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[Laura Visiers-Jiménez](#) , [Marta González-Ramos](#) ^{*} , Marta Benito-Miguel , Lourdes Navalpotro-Fuster , Nuria María De Castro-De Frutos , Elena García-García

Posted Date: 8 July 2024

doi: [10.20944/preprints202407.0649.v1](https://doi.org/10.20944/preprints202407.0649.v1)

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Article

Design a Digital Tool Using Design Thinking to Monitor Patients with Atopic Dermatitis

Laura Visiers-Jiménez ^{1,2,3} Marta González-Ramos ^{1,2 *}, Marta Benito-Miguel ^{1,2}, Lourdes Navalpotro-Fuster ^{1,2}, Nuria María de Castro-de Frutos ^{1,2} and Elena García-García ^{1,2}

¹ San Juan de Dios Foundation, Madrid, Spain San Juan de Dios. lvisiers@comillas.edu (L.V.J), mgonzalezr@comillas.edu (M.G.R), mbenitom@comillas.edu (M.B.M), ndecastro@comillas.edu (N.M.C.F), lnavalpotro@comillas.edu (L.N.F), elenagg@comillas.edu (E.G.G)

² Health Sciences, Department, Comillas Pontifical University, San Juan de Dios School of Nursing and Physical Therapy, Madrid, Spain lvisiers@comillas.edu (L.V.J), mgonzalezr@comillas.edu (M.G.R), mbenitom@comillas.edu (M.B.M), ndecastro@comillas.edu (N.M.C.F), lnavalpotro@comillas.edu (L.N.F), elenagg@comillas.edu (E.G.G)

³ Instituto de Investigación Sanitaria Gregorio Marañón, Madrid, Spain lvisiers@comillas.edu (L.V.J)

* Correspondence: mgonzalezr@comillas.edu; (M.G.-R.) Tel.: +34 915641868

Abstract: Background: Atopic dermatitis is a chronic condition that significantly affects the daily life of those who suffer from it, requiring complex and personalized management with active participation of the patient in the management of their disease. Objective: to describe the design and development process of a mobile application, using the Design Thinking method, for the follow-up of patients with atopic dermatitis. Methods: User-centered design and prototype creation method, differentiating the phases of the empathize, define, idea, prototype, and test. A purposive snowball sampling was used to recruit patients with atopic dermatitis, family members, and health professionals. Three two-hour workshops were held, attended by 25 people. Results: the parameters to be monitored will include objective data (physical, behavioral, treatments, environmental, integration of daily routines) and subjective data (user experience). On the other hand, it will figure out behavior patterns, set up rewards, foster a feeling of community, and use notifications and a chatbot. Conclusion: The active integration of all stakeholders at each stage of the design and development of the digital solution has improved its relevance and acceptance, resulting in a tool that is expected to significantly improve the management of atopic dermatitis.

Keywords: Dermatology; atopic dermatitis; e-health; self-management; life change events; m-health; patients

1. Introduction

Atopic dermatitis (AD) is a chronic inflammatory skin disease considered one of the leading causes of loss of disability-adjusted life years worldwide [1]. It is characterized by lesions of specific morphology and distribution, combined with dry skin, pruritus or intense itching, and often associated with respiratory symptoms of allergic origin [2]. In the last 20 years, its frequency has increased 2 to 5 times worldwide [3]. It affects 20% of children and almost 3% of adults, being more persistent in men [4].

AD negatively affects the quality of life of patients and their families [5], causing psychosocial problems such as sleep disturbance, depression, anxiety, altered eating habits, low self-esteem and difficulty concentrating. In addition, people often feel stigmatized and embarrassed by their skin lesions. Mothers of children with AD experience stress levels comparable to those of mothers of severely disabled children [6].

In 45% of the cases, the clinical picture presents in the first 6 months of life; 60% in the first year of life; 85% in the first 5 and only in 10%, it develops after 7 years of age. As age increases, the

incidence decreases with a reduction in the severity of the disease [2]. A higher prevalence has been described in densely populated urban areas, in people with a high socio-educational level, as well as in individuals with a family history of AD [7].

Its etiopathogenesis is complex and multifactorial, involving elements of skin barrier dysfunction, alterations in the immune response mediated by hypersensitivity and external causative factors that may vary with age, environment and lifestyle [8,9]. Early identification of risk factors, triggers or exacerbators of outbreaks, will favor personalized prevention [2]. Social determinants of health, such as ethnicity, race, socio-educational level, or access to health services and medications, have a negative impact on both symptoms and increased consumption of health resources [6].

The therapeutic goal in AD is the reduction of symptoms, number and management of outbreaks [10]. Recent studies show the high cost of long-term treatments for the health system, based on oral corticosteroids and immunosuppressants [11], whose success is affected by poor adherence to medication, associated with forgetfulness, side effects, difficulty in application, cost, or lack of understanding of the importance of properly applying the prescribed treatment, estimating that between 20 and 50% of patients do not take their medication properly. The World Health Organization classifies lack of adherence as a relevant global health problem, both because of the increase in healthcare resources used, and because of the need to resort to prescribing more potent drugs with greater toxicity, which increase the risk of side effects or dependence [12]. Addressing these barriers requires a multidisciplinary approach, involving family members and patients, which is an added barrier due to the time consumption involved [1,12].

In this context, the latest research on the impact of the incorporation of modern technologies emphasizes the rapid adoption of these technologies by the population, highlighting the good health outcomes of applications that promote therapeutic adherence [12].

Currently, advances in the development and implementation of artificial intelligence have allowed the use of complex data analysis techniques related to several aspects of AD care (lifestyle, environmental conditions, response to treatments...) collected in a non-clinical environment (real life), generating adequate support to professionals, improving decision making and improving disease management [13,14]. These new strategies contribute to the empowerment of patients and caregivers, being more engaged, active and independent in the self-management of their health status [1,15].

However, there is a lack of integration and involvement of key agents (patients, family members, professionals) in the co-design and development of healthcare products and services, even though the group of so-called "e-patients" is demanding active participation in decision-making and in the management of their health. This trend underlines the need to restructure the strategies for the development of digital solutions from the design stage, prioritizing the effective integration of all the agents involved in the ecosystem [16], thus allowing a better response of the healthcare systems to the needs of the people [17].

A systematic review found only 6 studies in which the design of the application was based on patient experience, 3 involving professionals, and one involving a technology expert and a caregiver [12].

With methodologies such as "Design Thinking", with a user-centered problem-solving approach, identification of needs, expectations and preferences of those involved, definition of challenges and search for innovative solutions [18,19], digital applications are designed with the aim of facilitating behavioral change related to health and the management of pathologies [20,21].

In a systematic review, 75 studies incorporated this type of design in the development of digital solutions, concluding that the main challenges experienced are patient engagement, and integration with information systems [20].

In developing SkinTracker, researchers conducted eight working sessions involving dermatologists, researchers, engineers and graphic designers [22], underscoring the importance of interdisciplinarity in the efficacy of digital solutions focused on chronic disease management [16]. Srivastava et al. concluded in their study that the co-design process empowered patients to share their needs and to develop, from that point, a solution that effectively resolved the identified pain points [16].

The general objective of this study is to describe the design and development process of a mobile application for monitoring patients with atopic dermatitis. The specific objectives are to identify unmet needs in the follow-up of people with AD through the "Design Thinking" method and to co-design and develop a mobile application to improve the follow-up of patients with AD.

2. Materials and Methods

The study used a design thinking approach, based on a user-centered problem-solving method, which begins by assessing people's needs, collaboratively searching for innovative solutions to efficiently address the identified problems. The "Design Thinking" model was devised in San Francisco in the 70's by Tim Brown [19,23] and consists of 5 phases: empathize, define, ideate, prototype and test. The concepts underlying each one and the methodologies used are summarized in Table 1.

The study was approved by the Research Commission of the San Juan de Dios Foundation (protocol code P_2023_005).

Table 1. Design Thinking Phases.

Phases	Conceptual description
Empathize	To approach the experience of the disease from the point of view of patients, relatives and health professionals, understanding physical, emotional and material needs, identifying the most relevant aspects for each interest group
Define	To establish in a clear, meaningful and actionable way the problem to be solved, consolidating needs and insights obtained in the previous phase, focusing the creative process towards specific and effective solutions in the next phase
Devise	To generate a wide variety of creative ideas and innovative solutions for the approach to the care of patients with atopic dermatitis.
Prototype	To generate a preliminary version of the product or service, which allows exploring and demonstrating concepts to the participants in the design-co-creation process, testing technical feasibility and refining functionalities before developing the final version.
Test	In the context of the design thinking, this last phase allows designers and development teams to evaluate designed ideas, experiment with different approaches and receive feedback from end users, which is key to making improvements and ensuring that the final product meets the patient's needs and expectations.

2.1. Data Collection

A purposive, non-probabilistic, snowball sampling was carried out. The development of focus groups was planned with participation of between 10 and 12 people. The dissemination poster to achieve recruitment was published in the social networks of the researchers' work environment. Interested people were contacted through the email provided.

A total of 22 people responded to the communication, meeting the established criteria of having AD, but only one of them finally participated. With the aim of standing for "the voice" of the patients, the researchers conducted a search for testimonials on social networks (Instagram and TikTok),

collecting information that would allow them to answer the questions of the empathy map, discussed with the group in the first working session.

At the beginning of the work sessions, the researchers explained the problems to be addressed and the "Design Thinking" method, and handed over and collected the signed informed consent form. The sessions were eased by a senior consultant, a nurse and an expert in innovation. Two of the researchers took notes.

2.2. Phase 1: Empathy

Divergent phase to understand the thoughts and physical and emotional needs about the experience of the disease.

Activity carried out: a focus group composed of patients, family members and health professionals were formed in a 2-hour session [16]. The empathy map was defined and analyzed through questions such as: what does the patient with AD think and feel; what does he hear; what does he see; what does he say and do; and finally, the results (what motivates him/her, what benefits does he/she expect to obtain, what needs does he/she have and how would he/she measure success in achieving the objectives).

2.3. Phase 2: Define

Convergent phase, to analyze the information and arrive at a concrete proposal to define the problem to be addressed.

Activity carried out: in focus groups, through brainstorming, the central problem, causes and consequences of an inadequate approach to AD were identified. The ideas collected were grouped into categories and prioritized according to the frequency of occurrence of issues.

2.4. Phase 3: Idea

Divergent phase, to enhance creativity and idea generation.

Activity carried out: participatory process involving students of the Industrial Design Degree [15]. Working in groups, innovative solutions were proposed to solve the detected need. A focus group was held with patients, family members and professionals [16] to validate and prioritize the identified solutions.

2.5. Phase 4: Prototype

Convergent phase to create simplified versions of the proposed solutions.

Activity performed: a functional prototype was designed in Figma, with developers interacting with end users, resolving doubts, differences, and testing ideas, reducing the investment of time and cost associated with the programming phase.

2.6. Phase 5: Test

Phase to analyze the usability and the suitability of the prototype to the detected problem.

Activity to be developed: a focus group was carried out with the participation of patients, family members, and health professionals [9] with the aim of confirming the prototyped screens, the incorporation of the sections described in the earlier phases, usability and aspects related to the content. With the results, the development team made the modifications and developed the application.

2.7. Data Analysis

An analysis was carried out through data triangulation of the information obtained from the focus groups, review of life histories in social networks, literature review (biological/physiological, nutritional, pharmacotherapeutic, environmental and nursing care aspects in the approach to AD) and internal team discussions.

From this iterative process, the technology company developed the first functional prototype. On this prototype, researchers and participants validated its usability and functionality according to the results of the earlier phases. This methodological approach ensures a robust integration of diverse data sources.

3. Results

Finally, 18 people were recruited, including patients (3), health professionals (2 physicians with ability in integrative medicine, 2 nurses, 1 psychologist, 2 biologists, 2 pharmacists, 2 technologists) and patients' relatives (5), with an average age of 39.4, 77.8% of whom were women. A total of three focus groups took part, where the conversation was directed to respond to the phases of empathy, definition and ideation. On the other hand, 5 engineers and data scientists took part in the development.

The results of the focus groups, the information gathered through the social network analysis and the literature review were transcribed and grouped into 3 relevant themes:

3.1. Physical and Emotional Aspects Of Living With The Disease

The psychological impact that atopic dermatitis has on those affected, the notable emotional burden associated with depression, anxiety, affecting the loss of functionality, quality of life and deterioration of social relationships, stands out in a relevant way. These aspects are provoked and worsened by the chronic itching, the stinging sensation and pain of the lesions, and the affection of sleep. The stigma associated with the physical manifestations of the disease is clear, especially in children and/or adolescents, aggravating the emotional suffering.

3.2. Aspects Related To Treatment Effectiveness In The Management of AD.

It highlights that the emotional, physical and psychosocial needs are not covered by current treatment protocols, with the condition sometimes being trivialized by some health professionals. It reflects insufficient access to innovative and effective treatments at the right time, especially in the most severe cases. Lack of empathy and psychosocial support contribute to increased emotional and social distress.

3.3. Physical or behavioral aspects that participants associate with the appearance, severity and evolution of AD outbreaks.

At the physical level, it is concluded that aspects related to increased body temperature, cortisol levels, oxygen saturation, heart rate, the presence of other allergies or inflammatory diseases, and the extent and degree of skin lesions are relevant.

At the behavioral level, physical activity, leisure activities, type of food, composition of clothing used, geographical location (pollution levels, humidity, temperature ...) or sleeping habits are relevant.

Inadequate management of these factors leads to an exacerbation of the frequency and severity of outbreaks, significantly affecting health outcomes and quality of life. It also reflects the need to improve the recording and communication of these aspects in the health care setting, improving diagnosis, personalizing treatment, improving shared decision making and adherence to treatment.

Some fragments that illustrate this section are: "when I go to soccer, I don't care about everything, although I know that I will itch a lot"; "when I am on vacation I feel better", "going back to school in September is related to an outbreak", "I cover my lesions when I am with people" (hiding behavior).

It was agreed to design a mobile application with the following premises: usability, user engagement and empowerment, in addition to providing sufficient information to improve the approach to AD from the prevention and control of outbreaks, allowing psychosocial aspects to be managed. It was identified as relevant that data collection should be done indirectly as far as possible.

To be able to collect user experience, the incorporation of unstructured data was identified as relevant. It was defined that the digital solution developed could incorporate open data from diverse

sources (environmental, consumption, access to health resources...) improving predictive algorithmic models and decision making. The algorithm-based system will play a proactive role, identifying when to alert the user or the family to manage the disease effectively (feedback). The aim is to promote self-awareness of the importance of each moment in the management of the disease.

Access to health education advice was identified as necessary, setting up a relationship between resources and needs based on the patient profile and the data collected in the application. Interaction with and assessment of resources will allow recommendations to be adapted.

4. Discussion

The design thinking approach to the study has allowed the development of a solution that identifies and resolves the specific needs detected (management and care of AD, physical, emotional and social aspects) through the experience of the different stakeholders involved [19] coinciding with the results obtained in the Life Report published by the IESE Business School [24], which describes how AD significantly affects the quality of life of patients in dimensions such as emotional well-being [25], physical well-being, interpersonal relationships (stigma, isolation, impaired interaction with others), personal development (impact on patient autonomy, associated with the severity and unpredictability of symptoms), rights (need to improve access to effective treatments), social inclusion (associated stigma), material well-being (costs associated with treatment), and self-determination (ability to make free and informed decisions about their care). In addition, self-care requires training and education, highlighting the role of care agent of the specialized nurse [26] in aspects such as nutrition or daily routines of hygiene and skin hydration [27]. Earlier studies show the existing needs and concerns about the management of AD, highlighting the need for a better understanding of the evolution and its triggers, the different pharmacological treatments and their use, as well as the lack of information on complementary and/or alternative treatments [27,28]. Among the concerns is the emotional impact of the disease on patients and on the family environment as a whole [27].

Other authors confirm how the use of digital tools enables advance care planning and improves healthcare [29]. However, in the case of AD, pre-existing applications do not take into account, in a holistic manner, all the needs of the patient and their caregiver or family member, as identified in the present study, being usual to collect data related to outbreaks and severity of the same, but not so clinical factors or social determinants that, through algorithm models, can guide the patient in the management of AD [30].

The main limitation of this study is attributed to the difficulties met in involving patients, a challenge reflected in previous studies. This has led to the substitution of direct patient participation by the analysis of testimonials in social

networks, which could be biased. The small first sample size used for the design of the prototype has been complemented by the multidisciplinary nature of the sample and the research team, as well as by conducting an extensive literature search.

5. Conclusions

The integration of all stakeholders from the first phase through to the design and validation of the digital solution has proven to be essential to effectively address the complexity of DA management, ensuring that it is not only functional, but that it responds specifically to the real needs detected, significantly improving the relevance and acceptance of the proposed solution.

The developed solution is expected to make it easier for people with AD to manage their self-care more effectively and individually.

Author Contributions: Conceptualization (L.V.J and E.G.G); methodology (E.G.G); investigation (L.V.J, M.G.R, M.B.M, L.N.F, N.M.C.F, E.G.G); resources (E.G.G); data curation (E.G.G); writing-original draft preparation (L.V.J, M.G.R, M.B.M, L.N.F, N.M.C.F, E.G.G); writing-reviewing and editing (L.V.J, M.G.R, M.B.M, L.N.F, N.M.C.F, E.G.G); project administration (L.V.J and E.G.G); funding acquisition (E.G.G). All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by Pfizer.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and approved by the Institutional Review Board of San Joan of God, Madrid, Spain (protocol code P_2023_005 on July 25th of 2023).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the participants to publish this paper

Conflicts of Interest: The authors declare no conflicts of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

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