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Transforming Self-Care: Infotechnological Solutions For Patients With Systemic Lupus Erythematosus

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ABSTRACT

Introduction: Systemic Lupus Erythematosus (SLE) is a chronic inflammatory and autoimmune disease of a multisystemic nature that requires lifestyle adaptation by those affected. Therefore, the importance of providing information and education to individuals with the disease is emphasized, focusing on self-care to mitigate stress, anxiety linked to uncertainty, and promote engagement in self-care practices. This need highlights the relevance of having technological methods and tools to facilitate effective disease management and improve the quality of life. **Objective:** To design an infotecnological tool aimed at strengthening the self-care capacities of patients with Systemic Lupus Erythematosus attending the Clínica de la Costa. **Material and Methods:** A descriptive quantitative approach was used, involving 444 lupus patients from the Clínica de la Costa in Barranquilla, Colombia. The short-term research was conducted in two phases: 1) characterization of the population in aspects such as age, gender, severity level, comorbidities, and disease knowledge; 2) design and pilot testing of the infotecnological tool.**Results:** The average age of the patients was approximately 41 years, with 87.2% (387) being women. The most prevalent comorbidities included hypertension (18.7%), diabetes mellitus (1.6%), dyslipidemia (1.4%), Cushing's syndrome (2%), osteoporosis

(2%), and metabolic syndrome (0.2%). 27% (120 patients) presented active disease, with 18.7% (83) at a severe level, 5.6% (25) at a moderate level, and only 2.3% (10 patients) presenting a mild severity level with high knowledge. **Conclusions:** The majority of patients were female and over the age of 39; most of them had inactive lupus with a high level of knowledge. The technological tool was validated by the users, who gave it ratings between 4 and 5 and qualitative evaluations ranging from good to excellent.

Keywords: Systemic Lupus Erythematosus, Self-care Education, Nursing, Autoimmune Diseases.

INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a chronic inflammatory and autoimmune multisystemic disease, whose clinical manifestations, severity, and organ involvement vary depending on ethnicity, gender, and age (1). Lupus nephritis (LN) is a significant complication of SLE and is more frequently diagnosed in young women, usually at least five years after the onset of SLE (2). It has been observed that approximately 60% to 70% of patients with SLE develop renal involvement, which is a major cause of morbidity and mortality. Approximately 5% to 10% of patients die within ten years of diagnosis, and 10% to 25% develop chronic renal failure, requiring dialysis therapy (1). Globally, the incidence of SLE is 2 to 7 new cases per 100,000 inhabitants per year, and the prevalence ranges from 12 to 50 cases per 100,000 inhabitants (3). Studies conducted in Latin America have demonstrated the influence of clinical variables on the quality of life of patients with this disease (4-10). In Colombia, the incidence is 0.8 to 0.9 cases per 100,000 inhabitants per year (11,12), and the prevalence in 2016 was 91.9 per 100,000 individuals, with a higher frequency in women (89%) and a peak in the age group of 45 to 49 years (13). In the Caribbean region of Colombia, LN presents with greater aggressiveness compared to other regions and countries. Despite significant advances and contributions from technology in treatment and increased patient survival, none of the current methods are curative, meaning that dealing with the chronicity of the disease and the restrictions from treatment is inevitable. This affects patients' quality of life and generates scientific need and interest from the health system, medical professionals, and academics to develop strategies that allow patients to acquire knowledge for self-care, aiming to manage their disease appropriately and improve their quality of life and that of their families.

The Clínica de la Costa treats 444 patients diagnosed with SLE, of whom 62.5% are on dialysis; 91.3% regarding the severity of the pathology, 46% of the population is at stage IV, and 38% is at stage 3A. That is, they present a moderate decrease in glomerular filtration; 78% of the population has been diagnosed with chronic kidney disease (CKD) for approximately 1 to 5 years, and 96% present diseases associated with CKD (14). The well-being of the patients is impaired in both physical and emotional functioning and performance; in physical functioning, 22.5% (dialyzed) and 42.5% (non-dialyzed); physical performance, 9% (dialyzed) and 25% (non-dialyzed); and emotional performance, 14% (dialyzed) and 26.6% (non-dialyzed) (14).

Regarding the level of knowledge of patients attending the consultation, it was observed that 34% are not familiar with the medications they should avoid and are unaware of the significance of elevated protein levels in the urine concerning renal health. Additionally, 88% of patients are unaware of the normal blood pressure range, while 60% cannot identify the type of treatment necessary in the case of renal failure (14).

Currently, the lack of adherence to pharmacological and non-pharmacological management is the cause of the failure of many treatments, leading to serious problems in the disease's progression. People who have developed SLE require comprehensive treatment to reduce, among other things, feelings of insecurity and anxiety, emphasizing the promotion of self-care, which helps minimize complication risks and adopt behaviors aimed at improving their quality of life.

Individuals with SLE face uncertainties related to their disease, its progression, and the treatments they undergo. This situation forces patients to adapt to changes that affect their quality of life in physiological, psychological, familial, occupational, and social aspects (1). In these situations, it is crucial to provide information to patients regarding their self-care to reduce stress, anxiety, and other emotions associated with uncertainty that influence their quality of life. Additionally, it is important to foster an attitude of commitment and responsibility in managing their self-care.

Consequently, self-care empowerment requires the availability of methods, techniques, and technological tools for better access to information, appropriation, and assertive monitoring. However, few electronic devices offer specialized tools to promote renal health self-care, adherence to medical treatment to avoid greater organic consequences related to the most severe complication of SLE, such as the program "Nefrosoft" developed by the University of Valencia, Spain. This program is tailored to meet the needs of chronic and acute dialysis patients and includes personal and clinical data, as well as generating reports and nursing records (2).

This article presents the findings of a research project that received funding from the Ministry of Science, Technology, and Innovation (MinCiencia) of Colombia through the 932 call. This call aimed to promote research with business purposes and strengthen the relationship between the academic sector, the actors of the National System of Science, Technology, and Innovation, and Colombian companies.

The purpose of the project was to design an infotecnological tool to strengthen the self-care capacities of patients with Systemic Lupus Erythematosus attending the Clínica de la Costa. Its scope was the creation of a prototype for an infotecnological tool to empower self-care practices that contribute to the patients' well-being.

MATERIAL AND METHODS

Study Type: Applied research with a descriptive quantitative approach.

Participants: 444 patients diagnosed with SLE who, at the time of the study, were attending the Clínica de la Costa in Barranquilla, Colombia, and gave their consent to participate in the research.

Phases of the Research Stay:

Phase 1: Characterization of patients (age, sex, and severity of SLE based on information collected from the NefroRed platform at the Clínica de la Costa, which provides a diagnosis of the health status and prognosis of the patient) and the administration of a survey on knowledge of SLE care. This instrument was validated for content through expert judgment (3).

Phase 2: Design and pilot testing of the infotecnological tool prototype (Resource file, code library, resources, digital content, and development of the prototype). The pilot test was conducted with a sample of 37 patients diagnosed with SLE.

Techniques and Instruments: A survey was designed to explore patients’ knowledge of SLE and its care, consisting of 24 closed-ended questions grouped into four areas: Knowledge of the disease, prevention and management of new flare-ups, treatment and management, and Care and self-care (sun protection, relaxation activities, hygiene, rest, complication prevention, hydration, vitamin supplements, among others). The survey was reviewed and analyzed by a group of expert nurses in the field with research experience before its application.

Processing and Analysis: The NefroRed database and the data derived from the knowledge survey were analyzed using the SPSS statistical software, version 26 for Windows. Central tendency and dispersion measures were defined for processing the quantitative variables, with a 95% confidence level and a 5% margin of error. The results were presented in the form of statistical tables (frequency and percentage), which facilitated the interpretation and understanding of the findings.

Ethical Considerations: For the development of the research stay, ethical considerations were followed according to the provisions of Resolution 008430 of 1993 by the Ministry of Health of Colombia (15), which classifies this as a "low-risk research" study, and the Declaration of Helsinki. Participants signed informed consent. The research was approved by the University Ethics Committee through approval record No. 00274.

RESULTS

Characterization of the Population

The average age of the patients is approximately 41 years, with the most frequent age among the study participants being 28 years. The mean age was 41.43, with a high dispersion (SD = 13.04). Regarding age distribution, the majority of patients are between 28 and 54 years old. The range between the youngest and oldest patient is 66 years. 5% of the youngest patients are under 22 years old, and 95% are under 67 years old. 87.2% (387) of the patients were women.

Type of Comorbidities in Patients with SLE

Table 1. Comorbidities Present in Patients with SLE

Hypertension						**Diabetes Mellitus**					
		Frequency	Percentage	Valid percentage	Cumulative percentage			Frequency	Percentage	Valid percentage	Cumulative percentage
Válid	0	361	81,3	81,3	81,3	Válid	0	437	98,4	98,4	98,4
	Hipertension	83	18,7	18,7	100,0		Diabetes Mellitus	7	1,6	1,6	100,0
	Total	444	100,0	100,0			Total	444	100,0	100,0	
Dyslipidemia						**Grade 2 Cushing's syndrome**					
		Frequency	Percentage	Valid percentage	Cumulative percentage			Frequency	Percentage	Valid percentage	Cumulative percentage
Válid	0	438	98,6	98,6	98,6	Válid	0	442	99,5	99,5	99,5
	Dislipidemia	6	1,4	1,4	100,0		Grade 2 Cushing	2	0,5	0,5	100,0
	Total	444	100,0	100,0			Total	444	100,0	100,0	

Osteoporosis						**Metabolic syndrome**					
		Frequency	Percentage	Valid percentage	Cumulative percentage			Frequency	Percentage	Valid percentage	Cumulative percentage
Válid	0	442	99,5	99,5	99,5	Válid	0	443	99,8	99,8	99,8
	Osteoporosis	2	0,5	0,5	100,0		Sindrome Metabolico	1	0,2	0,2	100,0
	Total	444	100,0	100,0			Total	444	100,0	100,0	

Source: NefroRed IT platform of the Clínica de la Costa

Severity Level – SLE

Table 2. Severity of SLE in Patients

Level	Frequency	Percentage(%)	Valid percentage
Inactivity	326	0,5	1,7
Mild	10	2,3	8,3
Moderate	25	5,6	20,8
Severe	83	18,7	69,2
Subtotal	120	27	100
Total	444	100	

Source: NefroRed IT platform of the Clínica de la Costa

Of the 440 patients, 27% (120 patients) show disease activity. Of these, 18.7% (83) are at a severe level, 5.6% (25) at a moderate level, and only 2.3% (10 patients) have a mild severity level.

Diagnosis of educational needs related to the disease and its care

The results related to the level of knowledge (LK) of the patients highlight that 69.1% have a high level and 16.4% have a low level. The dimension with the highest level of knowledge was general knowledge of the disease, and the lowest average knowledge was in the area of care and self-care, with a score of 3.91 (Table 3).

Table 3. Global Average Knowledge Level Score of SLE

Dimensions of Knowledge	**Global Average Knowledge Level (1-5)**
General Knowledge	4,07
Prevention	4,06
Treatment	3,92
Care, and Self-care	3,91

Source: Applied instrument

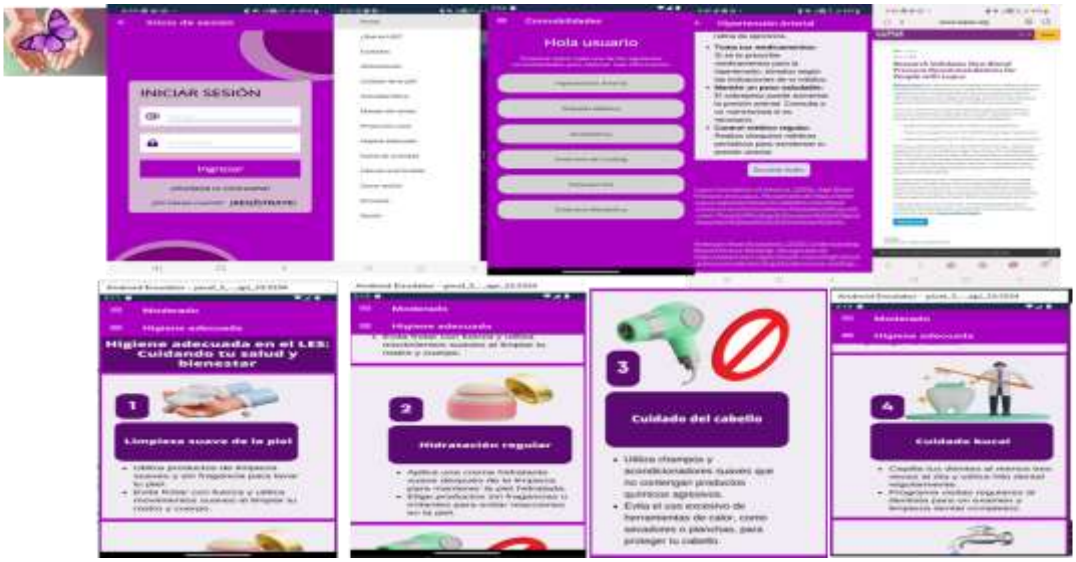
Design of the Tool - Tested Prototype

The name of the application was selected from several options, "Cuidado-Violeta." The development process opted for the implementation of the agile Scrum methodology as the main framework. The choice of Scrum was based on the need to effectively manage the project, prioritize key features, and ensure continuous delivery of product increments. During the development process, sprints with defined durations were established, and agile ceremonies, such as planning meetings, reviews, and retrospectives, were held to promote collaboration and transparency within the team. The use of clearly defined roles, such as Scrum Master and Product Owner, contributed to an efficient distribution of responsibilities. Additionally, the inherent adaptability of Scrum allowed for continuous adjustments based on emerging project needs, facilitating a quick response to changes and improving the overall quality of the development of the "Cuidado-Violeta" application.

The "Cuidado-Violeta" application was developed using the .NET MAUI (Multi-platform App UI) platform, a strategic choice supported by various technical and functional advantages. .NET MAUI offers a native mobile application development solution that enables the creation of consistent experiences across iOS, Android, and Windows devices from a single code base. This technical choice not only simplifies the development process but also optimizes code management and maintenance, reducing the complexity and efforts associated with multi-platform development. It is important to note that, although the application is designed to be multi-platform due to .NET MAUI, the initial release was exclusively for Android users. This strategic approach allows for a gradual market introduction, ensuring an optimal experience for Android users before expanding to other platforms.

In the design and development of the "Cuidado-Violeta" mobile application, specific aspects were addressed, from the selection of images to the implementation of features and the inclusion of relevant content for users. The application covers information on topics such as What is SLE?, care, nutrition, skin care, physical activity, stress management, sun protection, proper hygiene, activity index, SLEDAI score calculation, surveys, comorbidities, among other topics, providing a comprehensive resource for its users (Figure 1).

Figure 1: Some tabs of the application



Source :Photos of some tabs of the application

The results obtained from the pilot testing, in which 37 people downloaded the application and 31 people responded to the app validation questionnaire with ratings of 4 out of 5 and 5 out of 5 stars, reflect good and excellent ratings for the application regarding the technical criteria of the tool: usability, content, customization, interactivity, and reusability.

DISCUSSION

The findings related to the age variable in this study are consistent with those reported by Beltrán et al. (16), who report a median age of participants of 36 years. The most common sex was female, constituting 86%, similar to the report by Coronado-Alvarado (17) at 72.2% and Velásquez et al. (18) at 90.8%. These results confirm what current scientific evidence indicates regarding the predominance of SLE in women over men. Regarding the comorbidities present in the participants, they were: Hypertension (HTA), Diabetes Mellitus (DM), Dyslipidemia, Cushing's syndrome second degree, Osteoporosis, and Metabolic Syndrome (SM). The most predominant was HTA (18.7%), followed by DM (1.6%); SM had the lowest frequency, found in one patient (0.2%). These findings contrast with those reported by Batún-Garrido et al. (19), where 27.5% presented HTA and 6% DM, and those found by Castillo et al. (20), with 4% presenting SLE and DM in an age range of 46-55 years. However, they differ in the comorbidity of metabolic syndrome, where 41% had SM (60% of men and 39% of women). The frequency of metabolic syndrome was similar (2%) to the report by Montiel (21). Dyslipidemia was present in 1.4%, a figure that differs from the prevalence reported by the evidence, which ranges from 18.1% to 75% (22).

Additionally, the study conducted by Trentin et al. reports similar comorbidities in patients, such as hypertension, osteoporosis, diabetes, dyslipidemia, and chronic kidney disease (CKD), similar to those found in the present study, except for CKD.Regarding Cushing's comorbidity, the evidence suggests that it may go unnoticed when it is an iatrogenic Cushing, as it often goes undiagnosed, leading to delays in its diagnosis (23), requiring a differential diagnosis for timely detection.

On the other hand, the presence of osteoporosis in patients with SLE in the findings of this study is similar to those of Velásquez et al., where two postmenopausal women over 50 years old with osteoporosis were identified; menopause has been clearly identified as an independent risk factor for the development of changes in bone density (24-26).

Regarding Metabolic Syndrome (SM), numerous studies have indicated that individuals diagnosed with systemic lupus erythematosus (SLE) have a high incidence of SM, due to the combination of characteristic symptoms of this autoimmune disease, which increases the likelihood of developing cardiovascular disease (27); however, this study reports only one case. Regarding patients' knowledge of their disease, the scientific literature reports that a greater understanding and comprehension of the disease, more specialized management, and careful application of treatments lead to more positive outcomes (28). In this study, most patients had a high level of knowledge, with only 27% presenting disease activity. Of this group, 18.7% exhibited a high severity level, reflecting the importance of patients understanding their disease and learning to live with it, thus achieving greater autonomy with a positive impact on their quality of life (29).

This Application (App) is an important tool that provides education to patients with lupus about the disease and care, contributing to self-care management. One of the most significant and essential responsibilities of nursing in chronic diseases is guiding patients regarding their condition and treatment, addressing four fundamental aspects: understanding and coping with the disease, adherence to the therapeutic plan, prevention and management of potential relapses, and improving quality of life by promoting greater autonomy (30).

The information provided by the App covers daily routines, care, and self-care, contributing to stimulating independence, preventing the manifestation of acute symptoms, and raising awareness about beneficial lifestyle practices, which are crucial for improving quality of life (31, 32).

CONCLUSIONS

The majority of the population were female and over 39 years old; most of them had inactive lupus; most had a high level of knowledge. The technological tool designed to provide information on lupus care was validated by users, who rated its design and functionality (content and technical criteria) with scores between 4 and 5, reflecting a qualitative evaluation ranging from good to excellent.

This research has allowed us to recognize the upcoming challenges, such as the incorporation of more technologies to assist in managing patient care, and in this case, strengthening the technological tool with modules where patients can interact synchronously with the nurse or physician to obtain real-time responses to their questions related to the care and self-care of their disease.

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CONFLICT OF INTEREST: None

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