

Dermatite Atópica: Perspetivas e Atitudes de Doentes Adultos e de Cuidadores de Crianças Afetadas, Avaliadas por Focus Group

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RESUMO – Introdução: Dimensões importantes, tais como experiências pessoais, atitudes em relação à doença, suas causas e tratamentos, não são totalmente abordadas em ensaios clínicos. Os Focus Group (FG) surgiram como uma ferramenta interessante e valiosa na pesquisa clínica, complementando essa lacuna. O objetivo desta pesquisa qualitativa foi avaliar, tanto em cuidadores quanto em doentes adultos que lidam com dermatite atópica (DA), as suas atitudes, experiências pessoais e perspectivas em relação à doença e ao seu tratamento tópico, bem como o impacto na qualidade de vida (QV). **Material e Métodos:** Para as sessões de discussão foram recrutados 10 cuidadores e 10 doentes adultos. Foram realizadas duas sessões de FG e discutidos três temas principais: perspectivas em relação à DA, tratamentos tópicos e o impacto da doença na QV. Todas as atividades foram gravadas em vídeo e a discussão e anotações foram transcritas para um documento. A análise posterior foi realizada por dois investigadores. **Resultados:** No momento do diagnóstico, os sentimentos vivenciados que melhor o descrevem foram “preocupação” (30%) para os cuidadores e “qualidade de vida” (30%) para os doentes. A emoção ou estado de espírito “positivo” em relação à doença atual foi “superação” para os cuidadores (21%) e “controlo” para os doentes (17%). A principal emoção “negativa ou neutra” foi “medo” para os cuidadores (13%) e “resignação” para os doentes (18%), mas ao projetar para a criança doente ao seu cuidado, “frustração” (19%) foi a mais citada pelos cuidadores. Em relação aos tratamentos tópicos, a satisfação global média dos cuidadores foi alta (8,5/10) para o tacrolimus, exceto no item “preço”. No caso dos doentes, os corticosteroides receberam uma melhor pontuação (8,0/10), com a exceção do item “tolerabilidade/efeitos adversos”. Características como “tratamento preventivo com redução das agudizações” e “livre de cortisona” foram importantes para ambos. Todos os participantes demonstraram altos níveis de impacto negativo na QV, tendo respetivamente 47% e 64,6% considerado os scores de interferência “bastante” e “muito”. **Conclusão:** Estudos qualitativos na DA pela metodologia FG são escassos e, do nosso conhecimento, este é o primeiro a reunir doentes adultos e cuidadores de crianças. As dimensões obtidas por esta abordagem poderão ser úteis para complementar os dados dos ensaios clínicos e orientar decisões de investigadores e autoridades de saúde.

PALAVRAS-CHAVE – Criança; Dermatite Atópica; Grupos de Discussão; Inibidores da Calcineurina; Qualidade de Vida.

Atopic Dermatitis: Perspectives and Attitudes of Adult Patients and Affected Child Caregivers Assessed by Focus Group

ABSTRACT – Introduction: Important dimensions such as personal experiences, attitudes toward disease, its causes and treatments, are not fully addressed in clinical trials. Focus group (FG) has emerged as an interesting and valuable tool in clinical research complementing this gap. The aim of this qualitative research was to assess in both caregivers and patients dealing with atopic dermatitis (AD) their attitudes, personal experiences and perspectives toward the disease and its topical treatment as well as the impact in quality of life (QoL). **Material and Methods:** For discussion sessions, 10 caregivers of children and 10 adult patients were recruited. Two sessions of FG took place with 3 main themes discussed: perspectives toward AD, topical treatments and the impact in QoL. All activities were recorded in video and the discussions and notes were then transcribed to a document,

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followed by transcripts analysis. **Results:** The best descriptive feelings in the moment of diagnosis were “concern” (30%) and “quality of life” (30%) for caregivers and patients, respectively. The actual “positive” emotion or state of mind toward the disease was “overcoming” for caregivers (21%) and “control” for patients (17%). The main “negative or neutral” emotion was “fear” for caregivers (13%) and “resignation” for patients (18%), but when projecting to their child, “frustration” (19%) was the most mentioned. In relation to topical treatments, the mean global satisfaction of caregivers was high for tacrolimus (8.5/10), except in the item “price”. In the case of patients, corticosteroids received a better score (8.0/10), with exception for “tolerability/adverse effects”. Features like “preventive treatment with reduction of flares” and “free of cortisone” were important for both participants in an “ideal topical medicine” setting. All participants showed high levels of negative impact in their QoL due to AD, with 47% and 64.6% considering scores of “very much” and “a lot” of interference, respectively. **Conclusion:** Qualitative studies in AD by FG are scarce and to our knowledge this is the first one gathering both adult patients and caregivers. The dimensions yielded by this approach are useful to complement data retrieved from clinical trials and to drive decisions from researchers and health authorities.

KEYWORDS – Calcineurin Inhibitors; Child; Dermatitis, Atopic; Focus Groups; Quality of Life.

INTRODUCTION

Evidence-based medicine relies mainly on quantitative assessments of statistical-significant data drawn mostly from clinical trials.¹ In general, a high level of objectivity and reproducibility of the results obtained from these studies, if adequately designed, is the rule, in special in terms of efficacy and safety. However, important dimensions such as personal experiences, not only from patients but also from health care providers and caregivers, attitudes toward disease, its causes and treatments, are not fully addressed in clinical trials and a more “medicine-based evidence” is required.² In this setting, focus group (FG) have emerged as an interesting and valuable tool in clinical research, complementing not only the quantitative studies but also other qualitative approaches such as in-depth interviews and case studies.³ In addition, FG are useful to design intervention programs in the community for health promotion in a specific field.⁴

Atopic dermatitis (AD) is the most prevalent inflammatory skin disease in children and has a chronic, relapsing course.⁵ Although there is a trend to disease improvement over time, the patient and their caregivers usually face many years of disease activity, which may extend into adulthood. The psychosocial impact of the disease assessed by many quality of life (QoL) studies clearly transcends the patient boundary and involves his family, in special the caregivers.⁶ In general, the caregivers are the parents of the affected child, in particular the mother.

Tacrolimus and pimecrolimus belonging to the group of topical calcineurin inhibitors (TCIs) have gained an important place in the treatment armamentarium of AD.⁷ These compounds represent a pharmacological innovation in the last fifty years, during which corticosteroids, the actual gold-standard approach, reigned isolated. The role of TCIs, in special tacrolimus has been focused not only on disease treatment, but also in the prevention of flares, a feature that is of paramount importance in a chronic, waned disease like AD.⁸

The aim of this research was to assess attitudes and personal experiences of both caregivers and patients dealing

with AD, with a particular regard to the pharmacological treatment. In addition, the perspectives of participants toward AD and the impact of the disease in the QoL of both groups were also evaluated.

MATERIAL AND METHODS

Participants sampling and pre-sessions data collection

For the discussion sessions, 10 caregivers were recruited, 8 females and 2 males, with ages ranging from 33 to 45 years (mean of 38), caring for 12 children suffering from AD. The children, 10 males and 2 females, were aged from 3 months to 11 years (mean of 54.8 months or 4.6 years). None of the caregivers suffered from AD.

In addition, 10 adult patients, 8 females and 2 males, suffering from AD were also recruited, with ages ranging from 22 to 44 years (mean of 34 years).

The diagnosis of AD was confirmed by a dermatologist and the severity of the disease was not a pre-session requirement. For both groups of caregivers and patients, experience in the use of TCIs or other topical pharmacological therapies (hydrocortisone base or methylprednisolone) for the treatment of AD was also considered, but not the use of emollients.

All participants were informed about the aim of the study and written consent was obtained. Any participant received financial compensation for their participation, other than cost allowances for transportation.

Discussion groups design

Two sessions of FG took place in Spirituc facilities (Spirituc, - Investigaç o aplicada, Lda.), in order to offer a relaxed environment with a mean duration of two hours each. Three main themes were discussed in each session, with the following structure:

Theme 1 (caregivers and patients perspectives toward AD): in questions 1 (what were the first symptoms or signs, which led to a doctor appointment?), 2 (what was the speciality of the doctor who made the diagnosis?), 3 (after the

diagnosis by a doctor, did you search further information about AD in other sources?), 4 (in which age were the first symptoms detected and the diagnosis established?), 5 (what phrase better expresses your feelings when facing the diagnosis of AD?), all participants were free to answer the topic proposed; in question 6 (what are the three states of mind/emotions, which represent better the actual feeling toward the disease?), participants were asked to choose three options in list of "positive" ("overcoming", "control", "tranquility", "triumph") and "negative or neutral" emotions ("fear", "anxiety", "anger", "overwhelmed", "shame", "frustration", "resignation"). Additionally, in the case of caregivers, along with their own emotions, they were asked to choose the states of mind/emotions they thought were affecting their child (projected emotions).

Theme 2 (Topical treatments): in question 1 (how satisfied with the topical treatment) the participants were asked to give their satisfaction toward three types of AD treatment: the TCIs tacrolimus, pimecrolimus and topical corticosteroids (hydrocortisone and methylprednisolone), registering the answers in 1 to 10 scale (1- not satisfied; 10- totally satisfied). In question 2 (if you could create an "ideal topical medicine" for the treatment of AD, which 5 features were the most important?) the participants were asked to choose 5 among 10 of the following features randomly presented: "fast onset but short duration", "good smell of the compound", "preventive treatment with reduction of flares", "itch relief", "easy to apply", "not expensive", "suitable to be applied in any area of the skin", "more expensive but with a long-term efficacy", "free of cortisone", "reduced number of applications per week". In question 3 (if it was possible, what 3 wishes you made that will improve the QoL in AD?) participants were free to mention the 3 wishes.

Theme 3 (Impact of AD in the QoL): for this theme both caregivers and patients were asked to score the impact in their QoL of several topics (see Tables 3 4 for the list proposed) with the following scale: 1 (nothing/no impact), 2 (a little), 3 (a lot) and 4 (very much).

Each group of discussion began with an introduction for welcoming the participants, followed by the open-ended questions related to the theme used to generate discussion (see results section for detailed questionnaire). The facilitator, which provided the questions, did not participate in the discussion. All activities were recorded in video and the discussion was then transcribed to a document, along with the facilitator notes, taken during the sessions. Transcripts analysis was done by two investigators, one being a dermatologist, using coding procedures described elsewhere.³

RESULTS

Theme 1 - Caregivers and patients perspectives toward AD

Question 1 - What were the first symptoms or signs, which led to a doctor appointment?

All 10 caregivers mention that cutaneous xerosis, face

abrasions, irritation of skin folds and legs were the main signs and symptoms, which led them to make a physician appointment. However, a higher delay was observed in the case of skin dryness, possibly because it was considered a "normal" feature in the "fragile" skin of their child.

Similar to caregivers, the patients recall based mainly on their parents information, that dryness of the skin, face involvement and skin folds irritation were the main signs and symptoms.

Question 2 - What was the specialty of the doctor who made the diagnosis?

All caregivers consulted at first a pediatrician. Nevertheless, after this first appointment, six were referred to a dermatologist, one to an allergologist and one maintained the follow-up in the pediatrician.

For three patients the dermatologist was the first doctor (possibly due to a more late onset of AD, see below) and the pediatrician for the remaining. At the time of the focus group sessions all patients were in follow-up by a dermatologist.

Question 3 - After the diagnosis by a doctor, did you search further information about AD in other sources?

Although all caregivers stated that they were satisfactory enlightened by the information provided by their doctor, the internet followed as the second source of information, searching for topics such as "causes of AD", "dietary care" and "treatment options", not only conventional therapies but also "alternative" approaches, in special "non-pharmacological".

The internet was also the additional source of information used by all the patients in their adolescence or adult phase, searching mainly for "treatment-related issues".

Question 4 - In which age were the first symptoms detected and the diagnosis established?

All caregivers answered that the first months of the first year of life of their child, therefore as infant, were the period in which the diagnosis of AD was made.

Seven patients mention also the infant period, but the remaining three stated a later onset (2 in childhood, 1 in prepuberal period and other as adolescent).

Question 5 - What phrase better expresses your feelings when facing the diagnosis of AD?

Forty percent of caregivers mention the term "unknown" as the best descriptive of their feelings when they heard the diagnosis of AD for the first time (Table 1). In this setting, the others where "concern" (30%), "day life limitation" (20%) and "blame" (10%).

In the case of patients, they reported the actual feelings regarding the ongoing disease, as "quality of life" (30%), "resignation" (30%), "insecurity" (20%), "annoyance" (10%), "self-control" (10%) and "confusion" (10%). [Table 1]

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Table 1 - Differences of perceptions between caregivers and patients when facing the diagnosis of AD, which may be interpreted as evolving emotions.

What have you felt? (caregivers in the moment of diagnosis)	What you actually feel? (patients in the moment of focus group)
Unknown (40%)	Evolved to Confusion (10%)
Concern (30%)	Evolved to Insecurity (20%) / resignation (30%)
Limitation of day life (20%)	Evolved to Self-control (10%) / loss of QoL (30%) / annoyance (10%)
Blame (10%)	

Question 6 - What are the three states of mind/emotions, which represent better the actual feeling toward the disease?

Table 2 summarizes the results for this topic.

tacrolimus, in the caregiver’s perspective, but clearly inferior in respect to “tolerability/adverse effects”.

In the case of patients, the “other” treatment (topical corticosteroids) received a better score for global satisfaction (8.0),

Table 2 - Actual states of mind/emotions of caregivers and patients in relation to AD. In the case of caregivers, they were additionally asked to report what they thought were these emotions in their children (projected).

	“Positive” emotion/state of mind			“Negative or neutral” emotion/state of mind			
	Caregivers (own) [%]	Caregivers (projected) [%]	Patients (%)		Caregivers (own) [%]	Caregivers (projected) [%]	Patients (%)
Overcoming	21	7	10	Fear	13	7	0
Control	17	7	17	Anxiety	10	7	3
Tranquility	13	3	10	Anger	3	10	10
Triumph	0	0	3	Overwhelmed	3	17	13
				Shame	0	10	3
				Frustration	10	19	13
				Resignation	10	13	18
Total	51	17	40	Total	49	83	60

Theme 2 – Topical treatments

In relation to topical treatments the following proportion was obtained: 9 participants (4 caregivers and 5 patients) stated experience with tacrolimus, 5 participants (2 caregivers and 3 patients) with pimecrolimus and 6 participants (4 caregivers and 2 patients) with topical corticosteroids.

Question 1 – How satisfied with the topical treatment

For caregivers the mean global satisfaction was high for tacrolimus (8.5 in 10), followed by pimecrolimus (7.5) and corticosteroids (6.5) [Fig. 1]. Tacrolimus as well pimecrolimus were clearly inferior to corticosteroids in the item “price”. In the remaining items explored, tacrolimus was superior or similar to pimecrolimus, with the exception of the “easy to apply”. Corticosteroids seems to have a global efficacy similar to

followed by tacrolimus (5.2) and pimecrolimus (4.0). [Fig. 1]

Question 2 - If you could create an “ideal topical medicine” for the treatment of AD, which 5 features were the most important?

Caregivers elected “preventive treatment with reduction of flares”, “reduced number of applications per week”, “free of cortisone”, “not expensive” and “suitable to be applied in any area of the skin” as the main features. Patients mentioned “itch relief”, “not expensive”, “easy to apply”, “free of cortisone” and “reduced number of applications per week”.

Question 3 - If it was possible, what 3 wishes you made that will improve the QoL in AD

The caregivers mention in decreasing rank order “topical compound for the prevention of flares”, “total

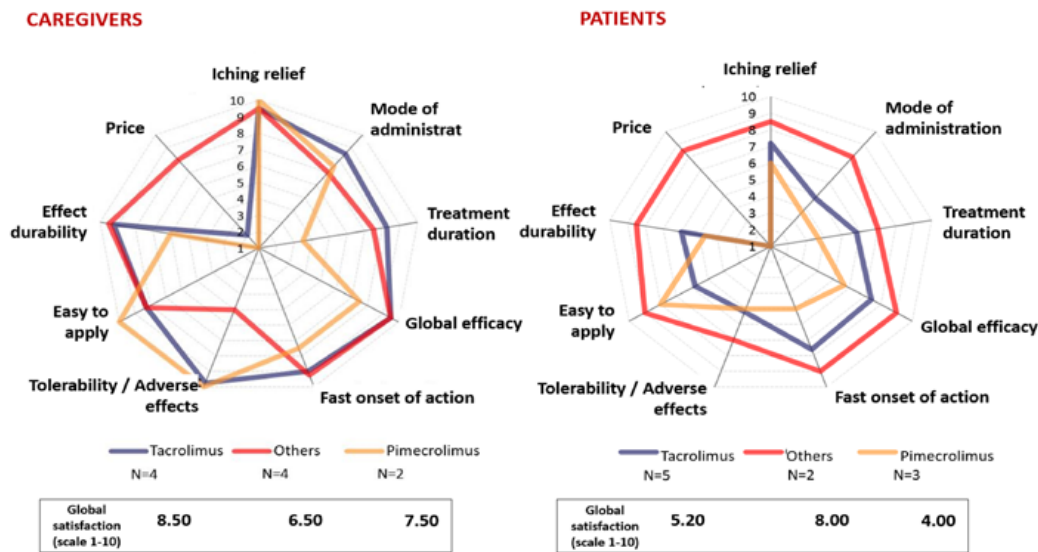


Figure 1 - Caregivers and patients satisfaction for topical treatments of AD, tacrolimus, pimecrolimus and others (topical corticosteroids). Each item was scored using a scale from 1 (not satisfied) to 10 (totally satisfied).

reimbursement” and “greater efficacy of a treatment”. In the case of patients, preferences were “oral treatment to relieve itch without somnolence”, “treatment free of cortisone”, “total reimbursement”.

Theme 3 - Impact of AD in the OoL

Tables 3 and 4 summarize the results for this topic.

DISCUSSION

Emerging from marketing analysis, FG have become noticeable in recent years as a valuable and reliable tool for qualitative analysis in healthcare research, including in the field of dermatology.^{3,9} In fact, by promoting an open free but structured discussion between persons sharing a common experience, like dealing with a chronic disease such as AD, it is possible to assess their attitudes, perspectives, concerns and needs.¹⁰ Quantitative studies like clinical trials, although fundamental for clinical research, do not always address these dimensions in a suitable manner.² Moreover, the conclusions drawn from FG may constitute a working base for other exploratory studies and to promote projects that will assist decision makers in the health field and pharmaceutical companies, among other entities, to meet in a more convenient way the real needs of patients, caregivers and healthcare agents.¹¹ Atopic dermatitis is the most common chronic inflammatory skin disease in children with an estimated prevalence of 10% - 20% in this age group.⁵ Although milder cases tend to improve with age, more severe presentations may extend into adulthood.¹²

Theme 1 - Caregivers and patient’s perspectives toward AD

It is noteworthy that half of the caregivers had a negative

view (“concern” and “day life limitation”) about the disease and the possible future negative impact on the QoL of their child when confronted the diagnosis of AD for the first time. However, as adults, the patients demonstrate mixed perspectives, ranging from the ability to live daily with the disease and their difficulties, to the feeling of being unfit and unable to cope with the affection. In addition, “insecurity” mentioned by 20% of patients reflects the fact that the AD itself has an unpredictable course, with unexpected flares occurring at any time, which underscores the need of a preventive treatment (see below). The difference in perception in this setting observed between caregivers and patients is possibly attributable to different feelings in distinct moments of this chronic disease, i.e. the impact in the moment of the diagnosis (caregivers) and the different ability to cope with a disease evolving for years (patients) [see Table 1].

In the case of emotions/state of mind toward AD, it is interesting to observe the optimistic view of the caregivers, with 51% expressing a “positive” perspective facing the disease. However, when projecting the emotions on their affected child, the results clearly contrast with the above mentioned, as the “negative” view predominates, with 70% of the participants considering that their child have a more ominous perspective than they do (if discounting “resignation” as a neutral emotion). This could mean that as caregivers of a child suffering from a chronic disease, they are aware of the paramount negative impact of AD in the QoL (see below). Consequently, they take a protective attitude as their child’s best chance of overcoming difficulties. In the case of patients, there was a more balanced perspective between “positive” (40%) and “negative” (41%) emotions, possibly reflecting different abilities to cope with AD as already discussed. However, it was noteworthy that

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Table 3 - Impact of several topics in the QoL of caregivers and graded by a scale. Some items reflect an indirect impact in QoL as projected in the child.

Question	Score				Mean score
	1 Nothing (%)	2 A little (%)	3 A lot (%)	4 Very much (%)	
1. Are you feeling stress caring for your child?	20	20	30	30	2.70
2. Have you sleep disturbances (in quality and number of hours) due to caring?	10	50	20	20	2.50
3. How much time you dispend in the treatment?	0	60	20	20	2.60
4. Are you feeling of guilt in relation to your child disease?	0	60	20	20	2.10
5. Do you feel shame by socially exposing your child? 6. (due to fear of mistreatment, neglect or contagiousness)	50	20	30	0	1.80
7. How much did your child feel itch, pain or skin irritation?	0	10	40	50	3.40
8. Did your child feel embarrassment with the skin appearance	50	10	30	10	2.00
9. Did the disease conditioned the garment choice for your child?	0	0	50	50	3.50
10. Did AD affect your social life or leisure time?	20	30	50	0	2.30
11. Did AD affect your physical or sport activity?	20	30	50	0	2.30
12. How much AD interfered with your child attending school or kindergarten? *	12.5	87.5	0	0	1.88
13. How much AD interfered in your relationship with friends, colleagues or relatives?	0	50	0	10	1.80
14. Did your child care interfered with your daily life activities?	10	50	30	10	2.40
Mean %	14.8	36.6	28.5	18.5	

* The score was only made by 80% of caregivers who mentioned that AD did not prevent the child from attending school or kindergarten. In the remaining 20%, 10% considered that AD totally prevented the attendance and it was not applicable to 10% of caregivers (the child stayed all time with caregiver).

“resignation” as a “neutral” state of mind predominated (18%), expressing a sort of accommodation or adaptation to a disease evolving for many years.

Theme 2 - Topical treatment discussions

In caregiver’s perspective the mean global satisfaction was high for TCIs, in special for tacrolimus, followed by pimecrolimus and topical corticosteroids. However, tacrolimus as well pimecrolimus were inferior to corticosteroids in the item “price”. Pimecrolimus seemed to be the “easiest to apply”, possibly due to its cream consistency, but the ointment formulation of tacrolimus is as expected more potent, explaining why this compound is indicated for moderate to severe forms of AD.¹³ Topical corticosteroids, considered the gold standard treatment, seemed in fact to have a global efficacy similar to tacrolimus, in the caregiver’s perspective, but clearly inferior in relation to “tolerability/adverse effects”. In this respect, the well-known tachyphylaxis¹⁴ of the corticosteroids and the fear of local and systemic effects

(“corticophobia”)¹⁵ appeared to have played a role. Patients, on the other hand, demonstrated a less “corticophobic” position, possibly by perceiving a more rapid onset of action with these compounds (Fig. 1). Nevertheless, in the case of TCIs, tacrolimus maintained superior in most scores in relation to pimecrolimus. Both groups of participants shared a vision of a compound that will increase their adherence to treatment (“not expensive” and “less number of applications”) with some degree of “corticoconcern” (“free of cortisone”). In fact, phobia to topical corticosteroids is a well-known and worldwide phenomenon,^{15,16} also addressed in FG session.¹⁷ In this respect, long-term studies are needed to demystify many of the reasons for corticophobia. Adult patients focused mainly in the immediate treatment of troubled symptoms (“itch relief”) contrasting with caregivers, which had a more long-term and prophylactic concern, i.e. the prevention of the feared disease exacerbations (“preventive treatment with reduction of flares”). Like this practical view of adult patients, adolescents also seems to

Table 4 - Impact of several topics in the QoL of patients with AD and graded in a score 1 to 4.

Question	Score				Mean score
	1 Nothing (%)	2 A little (%)	3 A lot (%)	4 Very much (%)	
1. How much did you feel itch, pain or skin irritation	0	0	50	50	3.50
2. Did you feel embarrassment with your skin appearance	0	30	30	40	3.10
3. How did AD affect your daily life activities such as shopping, home or garden care	0	30	30	40	3.10
4. The choice of your clothing was affected by AD	0	10	50	40	3.30
5. Did AD affect your social life an leisure	0	30	60	10	2.80
6. Did AD affect your physical or sport activity	0	10	50	30	3.00
7. How much the disease affected your work or studies*	0	44	56	0	2.44
8. How much AD interfered in your relationship with friends, colleagues or relatives	40	40	20	0	1.80
9. Did AD affect your sexual life	50	50	0	0	1.50
10. Did AD trouble your logistic or took some time of your day	0	10	60	30	3.20
Mean %	9.0	25.4	40.6	24	

* This question was scored by 90% of patients who stated that the disease did not prevent them to work or study

share this practical view of adult patients, preferring treatments with a fast and persistent effect, as reported in a recent FG study.¹⁸ On the other hand, the concern of caregivers is interesting, just because in recent years has been paid more attention not only to the need of early treatment of AD exacerbations for better efficacy, but also to the prevention of flares, increasing the disease-free period, an approach known as proactive treatment.^{19,20} When AD usually relapses on the same locations, it is possible to apply the topical drug in a biweekly approach after the improvement of the relapse in order to prolong the disease-free state. Tacrolimus has been to our knowledge the only topical TCIs with demonstrated efficacy in proactive treatment of AD, a feature that meets the caregivers expressed needs.^{8,19-21} Although this proactive treatment has also been demonstrated for corticosteroids, like fluticasone and methylprednisolone,^{22,23} TCIs, as a drug class, offers some advantages over the former, in special the lack of skin atrophy (enabling its application in problematic areas, such as the face and neck) and tachyphylaxis, reduced skin permeation and an efficacy similar to medium-potent corticosteroids, in special tacrolimus.²⁴ This could meet the wishes expressed by caregivers of a compound "free cortisone", "suitable to be applied in any area of the skin" and of "greater efficacy".

In both groups of participants, treatment seemed to play a major role as a modifier factor of their QoL. As expected

in a chronic disease, the economic impact of the treatment^{25,26} cost is present in all participants, a wish that is not usually shared by the reimbursement entities (public or private). In fact, the level of reimbursement for AD medications is far for being total and is lower compared with other chronic cutaneous diseases, such as psoriasis, a factor affecting treatment adherence. In fact, low economic income and the cost of medicines have been correlated with nonadherence to treatment in chronic diseases like AD,²⁷ which reduce QoL and can increase mortality.^{28,29} Nonetheless, adult patients once again manifest a more short-term preoccupation, in special with side effects of treatments ("cortisone" and "somnolence"), possibly fearing interference of the drugs with their active professions. Caregivers, on their side, have a more long-run concern, wishing that a more efficacious treatment will also decrease the frequency of flares ("prevention").

Theme 3 - Impact of AD in the QoL

WHO defines quality of life as "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".³⁰ This broad definition is subject to cultural variability and assessment tools need transnational validation. In this work both caregivers and patients showed high levels of negative impact in their

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QoL due to AD, with 47% and 64.6% considering scores of "very much" and "a lot" of interference, respectively (Table 3 and Table 4). The five items with the highest scores were in decreasing rank order "conditioning of garment choice", "level of itch, pain or skin irritation of the child", "time depended in caring", "level of stress in caring" and "sleep disturbances", in the case of caregivers (Table 3). The patients attributed to most items mean scores superior or equal to 3 ("a lot" or "very much" interference), in which "feeling itch, pain or skin irritation", "choice of clothing", "time spent on the day", "feelings of embarrassment due to appearance" and "interference with daily life activities" with the highest scores (Table 4). These results are in good agreement to those reported in different QoL assessments for AD.^{25,26} In relation to other chronic diseases, the psychologic impact of AD, in special to self-esteem and self-image, seems to surpass psoriasis, chronic urticaria, diabetes mellitus and arterial hypertension.^{31,32} Due mainly to pruritus, a negative impact in the quality and quantity of sleep is also evident, with patients reporting losing a mean of 2 hours by night and daytime somnolence with cognitive impairment.^{33,34} These disturbances persist even during the remission periods of inflammation. Also, the presence of notorious levels of stress (a well-known flare inducer), anxiety, depression, suicidal thoughts, frustration, hypochondria, feelings of insecurity, dependence on others and social isolation are noted in patients.³⁵⁻³⁸ In addition, a negative impact of AD in the QoL of caregivers and family members in general is also reported, turning AD not only an individual affection but also a "family" or "social" disease.³⁹ In fact, the presence of feelings of guilty, shame to expose the child fearing misinterpretations of the visible lesions as neglect or mistreatment and a negative social and economic impact due to high expenses in treatments and clothes, among others, have been reported in QoL studies.^{25,26} Furthermore, in parallel with this work, most caregivers report high levels of stress and time spent in child care, which can be higher than those in caring for a child suffering from diabetes mellitus, and sleep disturbances as well, increasing the risk of unemployment.^{34,40}

In conclusion, qualitative studies in AD by focus groups are scarce and to our knowledge, this is the first one gathering both patients and caregivers of children suffering from this common and chronic inflammatory skin disease. Although it is not possible to completely rule out biased conclusions by this methodology, it is noteworthy that dimensions yielded by this approach, such as personal experiences of patients and their attitudes toward disease and treatments, are able to complement clinical trials and are a source of insights that can drive decisions from pharmaceutical researchers and health authorities. In recent years, topical TCIs emerged as advantageous alternatives to topical corticosteroids in AD and its profile meets most of the needs of both patients and caregivers reported in this work. With a paramount impact in the quality of life, mainly due to its chronic course, public health authorities must face AD

like other chronic skin affections, such as psoriasis, in terms of reimbursement of expenditures in efficacious treatments, for both adult patients and caregivers of affected children, a major concern also addressed in this study.

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