

Research Article

A Qualitative Study on the Perception of Atopic Dermatitis by Malagasy Young Patients Regarding Self-Management

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Abstract

Atopic dermatitis (AD) is a chronic disease that usually begins in childhood and can persist at any age. It is essential for adolescents entering to adulthood to have a complete understanding of this disease, including its self-management responsibilities. This study aimed to explore Malagasy adolescents and young adults' perceptions of atopic dermatitis regarding the concept of self-management. This is a qualitative study using semi-structured interviews with adolescent and young adult patients suffering from AD, who were followed up at the Dermatology Department of the University Hospital Joseph Raseta Befelatanana, Antananarivo, Madagascar. Interviews were recorded, transcribed verbatim, and analyzed using NVivo software version 10.2.2 (QSR International, Doncaster, Australia). Five male and seven female patients with mild to severe AD were included according to the Patient-Oriented Eczema Measure (POEM). The mean age was 19.83 years and the mean interview duration was 21.3 minutes. Despite a relatively long duration of AD, the nature of this condition, and the principles and goals of treatment are still poorly understood among young people. Consequently, many still hope for a complete cure for their AD. Our patients adhered to treatment and did not fear topical corticosteroids. This study highlights the importance of providing information about atopic dermatitis during childhood, and emphasizes the need to recommunicate this information directly to these patients during adolescence, aiming for an optimal transition process regarding disease self-management.

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Received: 14 February 2024; **Accepted:** 1 March 2024; **Published:** 13 March 2024



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Keywords

Adolescents, Atopic Dermatitis, Self-Management, Transition

1. Introduction

Atopic dermatitis (AD), also called “atopic eczema” or “eczema” according to literature, is a chronic inflammatory disease which appeared usually in childhood and can persist in adulthood [1]. In Sub-Saharan Africa, its prevalence is increasing in recent years, reaching up to 16% [2]. In Madagascar, the prevalence of AD is 5.6% in children [3] and 0.6% [4] in adults. Atopic dermatitis is characterized by dry skin and itchy lesions, and has an episodic course. It cannot be cured and requires daily treatment [5]. Additionally, some reported it as a painful and upsetting condition that interfered with daily living and sleep [6]. Previous study in Antananarivo [7] shown a negative impact on quality of life in children suffering from AD and their family.

The definition of *self-management* in the context of chronic diseases includes all the actions taken by individuals to manage their condition more effectively and enhance their quality of life [8]. In cases of chronic diseases that emerge in childhood, such as AD, parents typically bear the primary responsibility for the management of the condition. However, as the child enters adolescence, there is a shift in this responsibility, which occurs through a process of transition. During this period, adolescents progressively acquire knowledge and develop self-care skills, enabling them to assume greater independence in managing their condition [9].

The transition process for individuals with asthma or eczema should ideally begin at an early age (11 to 13 years), with the support of both family members and healthcare providers [10]. This process takes time and should continue until the age of 25.

Little qualitative research of how young people manage eczema has been carried out. To the best of our knowledge, young people's perceptions of living with atopic dermatitis have not been studied in Madagascar. Therefore, we aimed to explore young patients' (adolescents and young adults) perceptions of atopic dermatitis in relation to the concept of self-management.

2. Methods

2.1. Design

We conducted a qualitative study through semi-structured interviews using an inductive approach. The study population was selected from the outpatient database of the Dermatology Department of the University Hospital Joseph Raseta Be-

felatanana in Antananarivo, Madagascar. Participants were invited to the interview by two dermatology residents (TIR and HNFPA) over telephone. We conducted a purposive selection process with the aim of ensuring a balanced representation of male and female patients who had persistent AD and varying degrees of severity.

2.2. Inclusion Criteria

Patients with atopic dermatitis who had lesions (dry skin, pruritus) during at least 3 months of follow-up, were aged between 13-25 years and had a preschool (≤ 4 years) or school-age ($> 4 - 16$ years) onset of AD were included. Patients who did not provide consent to participate in the study were excluded.

2.3. Data Collection

Interviews were conducted at the Dermatology Department of the University Hospital Joseph Raseta Befelatanana and by telephone. The interviews were performed by the first author (NHR), a dermatologist who had no connections to the study participants before. Study variables such as gender, age, age at the onset of AD, severity of AD self-assessed by the Patient Oriented Eczema Measure (POEM), treatments received and duration of treatment, were studied. Perception of atopic dermatitis was captured with a questionnaire, developed by the second author (SFA), encompassing themes related to life with AD: daily life, symptoms, treatment, care and consequences of the disease. Interviews were not limited in time; and during interviews, respondents were asked if their answers were correctly interpreted.

2.4. Analysis

Data were recorded (after obtaining the participants' consent) and transcribed verbatim. The data were then coded using inductive content analysis in NVivo software version 10.2.2 (QSR International, Doncaster, Australia). Participants were identified using acronyms.

All codes were derived from the data, and during the analysis, we tried to bracket all our preconceptions and knowledge about atopic dermatitis. The first author (NHR) thoroughly immersed the data by reading the full transcripts and coding them. After coding all the transcripts, the analyzing team (composed of two dermatology residents, TIR

and HNFPA, and a general practitioner, TSR) discussed the data and summarized themes arising from related codes.

This study was approved by the Ethics Committee of the University Hospital Joseph Raseta Befelatanana Antananarivo Madagascar.

3. Results

First, 15 patients were included in the study. Three patients were excluded from this study. We enrolled 12 patients (5 men and 7 women). The mean age was 19.83 years (range 14-25), and the mean duration of interviews was 21.3 minutes. Eight patients had school-age onset of AD, and four patients had preschool-age onset of AD. According to the POEM score, 2 patients had mild AD, 8 patients had moderate AD, and 2 patients had severe or very severe AD. All of the participants were under topical corticosteroids (TCS) and emollients at the time of interviews (Table 1).

Table 1. Characteristics of participants.

Variables	Number (n)
Gender:	
Male	5
Female	7
Mean age = 19.83 years	
Onset age of AD:	
Preschool (≤ 4 years)	4
School ($> 4 - 16$ years)	8
Severity of AD according to POEM:	
Mild (score 3-7)	2
Moderate (score 8-16)	8
Severe/very severe (score 17-28)	2
Topical corticosteroids	8
Emollients	8
Mean interview duration = 21.3 minutes	

Perception of AD among patients

After coding, two main themes emerged from data, and each theme was divided into 2 subthemes:

- 1) Atopic dermatitis was an integral part of life
 - a) Acceptance of atopic dermatitis as a long-term condition
 - b) Life's adjustments and adaptations to eczema
- 2) Knowledge about atopic dermatitis and its treatment were limited
 - a) misconception of the nature of AD

- b) misunderstanding of principles and goals of treatments

3.1. Perception of AD as an Integral Part of Life

3.1.1. Acceptance of AD as a Long-Term Condition

All respondents had an age of onset of AD during childhood. They expressed that they were used to living with eczema. During their lives with eczema, they had their own definition of normalcy. They accepted that this was a long-term and episodic condition. Some participants said that they had never experienced a symptom-free period.

"I'm used to it because I've had eczema since childhood [...], there's nothing special, life goes on as usual [while making quotation mark gestures with hands]" Ny T, age 17 years, Male

"I live normally [...] I just avoid eating certain foods" Seh, age 15 years, Female

"The lesions come and go...Right now, they have come back [sigh]" Mio, age 19 years, Female

"I don't see moments when it doesn't bother me... I feel like I constantly have eczema" Miar, age 14 years, Male

3.1.2. Adaptation and Adjustment of Life to Eczema

Some participants expressed thinking about their eczema almost all the time, when it was itching or visible. In any case, they developed their own strategies to prevent AD from worsening, such as identifying and avoiding triggers. They also adjusted their lives for eczema. Some expressed that having eczema influences their daily lives in different aspects, such as how to dress and food to avoid. Female respondents even expressed cosmetic issues due to their eczema.

"At first, we thought it was just an allergy...and later, I identified some trigger foods, so I avoided consuming them" Flav, age 22 years, Male

"[...] I can only wear long-sleeved clothes" Min, age 25 years, Female

"I can't wear clothes revealing parts of my body ... I can't even wear makeup when I go to events...like weddings" Tsi, age 19 years, Female

3.2. Limitations of Knowledge About Atopic Dermatitis

3.2.1. Misconception of the Nature of AD

Many of our patients believed that eczema was simply a food allergy or caused by liver or blood disorders. Others were unaware of the root cause of their condition and were simply advised to apply cream to their skin daily. They expressed frustration with the lack of information provided to them by their parents or primary care physicians during childhood.

"My parents told me that this was a drug allergy" Lan, age 21 years, Male

"Eczema is caused by microbes present in the skin..." Har, age 17 years, Male

"I didn't really know what this was caused by" Tsi, age 19 years, Female

3.2.2. Misunderstanding of Principles and Goals of the Treatment of AD

All participants received Topical corticosteroids and emollients. They did not express fear of TCS. They all had a good patient-doctor relationship with their treating dermatologists. They did not understand that the goal of treatment in atopic dermatitis is to control, and not to cure the disease. Therefore, they still hoped that it will go away.

"Treatments are effective but don't cure, they just stabilize" Flav, age 22 years, Male

"Treatments work well, but when stopped, lesions and itch come back" Mio, age 19 years, Female

"The point is that...these things always come back; I'm seeking a solution for that" Lan, age 21 years, Male

This misunderstanding of the treatment goals led participants to become frustrated. Some expressed that they used other therapies to treat their condition, and some did not follow the treatment regimen prescribed by the dermatologist.

"...I'm exhausted, sometimes I have no more hope" Mio, age 19 years, Female

"...Sometimes, during my not itching-time, I didn't put any cream even the Vaseline [...] Acquaintances and families told me also to apply certain products supposedly natural...and I did it once...or two times" Seh, age 15 years

4. Discussion

Our Study captured young Malagasy patients' perceptions of living with atopic dermatitis in relation to self-management. This is the first study of its kind conducted in Madagascar. This qualitative study used an inductive approach. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [11] was followed to conduct and report our study. We conducted semi-structured individual interviews, and the participants were free to share their experiences with no time limits. We strived to have an equal proportion of male and female patients and to have patients with different severities of AD self-assessed by the POEM score.

In our study, young Malagasy patients (adolescents and young adults) accepted that atopic dermatitis is a long-term and relapsing condition. They tried to live with their eczema and, over time, developed their own adaptation and adjustment strategies. They also expressed their own definition of normalcy. Our findings are consistent with those of other authors. D. Ghio et al. observed that young patients with AD accepted it as a long-term and episodic condition. They learned to live with their eczema. They expressed that there were constant changes in their lives as they adjusted to their eczema [12]. A study conducted in Sweden by Lundin S et al.

[13] likewise found that young individuals accepted AD as a normal part of life. According to the patients, they developed a variety of coping mechanisms to prevent their AD from getting worse. Participants in both our study and D. Ghio's reported having to make decisions about their everyday lives based on their skin condition. The same clothing constraints that we saw in our subjects were noted in another study [14].

In atopic dermatitis, the objectives of treatment are not to cure but to control the disease and extend the remission period as long as possible [1, 5]. Furthermore, to ensure effective self-management in AD, individuals must have complete knowledge of the disease and be aware of the goals of treatment. Self-management is acquired during the transition process through therapeutic patient education [15].

It is well established that a patient-centered approach is crucial in therapeutic patient education. Instead of imposing medical knowledge, we start with the patient's experience and past knowledge of their disease rather than imposing medical knowledge in order to create a learning process tailored to their needs and abilities. This fosters a better understanding of the disease and treatments, as well as greater autonomy in managing their condition [16, 17]. In our study, despite living with eczema since childhood, most of the participants showed limited knowledge about the nature of AD and the principles and goals of its treatment. Our patients were satisfied with the treatment but requested treatments with more lasting effects or were even able to cure them. This need for treatments with lasting and rapid effects - even curing AD - is common among young people [18].

So, emerging adults are not well-informed on atopic dermatitis, which is in contrast to their long experience of living with eczema. It is also observed in the literature [12, 13].

5. Conclusion

This study highlights the importance of recommunicate information about atopic dermatitis to young patients during the transition to adulthood. It will ensure the best possible transition process in terms of self-management. It could be done by strengthening therapeutic patient education through the creation of atopy schools in Madagascar. However, our study had limitations because we were not able to explore the experiences of patients living with AD of patients who were only seen by primary care physicians.

Abbreviations

AD: Atopic Dermatitis

COREQ: Consolidated Criteria for Reporting Qualitative Research

POEM: Patient Oriented Eczema Measure

TCS: Topical Corticosteroids

Ethics Approval

This study was approved by the Ethics Committee of the University Hospital Joseph Raseta Befelatanana Antananarivo Madagascar.

Conflicts of Interest

The authors declare no conflicts of interest.

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