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**PATIENT PAGE**

# The complexity of the care pathway for a patient with moderate to severe atopic dermatitis seeking a new treatment: Data from a qualitative anthropological study

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anthropology, atopic dermatitis, patient participation, patient therapeutic education, therapeutic dissatisfaction

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Atopic dermatitis (AD) is an inflammatory skin disease characterized by pruritus and erythematous lesions<sup>1</sup> and leading to a considerable change in the quality of life of patients and their relatives.<sup>2,3</sup>

The VECUDA study, conducted by anthropologists in collaboration with dermatologists and a sociologist and focusing on the experiences of these patients and their journey, described mechanisms of dissatisfaction related to therapeutic management from the point of view of patients with moderate to severe AD.<sup>4</sup> Factors that could generate dissatisfaction included the complexity of the care pathway. During this exploratory study emerged an unexpected patient figure, who had a 'feeling of a being chosen' in access to a new treatment, in this case, the first biologic in the treatment of AD. We are interested here in the experience of the patient's care pathway.

The VECUDA study is a research programme engaging participatory methods, through a multi-dimensional qualitative exploratory iterative approach. This study was carried out by the French Association of Anthropology—Ecole de Grenoble (AFA)<sup>5</sup> which offers personalized co-design methodologies for field surveys. The AFA specializes in the science of behavioural observation applied to the field of health and, more precisely, 'the culture of care' including the doctor-patient relationship (practices) and centred on the patient experience (needs). The VECUDA study was supported by a multidisciplinary scientific committee composed of two anthropologists, two dermatologists, and a sociologist.

The approaches that place the drug at the centre of the reflection have been taken in reverse, to question the

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different systems of thought of conception of the disease from the patient's point of view involving other dimensions, which are generally downplayed, or even ignored in the research on patient behaviour guiding their health choices.

## METHODS

The methodology relied on the stories of the actors' affects, on the meaning they attribute to their care pathways, to their practices, to understand the dynamics that underlie them.<sup>6,7</sup> Whether the emotions expressed by individuals are justifiable, legitimate, or not, is not the question; they are just analyzed as signs of a satisfactory interpretation or one that leads to dissatisfaction with the therapeutic relationship.

To be based on the story of affects favours the place and the role that affects take (without judging them). They are part of a set of interactions depending on the specificities of the different therapeutic proposals of the 'care pathway' when an injunction is made to patients to (i) treat themselves, (ii) follow a treatment (adhesion and compliance), and (iii) respect the process which accompanies their care.

This approach required analyzing communication on and through affects and the power of expressed emotions to define the person's feelings and assess their needs, both functional and symbolic. It is therefore different from the psychological approach, for which the analysis of emotions is based on their legitimacy in aiming at defining causal mechanisms.

This qualitative exploratory study was conducted in France from September to December 2020. This study in human and social sciences is not covered by the Jardé law and has not required the approval of an Institutional Review Board (IRB). This involved the recruitment of 24 patients recruited by the Association Française d'Anthropologie—Université de Grenoble (AFA) through several media (hospital and therapeutic education centres managing patients with AD, the Association Française de l'Eczéma (AFE), word of mouth and social networks).

Recruitment was the subject of a telephone interview lasting a minimum of 1 h. The criteria for patient enrolment in the study were: adults with a physician-confirmed diagnosis of moderate to severe AD, a history of dissatisfaction with their therapeutic management that they felt negatively impacted their management, and the ability to communicate about their emotions. Heterogeneous profiles were selected to stimulate debate and encourage the expression of different points of view. There were no restrictions on the treatments received.

The study was conducted in two phases: 1. a pre-study (four patients) allowed method co-design and identification of research leads; 2. the study itself (20 patients) to improve and refine the contributions of the pre-study. Two anthropologists specializing in communication facilitated the group interviews, using creative methods that facilitated the expression and qualification of emotions. Patients shared life stories related to their disease, management, and care pathway, as well as to opportunities to improve the physician–patient relationship meeting their identified needs.

The pre-study with four patients took place over an 8-h day in person, including a lunch break. For anthropologists, it was a question of accessing the stories of the affective experiences of these elements of the 'health journey' of patients with AD. The methods used to achieve this were:

1. collect life stories positioning the emotional elements linked to the illness, the mediations and the actors (positive and negative);
2. focus on consultation and prescription;
3. focus on techniques developed on an individual scale;
4. group reflection on the qualification of medical and emotional needs;
5. group reflection on acceptable levers (improvement tools).

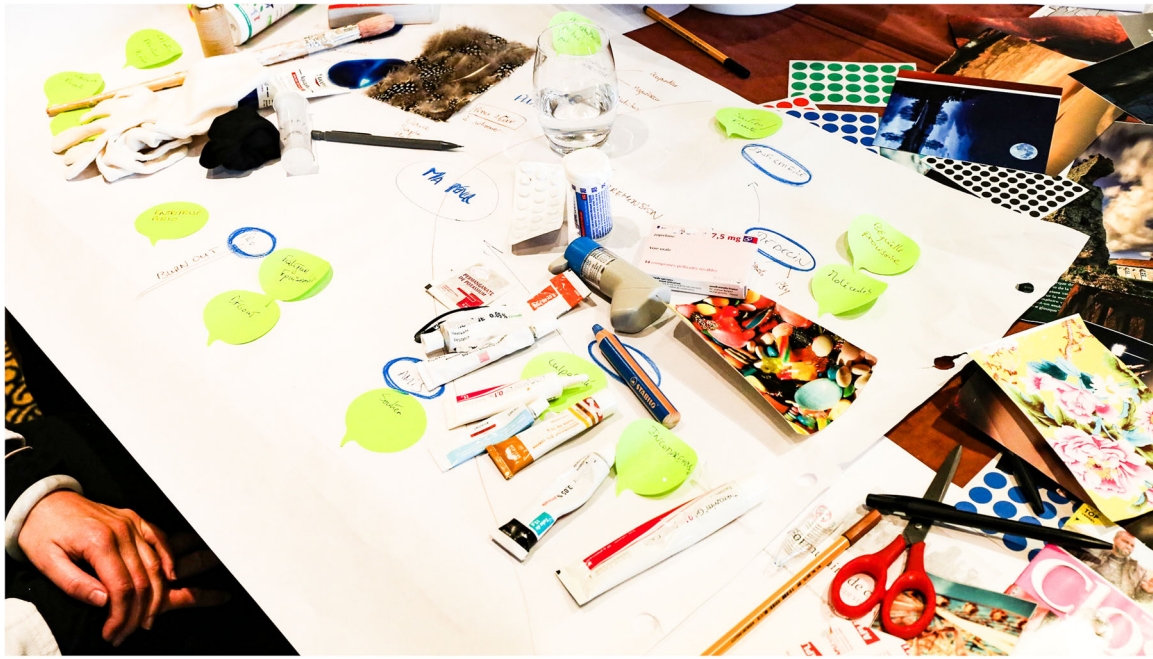
In the introduction, we presented a set of images to the respondents and asked them to choose 3 each, commenting on the reasons for their choices. This preliminary step allowed the participants to be immersed while breaking the ice. In addition, this stage provided interesting data on the participants' attitude toward their life journey. We preliminarily asked the patients to bring 5–10 objects from their respective therapeutic arsenal, as well as 1–5 of their totem objects, on the day of the study. The patients presented them to us. We gave them a set of skin textures and image sets. They commented on skin textures and chose certain images. Then they worked using representation techniques called mind mapping to illustrate emotional states, and promote their expressions and expectations (Figures 1–3, 6).

## RESULTS

The recorded stories were analyzed qualitatively by semantic and lexical item, using sociolinguistic methods and the expertise of anthropologists in health communication.

These creativity tools made it possible to initiate a shared exploratory communication of considerable





**FIGURE 3** Photography\_Collection AFA 2021 'AD series' n°3 - Courtesy S. Diochon.

The different stages of the care pathway, associated with the difficulties encountered in accessing a new treatment, are mentioned below and accompanied by a few direct quotes from patients:

1. Knowledge of the existence of treatment: Patients report a lack of information on the disease and on the new treatments available. For some patients, knowledge of new treatments is the result of personal research.

*Associated direct quote 'I went myself to look for articles in English on the first biologic'.*

It is interesting to note patients' appetite for novelty. For long years, patients may have felt abandoned due to a poorly recognized disease and a limited therapeutic arsenal. With the arrival of new treatments, patients are expressing hope.

*Associated Direct Quote: 'My dermatologist re-explained the disease and it reassured me, it gave me hope. He told me that knowledge about the disease has changed and we're going to take care of me' "Of course, I'm constantly looking for more information'.*

2. Access to treatment: On the one hand, some patients explain that they had to request this treatment from their doctor, when this option was not discussed and/or not well known. On the other hand, the treatment prescribing strategy raises the question of eligibility, which is often misunderstood. Prescription habits remain specific to each physician, based on their experience, and may vary from one management

centre to another, which may be perceived by patients as a random and unequal system.

*Associated Direct Quote: 'A very unclear communication about the first biologic. They didn't want to give it to me. I had to insist.' "The way it's done is very strange; there are negotiations, trial and error, for me they waited 3 months [before prescribing the biologic]", "I learned about the first biologic, and I was told: 'you won't be included'. What does this mean?", "You hear so many different things, you're lost. Everyone has an opinion, their own treatment", "I don't understand why they don't want to give it to me, my kids tried to help me with no success. Instead, they prescribed me twice a treatment that already didn't work! It's being insane. I am old and I just need it'.*

Access to treatment is lived as a fight, a quest. The difficulties faced give the impression that the treatment is reserved for certain people only. Beyond practice differences, lack of knowledge of regulatory aspects for access to treatment, such as the principle of therapeutic escalation or primary hospital prescription, may partly explain the perceived complexity and random and unequal aspects described by patients.

*Associated Direct Quote: 'I had to fight for that. They didn't want to give it to me. I won, I ended up getting it, after a long couple of years of suffering', "I have this extraordinary strength in me, out of the ordinary" "I can feel this strength, like a super-power", "I developed a 6<sup>th</sup> sense. I am spiritual", "I have an extraordinary destiny and strength in me, well outside the ordinary",*

*“I can find resources within myself. My body is cape. I am capable of it’.*

3. Treatment acceptance: Once prescribed, patients say they face a mix of emotions such as recognition, hope, relief and feeling of responsibility, but also fear.

*Associated Direct Quote ‘Today I am stable, and I am apprehensive of the negative effects.’, ‘Now I have reached the first biologic I know I will have a price to pay. I am ready for it’.*

All of this is associated with a strong symbolism: analysis of patient stories shows that they develop a ‘feeling of being chosen’ in accessing the treatment, which is explained by feelings of justice, pride and recognition felt when the fight and the quest come to an end. A symbolism is attributed to all characteristics, and each of them conditions these feelings, such as the galenic form, with the impression of switching to a stronger treatment when administered by the injectable route, or a price deemed high associated with a high-end product. The ‘being chosen’ comes with a fear of a price to be paid including potential side effects (this apprehension makes the acceptance of treatment a new stage to go through), but also a feeling of responsibility to other patients.

*Associated Direct Quote: ‘Don’t let it go, you have to force the way. I will tell you how.’, ‘Don’t let it happen, you have to fight to force them to prescribe it to you, even if they don’t want to’, ‘we can set up a group alongside this study for everyone who is interested in the latest biotherapy to exchange real information that doctors don’t give you’.*

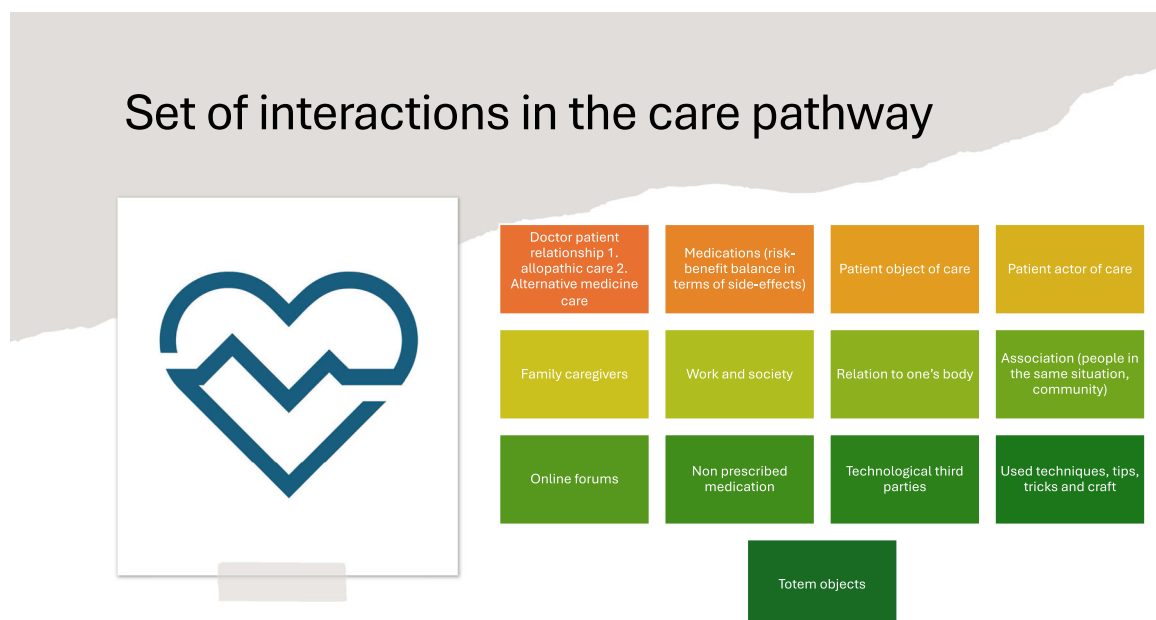
An ‘affective strength’ is claimed by patients, which can be described as sensitivity, or hyper-sensitivity; and sometimes resulting in a feeling of emotional superiority, justified by the experience of being patient and managing the emotional experience of the illness. At this stage of reflection, we do not qualify this force. This strength can, in fact, be categorized into faculties or abilities to manage and/or express affects, to decide with emotions.<sup>8</sup>

These patients only express themselves in terms of affects. They have a very important need for emotional expression, reflected by the high complexity of their life journeys. On these life history stories, we decide to anchor our approach in a systemic logic, because the disease disrupts an entire system.

This implicates several types of relationships (cooperation, control, power, negotiation) for a set of interactions covering the care pathway. This affective ‘strength’ is therefore developed in relation to others and to mediations, in respect of all systemic interactions (Figure 4).

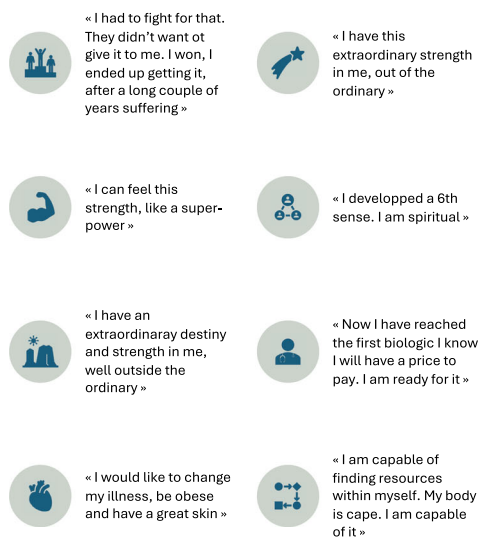
The feeling of ‘strength’ that these patients develop is not trivial, because it places them each in a relationship with life, death, suffering and resilience and positions them in a capacity to choose. Their emotions are the main tool for adaptive choices made in the face of their illness.

It is noted that all of these patients have common characteristics in terms of managing their care pathway: an ability to express their affects, to decide with their emotions, to develop strategies (e.g., a change of physician or negotiations), to communicate with other



**FIGURE 4** Set of interactions covering the patient care pathway.

## Access to a new treatment as a quest



**FIGURE 5** Symbolic level: access to treatment as a quest.

patients around these strategies and, once the treatment is prescribed, to accept the perceived risk (Figure 5).

Analyzing these data opens up a promising research avenue, showing that patients not only confer a therapeutic function to their care pathway but also a symbolic value. The description of the complexity of the care pathway can be compared to a true 'initiation journey'.

## LIMITATIONS

The study used an innovative methodology, focused on co-design with patients, based on understanding their experiences from affect narratives, the specific study of emotional communication from the perspective of the approach the anthropological. The VECUDA study adopted a multidisciplinary approach by bringing together a scientific committee of experts composed of two dermatologists, two anthropologists, and a sociologist. The exploratory qualitative method reduced bias by providing a series of creativity tools to encourage patients to express their feelings while respecting their experience and adding topics for discussion, thereby reducing bias in the elaboration of results. However, the main biases of this part of the study, which coincidentally brought out the level of symbolic understanding of the patient figure seeking a new treatment, was the low number of patients concerned in the pattern, that is, 8 patients out of 24 in total. Six were on bioterapy, while two were still seeking a new treatment. These significant results attracted our



**FIGURE 6** Photography\_Collection AFA 2021 'AD series' n°4 - Courtesy S. Diochon.

attention. A qualitative investigation specific to this type of patient should be continued to complete these results. More specific questions should be asked for a detailed understanding of this patient's situation and to be able to offer operational management tools.

The inclusion criteria used and the recruitment methods in the study to select the participants were dedicated to constituting a representative group of patients (moderate to severe AD, age, gender, treatment experience, experience of the care pathway, experience of dissatisfaction, ability to communicate emotions,

diversity of engagement rates in their care pathway). Our qualitative sample was only composed of (i) literate French patients, (ii) affected by our recruitment materials, (iii) with good communication skills. The generalizability of the results was influenced by the recruitment of patients able to communicate. These elements on the image of the “chosen patient” seeking the first biologic therapy were discovered without being expected, and the results may be biased on the recruitment of patients with introspective and communication skills.

## CONCLUSION

The overall conclusion is based on the observation of a gap between patient expectations and treatment decisions made by some HCPs, which may lead to unsatisfactory scenarios. Understanding ‘embodied knowledge’ through qualitative studies and the feelings expressed by the patient—their affects—is essential to improving knowledge grids. The integrative approach (centred on the person) only has good results, by strengthening satisfaction, and therefore promoting the optimization of medications, therapeutic adherence, to the point of increasing acceptability and reducing the impact of side effects of treatments.

These results suggest that the care pathway is perceived as complex by patients with moderate to severe AD. This can be explained by a lack of communication and information about the pathology and the therapeutic possibilities, misunderstanding, and a sense of inequality based on a lack of understanding of the regulatory obligations in addition to issues of access to care such as medical deserts, differences in care, or even therapeutic inertia in the AD.<sup>9</sup> The combination of these reasons leads certain patients to create strong symbolism around their journey. Let us not forget that myth is intended to give meaning where there is none. We did not have time to explore more precise symbolic identifications of these patients, for example, would give them strength (as possibly heroes), versus what would possibly weaken them. The totem objects mainly represented preferred author books, DJ headphones, a camera, photos of themselves as children, and cuddly toys. The use of humour is also a form of power, like this patient bringing a crab personifying the 3 cancers he/she contracted as side effects of his treatments as a totem object to present himself/herself; or this another quote ‘I would like to change my illness, be obese and have beautiful skin’ (Figure 5).

Understanding the symbolic level automatically comes into play on a daily basis without any particular desire. It is operational and applies to concrete and social reality. The order produced is often hidden because it is

covered by accommodating ideologies. The order formed by this system is coherent but does not conform to logic.

Better understanding the symbolic lived experience of this patient profile in relation to their journey could help healthcare professionals understand the needs and expectations of patients, with a view to improving the patient–doctor relationship and therapeutic satisfaction.<sup>10</sup>

These preliminary results would deserve further investigation to develop concrete and easy-to-use tools to deploy them in healthcare:

- (i) how health professionals could apply these lessons to improve the doctor-patient relationship and the care pathway;
- (ii) how health authorities could use the results to improve care;
- (iii) how patient organizations could build on these results and propose initiatives.

The symbolic value analysis given by patients to their care pathway when they are seeking a new treatment is an innovative approach that deserves to be further explored through a dedicated qualitative study.

## AUTHOR CONTRIBUTIONS

Taking overall responsibility for the integrity of the entire work, from inception to the *published article of the version to be published*: Judith Nicogossian. *Conception of design of the work*: Judith Nicogossian, Fabienne Martin Juchat, Laurent Misery, Claire Thénie, Stéphane Héas and Sébastien Barbarot. *Data management, analyses, and interpretation*: Judith Nicogossian and Fabienne Martin Juchat. *Drafting the article*: Judith Nicogossian. *Critical revisions of the article*: Sébastien Barbarot, Laurent Misery, Stéphane Héas, Fabienne Martin Juchat, Margaux Noël and Claire Thénie. All authors discussed the results and contributed to the final manuscript.

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## CONFLICT OF INTEREST STATEMENT

Judith Nicogossian is the Scientific Director of the VECUDA study. Claire Thénie is an employee of Sanofi. Margaux Noël is a service provider for Sanofi, Stéphane Héas, Laurent Misery and Sébastien Barbarot were consultants for Sanofi for this project. Fabienne Martin Juchat is a scientific advisor for the study.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.



## ETHICS STATEMENT

All patients in this manuscript have given written informed consent for participation in the study and the use of their deidentified, anonymized, aggregated data and their case details (including photographs) for publication.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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