IMPLEMENTATION AND EVALUATION OF A PATIENT ACTION PLAN FOR PATIENTS WITH ATOPIC DERMATITIS

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Table of Contents

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Abstract

Background: Management and treatment of atopic dermatitis (AD) are complex and therefore bear the risk of therapeutic failure. Individualized patient action plans for patients have been shown to improve AD management, eczema monitoring and therapy adherence.

Purpose: This project aimed at implementing a patient action plan to improve eczema management and evaluating its effects on disease severity and patient-related outcomes.

Methods: This quality improvement project had a pre- post-test design and evaluated AD severity and patient-related outcomes after implementing a patient action plan. A convenience sample of 20 adult patients with AD were included. Socio-demographic, diagnostic and clinical variables were collected from the electronic health records. Trained staff assessed AD severity (SCORAD) and person-centered dermatology self-care index (PeDeSi-G) pre as well as one month post intervention. Patients completed dermatology life quality index (DLQI) and patient benefit index (PBI). For comparison of SCORAD, DLQI, PeDeSi-G, paired t-test was applied. PBI was presented using descriptive statistics.

Results: Upon intervention, a significant decrease of disease severity ($p < .0001$), in parallel with a significant increase of DLQI ($p < .001$) and PeDeSi-G ($p < .0001$) was observed. A PBI ≥ 1 was reached in 95% of participants (mean 2.73; SD 0.9).

Recommendations and Conclusion: Our findings confirm the importance of providing patient action plans to AD patients with the aim of achieving best treatment results. Based on our experience, we plan to modify the action plan by including both topical and systemic therapy, and to translate it into several languages.

Key words: Atopic Dermatitis, Patient Action Plan

Introduction

Atopic dermatitis (AD) is a chronic, inflammatory skin disease presenting with chronic or recurrent eczematous skin lesions (Langan et al., 2020). Patients suffer from severe itch and/or pain, which may result in sleep disturbances and along with the skin lesions, in stigmatization. All clinical signs, symptoms and psychological aspects significantly affect patients' quality of life. Anxiety and depression are commonly reported by AD patients, correlating with disease severity (Eckert et al., 2019; Simpson et al., 2018). Topical therapies, ultraviolet light therapy and systemic therapies are used to treat AD (Wollenberg et al., 2022a, 2022b). However, therapeutic failure defined as "a failure to accomplish the goals of treatment as a result of inadequate drug therapy and not related to the natural progression of disease" (Kaiser et al., 2006, p. 580) is common (Eckert et al., 2019; Eichenfield et al., 2021; Simpson et al., 2018). Individualized patient action plans for patients with AD have been shown to improve eczema management, eczema monitoring and adherence (Feldman et al., 2017; Powell et al., 2018; Rea et al., 2018; Sauder, et al., 2016; Shi et al., 2013).

Background and Significance

Therapeutic failure and inadequate disease control in patients with atopic dermatitis (AD) are common and associated with poor quality of life and high disease burden (Eckert et al., 2019; Eichenfield et al., 2021; Simpson et al., 2018). To improve eczema management, individualized patient action plans have been proven to be useful tools (Powell et al., 2018; Rea et al., 2018; Sauder, et al., 2016; Shi et al., 2013).

Atopic Dermatitis

AD is a common chronic, inflammatory skin disease characterized by eczematous flares, intense pruritus and a relapsing disease course. The disease prevalence has increased significantly in the second half of the 20th century due to reasons summarized as hygiene hypothesis. Approximately 20% of children and 5-10% of adults are affected in Western countries, and approximately 30% of adult AD patients suffer from moderate to severe disease (Langan et al., 2020; Simon et al., 2019).

AD is based on a genetic predisposition determining skin barrier dysfunction and type 2 inflammation, and, in addition, is affected by environmental factors (e.g. stress, infections, allergic diseases). The clinical presentation varies by age. Infants often have oozing and crusting eczematous skin lesions on the face and extensor sites of the extremities, while the flexural folds are affected in children. In adults, the skin is often very dry, scaly or inflamed during exacerbation. All body areas can be affected, but in adults eczematous skin lesions are often found in the cubital and popliteal folds (Langan et al., 2020; Simon et al., 2019). Common co-morbidities are other atopic diseases, such as asthma, allergic rhinitis and eosinophilic esophagitis (Langan et al., 2020; Simon et al., 2019). Furthermore, AD can be associated with neuropsychiatric disorders (e.g. depression, anxiety) (Eckert et al., 2019; Simpson et al., 2018).

Burden of Atopic Dermatitis

Patients with AD are often stigmatized due to visible skin lesions. Moreover, the concomitant itch often results in sleep disturbances and affects daily activities and the ability to concentrate followed by impaired educational and working productivity (Eckert et al., 2019; Simpson et al., 2018). The patients' quality of life is reduced. Anxiety and depression have been found more frequently among patients with chronic skin diseases including AD compared to people without chronic skin diseases. AD is an immense burden on patients and also their families and caregivers (Eckert et al., 2019; Simpson et al., 2018).

Therapeutic Management of Atopic Dermatitis

The therapeutic management is based on the pathophysiology of AD. To restore the skin barrier function, patients need to apply a basic therapy with emollients. In addition, they require knowledge of how to clean their skin. This basic therapy needs to be carried out regularly (Wollenberg et al., 2022a, 2022b).

To reduce skin inflammation, a topical anti-inflammatory therapy (e.g. topical corticosteroids, topical calcineurin-inhibitors) is used. This therapy needs to be adapted to the

disease severity and affected body sites. In patients with severe AD, a topical anti-inflammatory therapy might not be sufficient, and ultraviolet light therapy and systemic therapies are indicated (Wollenberg et al., 2022a, 2022b).

Therapeutic Failure in Atopic Dermatitis

The treatment of AD is very complex, time consuming and requires both broad and detailed knowledge. Patients often have problems managing the disease at home due to a lack of knowledge, information and skills (Eichenfield et al., 2021; Powell et al., 2018). According to the International Study of Life with Atopic Eczema (ISOLATE), 77% of patients with AD did not feel confident managing their skin disease (Zuberbier et al., 2006). Patients and caregivers often sense a lack of adequate support and sufficient information by their providers (Eichenfield et al., 2021; Powell et al., 2018). Considerable knowledge and skills are crucial to understand the complex nature of the disease and to be able to manage the disease at home (Eichenfield et al., 2021). For more information, patients often search for answers on the internet. This can lead to misinformation and uncontrolled disease course (Eichenfield et al., 2021).

Individualized patient action plans providing structured written instructions are helpful to overcome these gaps (Powell et al., 2018; Rea et al., 2018; Sauder, et al., 2016; Shi et al., 2013).

Purpose

The purpose of this project was to implement an action plan for patients with AD under the guidance of a nurse practitioner at a department of dermatology of a university hospital in Switzerland with the aim of improving eczema management. Further, the effects of the action plan on disease severity and patient-related outcomes were evaluated.

Review of Current Evidence

Literature Search Strategy

The literature search was carried out on the electronic databases PubMed and Cinhal. Keywords were atopic dermatitis, patient action plan, self-management, burden of disease. Filters were not used. Following operators for PubMed were used:

Search Term PubMed: ((Atopic eczema OR Atopic dermatitis OR Eczema) AND (Patient care plan OR Patient action plan OR self-management)). Similar search methods were applied for the other database.

The search in all databases yielded 170 sources. Of those, 26 were duplicates. After reviewing titles and abstracts, 46 papers were excluded. Main themes of the review were patient action plan, burden of the disease and self-management in patients with AD. Overall, 21 articles met the inclusion criteria. Inclusion criteria were:

- Studies determine the effect of patient action plans for patients with AD (all ages included)
- Studies determine the burden of uncontrolled AD (all ages included)
- Studies written in English

Exclusion criteria were:

- Studies written in languages other than English

Current State of Knowledge

Therapeutic failure is common in AD patients for several reasons, including complex and time-consuming therapies as well as lack of knowledge and information. Therapeutic failure often leads to frustration and uncontrolled disease courses (Eichenfield et al., 2021). All these aspects can have an immense impact on the burden of the disease (Eckert et al., 2017, 2019; Simpson et al., 2018). Stigmatization, anxiety and depression are commonly reported by AD patients correlating with disease severity and poor quality of life (Eckert et al., 2017, 2019; Simpson et al., 2018). Furthermore, patients with uncontrolled disease courses need more emergency department visits and/or hospitalization due to severe flare-ups and/or infections (e.g. impetiginization or eczema herpeticum) (Simon et al., 2019; Simpson

et al., 2018). The social and economic impact of AD is high when considering direct (e.g. visits, medications, hospitalization) and indirect costs (e.g. missed work hours, reduced productivity) (Adamson, 2017). These costs are even higher in patients with uncontrolled AD (Adamson, 2017).

These observations demonstrate a significant need for interventions to avoid therapeutic failure. Action plans are highly recommended in the management of chronic diseases (Farag et al., 2018; Zhu et al., 2020). Individualized patient action plans for patients with AD have been shown to improve eczema management and adherence resulting in positive effects on disease severity and quality of life (Brown et al., 2018; Powell et al., 2018; Rea et al., 2018; Sauder, et al., 2016; Shi et al., 2013). Therefore, it is crucial to implement and provide a comprehensive patient action plan for patients with AD to improve self-management.

Gap in the Literature

There is general consensus that therapeutic failure is common in patients with AD. The main reason is a lack of information and knowledge. To support patients in their eczema management, a patient action plan is an effective tool (Gilliam et al., 2016; Powell et al., 2018; Sauder et al., 2016; Shi et al., 2013). However, little is known about the use of patient action plans in the adult setting. To our knowledge, only one study determined the effect of a patient action plan in adults (Shi et al., 2013). Moreover, no validated action plan is available. Recently, the American Academy of Dermatology developed and published a patient action plan that is consistent with international treatment guidelines (American Academy of Dermatology, 2021; Wollenberg et al., 2022a, 2022b). This action plan is available for public use (American Academy of Dermatology, 2021). However, it is designed for children and their caregivers. Still, there is a lack of an action plan adapted for adults.

Appraisal and Synthesis

<u>Uncontrolled AD Leads to an Increased Disease Burden</u>

Several peer-reviewed cross-sectional studies investigated the disease burden in patients with severe and or uncontrolled AD (Eckert et al., 2017; Eckert et al., 2019; Simpson et al., 2018). Recently published studies showed that patients with severe AD had significantly more itching, pain and sleep disturbance compared to patients with mild AD. The prevalence of anxiety and depression in patients with uncontrolled AD vs. patients with controlled AD was significantly higher. Overall, the disease burden in patients with uncontrolled AD was higher compared to controls. In addition, patients with uncontrolled AD had more emergency department visits and greater work and activity impairment compared to controls (Eckert et al., 2017; Eckert et al., 2019; Simpson et al., 2018).

Uncontrolled AD Has an Immense Economic Impact

Observational and survey studies assessed the economic impact of AD (Sicras-Mainar et al., 2018; Silverberg, 2015; Zuberbier et al., 2006). It has been estimated that in the United States, AD costs more than $5 billion per year (Adamson, 2017). This calculation included direct (e.g. visits, hospitalizations, prescription) and indirect costs (e.g. missed workdays, career modifications, loss of work). Direct and indirect costs increase with disease severity (Sicras-Mainar et al., 2018; Silverberg, 2015; Zuberbier et al., 2006). Indirect costs in particular can have a significant impact on the disease burden (Adamson, 2017). The International Study on Life with Atopic Eczema estimated the indirect costs for AD at more than $2 billion annually, which are mainly related to absent workdays (Zuberbier et al., 2006). The average number of absent workdays was approximately 2.5 days in patients with mild to moderate AD, whereas it reached 5.3 days in patients with severe AD (Adamson, 2017; Zuberbier et al., 2006). Compared to non-AD adults, patients with AD were more likely to have six or more absent workdays (Silverberg, 2015). Lost workdays can have a negative effect on the income of AD patients and their career (Adamson, 2017; Zuberbier et al., 2006). However, studies investigating the economic impact of AD are outdated (Silverberg, 2015; Zuberbier et al., 2006). These days, the indirect costs could be even higher

Patient Action Plans Improve AD Management and Adherence

Two systematic reviews and four randomized-control trials conclude the importance of and recommend written education materials such as patient action plans for patients with AD (Brown et al., 2018; Gilliam et al., 2016; Rea et al., 2018; Ridd et al., 2017; Sauder et al., 2016; Shi et al., 2013). Patient action plans have been shown to significantly improve AD recognition, management and prevention (Brown et al., 2018; Shi et al., 2013). Patients' understanding of the daily treatment improved. Patients gained knowledge on the application location and duration of a specific treatment. Furthermore, they were able to adjust the treatment to AD severity according to the treatment plan (Sauder, et al., 2016; Shi et al., 2013). This knowledge helps to prevent new AD flares and uncontrolled disease courses and has a positive impact on the disease burden and quality of life (Sauder, et al., 2016). Beside an improvement of AD management, patient action plans have even been shown to improve patient adherence (Feldman et al., 2017). Poor adherence and therapeutic failure are often due to a lack of information provided by healthcare professionals. Insufficient knowledge on the correct use of the treatment measures often results in therapeutic failure and/or uncontrolled disease course. Thus, a patient action plan is considered an important intervention to improve self-management and adherence in patients with AD (Feldman et al., 2017; Sauder, et al., 2016; Stringer et al., 2018).

Build a Case

Therapeutic failure, uncontrolled disease course and a high disease burden are very common in patients with AD.

What are the gaps?

- There might be a true lack of information and knowledge that should be provided by medical professionals. Information obtained via the internet and social media might be incomplete, not personalized, not practically relevant, and therefore not adequate to manage an individual AD case.

- Patients and caregivers miss sufficient support, information and practical skills on how to use therapeutic measures (Eichenfield et al., 2021; Powell et al., 2018).

How to bridge these gaps? High levels of knowledge and skills are crucial for AD patients to understand the disease complexity and to be able to manage the disease themselves (Eichenfield et al., 2021).

- Current literature shows the importance of providing accurate information and knowledge to patients with AD to improve self-management and adherence (Feldman et al., 2017; Powell et al., 2018; Rea et al., 2018; Sauder et al., 2016; Shi et al., 2013).
- Action plans are highly recommended in the management of chronic diseases as they provide accurate information about how to treat the disease (Farag et al., 2018; Zhu et al., 2020).
- Individualized patient action plans for patients with AD have been shown to improve eczema management and adherence resulting in positive effects on disease severity and quality of life (Powell et al., 2018; Rea et al., 2018; Sauder, et al., 2016; Shi et al., 2013).

Therefore, it was crucial to implement and provide a comprehensive action plan to AD patients in our clinic, with the aim of improving eczema management and quality of life as assessed by AD severity scores and patient-related outcomes (dermatology life quality index, patient benefit index, person-centered dermatology self-care index).

Conceptual Framework/Theoretical Model

Theoretical Model

The chronic care model developed by E.H Wagner was selected for this project. The purpose of the chronic care model is to re-organize primary care to address the needs of chronically ill patients and to improve health outcomes. The chronic care model identifies the following six fundamental elements for efficient, high-quality care for chronically ill patients: self-management support, delivery system, decision support, clinical information system,

organization of healthcare and community. In addition to these areas, a productive interaction between patients and healthcare professionals is needed (Wagner, 1998).

This project focused on one part of this model, which is self-management support. Healthcare professionals, such as nurses, must support patients in their self-management through evidence-based interventions and techniques. In patients with AD, there is often a lack of information, knowledge and skills for how to adequately manage skin lesions at various diseases stages. Patients must be enabled in their self-management. A patient action plan is a tool to support patients in their self-management.

Methods

Design and Setting

This quality improvement project had a pre- post-test design and evaluated AD severity and patient-related outcomes before and after implementing a patient action plan at the department of dermatology at a university hospital in Switzerland. This university hospital harbours 37 specialities (e.g. cardiology, neurology). Approximately 8.300 employees provide care for a total of 44.000 inpatients and 520.000 outpatients per year (Inselspital, 2022). The department of dermatology is responsible for diagnosing, treating and managing all kinds of skin diseases in children and adults. Our department provides more than 30`000 consultations at the outpatient clinic and has almost 500 discharges in the inpatient setting per year (Inselspital Dermatologie, 2022). A team of 42 nurses, 35 dermatologists and additional healthcare professionals (e.g., psychologist) are responsible for the medical treatment (Inselspital Dermatologie, 2022). In our eczema clinic, we see approximately 50 adult patients with AD per month. This project was conducted in this setting.

Translational Model

The Plan-Do-Study-Act (PDSA) cycle was used for this project. The goal of PDSA is to test a change in practice (Institute of Healthcare Improvement, 2021). In this project we planned (P = plan) how to test the patient action plan, and identified what kind of data was needed. Then we carried out the test (D = do) and analyzed its effects (S = study) and determined which modifications were necessary for the next cycle (A = act).

Sample and Sampling:

The project included adult patients with AD referred to our department. Inclusion criteria were defined as follow:

- 18 years or older
- Speaks and understands German

Exclusion criteria are defined as follows:

- Less than 18 years
- Does not speak and understand German

A convenience sample of 20 participants meeting the criteria outlined above was recruited from 20.06.2022 - 31.10.2022.

Project Implementation

We designed an action plan for adult patients with AD that provided a clear and simple treatment guidance for the topical basic and anti-inflammatory therapy of the skin. This action plan was the result of an intense discussion and joint work by two experts (dermatologist, nurse practitioner) at a university hospital in Switzerland in February 2022. It was based on the European guidelines on the management and treatment of AD, a position statement on patient education by the European Task Force of Atopic Dermatitis (Thormann et al., 2021) as well as the patient action plan set up for children by the American Academy of Dermatology (American Academy of Dermatology, 2017; Wollenberg et al., 2022a, 2022b).

The patient action plan included step-by-step instructions for skin care, application of anti-inflammatory therapy, itch control and recognition of exacerbations. Further information is available in Appendix A and B.

To guarantee a proper implementation of the patient action plan, the DNP candidate provided a staff training (two dermatologists) in June 2022. Staff training included, how to use the patient action plan, how to use the different scores, recruitment process and data collection. Implementation and use of the action plan started in June 2022.

Measurements, Tools

The following variables and measurements have been used in for this project and data analysis:

Demographic Variables: Age (years), sex (male and female)

Sociodemographic Variables: Education (unlearned, learned, academic)

Diagnostic and Clinical Variables: Start of atopic dermatitis (infancy (<1), childhood (1-12), adolescence (13-18), adulthood (>18), co-morbidities (food allergies, allergic rhinitis, asthma bronchiale, eosinophilc esophagitis), complications (bacterial infections, eczema herpeticum), therapy (topical, systemic and topical)

AD Severity: SCORAD (SCORing Atopic Dermatitis: a validated and reliable score that uses three components (objective: area, intensity, subjective: symptoms) to assess the extent and severity of atopic dermatitis. Range 0-103, 0-24 points correspond to mild AD, 25-49 points correspond to moderate AD, 50 and more points correspond to severe AD (Severity Scoring of Atopic Dermatitis: The SCORAD Index. Consensus Report of the European Task Force on Atopic Dermatitis, 1993)). Further information is available in Appendix C.

Quality of Life: DLQI (Dermatology life quality index: a validated and reliable questionnaire that uses 10 questions to measure the health-related quality of life of adult patients suffering from a skin disease. Range 0-30, 0 means no effect of the skin disease on quality of life, 30 is corresponds to an extreme effect on quality of life (Finlay & Khan, 1994)). Further information is available in Appendix D.

Self-management: PeDeSi-G (Person-centered Dermatology Self-care Index: a validated and reliable tool that uses 10 questions to assess the education and support needs of patients

suffering from a skin disease. Range 0-30, 0 indicates the person needs intensive education and support, while 30 stands for sufficient knowledge (Cowdell et al., 2012; Kottner et al., 2019)). Further information is available in Appendix E. PBI (Patient Benefit Index: a validated and reliable tool consisting of two questionnaires measuring patient-defined treatment objectives and benefits. Both questionnaires use 23 questions. Range questionnaire one: 0-4;0, not at all important; 4, very important. Range questionnaire two: 0-4; 0, no benefit; 4, maximal benefit (Augustin et al., 2009)). Further information is available in Appendix F. The Department of Dermatology obtained permission to use these tools by the original authors, if required.

Data Collection

For this project data were collected from June 20, 2022 until October 31, 2022 at the Department of Dermatology at a University Hospital in Bern, Switzerland. Data collection began, after both the University of North Carolina – Greensboro Institutional Review Board (IRB) and the Cantonal Ethics Committee Bern, Switzerland, stated that a formal IRB approval was not required. That is why written informed consent was not obtained

Patients were asked to be enrolled in the project by trained staff (DNP candidate and two dermatologists). If patients were willing to participate in this project, the trained staff gave information on AD treatment as usual and provided an individual written action plan. Data were collected pre- and post-intervention.

Socio-demographic, diagnostic and clinical variables were obtained from electronic health records. AD severity and PeDeSi-G were assessed by the trained staff during the first consultation pre-intervention. Additionally, DLQI and PBI questionnaires were completed by the patient. The assessment procedures (scores and questionnaires) were repeated one month post intervention.

All data were kept confidential. Patient data were pseudonymized. Socio-demographic data and questionnaires information were entered into an Excel file on the DNP candidate's password- and firewall-protected personal laptop which was under control at all times.

Ethical Considerations

This project was reviewed and approved by the IRB and determined to be a quality improvement project. The project team followed all IRB recommendations.

Statistical Analysis

To describe the project sample, descriptive data analysis was performed and presented as numbers (n), percentages (%), median (with range) or mean with standard deviation (SD) or standard error of mean (SEM) as indicated. To analyse the differences of SCORAD, DLQI, PeDeSi-G before and after receiving the patient action plan, paired t-test was applied. P values < 0.05 were considered statistically significant. All analyses were performed using Excel version 16 and GraphPadPrism 9 (GraphPadPrism, 2023).

Budget, Resources

For this project, costs for personnel resources were expected. This included salary costs related to time needed for staff training. Other resources included technical and structural aspects and printed material (patient action plan). All costs were covered by the Department of Dermatology.

Results

A total of 20 participants were included in this quality improvement project. Baseline characteristics including demographic data, diagnoses, therapy SCORAD and DLQI are summarized in Table 1 and Table 2. Five patients did not have any other atopic co-morbidities, whereas remaining participants had one or more co-morbidities. Patients had mild to severe AD at baseline (median: 37.6 [range: 7.7 – 97]). The quality of life was significantly affected in half of the patients (median: 11) with a broad range [2 – 23].

Table 1: Characteristics of twenty patients with atopic dermatitis

	Parameter		
Age	Mean, SD in years	36.5	15.5
	Median, range in years	31	19-69
	Parameter	N	%
Sex	Men	12	60%
	Women	8	40%
Education	Unlearned	1	5%
	Learned	12	60%
	Academic	7	35%
Start of atopic dermatitis	Infancy (< 1 years)	8	40%
	Childhood (1 – 12 years)	7	35%
	Adolescence (13 – 18 years)	1	5%
	Adulthood (> 18 years)	4	20%
Comorbidities	Food allergy	1	5%
	Allergic rhinitis	15	75%
	Allergic asthma	8	40%
	Eosinophilic esophagitis	0	0%
History on AD complications	Bacterial infection	3	15%
	Eczema herpeticum	5	25%
Therapy	Topical therapy	14	70%
	Topical and systemic therapy	6	30%

Table 2: Scores at baseline of twenty patients with atopic dermatitis

	Parameter		
SCORAD[a] at baseline	Mean, SD	38.1	20.8
	Median, range	37.6	7.7 - 97
DLQI[b] at baseline	Mean, SD	11.6	7.2
	Median, range	11.0	2 - 23

[a]SCORAD: SCORing Atopic Dermatitis, [b]DLQI: Dermatology life quality index

AD Severity

Upon intervention, namely receiving the patient action plan, we observed a decrease of AD severity as assessed by SCORAD (before: 38.1± 20.8 versus after: 22.0 ±12.5). The difference of SCORAD reached statistical significance ($p < .0001$) (Figure 2). The rate of patients achieving SCORAD 0-24 reflecting mild AD, was 12 (60%). Overall, 95 % of patients reported an improvement of their disease (Figure 2).

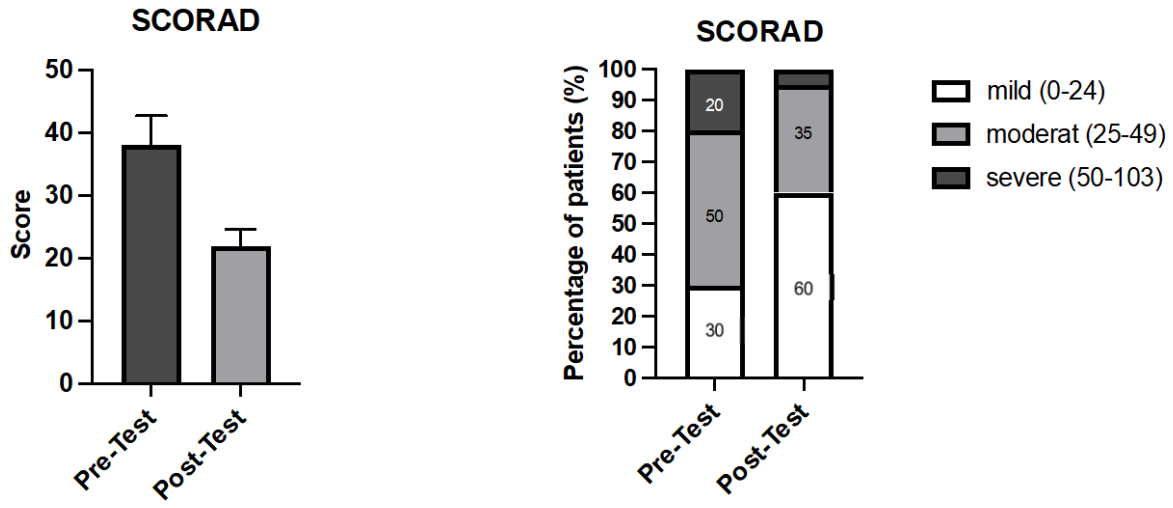


Figure 2: The effect of providing a patient action plan on SCORing Atopic Dermatitis (SCORAD). Graphs show SCORAD levels (mean ± SEM) pre- and post-test ($p <.0001$), and percentages of patients in defined ranges of SCORAD indicating atopic dermatitis severity levels.

Patient-related Outcomes

<u>DLQI</u>

Quality of life assessed by DLQI increased (before:11.6 ±7.2 versus after: 6.3± 5.0). The difference of DLQI reached statistical significance ($p < 0.001$) (Figure 3). Before intervention, the quality of life of 55% of patients was largely affected by AD. Upon receiving the patient action plan, DLQI ≥11 was noted in only 20% of patients, whereas AD did not or minimally affected the quality of life in 13 (65%) of patients (Figure 3).

<u>PeDeSi-G</u>

Furthermore, providing a patient action plan resulted in an improvement of self-care assessed by PeDeSi-G. PeDeSi-G significantly increased from 18.2 ± 2.1 before to 25.7±3.8 after intervention ($p < .0001$) (Figure 4). While the index reflected a need for intense and moderate education in 95% of patients before the intervention, this rate decreased to 5% upon providing the patients action plan. PeDeSi-G 21-29 indicating needs limited education was reported by 16 (80%), and PeDeSi-G 30 meaning has sufficient knowledge by 3 (15%) of patients (Figure 4).

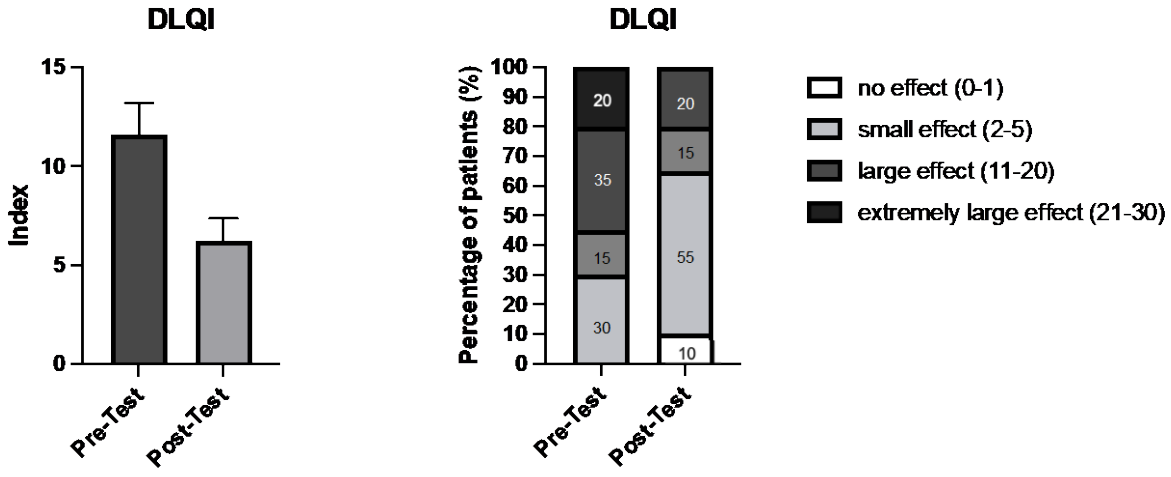


Figure 3: The effect of the patient action plan on dermatology life quality index (DLQI). Graphs show DLQI values (mean ±SEM) pre- and post-test ($p <.001$), and percentages of patients in defined ranges of DLQI indicating the impairment of life quality. (High DLQI levels correspond to severe impairment.)

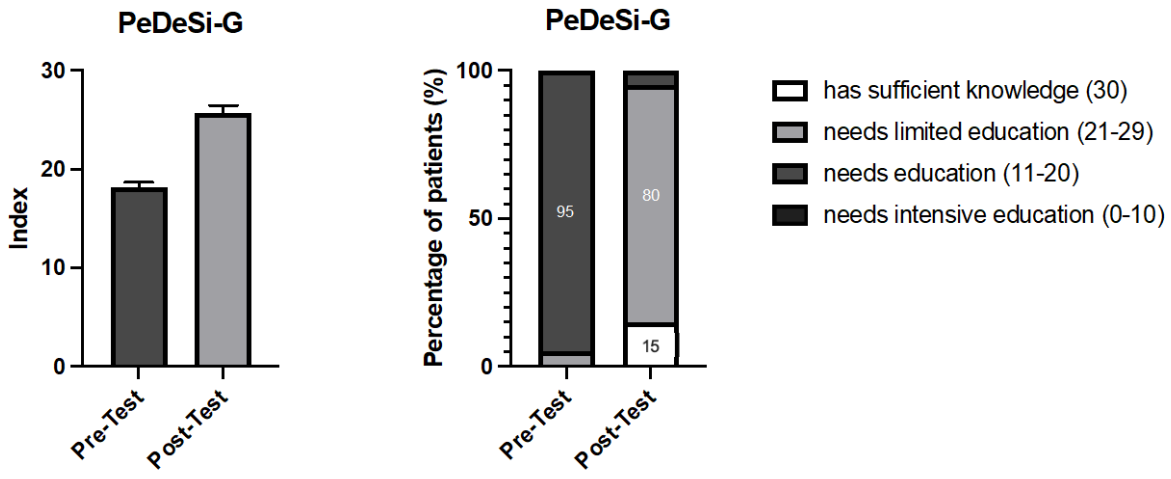


Figure 4: The effect of the patient action plan on PeDeSi-G. Graphs show PeDeSi-G levels (mean ± SEM) pre- and post-test ($p < .0001$), and percentage of patients in defined ranges of PeDeSi-G indicating the need for education.

Patient Benefit Index: Patient-defined Needs and Benefits

PBI was calculated on patient needs questionnaire (PNQ) and patient benefit questionnaire (PBQ). On average, 17 (SD: 4.3) items out of the 23 PNQ items were rated as "quite important" and "very important" indicating relevant treatment needs. The mean rate of "does not apply to me" was 3 (SD: 3.1). The most important need was "to be free of itch" stated by all patients (100%). The item "to be able to have more contact with other people" (35%) was of low importance of treatment needs (Table 2).

After receiving the patient action plan, on average 14 (SD: 6.3) out of 23 PBQ items were rated as "quite" or "very" achieved. The mean rate "does not apply to me" was 3 (SD: 3.6). The needs achieved best were "be able to live a normal life" and "need less time for daily treatment." Regarding the most important need "to be free of itch," 60% of the patients stated a high treatment benefit rated as "quite" or "very" (Table 3). The mean rates of missing values of the PNQ and PBQ were 0.2% and 0%, respectively.

Table 2: Importance of treatment goals assessed by the patient needs questionnaire (PNQ)[a]

Item no.	Patient need	N	Mean[b]	SD[b]	Does not apply to me (%)	Does apply to me (%)	Quite or very important (%)
1	...be free of pain	20	3.1	1.3	10	90	80
2	...be free of itching	20	3.7	0.5	0	100	100
3	...no longer have burning sensations on your skin	20	3.5	1.0	5	95	90
4	...be healed of all skin defects	20	3.3	0.9	0	100	85
5	...be able to sleep better	19	3.0	1.5	15	85	75
6	...feel less depressed	20	2.6	1.1	10	90	75
7	...experience a greater enjoyment of life	19	2.9	1.5	15	85	75
8	...have no fear that the disease will become worse	20	2.6	1.5	10	90	65
9	...be able to lead a normal everyday life	20	3.4	1.0	5	85	90
10	...be more productive in everyday life	20	3.2	1.3	10	90	80
11	...be less of a burden to relatives and friends	20	2.5	1.6	15	85	65
12	...be able to engage in normal leisure activities	20	3.1	1.1	5	95	85
13	...be able to lead a normal working life	20	2.6	1.5	20	80	65
14	...be able to have more contact with other people	20	1.9	1.7	35	75	35
15	…be comfortable showing yourself more in public	20	2.8	1.6	20	80	70
16	...be less burdened in your partnership	20	2.5	1.5	20	80	65
17	...be able to have a normal sex life	20	2.5	1.4	15	85	65
18	...be less dependent on doctor and clinic visits	20	2.7	1.3	5	95	65
19	...need less time for daily treatment	20	3.1	1.4	5	95	70
20	...have fewer out-of-pocket treatment expenses	20	2.3	1.5	10	90	55
21	...have fewer side effects	20	2.4	1.7	20	80	50
22	...find a clear diagnosis and therapy	20	3.4	1.0	5	95	85

23	...have confidence in the therapy	20	3.6	1.0	5	95	90

[a]Range: 0= not at all, 1= somewhat, 2 = moderate, 3 = quite, 4 = very important
[b]Mean, SD, refer to patients checking "does not apply to me" were not included in the analysis

Table 3: Treatment benefits assessed by the patient benefit questionnaire (PBQ)[a]

Item no.	Treatment benefits	N	Mean[b]	SD[b]	Did not apply to me (%)	Did apply to me (%)	Quite or very achieved (%)
1	...be free of pain	20	3.0	1.1	5	95	65
2	...be free of itching	20	2.5	1.2	0	100	60
3	...no longer have burning sensations on my skin	20	2.4	1.4	10	90	65
4	...be healed of all skin defects	20	1.9	1.4	0	100	50
5	...be able to sleep better	20	2.6	1.5	15	85	60
6	...feel less depressed	20	2.4	1.6	20	80	55
7	...experience a greater enjoyment of life	20	2.5	1.5	20	80	55
8	...have no fear that the disease will become worse	20	3.1	1.2	0	100	60
9	...be able to lead a normal everyday life	20	3.1	1.1	0	100	70
10	...be more productive in everyday life	20	2.3	1.6	15	85	55
11	...be less of a burden to relatives and friends	20	2.7	1.5	5	95	60
12	...be able to engage in normal leisure activities	20	2.5	1.6	20	80	65
13	...be able to lead a normal working life	20	2.2	1.7	25	75	60
14	...be able to have more contact with other people	20	2.4	1.6	25	75	55
15	…be comfortable showing yourself more in public	20	2.7	1.3	10	90	65
16	...be less burdened in your partnership	20	2.5	1.5	20	80	65
17	...be able to have a normal sex life	20	1.9	1.6	30	70	65
18	...be less dependent on doctor and clinic visits	20	2.6	1.2	5	95	65

19	...need less time for daily treatment	20	2.3	1.3	0	100	70
20	...have fewer out-of-pocket treatment expenses	20	1.8	1.5	15	85	25
21	...have fewer side effects	20	2.4	1.5	15	85	65
22	...find a clear diagnosis and therapy	20	2.8	1.4	10	90	60
23	...have confidence in the therapy	20	3.1	1.2	5	20	65

[a]Range: 0= not at all, 1= somewhat, 2 = moderate, 3 = quite, 4 = very helpful
[b]Mean, SD, refer to patients checking "did not apply to me" were not included in the analysis

Patient Benefit Index

A minimal benefit of 1 was achieved in 19 (95%) patients. In 15 (75%) patients, the PBI was between 2 to 4. In one (5%) patient the treatment needs have completely been fulfilled (PBI = 4) (Figure 7). Mean PBI was 2.73 (SD: 0.9).

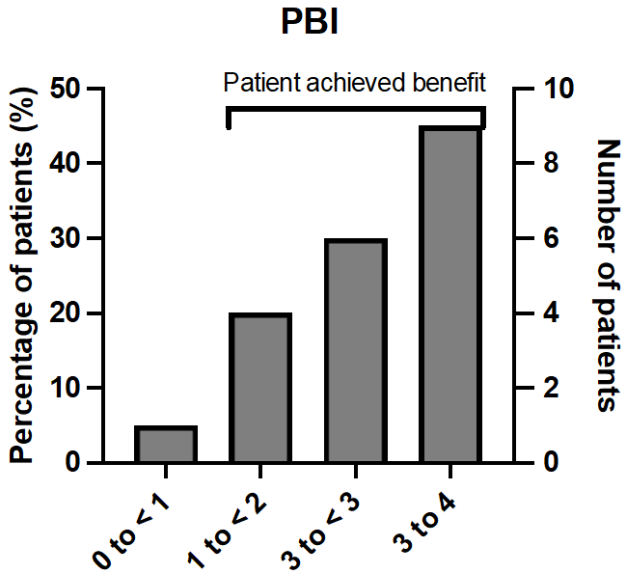


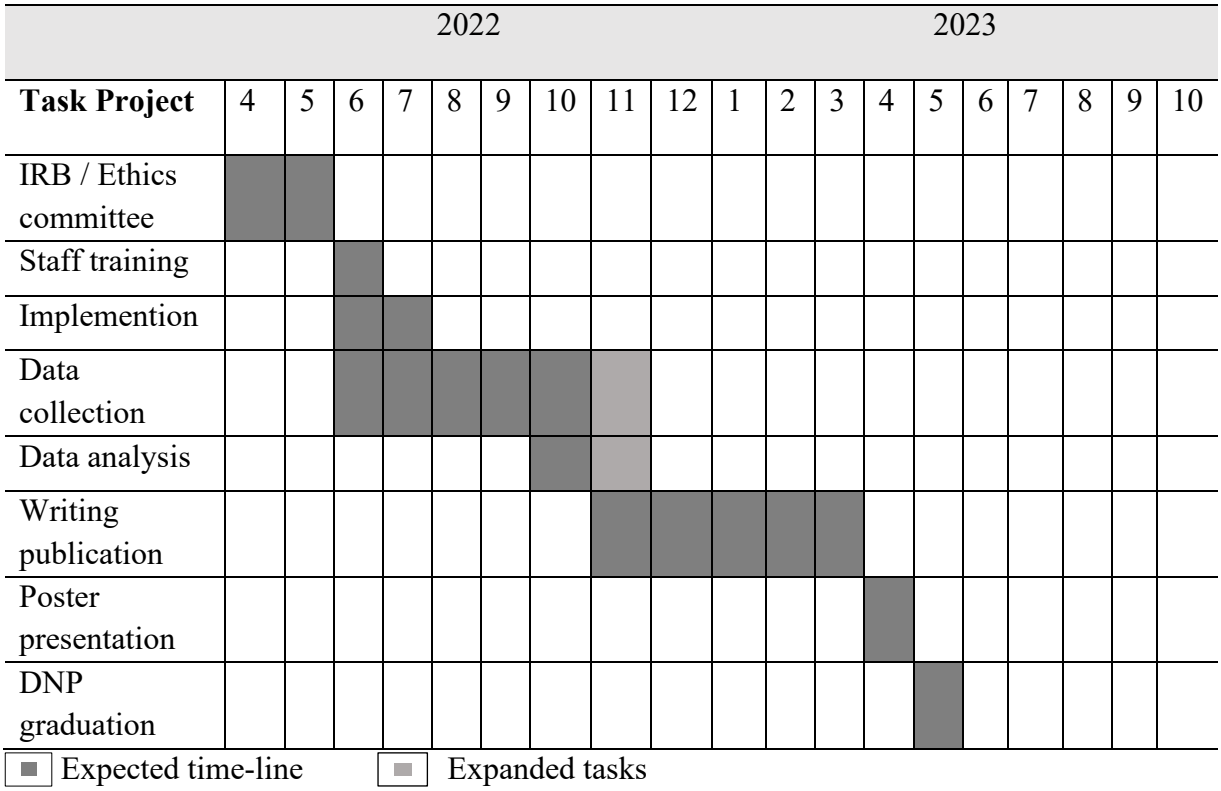
Figure 5: The effect of the patient action plan on PBI. Graphs show percentage and number of patients according to the PBI achieved. The minimal clinical benefit is PBI = 1.

Barriers to Success

In this project, no unexpected barriers occurred. However, the recruitment process and data collection had to be expanded one month, to achieve the expected sample size. Therefore, fact the data analysis was delayed.

Strength to Overcome the Barriers

To overcome the barriers, we expanded the data collection and data analysis according to the time-line.



Discussion

This quality improvement project evaluated the effect of individually tailored patient action plans on disease severity and patient-related outcomes in adult patients. Our results confirm that the patient action plan is an effective educational tool as part of AD management. This finding is in concordance with other studies (Sauder et al., 2016; Shi et al., 2013).

Main Findings Regarding Disease Severity Score and Patient-related Outcomes:

Participants experienced a significant decrease of SCORAD ($p < .0001$), and significant increase of DLQI ($p < 0.001$) and PeDeSi-G ($p < .0001$). To our knowledge, we provide the first quality improvement project evaluating the effects of providing a patient action plan based on SCORAD, DLQI and PeDeSi-G in adult patients.

Rea et al. 2018, reported a significant improvement of disease severity ($p < .0.001$) in children using patient-oriented eczema measure (POEM) and quality of life ($p < .0.001$) using infants and children dermatitis quality of life index (IDQOL, CDLQI). However, in this randomized controlled trial, there wasn't any significant difference between the intervention group who received the patient action plan and the control group (POEM differences -0.8 (-3.2 to 1.7); IDQOL difference -0.1 (-1.8 to 1.6)) (Rea et al., 2018). Duhovic et al., 2016 reported similar findings regarding SCORAD whereas Brown et al., 2018 had similar findings for quality of life (Brown et al., 2018; Duhovic et al., 2016). Due to the different study design, outcome measures used and patient population, a direct comparison of the results is not possible.

In this project, self-management was evaluated using PeDeSi-G. The knowledge of how to manage the skin disorder significantly increased ($p < 0.0001$). This finding is in concordance with other studies determining self-management in adults and children with AD upon using a patient action plan (Brown et al., 2018; Rea et al., 2018; Shi et al., 2013). However, all studies determined self-management based on different tools and questionnaires (Brown et al., 2018; Rea et al., 2018; Shi et al., 2013). Therefore, the comparability of these results is limited.

To our knowledge, our quality improvement project is the first to evaluate the effects of the patient action plan based on PBI. Our results confirm that 95% had at least minimal benefit of the prescribed treatment. So far, it remains unclear whether this effect can be ascribed to the patient action plan alone, or to both action plan together with topical therapy.

Nevertheless, it indicates that the prescribed treatment was done and gives an idea on how the patients were enabled to do the treatment (self-management) and if they were adherent.

Findings Linked to Conceptual Framework and Translational framework

The chronic care model was selected as the theoretical model of this project. The increase of self-management by introducing evidence-based interventions is the main purpose of this model. Therefore, we can conclude that this model was appropriate for this project.

A similar statement applies to the translational model. Here, the PDSA process was used. The whole project was set up and conducted according to the different steps (plan, do, study, act). The PDSA process was a supportive model to test a newly implemented intervention in practice. Our results demonstrate at different levels, how important behavioral changes initiated by providing a patient action plan, was. Moreover, the PDSA was also supportive to determine modifications in future.

Recommendation of How to Modify the Intervention

Based on our experiences of the project we plan the further modifications and developments:

- So far, the treatment plan is restricted to topical therapy. Our patients suggested to including systemic treatment as well.
- Most importantly, separate treatment plans for children, adolescents and adults need to be established.
- Patient action plans should be provided in various languages.
- The layout should be made more appealing.
- The suggested modifications will be discussed by our team of experts.

Limitations of the Project

This quality improvement project had a small sample size for different reasons (e.g. language barriers, timeline limitations) and was performed at a single site. As long as patient action plans in various languages (e.g. French, Italian, English) are available, more patients

can benefit from the intervention and be included in studies. Since ours was designed as a quality improvement project, we had no control group. Results comparing intervention versus control groups might differ from those obtained by pre- and post-intervention analyses. Future projects need to confirm the applicability of our results in large patient cohorts in a multicenter setting.

Conclusion

This project's purpose was to implement and evaluate a patient action plan based on disease severity and patient-related outcomes. Our findings confirm the importance of providing a patient action plan for adult patients with AD. The patient action plan is an additional tool by which disease severity can be decreased and quality of life and self-management are increased.

Relevance and Recommendations for Clinical Practice

The patient action plan has become an integral part of our patient care and is a sustainable tool in our local practice setting. In the future, we plan several modifications of our patient action plan (e.g., include systemic treatments, different languages) and provide a separate plan for children, adolescents and adults.

Recommendations for Future Studies

In the future, the long-term clinical effects of providing a patient action plan to patients with AD should be determined based on different clinical and patient-reported outcomes such as disease severity, quality of life and self-management in adult patients. Additionally, future studies should investigate the effect of patient action plans on adherence and on economic issues in AD patients at all age groups.

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Appendices

Appendix A

American Academy of Dermatology: Eczema Action Plan

Eczema Action Plan

Eczema under control

Skin soft, supple, maybe some dryness

1. Bathe (5-10 minutes) in lukewarm water every _____ .
2. Apply moisturizer to all skin within 3 minutes of finishing bath.
3. Apply moisturizer **2 more times** during day to skin that feels dry or often flares.

Eczema flare

Itchy skin with redness or rash

Use your child's medicine and moisturizer (shown below) as often as indicated.

Bathe your child (5-10 minutes) in lukewarm water every _____.

Within 3 minutes of bathing:

- Apply child's medicine (shown below) to the eczema.
- Apply child's moisturizer, skipping areas with medicine. You don't want to apply moisturizer on top of the medicine.

Medicine for mild flare (*redness, some itch*)

Face _____ Apply _____ times a day (maximum _____ days)

Scalp _____ Apply _____ times a day (maximum _____ days)

Body _____ Apply _____ times a day (maximum _____ days)

Medicine for moderate or severe flare (*very itchy rash*)

Face _____ Apply _____ times a day (maximum _____ days)

Scalp _____ Apply _____ times a day (maximum _____ days)

Body _____ Apply _____ times a day (maximum _____ days)

Cleanser

_____ Use _____ times a day

Moisturizer

Day _____ Apply _____ times a day

Night _____

Other medicine

Itching (*day*)
Take _____ tsp/cc/pills of _____ in the morning.

Itching (*night*)
Take _____ tsp/cc/pills of _____ before bed.

Skin
Take _____ tsp/cc/pills of _____ for ____ days,
taking ____ times per day.

When to call the dermatologist

- Skin weeping, oozing pus
- Skin very painful
- Severe itch
- Fever
- Chills
- Eczema remains the same or barely diminishes with treatment

If your child has a **fever and clusters of itchy blisters**, call your dermatologist immediately. If you cannot reach your dermatologist, take your child to the nearest emergency room.

Dermatologist _____

Phone _____

Appendix B

Inselspital: Patient action plan

INSELSPITAL
UNIVERSITÄTSSPITAL BERN
HÔPITAL UNIVERSITAIRE DE BERNE

Universitätsklinik für Dermatologie

Behandlungsplan Ekzem

Keine Ekzeme

Die Haut ist weich, geschmeidig, vielleicht trocken

Basistherapie

1. Einmal pro Tag im lauwarmen Wasser mit **xxx** duschen oder baden (5-10 min)
2. Nach der Dusche / Bad innerhalb von 3 Minuten mit **xxx** Eincremen
3. Je nach Bedarf mehrmals pro Tag die rückfettende Creme anwenden

---

Ekzeme

Entzündliche, juckende Hautveränderungen

1. Machen Sie die Basistherapie weiter
2. Wenden Sie die antientzündliche Therapie wie unten angegeben an

Therapie bei milden Ekzemen (etwas rot, etwas juckend)

Gesicht: **xxx xxx** pro Tag für **xxx** Wochen, dann **xxx** pro Woche

Körper: **xxx xxx** pro Tag für **xxx** Wochen, dann **xxx** pro Woche

Therapie bei moderaten, schweren Ekzemen (stark rot, stark juckend)

Gesicht: **xxx xxx** pro Tag für **xxx** Tage, dann **xxx xxx** pro Tag

Kopfhaut: **xxx xxx** pro Tag für **xxx** Wochen

Körper: **xxx xxx** pro Tag für **xxx** Tage, dann **xxx** pro Tag für **xxx** Tage, dann **xxx** pro Woche

Erhaltungstherapie

Gesicht: **xxx 1x** pro Tag oder **xxx** pro Woche

Körper: **xxx 1x** pro Tag Montag – Freitag, **xxx xxx** pro Tag Samstag und Sonntag

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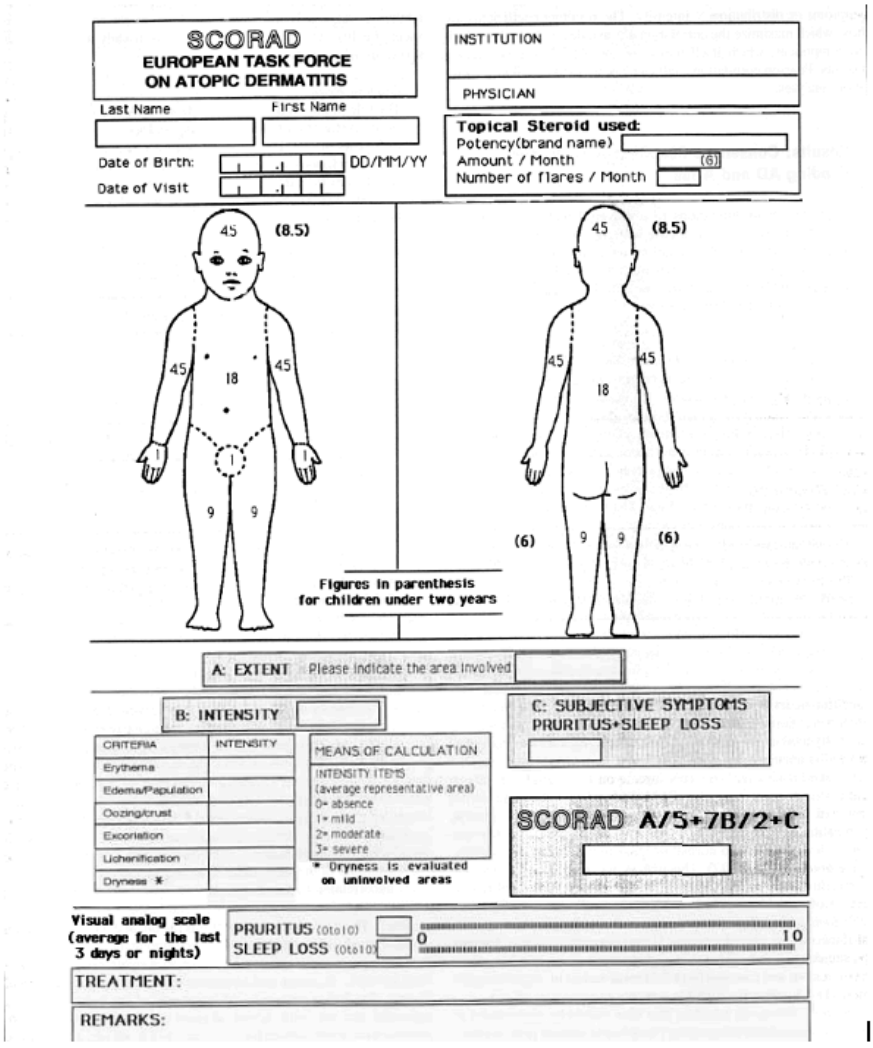
Autoren: Prof. Dr. med Dagmar Simon, Kathrin Thormann RN, MScN 15.02.2022

Appendix C

SCORing Atopic Dermatitis:

SCORAD

http://scorad.corti.li/



Appendix D

Dermatology life quality index:

DERMATOLOGY LIFE QUALITY INDEX

DLQI

Hospital No: Date:
Name: Score:
Address: Diagnosis:

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick one box for each question.

1.	Over the last week, how **itchy**, **sore**, **painful** or **stinging** has your skin been?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	
2.	Over the last week, how **embarrassed** or **self conscious** have you been because of your skin?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	
3.	Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden**?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	 Not relevant ❒
4.	Over the last week, how much has your skin influenced the **clothes** you wear?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	 Not relevant ❒
5.	Over the last week, how much has your skin affected any **social** or **leisure** activities?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	 Not relevant ❒
6.	Over the last week, how much has your skin made it difficult for you to do any **sport**?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	 Not relevant ❒
7.	Over the last week, has your skin prevented you from **working** or **studying**?	Yes No	❒ ❒	 Not relevant ❒
	If "No", over the last week how much has your skin been a problem at **work** or **studying**?	A lot A little Not at all	❒ ❒ ❒	
8.	Over the last week, how much has your skin created problems with your **partner** or any of your **close friends** or **relatives**?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	 Not relevant ❒
9.	Over the last week, how much has your skin caused any **sexual difficulties**?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	 Not relevant ❒
10.	Over the last week, how much of a problem has the **treatment** for your skin been, for example by making your home messy, or by taking up time?	Very much A lot A little Not at all	❒ ❒ ❒ ❒	 Not relevant ❒

Please check you have answered EVERY question. Thank you.

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Appendix E

Person-centered dermatology self-care index:

Person-Centered Dermatology Self-Care Index

A tool to assess the education and support needs that will enable people with long-term skin conditions to manage topical treatments on their own.

Name label: Condition: Topical treatment(s):

Please score each area of ability in discussion with the person using treatment(s) by ticking the relevant boxes.

PeDeSI number:	Degree of independence				
Ability	0 = No ability	1 = Some ability	2 = Sufficient ability	3 = Full ability	Agreed action plan
1. Do you have an understanding of your skin condition?					
2. Do you know what things make your skin condition better and worse?					
3. What is this treatment(s) used for?					
4. Are you aware of how long initial treatment will take to be effective?					
5. Do you know what the common side-effects of your treatment(s) are?					
6. Do you know how much cream/ointment/lotion should be applied each time and at what time(s)?					
7. Can you apply the treatment(s) to the affected areas? (demonstrate)					
8. Do you know how and when to adapt treatment/seek help if condition gets worse?					
9. Do you know how to obtain a repeat prescription?					
10. Do you feel confident to use treatment(s) at home yourself?					

Total Score/30 (maximum total score)
Total scores in range: 0-10 needs intensive education and support to develop knowledge, ability and confidence
Total scores in range: 11-20 needs some education and support to develop knowledge, ability and confidence
Total scores in range: 21-29 needs limited education and support to develop knowledge, ability and confidence
Total score of 30 has sufficient knowledge, ability and confidence to manage on their own

Signature Date

Appendix F

Patient Benefit Index:

PBI – Patient Benefit Index

Importance of Treatment Goals

With the help of the following questions, we'd like to know how important the below mentioned goals are to you personally in the **current treatment** of your skin disease.

For each of the following statements, please mark **how important** this treatment goal is to you. If a statement does not apply to you, e.g. because you do not have pain, please mark "*does not apply to me*".

	As a result of therapy, how important is it for you to...	**not at all**	**somewhat**	**moderately**	**quite**	**very**	*does not apply to me*
1	...be free of pain	O	O	O	O	O	O
2	...be free of itching	O	O	O	O	O	O
3	...no longer have burning sensations on your skin	O	O	O	O	O	O
4	...be healed of all skin defects	O	O	O	O	O	O
5	...be able to sleep better	O	O	O	O	O	O
6	...feel less depressed	O	O	O	O	O	O
7	...experience a greater enjoyment of life	O	O	O	O	O	O
8	...have no fear that the disease will become worse	O	O	O	O	O	O
9	...be able to lead a normal everyday life	O	O	O	O	O	O
10	...be more productive in everyday life	O	O	O	O	O	O
11	...be less of a burden to relatives and friends	O	O	O	O	O	O
12	...be able to engage in normal leisure activities	O	O	O	O	O	O
13	...be able to lead a normal working life	O	O	O	O	O	O
14	...be able to have more contact with other people	O	O	O	O	O	O
15	...be comfortable showing yourself more in public	O	O	O	O	O	O
16	...be less burdened in your partnership	O	O	O	O	O	O
17	...be able to have a normal sex life	O	O	O	O	O	O
18	...be less dependent on doctor and clinic visits	O	O	O	O	O	O
19	...need less time for daily treatment	O	O	O	O	O	O
20	...have fewer out-of-pocket treatment expenses	O	O	O	O	O	O
21	...have fewer side effects	O	O	O	O	O	O
22	...find a clear diagnosis and therapy	O	O	O	O	O	O
23	...have confidence in the therapy	O	O	O	O	O	O
24	...get better skin quickly	O	O	O	O	O	O
25	...regain control of the disease	O	O	O	O	O	O

Please check once more if you have exactly marked each statement with an 'x'.

Our sincerest thanks for your cooperation!

PBI-Patient Benefit Index (index of benefits and needs in therapy), Augustin 2006 | version: PBI-S, English for UK

PBI – Patient Benefit Index

Treatment benefits

At the start of the treatment, you indicated in a questionnaire how important various goals were in the treatment of your skin disease.

Please mark each of the following statements according to the extent that these treatment goals **were achieved**, thereby indicating if the treatment has benefitted you. If a statement did not apply to you, e.g. because you had no pain, please mark "*did not apply to me*".

	The current treatment has helped me to…	**not at all**	**somewhat**	**moderately**	**quite**	**very**	*did not apply to me*
1	...be free of pain	O	O	O	O	O	O
2	...be free of itching	O	O	O	O	O	O
3	...no longer have burning sensations on my skin	O	O	O	O	O	O
4	...be healed of all skin defects	O	O	O	O	O	O
5	...be able to sleep better	O	O	O	O	O	O
6	...feel less depressed	O	O	O	O	O	O
7	...experience a greater enjoyment of life	O	O	O	O	O	O
8	...have no fear that the disease will become worse	O	O	O	O	O	O
9	...be able to lead a normal everyday life	O	O	O	O	O	O
10	...be more productive in everyday life	O	O	O	O	O	O
11	...be less of a burden to relatives and friends	O	O	O	O	O	O
12	...be able to engage in normal leisure activities	O	O	O	O	O	O
13	...be able to lead a normal working life	O	O	O	O	O	O
14	...be able to have more contact with other people	O	O	O	O	O	O
15	...be comfortable showing myself more in public	O	O	O	O	O	O
16	...be less burdened in my partnership	O	O	O	O	O	O
17	...be able to have a normal sex life	O	O	O	O	O	O
18	...be less dependent on doctor and clinic visits	O	O	O	O	O	O
19	...need less time for daily treatment	O	O	O	O	O	O
20	...have fewer out-of-pocket treatment expenses	O	O	O	O	O	O
21	...have fewer side effects	O	O	O	O	O	O
22	...find a clear diagnosis and therapy	O	O	O	O	O	O
23	...have confidence in the therapy	O	O	O	O	O	O
24	...get better skin quickly	O	O	O	O	O	O
25	...regain control of the disease	O	O	O	O	O	O

Please check once more if you have exactly marked each statement with an 'x'.

Our sincerest thanks for your cooperation!