ORIGINAL ARTICLE



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Implementation and evaluation of a patient action plan for patients with atopic dermatitis

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Abstract

Background: Management and treatment of atopic dermatitis (AD) are complex and therefore bear the risk of therapeutic failure. Individualised patient action plans for patients and for caregivers have been shown to improve AD management, eczema monitoring and therapy adherence. Little is known about the use of patient action plans in the adult setting.

Objectives: 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 pretest–posttest design and evaluated AD severity and patient-related outcomes after implementing a patient action plan. A convenience sample of 20 adult patients with AD was included. Socio-demographic, diagnostic and clinical variables were collected from the electronic health records. Trained staff assessed AD severity using SCORing Atopic Dermatitis (SCORAD) and person-centred dermatology selfcare index (PeDeSI-G) pre as well as 1-month postintervention. 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 < 0.0001), in parallel with a significant decrease of DLQI (p < 0.001) and PeDeSI-G (p < 0.0001) was observed. A PBI ≥ 1 was reached in 95% of participants (mean 2.73; SD 0.9).

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

KEYWORDS

atopic dermatitis, patient action plan

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INTRODUCTION

Atopic dermatitis (AD) is a chronic, inflammatory skin disease presenting with chronic or recurrent eczematous skin lesions. 1,2 Patients suffer from severe itch and/or pain, which may result in sleep disturbances and along with the skin lesions, in stigmatisation. 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.^{3,4} Topical therapies, ultraviolet light therapy and systemic therapies are used to treat AD.5,6 Therapeutic failure and inadequate disease control in patients with AD are common and associated with poor quality of life and high disease burden. 3,4,7,8 Individualised patient action plans for children with AD have been shown to improve eczema management, eczema monitoring and adherence.9-15 However, little is known about the use of patient action plans in the adult setting. 16 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. 5,6,17 This action plan is available for public use.¹⁷ However, it is designed for children and their caregivers. Still, there is a lack of an action plan adapted for adults.

OBJECTIVES

This project aimed at implementing a patient action plan to improve eczema management, and evaluating its effects on disease severity and patient-related outcomes in adult patients with AD.

METHODS

Design, setting, sample

This quality improvement project had a pretest-posttest design and evaluated AD severity and patient-related outcomes before and 4 weeks after implementing a patient action plan at the Department of Dermatology at the Inselspital, University Hospital in Bern, Switzerland. A convenience sample of 20 adult patients meeting the inclusion criteria (18 years or older, speaks and understands German) was recruited from 20 June 2022 to 31 October 2022.

Patient action plan development

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 our department, 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 as well as the patient action plan set up for children by the American Academy of Dermatology. 5,6,17,18 The patient action plan included step-by-step instructions for skin care, application of anti-inflammatory therapy, itch control and recognition of exacerbations (see Supporting Information S1) To guarantee a proper implantation, a staff training was provided.

Measurements

AD severity

SCORing Atopic Dermatitis (SCORAD): 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. ¹⁹

Patient-related outcomes

Dermatology life quality index (DLQI): 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 corresponds to an extreme effect on quality of life.²⁰

Person-centred dermatology self-care Index (PeDeSI-G): 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 means the person needs intensive education and support, while 30 stands for sufficient knowledge. ^{21,22}

Patient benefit index (PBI): 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.²³

Data collection

Data were collected from 20 June 2022 until 31 October 2022 at the Department of Dermatology, Inselspital, Bern

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University Hospital. 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 (IRB-FY22-603, Req-2022-00403). All patients provided general consent for further use of data.

Pretest: Patients willing to participate in this project were informed on AD treatment as usual (oral instructions). After 4 weeks, the pretest visit was performed. Socio-demographic, diagnostic and clinical variables were obtained from the electronic health records. AD severity and scores were assessed. Then, individual detailed patient action plans were provided to all participants by the trained staff. Posttest: After a 4 weeks-period of treatment according to the individual action plan (postintervention), the assessment procedures (scores and questionnaires) were repeated.

Statistical analysis

To describe the project sample, descriptive data analysis was performed and presented as numbers (n), percentages (%), median (with ranges) or mean with standard deviation (SD) or standard error of mean (SEM) as indicated. To analyse the differences of SCORAD, DLQI, PeDeSI-G pre- and posttest, paired t-test was applied. p-values < 0.05 were considered statistically significant. All analyses were performed using Excel version 16 and GraphPadPrism 9. 24 PBI was presented using descriptive statistics.

RESULTS

A total of 20 participants were included in this quality improvement project. Baseline characteristics including demographic data, diagnoses, therapy, SCORAD and DLQI are summarised in Tables 1 and 2. Atopic comorbidities were reported by 15 participants. 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].

AD severity significantly decreased upon intervention

Upon intervention, namely receiving the patient action plan, we observed a significant decrease of AD severity as assessed by SCORAD (pretest before: 38.1 ± 20.8 posttest:

TABLE 1 Characteristics of 20 patients with atopic dermatitis.

TABLE 1 Characteristics of 20 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	Bacterial infection	3	15%	
complications	Eczema herpeticum	5	25%	

Abbreviation: AD, atopic dermatitis; SD, standard deviation.

TABLE 2 Scores at baseline of 20 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

Abbreviation: SD, standard deviation. aSCORAD: SCORing Atopic Dermatitis.

^bDLQI: Dermatology life quality index.

 22.0 ± 12.5 ; p < 0.0001) (Figure 1). The rate of patients achieving SCORAD 0–24 reflecting mild AD, was 12 (60%). Overall, in 95% of patients, an improvement of their disease, and in eight patients a SCORAD-50 were observed (Figure 1, Table S1 and Figure S1).

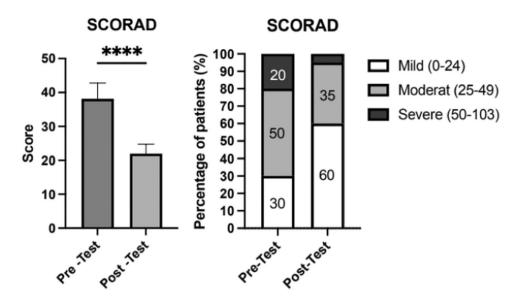


FIGURE 1 The effect of providing a patient action plan on SCORing Atopic Dermatitis (SCORAD). Graphs show SCORAD levels (mean \pm SEM) pre- and posttest (****p < 0.0001), and percentages of patients in defined ranges of SCORAD indicating atopic dermatitis severity levels. SEm, standard error of mean.

Following the patient action plan results in an improved quality of life

Patients' quality of life assessed by DLQI significantly increased (pretest: 11.6 ± 7.2 ; posttest: 6.3 ± 5.0 ; p < 0.001) (Figure 2). Before intervention, the quality of life had largely been affected by AD in 55% of patients. Upon receiving the patient action plan, AD did not or minimally affected the quality of life in 13 (65%) patients, whereas DLQI \geq 11 values were noted in only 20% of patients (Figure 2, Table S1 and Figure S1).

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 < 0.0001) (Figure 3). While this 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. Postintervention, PeDeSI-G 21-29 scores indicating limited education needs, were reported by 16~(80%), and PeDeSI-G 30 scores meaning sufficient knowledge available, by three (15%) of patients (Figure 3, Table S1 and Figure S1).

PBI was calculated on patient needs questionnaire (PNQ) and patient benefit questionnaire (PBQ). A minimal benefit of 1 was achieved in 19 (95%) patients. Of those, the PBI reached 2–4 in 15 patients. In one (5%) patient the treatment needs have completely been fulfilled (PBI = 4) (Figure 4). The mean PBI was 2.73 (SD: 0.9).

DISCUSSION

Here, we report on the first quality improvement project evaluating the effects of individually tailored patient action plans on disease severity and patient-related outcomes in adult AD patients. Our results demonstrate a significant improvement of both AD severity and patient-related outcomes upon intervention. Thus, patient action plans could be considered an effective educational tool as part of AD management in both paediatric and adult patient groups. ^{14,16}

The development of the patient action plan was the results of our efforts to improve patient education and by that disease management in adult AD patients for many years. To evaluate the feasibility and effects of patient action plans in daily practice, we started this quality improvement project.

Upon providing a patient action plan, the participants experienced a significant decrease of AD severity, in parallel with a significant increase of quality of life and improved self-care as assessed by SCORAD, DLQI and PeDeSI-G, respectively.

Based on the pathomechanisms and disease course of AD, the disease management is very complex, and requires patients actively get involved in, to follow and adapt basic, proactive and reactive therapeutic interventions according to the severity of AD signs and symptoms. ^{17,18} In our project, self-management was evaluated using PeDeSI-G. Upon providing a patient action plan, the knowledge how to manage the skin disorder

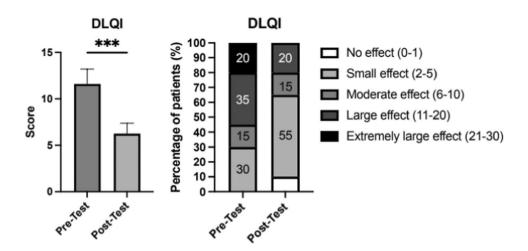


FIGURE 2 The effect of the patient action plan on dermatology life quality index (DLQI). Graphs show DLQI values (mean \pm SEM) preand posttest (***p < 0.001), and percentages of patients in defined ranges of DLQI indicating the impairment of life quality (high DLQI levels correspond to severe impairment of life quality). SEM, standard error of mean.

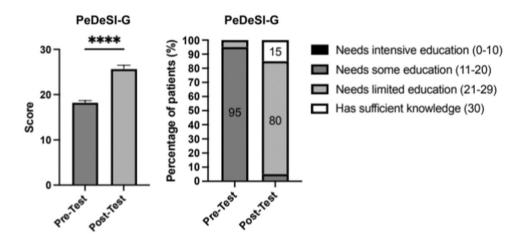


FIGURE 3 The effect of the patient action plan on Person-Centred Dermatology Self-Care Index (PeDeSI-G). Graphs show PeDeSI-G levels (mean \pm SEM) pre- and posttest (****p < 0.0001), and percentage of patients in defined ranges of PeDeSI-G indicating the need of education. SEM, standard error of mean.

significantly increased. This finding is in concordance with other studies determining self-management in adults and children with AD upon using a patient action plan. 12,13,25 To mention, all studies determined self-management based on different tools and questionnaires. 12,13,25 Therefore, the comparability of these results is limited.

So far, reports on the effects of patient action plans in AD patients are scarce. Most of them are designed for caregivers. Moreover, due to different study designs, outcome measures used and patient populations, a direct comparison of the results is not possible. Rea et al.¹² reported a significant improvement of disease severity

(p < 0.0.001) in children using patient-oriented eczema measure (POEM) and quality of life (p < 0.0.001) using infants and children dermatitis quality of life index (IDQOL, CDLQI). However, in this randomised 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))¹². Duhovic et al.²⁶ reported similar findings regarding SCORAD whereas Brown et al.²⁵ had similar findings for quality of life.^{24,25}

To our knowledge, our project is the first one that evaluated the effects of the patient action plan based on PBI. The value of PBI in assessing treatment effects in

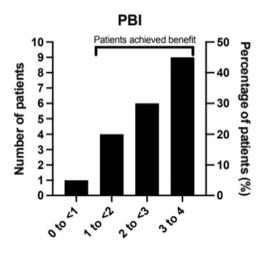


FIGURE 4 The effect of the patient action plan on the patient benefit index (PBI). Graphs show percentage and number of patients according to the PBI achieved. The minimal clinical benefit is PBI = 1.

skin diseases has been reported for psoriasis, rosacea and hand eczema, and is applicable for AD as well as shown in our study.^{27–29} Our results confirm that 95% of patients experienced at least a minimal benefit of the prescribed treatment. Still, it remains uncertain whether all observed effects can be ascribed to the patient action plan alone, or are a result of a combination of action plan together with concomitant factors such as patient education, motivation, encouragement and topical therapy. Nevertheless, our results indicate that the prescribed treatment was applied, and gives an idea on how the patients were enabled to do the treatment (self-management) and if they were adherent.

LIMITATIONS OF THE PROJECT

Limitations of this project are the small sample size, which was due to restricted time and personnel resources, and the single centre design. Since our project was designed as a quality improvement project, we had no control group. Probably, the validity of results comparing intervention versus control groups differs from those obtained by pre- and postintervention analyses. Translation of the patient action plan in various languages (e.g., French, Italian, English) is required before distributing it to large patient cohorts to test it in a multicenter setting. Moreover, subsequent studies should include a long-term patient follow-up to evaluate the effects of the patient action plan over time.

CONCLUSION

This project had the purpose to implement and evaluate a patient action plan based on disease severity and patient-related outcomes. Our findings provide evidence that a patient action plan for adults with AD is an additional valuable tool to increase self-management resulting in improving clinical signs and symptoms of AD.

AUTHOR CONTRIBUTIONS

K. Thormann: Study concept; methodology and design; analysis and interpretation of data; drafting of the manuscript; final approval of the version to be published.
L. Lupe: Study concept; methodology and design; analysis and interpretation of data; drafting of the manuscript; final approval of the version to be published.
S. Radonjic-Hoesli: Study concept; methodology and design; drafting of the manuscript; final approval of the version to be published.
C. von Dach: Study concept; methodology and design; drafting of the manuscript; final approval of the version to be published.
D. Simon: Study concept; methodology and design; analysis and interpretation of data; drafting of the manuscript; final approval of the version to be published.

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CONFLICTS OF INTEREST STATEMENT

D. Simon is an investigator and/or advisor for AbbVie, Almirall, Amgen, AstraZeneca, Galderma, Incyte, LEO, Eli Lilly, Novartis, Pfizer and Sanofi Genzyme. S. Radonjic-Hoesli has been an advisory board member for Sanofi, Leo Pharma, Almirall and Blue Print and consultant for LEO pharma. K. Thormann has been an advisor for Sanofi and got consulting fees from Leo pharma. The remaining authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Author elects to not share data.

ETHICS STATEMENT

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 (IRB-FY22-603, Req-2022-00403). All patients enroled in the study have given general informed consent for the further use of their pseudonymized aggregated data and their case details for research and publication.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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