

## Designing an Atopic Dermatitis Community that Integrates Patient Self-Uploaded Information into the EHR to Optimize Follow-up

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### Abstract

*Atopic dermatitis is a common chronic dermatological disease in childhood that can affect people's quality of life. The aim of this study was to inquire about the difficulties, needs and interests related to the disease that people with eczema and their caregivers have; in order to develop a tool that is useful for the follow-up of the illness. Electronic surveys were sent to potential users and interviews were conducted with professionals who are specialized on the subject. The main findings allowed us to understand the challenges and situations they face on a daily basis, such as the difficulties related to the family support, the queries on the eczema flare-ups, the struggles with the adherence to treatment and the needs of optimizing their quality of life. These results helped us design a tool that allows patients and their companions to better monitor their disease while optimizing communication with their health professionals.*

### Keywords:

Personal Health Records, Virtual Community, Atopic dermatitis

### Introduction

Atopic dermatitis (AD) is the most common chronic dermatological disease in childhood and one of the most prevalent pediatric illnesses [1]. This disease affects people's quality of life, since it can make it difficult for individuals who suffer from it to sleep, concentrate or carry out their daily life activities. People with AD also report shame, anxiety, or depression related to their illness [2]. Treatments are available [3], but to be effective, the patient and/or their caregivers need to understand the importance of treatment and commit to adherence [4].

The rapid development of mobile technology and the popularization of smartphones are promoting the development of mobile health applications, which can improve patient compliance with chronic disease management. In addition, it is expected to reduce the amount of time and resources on patient healthcare by providing personalized self-management strategies [5]. Likewise, virtual communities of patients offer users education on the disease and give psychological and social support. These benefits can be enhanced by involving physicians in these communities [6].

The Personal Health record of the Hospital Italiano de Buenos Aires (PoPeS), aims to provide patients and their families access to their personal health information and facilitate the communication with their health team [7]. In 2019, the virtual

community of patients with Psoriasis [8] was implemented within the PoPes, in order to provide information to patients about their pathology, facilitate exchange among peers and allow them to share experiences and promote better monitoring of their disease. Fourteen months after the implementation of the community, 16,116 entries were registered, corresponding to 10,293 PoPes users. Along these lines of work, we propose to design within the PoPes, a virtual community for patients with AD and their caregivers. The goal of this study is to inquire about the difficulties, needs and interests related to the disease that people with AD and their caregivers have in order to develop a tool that is useful for the follow-up of the disease.

### Methods

Hospital Italiano de Buenos Aires (HIBA) is an academic non-profit tertiary level organization that covers all health specialties at different levels of the care system. Since 1998, HIBA has its own health information system. An integrated personal health record (PHR) has been available since 2007. Its main functionalities include: appointment scheduling, test results visualization, patient-physician secure messaging, management of prescribed medication, and different modalities of teleconsultation. In the present, our PHR has approximately 400,000 registered users.

The research team developed a survey aimed at AD patients and their caregivers, consisting of 5 questions with structured response options and 5 open-ended questions. The invitation to participate in the research was sent by e-mail to potential users of the virtual community. The list of candidates and their e-mail addresses were provided by the HIBA Dermatology Service, guaranteeing representativeness of the sample (adult patients and caregivers of pediatric patients, with different age of diagnosis and different degrees of severity). Once the invitation was accepted, the electronic survey was sent, with prior informed consent.

Semi-structured interviews were conducted with specialists in atopic dermatitis, both dermatologists and allergists, with questions previously developed to guide the meetings. These interviews were individual, lasting approximately 45 minutes. They were audio recorded for later analysis, with prior informed oral consent.

A descriptive analysis of the sociodemographic variables of the survey of potential users was carried out. The material of the surveys and interviews were analyzed through content analysis,

segmenting the textual material according to emerging analytical categories.

The research project was approved by the institutional ethics committee (CEPI # 5733). The study was performed in full agreement with current national and international ethical regulations.

## Results

The invitation to participate was sent to 78 people and the survey was answered by 47 people in May 2020, of which 86% were women. The age of the respondents ranged from 20 to 65 years, with an average of 34.

81% of the participants were interested in atopic dermatitis because they had a person with this disease in their care, while only 19% of the respondents suffered from the disease.

On the other hand, 5 HIBA physicians were interviewed in June 2020, representing both genders with different ages and years of experience. Two were allergy specialists and three were dermatologists, specialized in eczema and atopic dermatitis.

From the inquiries made to patients and caregivers as well as the interviews with the doctors, four categories emerged, which account for the psychosocial component of the disease: the need for information and social support of infants caregivers, children and adolescents with AD; the implications of the illness in the quality of life of the patients; the stressful situations generated by outbreaks, for the patient and for their environment; and the importance of adherence to treatment, even in asymptomatic periods to prevent flare-ups.

### Family support

Given that AD is a disease that manifests mainly in childhood, most of our potential users are parents of people with a diagnosis of AD.

When consulting about the main information needs those potential users have, patient caregivers agree that they need information to help them accompany and assist their children during the course of their illness. They need to have reliable information edited by health professionals who are experts on the subject, but they are also interested in learning about the experiences of other parents who have gone through or are going through similar situations. These experiences vary depending on whether it is accompanying babies, children or adolescents.

*"I am a mother, new on the subject, and I would like to read testimonials from other people so that I can better help my baby" (Mother of a patient with AD)*

### Quality of life

Doctors, patients and caregivers agree that AD can negatively impact on the quality of life of those who suffer from it, not only because of the discomfort caused by the symptoms (such as intense itching) but also because of the social discomfort that skin lesions can generate, both from an aesthetic point of view and in terms of interruption of activities of daily life. Along these lines, the need to talk about issues such as sleep disorders, clothing, makeup, jewelry, nutrition, exposure to the sun, among others, emerges.

*"I'm not sure what foods to avoid or what clothes to wear" (Patient with AD)*

### Eczema flare-ups

The two groups that participated in the inquiry mentioned the Eczema flare-ups as a central issue for those with AD. These are times when patients' manifest outbreaks that generate lesions on their skin. This particular moment produces nervousness and stress, both for the patient and for their environment, since, for example, because of the intense itching, children cannot sleep and consequently neither can their parents.

Injuries generated in these flare-ups are generally not seen by professionals in the office, because when patients get to their doctor's appointment, the injuries tend to be already gone or seriously diminished. Doctors need to be able to see these injuries in order to better adjust the indicated treatment, and thus reduce these crises. Likewise, doctors pointed out that there are several validated self-report tools that can help them have accurate data on the patient's evolution between one visit and another.

*"We believe it is important to have some records of the injuries at the time of the flare-ups" (Allergist)*

### Adherence to treatment

The health professionals who were interviewed emphasize the importance of adherence to treatment, particularly the continuous care of the skin even when the patient does not show any lesions. This is especially important for the prevention of flare-ups.

Adherence is perceived as a challenge by patients and their caregivers. On the one hand, the costs of the products that must be applied on a daily and chronic basis is still very high. On the other hand, it is difficult to adopt the habit of taking care of the skin in the absence of symptoms, mainly when dealing with children or adolescents.

*"The best way to prevent the flares-ups is to keep the skin moisturized, and this requires a commitment from the patient with its treatment" (Dermatologist)*

## Discussion

The inquiry about the perceptions of patients and their caregivers about AD allowed us to understand the challenges and situations they face on a daily basis, such as the difficulties related to the family support, the queries on the eczema flare-ups, the struggles with the adherence to treatment and the needs of optimizing their quality of life. These results helped us design a tool that allows patients and their companions to closely monitor their disease while optimizing the communication with their health professionals.

Among the main findings of our research, the need for reliable pieces of information stands out. The evidence shows that education improves patient adherence to the treatment of AD [9]. In line with what is described in the bibliography, we decided to include in our AD community a section where specialists generate reliable pieces of information, elaborated for the therapeutic education of patients and their families.

The results also highlighted the need to learn about other patients and families' experiences who have gone through similar situations. Creating forums for patients with chronic diseases has shown positive effects among its users, promoting self-care and regulating the demand for health services [10]. According to these findings, we have designed a forum within the community, where patients and their families can exchange experiences about the disease, with the moderation of health professionals who control the information and can avoid the spread of incorrect or inadequate data.

As evidence indicates, providing health professionals with the access to information uploaded by patients, facilitates the interaction between the patient and the professional [11] and can mitigate the stress generated by the limited time during medical consultations [12]. Most physicians value the information provided by patients and recommend that it be uploaded to the PHR. Following the bibliography recommendations and the emerging findings of our research, we will integrate the AD virtual community to the EHR of each patient, so that the doctor can easily access the data uploaded by the patient or his family from the community in their PHR, even at the time of the medical visit. In that manner, patients will be able to photograph their injuries during the flare-ups and doctors will have access to them at any time. This will also happen with the self-report validated questionnaires, which will be available for patients to complete from the virtual community, and for doctors to see the results in the EHR, and eventually adjust the treatment to the patient's needs.

## Conclusions

Knowing the difficulties, needs and interests of people with AD and their caregivers, allowed us to design a tool that favors the empowerment of patients and their families in the control and monitoring of their disease while providing a useful tool for professionals.

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