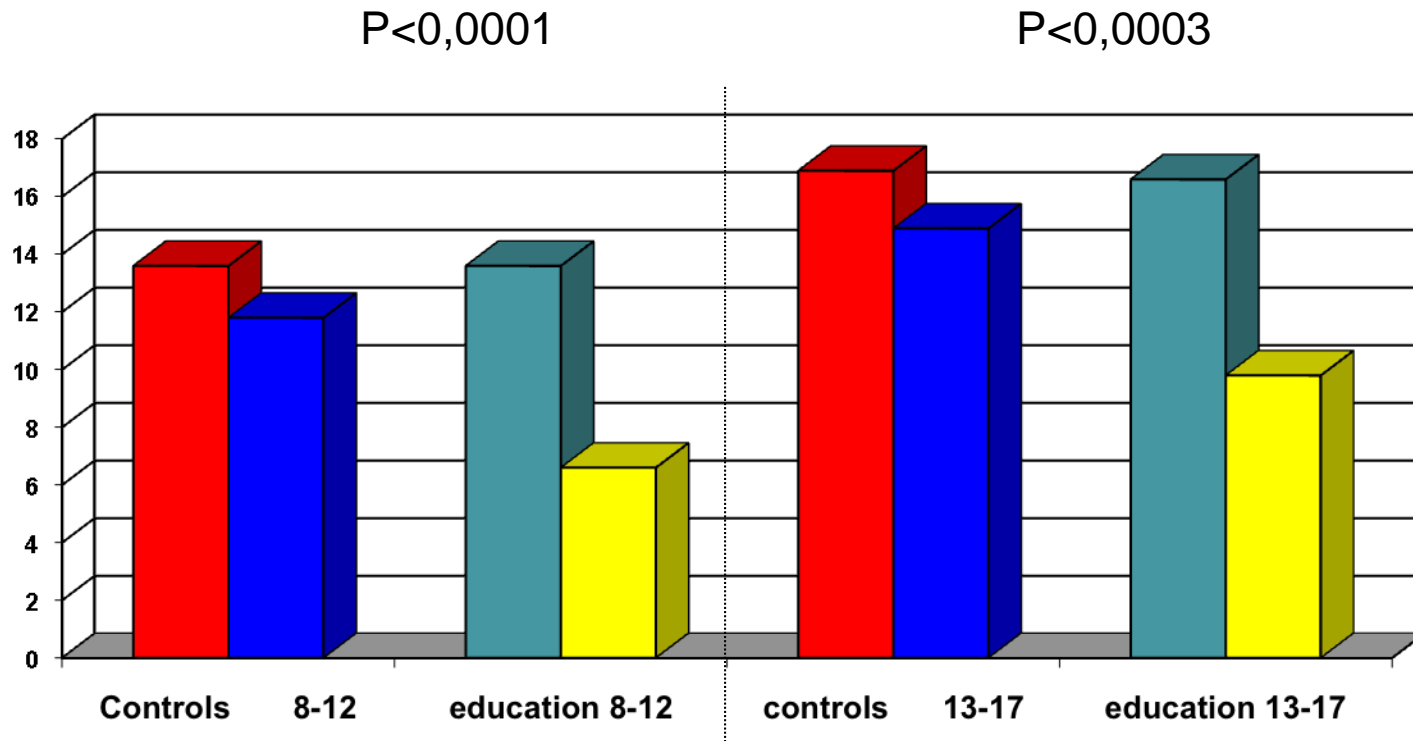


Parents QoL

Satisfaction with medical care



Itching Cognition catastrophizing



N = 73

N = 96

N = 46

N = 66

Implementation

- Spread all over Germany
- 115 Centers who offer AD education
- 880 certified AD trainers
(AD Train-the trainer-academies –
40 hours theoretical seminars,
hospitation, supervision)
- Reimbursement by health insurance
- www.neurodermitisschulung.de

Modularised education programs

Modul	Generic vs. disease specific	Primary responsibility
I. welcome, introduction, group cohesion	generic	Physician and psychologist
II: Motivational explanation of the disease – pathophyiology and treatment	specific	Physician, dietician
III: : comptence and motivation for therapy in stable condition	specific	Physician, nurse, dietician
IV: competence for acting in acvute exacerbations	specific	Physician
V: coping in the family system	generic	Psychologist and all

Advantage

- It is easy to develop new programs for different indications on the basis of this pattern
- Any part of the program can be used independently in different settings
- It is easier to get reimbursement by the health system for programs developed according to this standard
- Standardised trainer education
 - A) basic trainer competence
 - B) specific disease competence

Summary I

(German program)

- Patient and family education for atopic dermatitis is effective in all age groups
- The program is very well accepted by parents, children and adolescents are difficult to reach
- Similar programs are run in France and Italy, their evaluation showed similar results
- Interventions in other countries vary from 1 – 6 hours

Summary II

(international programs)

- The setting is either group intervention or individual sessions face-to-face or via internet
- They are either nurse led or provided by an interdisciplinary team
- They also have shown to be effective
- Outcome parameters and time of observation vary, making a direct comparison impossible
- Funding from health insurances is rare, mostly charity donations and grants from pharmaceutical industry made the programs possible.

Conclusion

- Since all programs have shown to be effective, therapeutic patient education should be claimed as integral component of treatment of atopic dermatitis
- It should be integrated as an essential part of therapy in all international guidelines
- Programs might differ from country to country, but we should agree on standards for evaluation