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The impact of therapeutic patient education through play-based workshops on the quality of life of patients with atopic dermatitis

El efecto de la educación terapéutica en la calidad de vida de los pacientes con dermatitis atópica, a través de talleres lúdicos

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ABSTRACT

INTRODUCTION: atopic dermatitis (AD) affects patients' quality of life (QoL) similarly to other chronic diseases. Therapeutic patient education (TPE) allows patients to acquire knowledge about their disease and take responsibility for their own care, improving severity and QoL. We aimed to evaluate how attending play-based therapeutic educational workshops improved a group of patients' QoL and AD severity.

METHODS: a prospective longitudinal study including patients 2-18 years old with AD who consented to participate was performed. Before the first workshop, a questionnaire about treatment and skin-care practices was applied, and the Severity Scoring of AD (SCORAD) index was measured. Patients' QoL was evaluated using Pediatric QoL Inventory™ (PedsQL™), applied to patients and their parents. Questionnaires were applied again after attending one and three TPE workshops. Statistical analysis was performed using Wilcoxon Rank sum test.

RESULTS: We included 32 children, 51.6% were girls, with a median age of 7.5 years. Initial median SCORAD was 36.05, this decreased to 18.6 after the 1st workshop (p = 0.05) and 23 after the 3rd workshop. Parent-reported PedsQL™ total score significantly improved across time points (62.5, 72.8 and 70.6) in all domains, including physical, emotional and social domains with the exception of school functioning. Child-reported PedsQL™ total score improvement was more evident after the 1st workshop, but individual emotional and social scores improved significantly only after the 3rd workshop.

RESUMEN

INTRODUCCIÓN: como otras enfermedades crónicas, la dermatitis atópica (DA) afecta la calidad de vida (CdV) de los pacientes. La educación terapéutica permite al paciente (ETP) adquirir conocimientos sobre su enfermedad y empoderarse mediante la disminución de la severidad y mejor CdV. Este estudio buscó evaluar el efecto de talleres de ETP en la severidad de la DA y en la CdV de los pacientes.

MÉTODOS: se realizó un estudio prospectivo longitudinal que incluyó a pacientes de dos a 18 años con DA. Se aplicaron cuestionarios sobre tratamiento de DA, se midió la severidad mediante SCORAD y se evaluó la CdV mediante Pediatric QoL Inventory™ (PedsQL™) en padres y pacientes al inicio y después de uno y tres talleres ETP. El análisis estadístico se realizó con suma de rangos de Wilcoxon.

RESULTADOS: se incluyó a 32 niños, 51.6% niñas, con mediana de edad de 7.5 años. La mediana de SCORAD inicial fue de 36.05; disminuyó a 18.6 (p = 0.05) y a 23 después del primer y tercer talleres, respectivamente. La puntuación de PedsQL™ reportada por los padres mejoró de manera progresiva (62.5, 72.8 y 70.6) en los dominios físico, emocional y social. La mejoría en el puntaje de PedsQL™ informada por los niños fue más evidente después del primer taller, sin embargo, las puntuaciones emocionales y sociales mejoraron significativamente sólo después del tercer taller.

CONCLUSIONES: la asistencia a talleres de ETP disminuyó de forma importante la severidad de la enfermedad y mejoró la CdV

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CONCLUSIONS: TPE effectively decreased disease severity and improved QoL in AD patients, especially emotional and social aspects. Attending >1 workshop may improve QoL more than AD severity.

KEYWORDS: *atopic dermatitis, therapeutic patient education, quality of life, pediatrics.*

en pacientes con DA, en especial aspectos emocionales y sociales. Asistir a más de un taller de ETP posiblemente mejora la CdV más que la severidad en DA.

PALABRAS CLAVE: *dermatitis atópica, educación terapéutica del paciente, calidad de vida, pediatría.*

Introduction

Atopic dermatitis (AD) is the most common chronic inflammatory skin disease in childhood, affecting 20% of children.[1] It is characterized by intense itching and recurrent eczematous lesions. This condition has a multifactorial etiology, including abnormalities in epidermal structure and function that facilitate trans-epidermal water loss and cutaneous inflammation due to inappropriate immune responses to antigens.[2]

AD can be disabling and affect the quality of life (QoL) of patients and their families to a greater extent than other chronic diseases of childhood, including asthma and type 1 diabetes.[3,4] Skin diseases are frequently more visible than other chronic diseases; therefore, they can negatively impact emotional status, social relationships and daily activities of affected patients.[5]

Therapeutic patient education (TPE) is a patient-centered process that entails the transfer of skills from a trained healthcare professional to patients and/or their parents.[6,7] TPE has been recognized by the World Health Organization (WHO) as an effective tool for the management of chronic diseases, such as AD, asthma, chronic obstructive pulmonary disease, diabetes, cardiovascular disease, hypertension, psoriasis, obesity, oncologic and rheumatologic diseases, because it improves adherence, prevents complications and improves QoL of patients.[3,7] TPE is a four-step process that includes the following: understanding what the patient or parents know, believe or fear; setting educational objectives; helping the patient (or caregiver) acquire skills; and assessing the success of the program.[7] Various types of TPE approaches have been implemented for patients with AD that differ with regard to modality, content, health professionals involved, organization, scheduling, and evaluation methods.[6]

This study aimed to measure the impact of TPE in the form of play-based workshops on the QoL of Mexican pediatric patients with AD and their disease severity.

Methods

Study design

We conducted an observational prospective study approved by our institutional review board (number 058/16) of pediatric patients with AD who attended the TPE workshops held at the National Institute of Pediatrics in Mexico City during the period between April 1, 2017 and March 2, 2019. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

The inclusion criteria were children diagnosed with AD aged two to 18 years old who agreed to participate in the study and attend three TPE workshops. Exclusion criteria included being exposed to another formal TPE intervention before this study. All participants' caregivers provided written consent regarding their participation, publishing their data and photographs, and all patients ≥ 12 years of age provided written assent.

Intervention

Play and art-based educational therapeutic workshops for patients with AD are held four times per year in our institution with an average duration of five hours each and approximately patients in attendance. The team of trainers is multidisciplinary, including pediatricians, pediatric dermatologists, psychologists and nurses. These workshops are structured to begin with a 30-45 min educational talk to explain what AD is and how it can be improved for both patients and their caregiver(s). Occasionally, an educational video is also presented. Afterwards, patients are divided according to age groups and participate in different activities related to learning about and managing their disease, such as playing table games, reading children's books about AD, making arts and handcrafts, or group dynamics involving their participation (figure 1). Adolescents join support groups to work on self-esteem and coping strategies. Parents participate in group activities led by psychologists where they share experiences and preoccupations related to their children's condition and tips on management, with the objective of empowerment. Fundamental issues are addressed, such as the impact of the diagnosis, grief due to loss of health, guilt or feeling responsible, management of limits and family crises, and frustration secondary to not being able to improve the physical, emotional and/or social health of patients.

Outcome measures

Pediatric Quality of Life Inventory™ (PedsQL™) version

Figure 1. Different educational activities related to atopic dermatitis are performed based on age groups, such as (**a, b**) art and handcrafts, (**c**) reading books, and (**d**) coloring books.

4.0 questionnaires were used to measure QoL. The questionnaires were completed by patients based on age group and their caregivers with assistance by two researchers (MP-R and GE-G) who read questions aloud when necessary and answered doubts about questions. Severity of disease was evaluated using the Severity Scoring of Atopic Dermatitis Index (SCORAD), and two investigators (EM-V and BC-C) asked specific questions about the treatment used. All of these instruments were applied before attending the first workshop, one month after attending the first workshop, and one month after the third workshop.

The PedsQL^{TM} tool is composed of questions regarding different aspects of life affected by the disease in the past month and involves four domains: physical, emotional, social and school functioning. There are four questionnaires adapted for the following age groups: 2-4, 5-7, 8-12 and 13-18 years. For each age group, one questionnaire is given to the child and one to parents, except for children under two years (parental questionnaire only). Each question is evaluated according to a Likert scale of five categories (0 = never a problem, 1 = almost never a problem, 2 = sometimes it is a problem, 3 = often a problem, and 4 = almost always a problem). At the end of the questionnaire, the scores obtained from each question are added and transformed into a score on a scale of 0 to 100; higher values indicate a better quality of life.[8,9]

Statistical analysis was performed using the Wilcoxon Rank sum test to compare groups with SPSS software (IBM SPSS Statistics, Version 21.0. Armonk, NY: IBM Corp.).

Results

In total, 32 children with a median age of 7.5 years (range 2-16) were eligible to participate, and 51.6% were girls. All participants attended the first workshop. However, seven did not attend the follow-up appointment, and six more did not attend the 3rd workshop and/or the follow-up appointment. Participants were called to inquire about their absence, and the most common reasons for not returning to the workshops were clinical improvement, lack of time or money, and parental work responsibilities.

Demographic and clinical characteristics are presented in table 1. After the first workshop, the baseline total

Table 1. Clinical characteristics and PedsQL™ questionnaire scores of children with atopic dermatitis

	Baseline N = 32	After the 1st workshop N = 25	p	After the 3rd workshop N = 19	p
Age in years, median (range)	7.5 (2-16)				
Gender distribution Female sex (%)	16 (51.6)				
SCORAD, median (range)					
Total	36.05 (0-82.50)	18.60 (3.50-72.20)	0.05	23 (4.20-67.40)	0.091
Objective	23.9 (0-62.50)	13.50 (0-64)	0.09	18.20 (3.50-53.40)	0.178
Parent-reported PedsQL™ total score, median (range)	62.50 (18.40-93.40)	72.80 (17.30-97.80)	0.03	70.60 (26-95.60)	0.006
Physical functioning	62.50 (6.25-100)	81.20 (15.60-100)	0.089	81.20 (34.40-100)	0.031
Emotional functioning	50 (0-90)	55 (0-100)	0.035	55 (0-90)	0.034
Social functioning	62.50 (5-100)	80 (0-100)	0.011	80 (30-100)	0.003
School functioning	56.65 (10-95)	62.50 (0-100)	0.277	67.50 (10-100)	0.196
Child-reported PedsQL™ total score, median (range)	64.10 (8-86.90)	70.60 (35.80-86.90)	0.05	68.75 (41.30-93.40)	0.036
Physical functioning	71.90 (6.20-93.70)	81.20 (37.50-100)	0.161	78.10 (34.40-100)	0.181
Emotional functioning	51 (20-100)	55 (10-80)	0.866	70 (20-95)	0.024
Social functioning	75 (0-100)	77.50 (15-100)	0.202	80 (40-100)	0.008
School functioning	57.50 (10-95)	67.50 (0-90)	0.083	60 (30-100)	0.378

Pedsql™: Pediatric Quality of Life Inventory™; scorad: severity scoring of atopic dermatitis.
*We used mean instead of median because the value was non-descriptive.

SCORAD (median 36.05) decreased to 18.6 (p = 0.05). The value further decreased to 23 (not statistically significant) after the 3rd workshop. There was no change in the number of times patients applied emollients and/or steroids.

The child-reported PedsQL™ total score improved significantly after the 1st, 2nd and 3rd workshops (64.1, 70.6 and 68.75, respectively); however, individual emotional and social scores improved significantly only after the 3rd workshop (figure 2a).

Parents reported significantly better QoL after one and three workshops, and improvements were particularly noted in physical, emotional and social functioning (figure 2b).

Comparing child *vs.* parent-reported scores, children scored higher emotional functioning at baseline and after the 3rd workshop. No significant discrepancies were found for physical, social and school functioning. After the 3rd workshop, parents reported significantly increased physical functioning than did their children (table 2).

Discussion

Health-related QoL has been defined as a multidimensional construct comprising impairments in different aspects of life, such as physical, emotional, cognitive, and psychosocial health as well as everyday functioning.[4]

Health-related QoL is often markedly impaired in children with AD[5] due to symptoms, such as extreme pruritus, scratching and sleep disturbances that affect productivity at school;[4] however, reduced health-related QoL is also attributed to an increased number of mental health comorbidities that increase proportionally with the severity of AD. Children often feel socially isolated because they cannot participate in all activities and receive negative

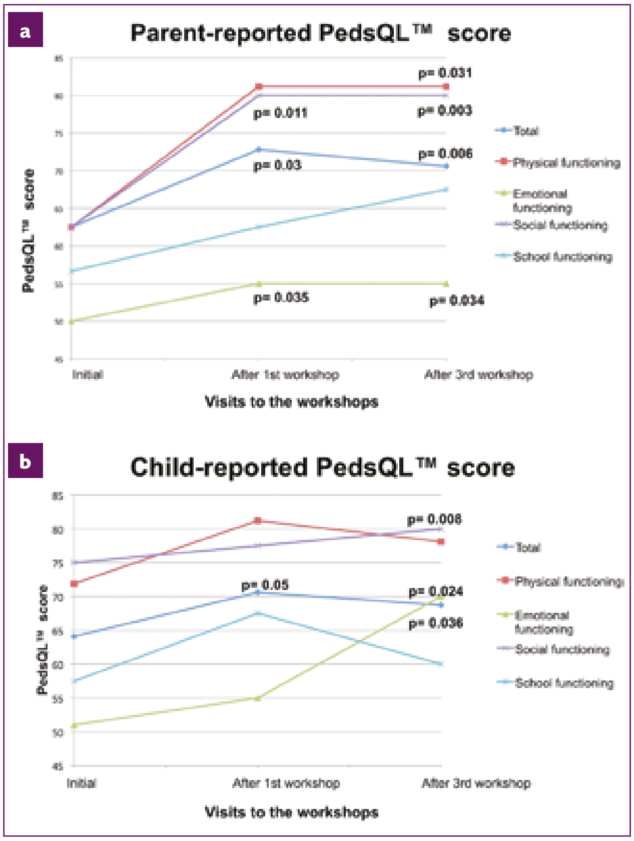

Figure 2. A: Parent-reported PedsQL™, **B:** child-reported PedsQL™ at baseline, after the 1st and 3rd workshops.

comments from peers, and children with AD are at an increased risk of experiencing depression, anxiety, conduct disorders and autism.[10]

Patients' parents also experience decreased QoL caused by their children's sleep disorders and daytime tiredness. Parents can suffer emotional distress because treatment can be time consuming and expensive.[4,5]

As previously noted, TPE has become a cornerstone in the management of chronic diseases, including AD. TPE is a continuous process managed by a multidisciplinary team of healthcare professionals for patients and their families, and the objective is for patients and families to maintain skills to manage their illness, optimize their treatment and avoid complications while improving QoL.[6,7] An important step in TPE is the assessment of its efficacy. Assessment should include biomedical outcomes (such as evaluation of severity of AD using SCORAD or Eczema Area and Severity Index [EASI] scales) and evaluation of patient's QoL based on QoL scores.[6,7]

Several tools are used to measure health-related QoL in pediatric patients, and some of these tools have been validated and standardized. In our study, we used the PedsQL™ version 4.0 questionnaire, a practical and multidimensional instrument that aims to assess health-related QoL in children and adolescents. This tool has been validated in multiple conditions, and its results are re-

Table 2. Parent vs. child-reported PedsQL™

Baseline	Parent report, median (range) N = 32	Child report, median (range) N = 25	p-value
Total score	**62.50 (18.40-93.40)**	**64.10 (8-86.90)**	**p = 0.42**
Physical functioning	62.50 (6.25-100)	71.90 (6.20-93.70)	p = 0.42
Emotional functioning	50 (0-90)	51 (20-100)	p = 0.05
Social functioning	62.50 (5-100)	75 (0-100)	p = 0.28
School functioning	56.65 (10-95)	57.50 (10-95)	p = 0.40
After the 1st workshop	**N = 25**	**N = 20**	
Total score	**72.80 (17.30-97.80)**	**70.60 (35.80-86.90)**	**p = 0.65**
Physical functioning	81.20 (15.60-100)	81.20 (37.50-100)	p = 0.79
Emotional functioning	55 (0-100)	55 (10-80)	p = 0.51
Social functioning	80 (0-100)	77.50 (15-100)	p = 0.49
School functioning	62.50 (0-100)	67.50 (0-90)	p = 0.96
After the 3rd workshop	**N = 19**	**N = 16**	
Total score	**70.60 (26-95.60)**	**68.75 (41.30-93.40)**	**p =0.85**
Physical functioning	81.20 (34.40-100)	78.10 (34.40-100)	p = 0.55
Emotional functioning	55 (0-90)	70 (20-95)	p = 0.05
Social functioning	80 (30-100)	80 (40-100)	p = 0.40
School functioning	67.50 (10-100)	60 (30-100)	p = 0.90

PedsQL™: Pediatric Quality of Life Inventory™.

liable and reproducible, distinguishing between healthy children and children with acute or chronic conditions. This tool has been validated in Spanish, making it practical for use in our population.[8,9,11,12]

Using child-reported PedsQL™ and parent-reported PedsQL™, we found that the initial median PedsQL scores of both patients and their parents were 64.1 and 62.5, respectively, which is lower than the average score in healthy children. Varni and collaborators reported an average of 80.64 ± 13.34 for child self-reported responses and 76.92 ± 16.81 by parent-reported responses in healthy school-age children in the US.[13] Another study found an average of 86.4 ± 2.3 for child self-reported responses and 82.3 ± 2.6 in parent-reported responses to PedsQL™ in healthy Iranian children.[14] Scores were also lower than PedsQL™ scores reported in other chronic diseases of childhood, such as asthma (71.81),[15] type 1 diabetes (82.33),[16] type 2 diabetes (78.83) and inflammatory bowel disease (77.06).[17]

Baseline emotional functioning was lower in parents compared with their children. These differences in baseline emotional function may rely on parents own health-related QoL, which is highly dependent on their involvement in treatment and their responsibility for their child's daily care. Eiser and collaborators described a relation between parental emotional distress and negative perceptions of their child's QoL.[18]

We found that child-reported PedsQL™ improved after at least one play-based educational workshop, but individual emotional and social scores improved significantly only after the 3rd workshop. When we compared child- *vs.* parental- reported scores, we found that children scored significantly higher on emotional functioning compared with their parents after the 3rd workshop. The discrepancies between child's and parent's perceptions have already been reported in the literature. Parents agree with their children on objective domains but less so in terms of emotional functioning. Children scored better than their parents potentially because their self-reports are better representations of their actual symptoms and the immediate effects of treatment. In contrast, parents may take into account the current state but also other time points when the disease may have been more severe (e.g., eczematous lesions and pruritus). After all, it may be that children are the best to report their symptoms and QoL.[18]

Children's learning capacities and cognitive skills vary according to their age and development stage; this should be taken into account when planning the TPE program's methods. Pélicand and collaborators developed a TPE program for diabetic children based on recreational and creative methods, including a special children's book about diabetes, drawing, creating a set of cards for coloring, and use of puppets. This program was offered during a 3-week summer camp that included seven workshops consisting of group discussions about diabetes-related situations in which children expressed themselves through improvised puppet shows. They found that this strategy was successful for teaching difficult aspects of disease and treatment-related issues and behaviors.[19]

Several trials have evaluated the impact of TPE in QoL of patients with AD (table 3). TPE improved QoL and/or disease severity in most; however, given that educational programs and QoL evaluations used in each trial vary greatly, comparisons between studies are difficult. Weber and collaborators evaluated 32 patients and their relatives and found that QoL measured using Children's Dermatology Life Quality Index (CDLQI) in patients improved significantly after attending a biweekly support group that included playful activities, such as playing, drawing, simulations and performances to educate children about their disease. However, they did not find an improvement in the QoL of a patient's relatives using the Family Dermatitis Impact Index.[24] Staab and collaborators reported that weekly educational sessions for six weeks improved the severity of eczema and QoL, which is similar to the findings noted in our study. However, they evaluated QoL using a "disease specific questionnaire on QoL of parents of children with AD" not a validated and standardized questionnaire.[21] In contrast, Grillo and collaborators evaluated the impact of an educational program (two hours workshop) on the severity of AD and QoL and found that even if the intervention group had a significant improvement in SCORAD, QoL did not significantly improve, except in the group of children aged 5-16 years.[22]

Studies that failed to demonstrate the effects on QoL had very short educational interventions, which could indicate that time is a determinant factor.[20,25]

One of the strengths of our study is the use of a validated and standardized questionnaire to assess QoL evaluating both child and parental reports and the use of SCORAD to assess AD severity in our patients. Studies that assess the QoL of patients with AD before and after receiving a TPE program for disease care have not been reported in Mexico to date. The 5-hour play and art-based TPE program that we evaluated is more elaborate and complete than other interventions.

The limitations of our study include the small sample size and patient loss to follow-up, which was mostly due to clinical improvement and lack of time/resources to attend the workshops.

Table 3. Comparative table of trials evaluating the impact of TPE in QoL of patients with AD

Author	Year	Setting	TPE	Patients	Results
Chinn *et al.*[20]	2002	Primary care	One 30-min individual session with a nurse	197 children aged 0.5-16 years	No significant difference in QoL at 4 or 12 weeks
Staab *et al.*[21]	2002	Interdisciplinary clinic	6 group sessions of 2 hours each	204 families, children aged 0.5-12 years	No significant difference in SCORAD, trend towards improved QoL and significant improvement in behavioral changes (use of emollients, antiseptics and topical steroids)
Grillo *et al.*[22]	2006	Dermatology clinic	2-hour workshops, group sessions	58 children aged 0-16 years	Significant improvement in SCORAD. No significant difference in QoL
Staab *et al.*[23]	2006	Interdisciplinary clinic	2-hour group sessions weekly for 6 weeks	823 parents and children aged 8-18 years	Significant improvements in SCORAD, subjective severity and effect on parents QoL
Weber *et al.*[24]	2008	Interdisciplinary clinic	90-min group sessions weekly for 24 months	32 parents and children aged 2-16 years	QoL improved significantly, personal relationships and leisure showed marked enhancement. There were no differences in the QoL of family members of patients after treatment
Shaw *et al.*[25]	2008	Dermatology clinic	15-min individual session	106 children aged 0-18 years	No significant difference in SCORAD or QoL between control (standard therapy) and intervention (standard therapy plus interaction with AD educator) groups
Ricchi *et al.*[26]	2009	Interdisciplinary clinic	Group discussion, 6 weeks, 90 min weekly	30 families of children aged 0.5-5 years	Improvement in QoL in both parents and children. Lower levels of anxiety were observed
Schuttelaar *et al.*[27]	2010	Dermatology clinic	Dermatologist group: first visit took 20 min and sfollow-up visits took 10 min. Nurse practitioner group: first visit took 30 min and follow-up visits took 20 min or involved a 2-hour group session (4 visits)	80 children aged <4 years and 80 children aged 4-6 years	Both treatment groups showed significant improvements in QoL and SCORAD
Futamura *et al.*[28]	2013	Hospital stay	2-day parental education program on childhood AD comprising 3 lectures, 3 practical sessions and a group discussion	59 children (6 months to 6 years)	Participants in the education program had a significantly lower SCORAD, and anxiety scores were significantly better than in controls
Pustišek *et al.*[29]	2016	Pediatric dermatology clinic	Two-hour lecture	134 children aged 3 months to 7 years	Participants in the intervention group had a significantly lower SCORAD, and a significantly lower impact of AD was noted for the total quality of family life
Liang *et al.*[30]	2018	Hospital	Four once-weekly group sessions with a 2-hour lecture	580 children, ages 2-14 years	The intervention group showed a greater reduction in mean SCORAD and Infant's Dermatology Life Quality Index scores (ages 2-4 years) than the control group. No significant difference was found between groups in Children's Dermatology Life Quality Index scores (ages 5-16 years)

TPE: therapeutic patient education; QoL: quality of life; SCORAD: severity scoring of atopic dermatitis; AD: atopic dermatitis.

Conclusion

The TPE workshops based on play and art that are offered for patients with AD at our institution effectively decrease disease severity and improve QoL, especially emotional and social aspects. We found similarity between scores reported by parents and children in this study, which supports a real effect of the intervention on measured outcomes. We consider the use of TPE fundamental for the successful management of patients with AD, as there is ample evidence of its role in improvement of disease and QoL.

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