ORIGINAL ARTICLE

Qualitative study with mothers of children with atopic dermatitis: Emotional and social impacts

Etude qualitative auprès de mères d'enfants atteints de dermatite atopique: Impacts émotionnels et sociaux

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Abstract

Introduction: Atopic Dermatitis (AD) is the most common skin disease in childhood and its control requires the support of the family members. This disease significantly interferes with the Quality of Life (QoL) of children and families, however, literature on the social and emotional impact of the disease on the caregivers is lacking.

Objective: To evaluate the emotional and social impact of AD on mothers of children with the disease.

Method: This is a qualitative study of semi-structured interviews with mothers of children diagnosed with AD. The following variables were evaluated: diagnosis and start of treatment, knowledge about the disease, and impact on the mothers' lives. The material was analyzed using Lawrence Bardin's content analysis technique. The AD severity was assessed by SCORAD.

Results: A total of 23 interviews were conducted with mothers of children diagnosed with AD. In 82.6% of the cases, the mothers presented conflicts in the face of the first contacts with the disease. In 43.5% of cases, mothers were solely responsible for their children's treatment. About 56.6% defined AD as a cause of suffering and difficulty and 21.7% pointed out the AD experience as a learning experience.

Conclusion: The AD is a chronic disease that has a psychological and social impact on the lives of mothers. In the treatment of AD, mothers must be screened and offered psychological support to improve adherence to treatment in the long term.

Key words: atopic dermatitis, emotional impacts, mothers

Résumé

Introduction: La dermatite atopique (DA) est la maladie cutanée la plus fréquente chez l'enfant et son contrôle nécessite le soutien des membres de la famille. Cette maladie nuit considérablement à la qualité de vie des enfants et des familles, mais la littérature sur l'impact social et émotionnel de la maladie sur les soignants est rare.

Objectif: Évaluer l'impact de la DA sur les mères d'enfants atteints.

Méthode: Il s'agit d'une étude qualitative d'entretiens semi-structurés avec des mères d'enfants avec la DA. Les variables suivantes ont été évaluées: diagnostic et début du traitement, connaissances sur la maladie et impact sur la vie des mères. Le matériel a été analysé pour la technique d'analyse de contenu de Lawrence Bardin. La sévérité de la DA a été évaluée pour SCORAD.

Résultats: 23 entretiens ont été réalisés avec des mères d'enfants avec la DA. Dans 82,6 % des cas, les mères ont eu des conflits lors de leur premier contact avec la maladie. Dans 43,5% des cas, les mères étaient seules responsables du traitement de leur enfant. Environ 56,6 % ont défini la DA comme une cause de souffrance et de difficulté et 21,7 % ont décrit l'expérience de la DA comme une expérience d'apprentissage.

Conclusions: La DA est une maladie qui a un impact psychologique et social sur la vie des mères. Dans le cadre du traitement de la DA, les mères devraient faire l'objet d'un dépistage et bénéficier d'un soutien psychologique afin d'améliorer l'observance du traitement à long terme.

Mots clés: dermatite atopique, impacts émotionnels, mères

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INTRODUCTION

Atopic Dermatitis (AD) is the most common skin disease in childhood. A systematic review found that the overall variation in prevalence among children is from 1.7% to 32.8% (1). In Brazil, the prevalence is 8.2% among children and 5.0% among adolescents (2). The diagnosis is clinical, and severity can be assessed by scoring indices, such as the Scoring Atopic Dermatitis (SCORAD). The SCORAD evaluates the extent, characteristics, and severity of dermatological lesions on physical examination and the importance given by the child or guardian to the amount of pruritus and changes in sleep in the last 48 hours prior to the evaluation. The SCORAD score ranges from 0 to 103, and the disease is stratified as follows: mild (from 0 to 25 points), moderate (26 to 50 points), and severe (greater than 50 points) (3).

Among all AD symptoms, pruritus is reported to be the most bothersome, affecting nearly 91% of patients daily (4). Sleep disturbance is also a significant consequence of itching in children with AD and has been linked to daytime fatigue, irritability, loss of concentration, headache, and attention deficit hyperactivity disorder (ADHD) (5).

The AD also has a negative impact on the emotional lives of the caregivers (6). Mothers and fathers of children with AD report feeling powerless and distressed in the face of the care for the disease. In addition, recent studies show that mothers also experience sleep disturbances and exhaustion during the day for the first eleven years of age of children with AD (7).

Recent research evaluated the relationship between AD in children and their mothers' quality of life, stress, sleep quality, anxiety, and depression. This study observed that mothers of children with AD had significantly higher anxiety and depression scores compared with mothers of children without AD (8).

Considering that women are often the primary caregivers of children around the world, both healthy children and children with chronic illnesses. Although several studies indicate that women have worse stress scores compared to men when it comes to caring for sick children (9-11), the literature is inconclusive about the relationship between stress rates and gender differences among caregivers resulting from the exercise of care. Caregiving burden reflects many intertwined variables, including the sex of caregivers, marital status, level of education, subjective perception of burden, degree of kinship with the child, severity of the disease, level of dependence of the patient in activities of daily living, occupational status of the caregiver, fragile health and presence of mental disorders in the caregiver, among others (12-16). This study addresses a specific group: the group of mothers who care for children with AD and aimed to evaluate the emotional and social impact of AD on these women

METHODS

Design

This is an observational, exploratory, and qualitative study, with prospective data collection. Semi-structured interviews were conducted with mothers of children diagnosed with AD. The data analysis method used was Content Analysis (Bardin, 2016). The study was approved by the Research Ethics Committee of the researchers' affiliated institution (CAAE No. 91350718.7.0000.0096).

Participants and Sample

This is a non-probabilistic, convenience, and systematized sample. The population comprised 23 mothers of children of both sexes, between 2 and 10 years of age, diagnosed with AD for at least one year, without mental disorders and other chronic diseases other than those of the atopic triad (allergic rhinitis, asthma, and AD), followed up at the pediatric dermatology service of a university hospital in southern Brazil.

The AD severity was measured using SCORAD. After the routine medical consultation, the mothers participated in a semi-structured interview (Table 1), with audio recording. From the initial questions of the script, the mothers were encouraged to talk about their experience with the disease, interspersed with questions to clarify or deepen the content of the statements.

Table 1. Semi-structured interview script

Diagnosis and start of treatment
When did you discover the disease?
How long has your child been on treatment specific for AD*?
For how long?
How was the beginning of the treatment and what is it like today?
Which medication does your child use?
Knowledge about the atopic dermatitis
What you known about AD?
Why do people develop this disease?
Impact on mothers' lives
How would you define the AD, in one word?
What changed in your life after the discovery of the disease?

Note:*AD: atopic dermatitis

Data analysis

For data analysis, the Content Analysis technique was used, which is a set of systematic analysis techniques aiming to obtain the description and infer the message content (Chart 1) (17)

Chart 1. Step-by-step data analysis, according to Bardin's Content Analysis (17)

Organization of the analysis: The interviews were transcribed, read, and reread several times to obtain first impressions of the material. Then, the relevant statements that emerged in each interview were noted, composing what we called "text indexes."

Encoding: In this step, the indexes have been compiled to provide an overview of the material. From this grouping, the indices were divided into groups and named.

Categorization: The encoded material is grouped into categories, according to common elements or affinities between the encoded elements.

Data interpretation: It is the process of making inferences from the information found in the previous steps.

RESULTS

The sample consisted of 23 mothers with a mean age of 33.1 ± 12, most of whom were married (91.4%) and had attended high school (69.6%) (Table 2).

The time of each interview ranged from 14 minutes and 30 seconds to 54 minutes and 9 seconds. The severity classification of the children's AD was assessed using SCORAD as: mild, 43.5% (n = 10); moderate, 47.8% (n = 11); and severe, 8.7% (n = 2) The severity classification is illustrated in figure 1.

Figure 1. Example of atopic dermatitis severity by SCORAD.

Table 2. Characteristics of mothers of children with atopic dermatitis

Characteristics	**n (%)**
Age the mothers (years)	
21 – 30	7 (30.4%)
31 – 40	13 (56.5%)
41 – 50	3 (13.1%)
Marital status	
Single	1 (4.3%)
Married	21 (91.4%)
Divorced	1 (4.3%)
Education	
Primary education	5 (21.7%)
Secondary education	16 (69.6%)
Higher education	2 (8.7%)
Family income	
From 1 to 2 minimum wages (BRL 954 to BRL 1,908).	10 (43.4%)
From 2 to 4 minimum wages (BRL 1,909 to BRL 3,816).	11 (47.8%)
From 4 to 5 minimum wages (BRL 3,817 to BRL 4,770).	2 (8.7%)

The semi-structured interview was divided into 3 categories, namely: "first contacts with the disease," "knowledge about the disease," and "impact on the caregiver's life" and provided the following results:

Diagnosis and start of treatment

The results of the category "diagnosis and start of treatment" indicated that 19 (82.6%) mothers presented conflict in the face of the first contacts with the disease, described as: "*despair*," "*very shaken*," "*terrified*," "*scared*," "*suffering*," "*a shock*," "*difficult*." Of these, 9 (39.1%) reported not knowing what to do about their child's disease.

The mothers' reports commonly showed that professionals prioritized in previous treatments the prescription of medications and general guidance about the disease, but without clearly transmitting specific information about their role in AD control. This factor contributed to the ineffectiveness of treatment. They also reported more detailed guidance on the necessary changes in the environment and in the daily life of the child with the dermatosis, to avoid triggering and worsening the lesions, as in the examples of Table 3:

Regarding diagnosis, 12 participants (52.6%) obtained diagnosis and effective treatment in less than 6 months from the onset of symptoms. In 6 (26.1%) cases, it took between 1 and 5 years of disease to obtain adequate treatment; 2 (8.7%) mothers reported that the diagnosis arose in consultations due to other demands; and in 3 (13%) cases, the mothers were unable to specify the time elapsed from diagnosis to effective treatment.

Table 3. Examples of mothers' reports about diagnosis and start of treatment during the interview

Identification	**Mothers' reports**
E23 **(SCORAD mild)**	*"It was hard when I found out. Because I didn't know about it, I didn't have any information about it, I had never read about anything, you get kind of lost. I was desperate, because I didn't know what to do to get rid of the itching, for her to sleep, she slept a little and started to grumble at night, then she scratched herself, she beat herself all night to sleep scratching herself… it was really hard."*
E10 **(SCORAD severe)**	*"At first I cried a lot. My God, how I cried. I cried, sometimes I felt like putting a rope around my neck, I couldn't stand to see him like that, you know?"*
E19 **(SCORAD moderate)**	*"My pregnancy was 'a breeze'… And I took care for her to be born healthy, but unforeseen events happen (laughs). I brought, for example, a little outfit, which we got as a gift, a lot of wool clothes, you know? Then the doctor looked at me and said that she wouldn't wear woolen clothes, she wouldn't use talcum powder, she wouldn't use wet wipes, she wouldn't wear perfume… I couldn't wear perfume… And so it was (laughs). So it began. It was scary (laughs)."*
E6 **(SCORAD mild)**	*"There were many breakouts. I was terrified, I didn't know what to do! I took her to the doctor, they said it was dermatitis and they gave her a 'light' treatment."*
E23 **(SCORAD mild)**	*"In the beginning it was difficult because we can't wear even a 'little bit of perfume.' It can't be what all kids wear, it has to be another kind of thing. It wasn't easy… So, it was very difficult, we as mothers never want our daughter to be different from everyone else."*

SCORAD: *Scoring of Atopic Dermatitis.*

Knowledge about the disease

The category "knowledge about the disease" showed that knowledge and understanding of AD occurred mainly from three paths: information presented in medical consultations, research carried out autonomously on the internet about AD, and participation in support groups for AD.

Caregivers' knowledge about AD was categorized into: 14 (60.8%) mentioned factors related to skin dryness, genetics, chronicity of the disease, diet, emotional aspect, or a combination of these factors, six (26.1%) reported not knowing or understanding about AD and three (13.1%) did not answer.

Mothers also reported difficulties regarding diagnosis and treatment (Table 4):

Table 4. Examples of mothers' reports of difficulties regarding diagnosis and treatment during the interview

Identification	Mothers' reports
E12 (SCORAD mild)	*"It took us a while to find a way to control it, to see what was going on, (...). Look, I even had it (the diagnosis). But we couldn't get anything that would work for him (...). I knew more or less what it was, but then they gave anti-allergy and sometimes a little ointment to apply to the lesions. It disappeared, but it came back. It's something like that comes and goes."*
E7 (SCORAD moderate)	*"Look, at about nine months old, we started noticing some itching in her, you know? Then, at that time, we had a health plan and she had treatment with a dermatologist, allergist, but they never said it was atopic dermatitis, but when she was under treatment she was fine. The treatment stopped, it'd come back."*

SCORAD: *Scoring of Atopic Dermatitis.*

Impact on mothers' lives

The results of the category "impact on the mothers' lives" showed that women are primarily responsible for the care of children with AD. In 10 (43.5%) of the cases, the mothers were solely responsible for the treatment of their children. In 4 (17.4%) of the cases, the mothers were assisted by the child's father. In 7 (30.4%) cases, they had the help of other family members (siblings, grandparents, uncles) and in 2 (8.7%) of the cases, they were helped by several family members.

Regarding the impact of AD on the lives of mothers, 13 (56.6%) defined AD as something that causes suffering and makes their lives difficult, 5 (21.7%) pointed out the experience of AD as learning, and 5 (21.7%) reported it as a difficult experience to name. The group of mothers who cited the disease as "suffering and difficulty" reported that this suffering was due to three reasons: 1) the experience of living with the disease itself; 2) the greater care and concern for the child; and 3) the dermatosis, modifying the mother's ideals regarding the child.

Table 5 shows some of the reports of the impact of AD on maternal life.

DISCUSSION

The results of this study indicate that AD emotionally and socially impacts mothers of children with the disease.

Diagnosis and start of treatment

In 82.6% of the cases, the mothers presented a conflict regarding the diagnosis and the first contacts with the disease. Diagnosis and effective treatment were obtained in less than 6 months in 52.6% of the cases. The earlier the diagnosis, the more time mothers will have to seek information, understand the diagnosis and, gradually, deal with the feelings inherent to this condition (18).

Table 5. Examples of reports of *mothers' impact* of AD on *maternal life* during the *interview*.

Identification	Mothers' reports
S15 (SCORAD moderate)	*"Because they (people, in general) thought the disease was transmissible. They thought it would be passed on to other children... and I suffered 'a lot' in the beginning (...) I couldn't eat or sleep..."*
E18 (SCORAD mild)	*"Sometimes he (son) goes out to play with someone. If he shows the wound, they ask "Mom, doesn't this go away?". And I say "no, it doesn't." Then we feel a little sad."*
E4 (SCORAD moderate)	*"I used to work there in the chocolate factory, I did the cleaning. But I left... there's no one to take care of it, so I'll do it."*
E16 (SCORAD moderate)	*"I thought about working, but there's no way. I have to spend the whole night taking care of her. The next day, if I go out to work, I can't."*
E19 (SCORAD moderate)	*"Then you have to keep comparing your child, to see which one is more important to you. Then I get anxious. Because, for example: sometimes the oldest... I just bought her treatment, but she gets a breakout. Then you keep thinking: do I buy the one for the youngest or the oldest today?"*
S15 (SCORAD moderate)	*"Oh, from my experience, it's very tiring! I'm a mother, it's a disease that you have to be very careful with, it's a tiring disease. A lot of things change, sleep changes, more often we go to the doctors."*

SCORAD: *Scoring of Atopic Dermatitis.*

Knowledge about the disease

In this study, in 60.8% of the cases, the mothers' knowledge about AD was related to skin dryness, genetics, disease chronicity, diet, emotional aspect, or a combination of these factors. In 26.1% of cases, they reported a lack of knowledge about the disease and 13.1% did not answer.

Several authors point out the need for specific training for professionals who provide care and information about AD treatment with family members (19-21). The education of all people involved in the care of children with AD is critical in the disease management. Thus, professionals need to provide simple and clear information, since the lack of information about the disease and its treatment increases parents' anxiety and hinders adherence to treatment and general care, which are essential for therapeutic success (22).

Impact on mothers' lives

This study observed the great impact of AD on the lives of mothers. More than half (56.5%) defined AD as a cause of suffering in daily life, including daily living with the disease and excessive concern for the child.

These data corroborate another study, which points out that 48% of caregivers of children with AD worry about leaving their children with other people due to the disease, 46% reported that they frequently avoid social situations, and 51% reported that they feel guilty or judged that AD symptoms persist despite treatment (23).

The impact of AD on the lives of mothers is aggravated, considering that in 43.5% of the cases in this study, mothers are the only ones responsible for the care related to their children's treatment. Other studies also point to mothers as the main caregivers of children with AD,(24) and that maternal mental health is more affected than that of fathers (25) and of the general population (26).

The lack of support to care for children with AD negatively influences maternal mental health, with higher levels of stress and lower life satisfaction scores. Regarding stress, mothers of children with AD reported high levels of stress, among them, 67% had coexisting insomnia. In addition, 58 and 50% of mothers of children with AD reported symptoms of anxiety and depression, respectively (27).

CONCLUSION

AD is a chronic disease that has a psychological and social impact on the lives of mothers who have lived with their children's illness for years. Therefore, when treating AD, mothers should be screened and advised on the importance of taking care of their own mental health to ensure adherence to long-term treatment, considering that they are primarily responsible for caring for the disease in most families. Pediatricians can offer these mothers support through active listening and encourage self-care. When necessary, they should be referred for individual psychotherapy and advised to seek or expand their support network.

AD educational groups can also be places of support for all family members responsible for treating children, as they offer support and health education. Caring for caregivers is essential to ensure better adherence to treatment and quality of life.

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