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Treatment adherence and quality of life in colombian patients with lupus nephritis

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Abstract

Background: As with many other chronic diseases, systemic lupus erythematosus (SLE) and lupus nephritis (LN) have significant impacts on the health-related quality of life (HRQoL). Medication non-adherence is a significant challenge in the management of SLE, with consistently up to 75% of patients being non-adherent with their SLE medications. There is a need to assess the patient's perspective using patient-reported outcomes (PROs) to better understand the current impact of LN on HRQoL and treatment adherence in our region. The aim of this study was to explore the relationship between HRQoL and treatment adherence in patients with LN from the Colombian Caribbean.

Methods: A cross-sectional study was conducted from June to December 2022, including patients with biopsy-proven LN. HRQoL and treatment adherence were assessed using the Lupus Quality of Life (LupusQoL) and the Compliance Questionnaire in Rheumatology 19 (CQR19) instruments, respectively. Patients were categorized as adherent or non-adherent based on medication intake (defined as >80% correct dosage). Principal component analysis (PCA) was employed to identify principal components between adherent and non-adherent patients.

Results: A total of 42 patients with LN were included. Of these, 38 (90%) were female, and the mean age was 31 ± 10 years. Proliferative class IV was the predominant histopathological profile (90%). Twenty-five (60%) patients were categorized as non-adherent. Across all LupusQoL domains, a comprehensive range of responses was observed. Pain, planning, and intimate relationships domains remained unaffected, while burden to others domain had the lowest score. Poorer planning score correlated with older age ($r = -0.72$; $p < .05$) and longer disease duration ($r = -0.74$; $p < .05$). SLEDAI-2 K correlated with the pain domain ($r = -0.78$; $p < .05$). Non-adherent patients exhibited significantly worse pain domain scores compared to adherent counterparts ($p < .05$). PCA showed strong interactions between planning and pain, as well as between physical health and body image domains.

Conclusions: LupusQoL pain domain scores were significantly worse in non-adherent patients compared to adherent patients. Effective pain management could be a determinant in HRQoL and treatment adherence rates in our population.

Keywords

Lupus nephritis, treatment adherence, quality of life, patient-reported outcomes

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Introduction

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease characterized by autoreactive B cells and autoantibodies. It manifests as a relapsing-remitting autoimmune disorder with a wide spectrum of clinical phenotypes, which can range from mild to life-threatening.[1] Lupus nephritis (LN) is a common and severe complication of SLE

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which occurs in up to 50% of patients with SLE. LN is a significant risk factor for morbidity and mortality with end-stage renal disease occurring up to 30% of patients.[2]

SLE and LN have significant impacts on patients health-related quality of life (HRQoL) including physical functioning, ability to carry out activities of daily living, emotional well-being, work, and participation in family, social and leisure activities.[1,3] The utilization of disease-specific questionnaires for assessing HRQoL has garnered significant attention due to their heightened sensitivity to change and treatment effects.[4,5] The Lupus Quality of Life (LupusQoL) emerges as a validated, reliable, patient-derived, disease-specific HRQoL measure, encompassing the most pertinent domains for individuals with SLE.[3,4,6] The LupusQoL demonstrates robust internal reliability (Cronbach's α: 0.88–0.95), consistent test–retest reliability (r = 0.72–0.93), and commendable concurrent validity, comparable to the domains of the Medical Outcome Survey Short Form 36 (SF-36) (r = 0.71–0.79).[4,5,7]

Despite the advancements in treating LN that have led to improved survival rates, patients' HRQoL is negatively impacted by the substantial morbidity resulting from both the disease and potential drug adverse effects.[8] Medication non-adherence is a significant challenge in the management of SLE, with consistently up to 75%, of patients being non-adherent with their SLE medications.[9,10] Observational studies indicate that medication non-adherence contributes to flares, disease progression, increased morbidity and mortality, and elevated hospitalization rates in SLE patients.[11,12] Thus, treatment adherence is considered an important, controllable factor in the long-term management of the disease and can improve patients HRQoL.[11]

In order to address the issue of treatment non-adherence, the Compliance-Questionnaire-Rheumatology (CQR19) has been developed as a patient-centered questionnaire designed to explore factors related to patient adherence to antirheumatic drug regimens.[13] This 19-item tool has exhibited promising psychometric characteristics, including favorable test-retest reliability and moderate internal consistency. Through validation using discriminant analyses, comparing it to a comprehensive patient self-report compliance measure, the CQR demonstrated a high sensitivity of 98%, a specificity of 67%, and an estimated kappa of 0.78 for detecting instances of low compliance.[13–15]

There is a growing recognition of patient-reported outcomes (PROs) as an integral component for SLE assessment in longitudinal studies and randomized controlled trials. PROs enable to measure information concerning patients' perspectives and viewpoints regarding their condition, which conventional physician-reported disease activity scores cannot measure.[3,7] HRQoL has yet to be studied using validated questionnaires in Colombian patients with SLE.[16–18] Medina et al[17] found that HRQoL, as measured by the SF-36 was low in Colombian patients with SLE. The main domain affected were physical component summary and mental health. Despite these findings, correlations between HRQoL and treatment adherence remain unexplored within the Colombian SLE population. Therefore, due to the clinical relevance of HRQOL in treatment adherence, the aim of this study was to explore potential associations between LupusQoL domain and CQR19 in Colombian patients with LN.

Methods

Participants

The study enrolled participants between the ages of 18 and 80 years, diagnosed with SLE and biopsy-proven LN. Eligible participants were those who had been prescribed at least one disease-modifying anti-rheumatic drug (DMARD) and/or biologic agent. Recruitment took place at the nephrology department of a tertiary referral hospital located in Barranquilla, Colombia. This hospital functions as a reference center for the Colombian Caribbean region. All patients fulfilled four or more of the revised American College of Rheumatology (ACR) criteria for SLE.[19] Demographic (age, sex) and clinical information (disease duration, LN class, disease activity, and medication class) were recorded at the time of consent. Disease activity was assessed using the Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2K).[20] Patients who were not responsible for their own medication management or who were unable to provide informed consent were excluded from the study.

The compliance questionnaire for rheumatology (CQR19)

The CQR19 is a 19-item, self-administered questionnaire that accurately identifies patients classified as "low" adherers (taking less than 80% of their medication correctly).[13,21] The questionnaire uses a four-point Likert scale, ranging from "Definitely don't agree" (scored as 1) to "Definitely agree" (scored as 4), with lower scores indicating lower levels of adherence. In addition to measuring adherence, the CQR19 also provides insight into the social and cognitive factors that may contribute to non-adherence. The questionnaire has been validated against electronic medication event monitoring (eMEMs), which is considered the "gold standard" for measuring adherence.[13] Barbich et al[22] have validated a Spanish version of the CQR19 in Argentinian patients with rheumatoid arthritis. The CQR19, when used in conjunction with specialized psychosocial measures, provides healthcare professionals with the ability to address barriers to medication adherence identified by the questionnaire.[13] In this study, a Spanish version of the CQR19 was used.[23] Patients with adherence

rates ≥80% (high adherence) were considered adherents and patients with adherence rates <80% (low adherence) were considered non-adherent.

Lupus quality of life (LupusQoL)

LupusQoL is a patient-derived disease-specific HRQOL measure for adults with SLE.[4] It consist of 34 items total. Individual subscales include the following: physical health (8 items), emotional health (6 items), body image (5 items), pain (3 items), planning (3 items), fatigue (4 items), intimate relationships (2 items), burden to others (3 items). Questionnaire has a five-point Likert response format (0 = all the time, 1 = most of the time, 2 = a good bit of the time, 3 = occasionally, and 4 = never). Scoring of the LupusQoL is such that 0 represents worst health and 100 represents best health for each domain.[4] Carrion et al[24] have previously confirmed the validity of LupusQoL for Venezuelan patients with SLE. In this study, a Spanish version of the LupusQoL was utilized, and a usage license was obtained through the online system of RWS Life Sciences, Inc.

Statistical analyses

Continuous variables are presented as median with interquartile range (IQR) or mean with standard deviation, according to the normality of the data. Categorical variables are described with count and percentage. Differences between groups were assessed with *t* test, fisher exact test and chi-square test, wherever appropriate. Spearman's rho correlation coefficients (rs) were used to assess correlation between LupusQoL domains and disease-specific characteristics (age, disease duration, and SLEDAI-2K). A principal component analysis (PCA) was performed to determine the interplay of the eight LupusQoL domains and treatment adherence groups. p values <0.05 were considered statistically significant. Statistical computations were conducted using R-CRAN version 4.2 software.[25]

Results

Patient characteristics

Forty-two patients with LN were included in the data analysis. The demographic and disease-specific characteristics of the patients are summarized in Table 1. The mean age of the overall group was 35.2 ± 12.2 years old, with a higher proportion of women (90%) than men. Mean disease duration was 22 ± 14.5 years. The overall mean SLEDAI-2K score was 16.8 ± 10.3. The most frequently histopathological class was class IV (45%), followed by class III (26%).

Treatment adherence

After the administration of the CQR19 questionnaire, the patients were categorized into two groups: adherent (n = 17, 40%) and non-adherent (n = 25, 60%). No statistically significant differences were observed in patient demographics, disease-specific characteristics, or the classes of medications used for LN when comparing non-adherent and adherent patients (Table 1). At the time of the study, 64% of patients were taking steroids, 79% antimalarials, 57% mycophenolate mofetil (MMF), 29% cyclophosphamide (CYC), and 7% biologic medications. Of the three patients (n = 3) receiving biologic therapies, two were receiving Rituximab and one was being treated with Belimumab. Differences in adherence between users of different medications could be observed (Figure 1). The highest proportions of patients with low adherence were those receiving CYC (52%) and steroids (45%). A statistically significant difference was observed in patients receiving antimalarials (low adherence: 35% vs high adherence: 65%; p = .03) and MMF (low adherence: 37% vs high adherence: 68%; p = .02).

Health-related quality of life

LupusQoL in these patients with LN was impaired but exhibited differentially across the domains, as shown in Table 2. The complete range of responses was observed for all domains, with scores ranging from 0 (indicating the worst health) to more than 100 (representing the best health). In this population, the planning domain (median 117), pain (median 100) and intimate relationships (median 100) were unaffected domains, while burden to others was the worst affected (median 67).

No statistically significant differences were found between men and women. Table 2 displays the Spearman's correlation coefficients (r) between age, disease duration, SLEDAI-2K, and the LupusQoL domains. There was strong correlation between the planning domain and age (Spearman's r = −0.72, p = .03), as well as a strong correlation with disease duration (Spearman's r = −0.74, p = .02). Likewise, there was a strong correlation between pain domain and SLEDAI-2K (Spearman´s r = −0,78, p = .02). No significant correlations were found between age, disease duration, SLEDAI-2K, and the other LupusQoL domains.

Treatment adherence and LupusQoL

The scores obtained by patients in the LupusQoL domains were compared based on the treatment adherence group (adherent vs non-adherent) (Table 3). A significant difference was observed between the groups for the pain domain of the LupusQoL, with non-adherent patients having the lowest median value (worse health) compared to adherent

Table 1. Lupus nephritis patient demographics and disease-specific characteristics.

Characteristic	Overall (n = 42)[1]	Adherent (n = 17)[a]	Non-adherent (n = 25)[a]	p-value
Age (yrs)	35.2 ± 12.2	36.8 ± 15.7	34.1 ± 9.3	0.5[b]
Sex				0.3[c]
Female	38 (90)	14 (82)	24 (96)	
Male	4 (9.5)	3 (18)	1 (4.0)	
LN symptoms duration (yrs)*				0.7[c]
Less than 5	34 (81)	14 (82)	20 (80)	
6-10	6 (14)	2 (12)	4 (16)	
16 and over	2 (5)	1 (6)	1 (4)	
LN class				0.5[c]
II	7 (17)	3 (18)	4 (16)	
III	11 (26)	3 (18)	8 (32)	
IV	19 (45)	10 (59)	9 (36)	
V	5 (12)	1 (5.9)	4 (16)	
Renal disease activity				
SLEDAI-2K	16.8 ± 10.3	18.6 ± 11.0	15.6 ± 9.9	0.4[b]
24h proteinuria (g/day)	1.8 ± 1.3	1.6 ± 1.2	1.7 ± 1.3	0.1[b]
sCrt (mg/dl)	1.4 ± 0.9	1.5 ± 0.8	1.4 ± 1.1	0.09[b]
Medication use				
MMF	24 (57)	8 (47)	16 (64)	0.3[d]
CYC	12 (29)	6 (35)	6 (24)	0.5[c]
Steroids	27 (64)	10 (59)	17 (68)	0.5[d]
Biologic	3 (7.1)	3 (18)	0 (0)	0.059[c]
Antimalarials	33 (79)	14 (82)	19 (76)	0.7[c]

SLEDAI-2K: Systemic lupus erythematosus disease activity index; ISN/RPS: International Society of nephrology/Renal pathology Society classification; LN: Lupus nephritis; sCrt: Serum creatinine; CYC: Cyclophosphamide; MMF: Mycophenolate mofetil*Duration of LN symptoms prior to diagnosis.
[a]Mean ± SD; n (%).
[b]Welch Two Sample t test.
[c]Fisher's exact test.
[d]Pearson's Chi-squared test.

patients (median 92 vs median 108, p = .045), respectively (Figure 2).

In this study, a PCA was performed to explore the interplay of the LupusQoL domains and treatment adherence groups (Figure 3). PC1 represents the group of domains that induced the most variation in the data as possible, while PC2 in turn has the highest variance possible under the constraint that it is perpendicular to the preceding component. In treatment groups, the PC1 (55%) and PC2 (12.1%) cumulatively accounted for 67.1% of the variance of the data for eight LupusQoL domains. A statistically significant positive correlation was observed between the pain and planning domains (Spearman's r = 0.77, $p < .01$), as well as a positive correlation between physical health and body image domains (Spearman's r = 0.68, $p < .01$).

Discussion

This is the first study in the Colombian Caribbean region that explore the relationship between HRQoL and treatment adherence in patients with LN. We used reliable, validated, patient-reported, and disease-specific PROs—LupusQoL and CQR19. Our findings reveal that the majority of LupusQoL domains remained unaffected. Notably, non-adherent patients exhibited lower scores in the pain domain compared to adherent patients. This finding aligns with the outcomes of HRQoL assessments using the LupusQoL questionnaire among patients in Peru,[26] Venezuela[27] and Mexico.[28] Individuals with SLE commonly report lower HRQoL compared to the general population.[3–5,7] The significant morbidity burden associated with SLE significantly affects patients' physical functioning, emotional well-being, and overall HRQoL, highlighting the imperative for comprehensive management strategies.[6] It is essential to note that even when overall HRQoL results are favorable, careful consideration of the potential impact on specific domains is crucial.[3,26,28]

Adherence is defined as the degree to which a patient's health-related behaviors align with the advice and recommendations provided by their treating physician. This encompasses adherence to prescribed therapies, non-drug interventions, lifestyle modifications, and appointment attendance.[29] Distinctive features specific to SLE may pose particular challenges to treatment adherence.[30] These

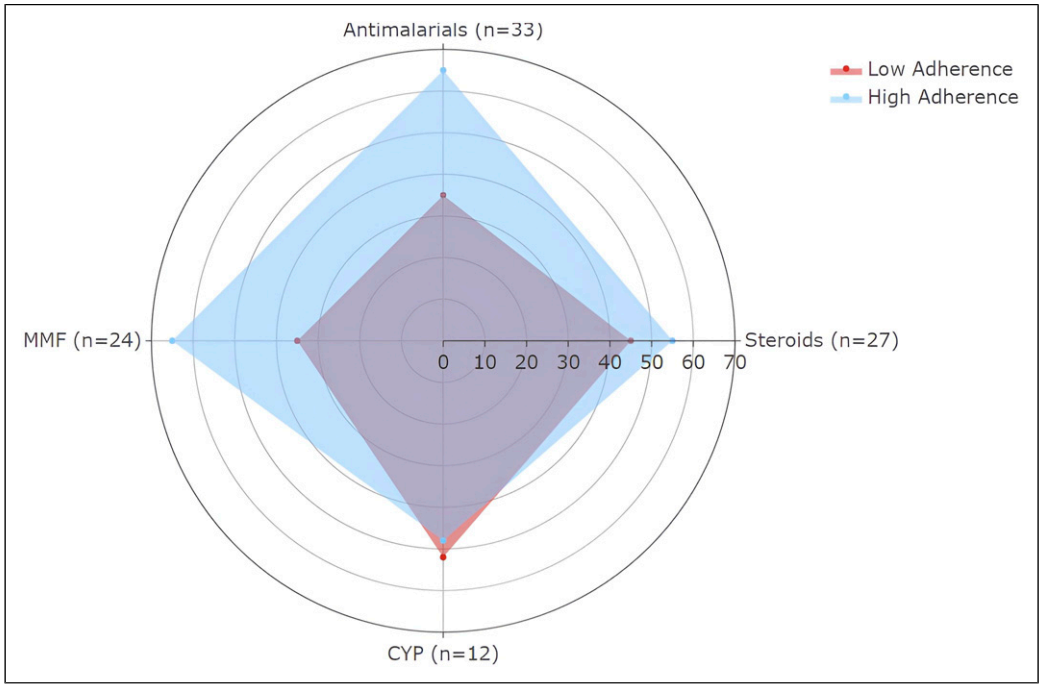

Figure 1. Proportions of adherence stratified by lupus nephritis medication (data shown for selected medication). CYC: cyclophosphamide, MMF: mycophenolate mofetil.

Table 2. LupusQoL scores and correlations between domains and age, disease duration and SLEDAI-2K.

LupusQoL domains	Median LupusQoL (IQR)	Spearman r correlation with age	Spearman r correlation with disease duration	Spearman r correlation with SLEDAI-2K
Physical health	98 (41, 125)	−0.28	−0.06	−0.14
Pain	100 (50, 125)	−0.24	−0.09	−0.78*
Planning	117 (25, 125)	−0.72*	−0.74*	−0.32
Intimate relationships	100 (0.125)	−0.14	−0.12	−0.23
Burden to others	67 (25, 125)	−0.07	−0.08	−0.71
Emotional health	98 (42, 125)	−0.02	−0.14	−0.63
Body image	95 (35, 125)	−0.12	−0.09	−0.06
Fatigue	84 (38, 125)	−0.13	−0.05	−0.01

SLEDAI-2K: Systemic lupus erythematosus disease activity index 2000; LupusQoL: Lupus quality of life; IQR: Interquartile range.
*$p < .05$.

include recurrent fluctuations in disease activity, the intricate and potentially toxic nature of medication regimens, elevated disease burden within lower socioeconomic status groups, and cognitive as well as psychological manifestations.[31,32] Non-adherent SLE patients may be at a higher risk of adverse outcomes, with end-stage renal disease being notably more frequent.[33]

Optimal treatment adherence is crucial for improving HRQoL and achieving a near-normal life expectancy in individuals with autoimmune diseases. Conversely, a lack of adherence is directly linked to suboptimal treatment outcomes.[9] Studies indicate that non-adherence is a notably widespread issue, with only 30 to 60% of patients with SLE adhering to prescribed medication regimens.[31,34–36] In the present study, the evaluation of treatment adherence through the CQR19 questionnaire revealed a non-adherence rate of 60%. These results are consistent with the findings reported by Garcia-Gonzalez et al.[29] In a cross-sectional study that included patients with rheumatoid arthritis (n = 70) and systemic lupus erythematosus (SLE) (n = 32). In the SLE group, a comparable non-adherence rate of 68% was observed. Data on adherence to single immunosuppressants in LN are scarce, with most studies focusing primarily on antimalarials.[10,34,36] Antimalarials are used not only during

Table 3. LupusQoL domain scores in treatment adherence groups.

LupusQoL Domains	Adherent (n = 17)[a]	Non-adherent (n = 25)[b]	p-value
Physical health	100 (41, 125)	94 (41, 125)	0.3[b]
Pain	108 (50, 125)	92 (50, 125)	0.045[b]
Planning	117 (50, 125)	108 (25, 125)	0.2[b]
Intimate relationships	100 (0, 125)	88 (0, 125)	0.5[b]
Burden to others	67 (33, 125)	58 (25, 125)	0.3[b]
Emotional health	104 (54, 125)	96 (42, 125)	0.2[b]
Body image	95 (60, 125)	85 (35, 125)	0.6[b]
Fatigue	94 (38, 125)	81 (38, 125)	0.3[b]

LupusQoL: Lupus quality of life.
[a]Median (Range).
[b]Wilcoxon rank sum test.

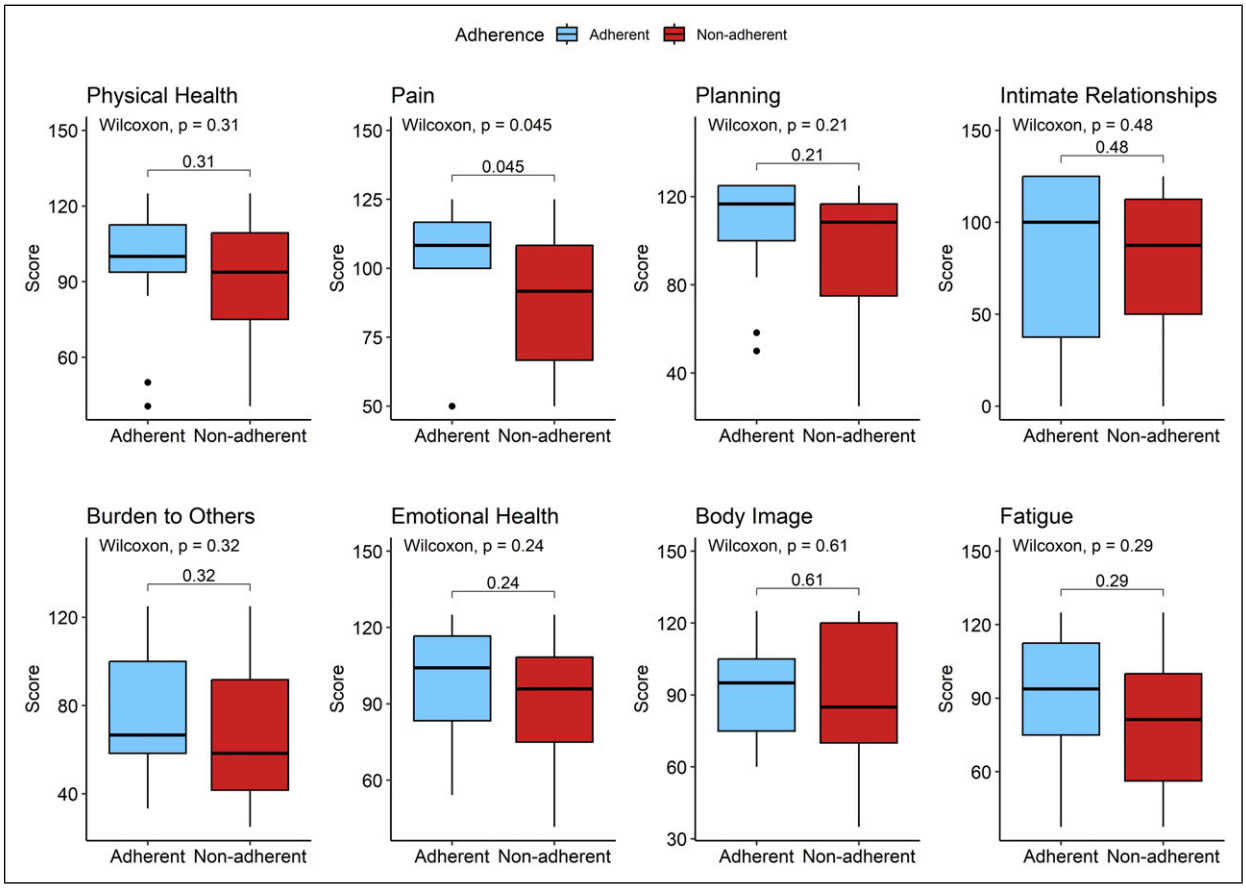

Figure 2. LupusQoL domains scores and treatment adherence groups.

active disease states but also in quiescent periods to prevent disease flares. In this study, adherence to antimalarials was found to be comparable to that reported in previous studies.[12,30,37]

Higher rates of non-adherence are observed when compared with other treatment adherence instruments. Shenavandeh et al.[38] measured treatment adherence using the eight-item Morisky's Medication Adherence scale and reported a medication non-adherence rate of 90.4% in the SLE group. Additionally, Xie et al.[39] reported a non-adherence rate of 75% among patients, utilizing the same instrument. Sallier et al[40] also evaluated compliance using a self-reported questionnaire on a scale from 0 to 10, where a score greater than or equal to eight indicated compliance.

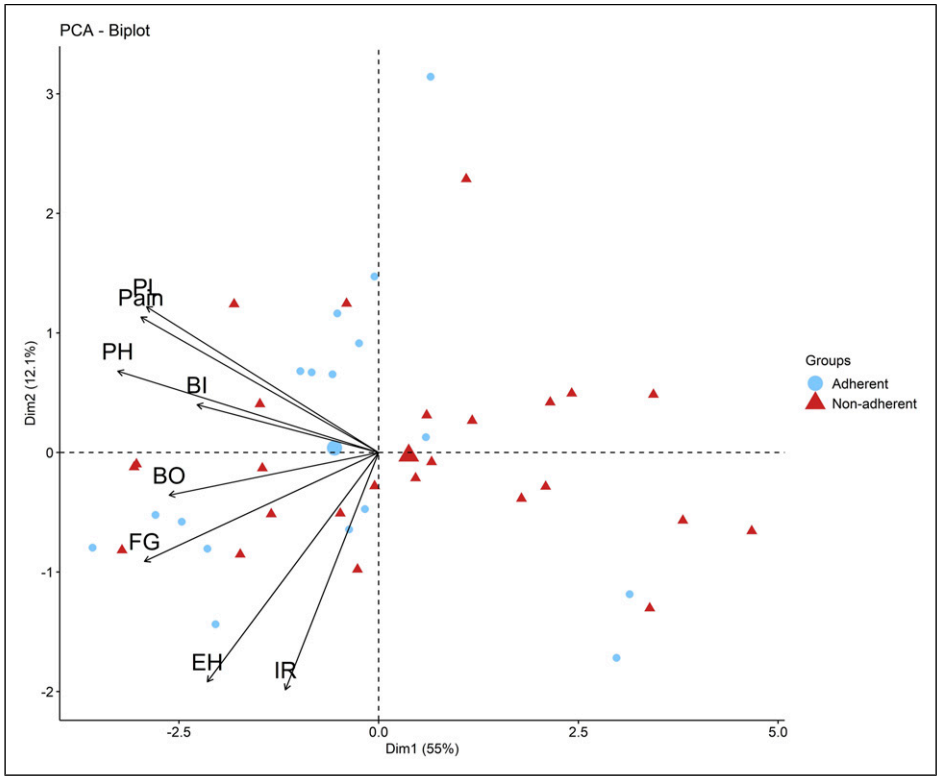

Figure 3. Principal component analysis of treatment adherence groups and LupusQoL domains. PH: physical health, PL: planning, IR: intimate relationships, BO: burden to others, EH: emotional health, FG: fatigue, BI: body image.

Among their 58 current hydroxychloroquine users, 79% of patients with SLE reported being adherent. The variation in reported adherence rates across studies underscores the multifaceted nature of adherence in SLE. Factors such as patient demographics, disease severity, and healthcare systems may contribute to these differences.[30,37]

HRQoL in patients with LN as measured by the LupusQoL was impaired specially in burden to others domain. Etchegaray-Morales et al[28] also reported that the Burden to others domain was the most affected in a Mexican cohort of 138 patients with SLE. This domain is crucial for understanding the social and emotional aspects of living with SLE. It considers factors related to how the disease affects the patients' relationships, interactions, and the potential emotional burden they feel they impose on others.[3,5] Digital therapeutic intervention has been developed for patients with SLE, incorporating a mobile app that facilitates self-tracking of dietary, environmental, and lifestyle triggers and has been integrated into standard care protocols with the aim of improving the HRQoL for individuals with SLE.[41–43] Khan et al,[43] have highlighted significant improvements in LupusQoL Burden to Others scores after digital therapeutic interventions (median of 25.0 at the end of study vs 16.7 baseline, $p = .04$). Further studies are required to assess the impact of digital intervention on improving HRQoL in this population.

The planning domain encompasses aspects related to future goals, organization, and decision-making.[3] Our study revealed that older age and longer disease duration were linked to lower scores in the planning domain. Likewise, Carrión-Nessi et al,[27] in a cross-sectional study involving 100 Venezuelan patients with SLE, identified a negative correlation between older age and the planning domain. However, the correlation was relatively weaker ($r = -0.22$, $p < .05$). Certainly, older patients may experience a diminished HRQoL due to prolonged disease duration and a higher accumulation of organ damage associated with the disease.[44] Additionally, the aging process often accompanies an increased prevalence of comorbidities, further contributing to the potential decline in HRQoL and significantly impacting the planning and decision-making abilities of the patients.[44,45]

Pain emerges as a commonly self-reported symptom among patients with active systemic SLE attributed to inflammation.[45,46] This study revealed a negative correlation between disease activity, as measured by SLEDAI-2K, and the pain domain. Consistent with this observation, numerous studies have reported similar findings.[27,28,45] Musculoskeletal symptoms have the potential to influence patients' perceptions within the pain domain.[46] Nearly all individuals with SLE will encounter muscle and/or joint pain at some point in their disease progression. Moreover,

pain has been identified as a contributing factor to fatigue, anxiety, and depression in this patient population.[46]

Fatigue and pain have both been identified as influencing factors on treatment satisfaction and adherence in qualitative studies among patients with SLE.[47,48] In this study, non-adherent patients exhibited worse pain scores compared to adherent patients. Birt et al[49] explored experiences, satisfaction and treatment expectations in 500 patients with SLE, identifying common patient-reported treatment goals categorized as 'very important,' including reducing fatigue, alleviating pain, and minimizing the frequency or severity of flares. Additionally, Emamikia et al,[50] in a qualitative study involving 205 patients with SLE, identified factors influencing medication adherence. Unintentional non-adherence is frequently associated with forgetfulness, while intentional non-adherence involves various challenges related to medication intake, such as side effects and financial constraints—more prevalent in developing countries—or disagreement regarding the necessity of pharmacological treatment.[11,30] Negative perceptions about medications in general or specific medications are also probable contributors to intentional non-adherence.[37,38] In our study population, therapeutic interventions aimed at optimizing pain management in patients with SLE could significantly impact higher treatment adherence rates.

In this study, PCA revealed distinct patterns in the interplay of LupusQoL domains and treatment adherence groups. A positive correlation between the pain and planning domains was observed, suggesting that the capacity for planning, organizing, and decision-making may influence the perception of pain in individuals with SLE. Factors associated with planning, including coping strategies, may play a role in shaping the experience of pain in these patients.[27,45] Similarly, a positive correlation between the body Image and physical health domains was identified. This finding emphasizes the intricate interplay between psychological and physical aspects of well-being in individuals with SLE, particularly regarding the impact of body image on overall damage and depression.[3,26,44] Accrued organ damage, notably affecting the kidney, lung, central nervous system, and skin, along with the long-term adverse effects of corticosteroids, can significantly influence the HRQoL in patients with SLE by negatively affecting body image and physical health domains.[3,27,28]

Our study has several limitations. Firstly, the sample size is small, potentially limiting the generalizability of the findings and no size/power analysis was conducted. Secondly, the cross-sectional and correlational nature of the study restricts making causal inferences. Thirdly, the absence of an assessment of objective measures of therapeutic efficacy is a limitation, as these measures could provide valuable insights into understanding and enhancing overall treatment adherence. Longitudinal studies incorporating additional methods to measure compliance, such as the Medication Adherence Self-report Inventory (MASRI), pill counts, and eMEMs, are required to validate and extend the findings outlined in this study.

Conclusions

Non-adherent patients reported significantly worse LupusQoL pain scores compared to adherent patients. These findings underscore the potential of targeted interventions to enhance pain management and support planning and decision-making capabilities to improve adherence and overall HRQoL in patients with LN. Future research should focus on longitudinal and multicenter studies to validate these findings and explore additional factors influencing adherence in this population.

Authors' contributions

A.D.-V., H.G.-T. and G.A.-M. conceptualized and designed the study. A.M.-B., M.S.-J., M.V.-V. and A.C.-B. carried out the clinical data collection. A.D.-V. and H.G.-T. analyzed and interpreted the clinical data. A.D.-V. and H.G.-T. wrote the first draft of this manuscript. C.G.-M., S.D., E.E., and G.A.-M. reviewed and revised the manuscript. All authors read and approved the final manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Consent to participate

All authors have given their consent for publication.

Ethical statement

Ethical approval

The study protocol was reviewed and approved by Clínica de la Costa Ethics Committee, Barranquilla, Atlántico, Colombia (Approval # 00,062, 15 October 2021). The study was carried out in accordance with the ethical principles for medical research in humans of the Declaration of Helsinki and the Colombian regulations for this type of research, with the corresponding signed informed consent of all patients.

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Appendix

Abbreviations

SLE:	Systemic Lupus Erythematosus
LN:	Lupus Nephritis
HRQoL:	Health-Related Quality of Life
PRO:	Patient-reported outcome
LupusQoL:	Lupus Quality of Life
CYC:	Cyclophosphamide
MMF:	Mycophenolate Mofetil
CQR19:	compliance questionnaire in rheumatology-19
PCA:	Principal Component Analysis
SLEDAI-2K:	Systemic Lupus Erythematosus Disease Activity Index 2000
DMARD:	Disease-Modifying Anti-Rheumatic Drug
ACR:	American College of Rheumatology
eMEM:	Electronic Medication Event Monitoring