

Paediatric rheumatic diseases: pattern, health-related quality of life and its associated factors among patients in a tertiary hospital in Nigeria, a comparative cross-sectional study

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Abstract

Background

There is limited data on the patterns of paediatric rheumatic diseases (PRDs) in Nigeria, and the health-related quality of life (HRQOL) of children living with rheumatic diseases is unknown. This study aimed to describe the patterns of PRDs at Lagos State University Teaching Hospital (LASUTH). Additionally, it compared HRQOL among children with PRDs and apparently healthy controls, and factors associated with HRQOL in children living with PRDs.

Methods

A comparative cross-sectional study conducted between June 2023 and May 2024, involving 110 children (55 with PRDs and 55 controls that were matched for age and sex).

Paediatric Quality of Life generic core scale version 4.0 (PedsQL), Paediatric rheumatology module 3.0, Childhood Health Assessment Questionnaire (CHAQ), and visual analogue scale (VAS) for pain scores were recorded. Disease activity at diagnosis for juvenile idiopathic arthritis (JIA) and juvenile systemic lupus erythematosus (JSLE) was assessed using validated disease activity measures and references. The Harter Social Support Scale was used to assess the perception of social support.

Results

Among the 55 children with PRDs, 27 (49.1%) had JSLE, 14 (25.5%) had JIA, and 14 (25.5%) had other rheumatic diseases: three with chronic musculoskeletal pain, three with fibrodysplasia ossificans progressiva, two with juvenile dermatomyositis, one with polymyositis, two with polyarteritis nodosa, one with systemic sclerosis, one with aquaporin-4 antibody optic neuritis and one with Periodic fever, aphthous stomatitis, pharyngitis and adenitis.

The median (IQR) PedsQL score was significantly lower in cases than in controls [76.9 (57.5-90.0) vs 87.5(82.5-95.0), respectively; $p < 0.001$]. HRQOL was significantly associated with functional disability ($p = 0.003$) and VAS for pain ($p = 0.042$) but not with social class, disease activity, and perception of social support. Functional disability was an independent predictor of HRQOL (OR = 7.38, CI = 1.38–39.42, $p = 0.019$).

Conclusion

Health-related quality of life in patients with PRDs is significantly associated with functional disability and VAS scores. These should be assessed regularly in the clinic.

Introduction

The worldwide burden of paediatric rheumatic diseases (PRDs) is not well understood, due to paucity of data on epidemiology, outcomes, and management guidelines from many regions of the world [1]. It has

been estimated that 6–7 million children are affected worldwide, which accounts for 10%–20% of the total burden of rheumatological disorders [2, 3]. In the United States of America, 294,000 children have been reported to be diagnosed with PRDs annually [4], and 32–42/100,000 children in the United Kingdom annually [5]. Currently, no representative annual estimates exist for Nigeria or other African countries, but a few reports describe PRDs [6–14]. PRDs are believed to be rare in most developing nations, and it has been difficult to establish their frequency because of under-diagnosis, poor access to health care, low disease recognition among health practitioners, limited access to diagnostic tools, and inadequate numbers of paediatric rheumatologists [15–17]. In addition, the clinical presentation of most PRDs mimics the presentation of common tropical diseases such as malaria and tuberculosis, thus contributing to their diagnostic challenge [18].

The chronic nature of these conditions, with waxing and waning episodes, may lead to significant disability, loss of economic productivity, as well as disability-adjusted life years [19]. Furthermore, PRDs have been associated with growth/development impairment and severe fatigue compared to the general population, leading to school absenteeism and decreased physical functioning [12, 20, 21]. They also pose a long-term risk of disability and high mortality if not diagnosed early and treated promptly [22, 23]. Furthermore, their treatment is associated with toxic [24], metabolic [25], neoplastic [26], and infectious [27] side effects. PRDs therefore constitute a considerable burden to children and their families [8].

Health-related quality of life (HRQL) focuses on the impact of a disease or its treatment on a person's ability to live a fulfilling life. It represents a broad concept of physical, psychological, and social functioning or well-being that includes both positive and negative aspects [28]. For people with chronic medical conditions such as rheumatic diseases, it includes how their disease and treatment affect everyday functioning [28]. Advancements in biomedical science and technology have resulted in marked improvements in the healthcare of paediatric chronic conditions, and this has led to increased survival; hence, HRQOL issues have become more pertinent [29].

Determinants such as demographic and economic factors, school absenteeism, social support, disease activity, functional status, and treatment-related factors have been associated with impairment of quality of life in children with juvenile idiopathic arthritis (JIA), the most common PRD [30–33].

The greater consideration given to communicable compared to non-communicable diseases and inadequate research efforts in the area of PRDs may be contributing to 'neglect' of research on PRDs and have negatively affected the recognition of PRDs as a major cause of disability and reduced quality of life, especially in low-resource countries [34–35]. Consequently, health professionals and policy-makers have not considered PRDs a public health priority because of limited awareness and understanding of their burden and impact [36].

Hence, it is important to fill the knowledge gap on the burden and quality-of-life impact of PRDs in Nigeria; this will enhance education and advocacy at all levels of healthcare, which may, in turn, translate into a higher index of suspicion, earlier diagnosis/treatment, and improved outcomes.

We therefore aimed to describe the pattern of PRDs among children attending the paediatric rheumatology clinic at LASUTH, compare HRQOL among children with PRDs and age- and sex-matched apparently healthy controls; and determine factors associated with HRQOL among children with PRDs.

Methods

Study design and site

We conducted this cross-sectional comparative study of the HRQOL of children aged 2–18 years with PRDs and apparently healthy age- and sex-matched peers. The study was conducted between June 2023 and May 2024 at the Paediatric Rheumatology Clinic and the General Out-Patient Clinic of the Department of Paediatrics, Lagos State University Teaching Hospital (LASUTH) in Ikeja, Lagos State, which is one of the public tertiary health facilities located in the state.

Study population

The study population comprised children who had been previously diagnosed with any PRDs and had been receiving treatment for at least three months, and a control group of apparently healthy children with no known rheumatologic symptoms who visited the General Paediatric Outpatient Clinic for medical certification or treatment of minor ailments like mild respiratory tract infections, uncomplicated malaria, and others during the study period.

Inclusion criteria

Children aged 2–18 years who had been diagnosed with PRDs (as per validated criteria for each disease), on treatment for at least three months, and whose parents or guardians gave consent to participate in the study. Children of similar age and sex who are not living with any chronic disease constituted the control group.

Exclusion criteria

Children with other chronic medical conditions such as sickle cell disease, bronchial asthma, diabetes mellitus, cerebral palsy, nephrotic syndrome, seizure disorders, etc., that can also affect health-related quality of life.

Sample size determination

This was determined using the formula for comparing means between two groups [37].

$$n = \frac{2 (Z_{\alpha} + Z_{\beta})^2 \times SD^2}{D^2}$$

Where:

n = minimum sample size

Z_{α} = Z-coefficient for the false-change (Type I) error rate at a 95% Confidence Interval = 1.96

Z_{β} = Z-coefficient for the missed-change (Type II) error rate for 80% Power = 0.84

SD = standard deviation obtained from a previous Nigerian study, which reported a mean (SD) composite health-related quality of life score for healthy subjects as 92.28 ($\pm$ 8.93) [38].

D = minimum detectable change considered important; a difference of 5 points from the mean score was considered important for this study.

Thus: Z_{α} = 1.96, Z_{β} = 0.84, SD = 8.93, D = 5

Putting these figures into the equation:

$$n = \frac{2(1.96+0.64)^2 \times 8.93^2}{5^2} = \frac{12.96 \times 80.10}{25} \approx 42$$

$$2(6.76 \times 79.74) = 43.1$$

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In anticipation of a possible 20% non-response rate, the calculated sample size was adjusted as follows:

$$N = n / (1 - 0.1) = 43.1 / 0.8 \approx 53.9$$

Thus, 55 children living with rheumatological diseases and 55 apparently healthy children were recruited into the study.

Sampling Technique

Eligible children with PRDs and the control group were consecutively recruited from the paediatric rheumatology and paediatric outpatient clinics, respectively. This sampling technique was used because the total population of children with PRDs aged 2 to 18 years in the clinic was 65, and the study sample size was 55; therefore, as many subjects as were accessible and gave consent were recruited. The children with PRDs were matched with the control group by age and sex.

DATA COLLECTION PROCEDURE

A data collection form was used to obtain information on the socio-demographic and educational status of both study subjects and the controls. Also, diagnosis, symptom duration before diagnosis, disease

activity, and functional status in children with rheumatic diseases were documented.

Age-appropriate PedsQL 4.0 generic core scales [39] were used to obtain data on physical, emotional, social, and school functioning from study subjects and apparently healthy age- and sex-matched children, while age-appropriate PedsQL 3.0 Rheumatology modules [40] were used to obtain data on pain, daily activities, treatment, worry, and communication from children with PRDs only.

A childhood health assessment questionnaire (CHAQ) was used to obtain functional status from children with PRDs only [41].

The Harter Social Support Scale for Children (HSSC) was completed by children aged 8 to 18 years living with PRDs. This 21-item social support scale assesses support from parents, classmates, teachers, and friends; each item is scored from 1 to 4, with higher scores indicating stronger support [42].

The Systemic lupus erythematosus disease activity index (SLEDAI-2K) was used to measure the disease activity of children with systemic lupus erythematosus at diagnosis [43].

The clinical juvenile arthritis disease activity score (cJADAS) was used to measure the disease activity of children with oligoarticular and polyarticular juvenile idiopathic arthritis [44].

The socioeconomic class was assigned using a method described by Oyedemi [45]. This social classification utilizes parental education and occupation. The social classes were regrouped as the upper class (classes 1 and 2), middle class (class 3), and lower class (classes 4 and 5).

Ethical considerations and approval

The Health Research & Ethics Committee of the Lagos State University Teaching Hospital approved the study (Reference number: LREC/06/10/1582).

Data management

Information obtained was analyzed using the International Business Machines Statistical Package for Social Sciences (IBM SPSS) version 26.0.

Data analysis

We used descriptive statistics, such as the median with interquartile range, to summarize quantitative variables (such as age) and frequencies with percentages to summarize qualitative variables (such as socioeconomic class). Associations between categorical variables were tested using the Chi-squared test. The Kruskal-Wallis test was used to compare medians of variables, e.g., HRQOL scores, across different rheumatic diseases. Factors associated with HRQOL in children with PRDs were determined by multivariate logistic regression analysis. All analyses were conducted at the 5% significance level, and p-values < 0.05 were considered statistically significant.

Results

Socio-demographic data

As shown in Table I, 110 children, comprising 55 with PRDs and 55 age- and sex-matched apparently healthy children (controls), participated in the study. Age groups were selected to fit into the pattern of the PedsQL 4.0 generic core scale (2 to 4 years, 5 to 7 years, 8 to 12 years, and 13 to 18 years).

The median (IQR) age was 13.0 (9.0–15.0) years for children living with rheumatic diseases and 13.0 (9.0–15.0) years for controls. The female-to-male ratio was 2.6:1 in both subgroups (Table I). Median age at diagnosis of rheumatic diseases was 12.0 (9.0–14.0).

The majority of participants (cases and controls) were of middle socioeconomic class, and Yoruba was the predominant tribe.

Table I: Sociodemographic characteristics of study participants

Variables	Cases n = 55 (%)	Control n = 55 (%)	Total	χ^2	P value
Age group (Years)	2 (3.6)	2 (3.6)	4 (3.6)	0.000	1.000
2–4	6 (10.9)	6 (10.9)	12 (10.9)		
5–7	19 (34.5)	19 (34.5)	38 (34.5)		
8–12	28 (50.9)	28 (50.9)	56 (50.9)		
13–18	13.0 (9.0–15.0)	13.0 (9.0–15.0)			
Median (IQR) (years)					
Sex	15 (27.3)	15 (27.3)	30 (27.3)	0.000	1.0000
Male	40 (72.7)	40 (72.7)	80 (72.7)		
Female					
Social class	6 (10.9)	10 (18.2)	16 (14.5)	1.181	0.554
Upper	31 (56.4)	28 (50.9)	59 (53.6)		
Middle	18 (32.7)	17 (30.9)	35 (31.8)		
Lower					
Ethnic group	28 (50.9)	35 (63.6)	63 (57.3)	2.170	0.538
Yoruba	20 (36.4)	14 (25.4)	34 (30.9)		
Igbo	2 (3.6)	1 (1.8)	3 (2.7)		
Hausa	5 (9.1)	5 (9.1)	10 (9.1)		
Others					
χ^2 : Chi-Square test, IQR : interquartile range					

Pattern of PRDs

As shown in Table II, three groups of paediatric rheumatic diseases were recruited. The most common was juvenile systemic lupus erythematosus (JSLE) (49.1%). The other two groups were juvenile idiopathic arthritis and other rheumatic diseases [made up of non-homogeneous conditions: chronic musculoskeletal pain, fibrodysplasia ossificans progressiva, juvenile dermatomyositis, polyarteritis nodosa, polymyositis, systemic sclerosis, aquaporin-4 antibody optic neuritis, periodic fever, aphthous stomatitis, pharyngitis and adenitis (PFAPA)], which occurred at the same frequency of 25.5% of the total cases, respectively.

Systemic onset juvenile idiopathic arthritis and polyarticular juvenile idiopathic arthritis occurred with equal frequency.

Chronic musculoskeletal pain and fibrodysplasia ossificans progressiva (FOP) were the commonest among other rheumatic diseases.

Table II: Pattern of paediatric rheumatic diseases in the study participants

Types of paediatric rheumatic diseases	Frequency (%)
Juvenile systemic lupus erythematosus (JSLE)	27(49.1)
Juvenile idiopathic arthritis (JIA)	14(25.5)
Systemic onset	6 (10.9)
Polyarticular	6 (10.9)
Oligoarticular	2 (3.6)
Other rheumatic diseases	
Chronic musculoskeletal pain	14(25.5)
Fibrodysplasia ossificans progressiva (FOP)	3(5.4)
Juvenile dermatomyositis	3(5.4)
Polyarteritis Nodosa (PAN)	2(3.6)
Polymyositis	2(3.6)
Systemic sclerosis	1(1.8)
Aquaporin-4 antibody optic neuritis	1(1.8)
Periodic fever, aphthous stomatitis, pharyngitis and adenitis (PFAPA)	1(1.8)
JSLE: juvenile systemic lupus erythematosus, JIA: juvenile idiopathic arthritis, FOP: Fibrodysplasia ossificans progressiva, PAN: polyarteritis nodosa, PFAPA: Periodic fever, aphthous stomatitis, pharyngitis and adenitis. Subtypes of JIA were based on the International League of Associations for Rheumatology (ILAR) classification	

PFAPA was diagnosed based on clinical presentation, specifically the pattern of recurring fevers (periodicity) and associated symptoms after excluding bacterial infections, tuberculosis, and connective tissue disorders. Response to colchicine and corticosteroids also supported the diagnosis.

Median age of participants

The median age of children with JSLE at diagnosis was the highest, followed by JIA. However, there was no statistical significance ($p = 0.07$). The difference across the board for the duration of symptoms before diagnosis was statistically significant ($p = 0.022$) (Table III).

Table III: Age and duration of symptoms across groups of rheumatic diseases

Variables	JSLE n = 27	JIA n = 14	Other rheumatic diseases n = 14	H	p-value
Age (years) Median (IQR)	14.0(9.0–15.0)	10.5(8.3–16.0)	11.00 (9.5–15.0)	1.002	0.606
Age at diagnosis Median (IQR)	14.0 (9.0–15.0)	10.5 (8.3–14.0)	10.0 (7.0–12.0)	5.314	0.070
Duration of symptoms before diagnosis (months) Median (IQR)	3.6(2.4–12.0)	7.2(3.6–36.0)	24.0 (4.8–51.6)	7.663	0.022*
JIA: juvenile idiopathic arthritis, JSLE: juvenile systemic lupus erythematosus *significant, IQR: interquartile range. Statistics: Kruskal-Wallis test					

Sex distribution across subtypes of paediatric rheumatic diseases (PRDs)

Girls were much more common in the JSLE subtype than in others. However, boys were significantly more common than girls in the JIA subtype compared to other groups of PRDs ($p = 0.008$) (Table IV)

Table IV: Sex distribution across subtypes of paediatric rheumatic diseases

Gender	JSLE n = 27	JIA n = 14	Other rheumatic diseases n = 14	f	p-value
Male	3 (11.1)	8 (57.1)	4 (28.6)	9.414	0.008
Female	24 (88.9)	6 (42.9)	10 (71.4)		
JSLE: juvenile systemic lupus erythematosus, JIA: juvenile idiopathic arthritis, Others: other rheumatic diseases, PRDs: paediatric rheumatic diseases f: Fisher’s Exact value					

Factors associated with HRQOL

Table V summarizes the median (IQR) scores of HRQOL (Paediatric Quality of Life 4.0 scores and paediatric rheumatology module 3.0 scores), functional status (CHAQ scores), duration of symptoms before diagnosis, perceived social support, and disease activity scores [clinical juvenile arthritis disease activity scores (cJADAS) and systemic lupus erythematosus disease activity index 2000 (SLEDAI-2K)].

Table V: Health-related quality of life and related factors among children with rheumatic diseases

Index	Score	
	Median (IQR)	Observed range
HRQOL (PedsQL)		
Generic module	76.9 (57.5 to 90.0)	27.5 to 100.0
Rheumatology module	75.0 (58.3 to 90.0)	18.8 to 100.0
CHAQ	0.1 (0.0 to 0.5)	0.0 to 2.0
Pain, VAS	3.0 (1.0 to 5.0)	0.0 to 8.0
Interval (months) before diagnosis	6.0 (3.0 to 24.0)	0.9 to 96
Perceived social support (Harter SSSC)		
Parents	3.2 (2.8 to 3.7)	0.5 to 4.0
Classmates	3.0 (2.8 to 3.3)	0.5 to 3.8
Teachers	3.3 (3.0 to 3.5)	0.5 to 4.0
Friends	3.2 (2.8 to 3.7)	0.5 to 4.0
Disease activity		
cJADAS*	1.2 (0.8 to 1.3)	0.5 to 1.4
SLEDAI-2K	14.0 (9.0 to 15.0)	0.0 to 39.0
HRQOL: Health-Related Quality of Life, PedsQL: Paediatric Quality of Life Inventory, CHAQ: Childhood Health Assessment Questionnaire, VAS: Visual Analogue Scale, SSSC: Social Support Scale, cJADAS: Clinical Juvenile Arthritis Disease Activity Score (cJADAS was only for oligoarticular and polyarticular JIA), SLEDAI-2K: Systemic Lupus Erythematosus Disease Activity Index 2000		

PedsQL scores range from 0 to 100; the higher the score, the better the HRQOL. **CHAQ** score ranges from 0 to 3; the higher the score, the poorer the HRQOL. **VAS** scores range from 0 to 10; the higher the score, the worse the pain. **SSSC** scores range from 1 to 4; higher values indicate stronger social support. **cJADAS** score ranges from 0 to 10; inactive disease is ≤ 1 , low disease activity: 1.1–1.5 for oligoarticular JIA, 1.1–2.5 for polyarticular JIA, moderate disease activity: 1.51–4 for oligoarticular JIA, 2.51–8.5 for polyarticular JIA, High disease activity: > 4 for oligoarticular JIA, > 8.5 for polyarticular JIA. **SLEDAI-2K** scores range from 0 to 105; the higher the score, the worse the disease activity.

Health-Related Quality of Life (HRQOL) in cases versus controls

Overall, Paediatric Quality of Life Questionnaire (PedsQL) scores were significantly lower in cases than in controls. This pattern was observed in all four domains (physical, emotional, social, and school functioning) of HRQOL, but more in the physical and school domains. (Table VI)

Table VI: Comparison of PedsQL generic scores between cases and controls

Scale scores	Cases Median (IQR)	Control Median (IQR)	U	p-value
Physical	68.7(46.9–87.5)	86.9(78.1–93.8)	777.5	< 0.001*
Emotional	78.1(60.0-93.8)	90.0(80.0-98.1)	987.5	0.002
Social	85.0(65.0-100.0)	90.0(80.0-100.0)	1117.0	0.016
Schooling	75.0(60.0–90.0)	85.0(80.0-100.0)	936.0	< 0.001*
Overall	76.9(57.5–90.0)	87.5(82.5–95.0)	905.0	< 0.001*
IQR= interquartile range; PedsQL: Paediatric Quality of Life Questionnaire				

Comparisons were done using the Mann-Whitney U test

Association between HRQOL and socioeconomic status, functional status, disease activity, perceived social support and duration of symptoms before diagnosis

Twenty-seven (49.1%) children had Paediatric Quality of Life (PedsQL) generic score below the group median of 76.9. Those children were regarded as having poor HRQOL. Thus, 28 (50.9%) children had good HRQOL (PedsQL generic scores of ≥ 76.9).

On univariate analysis, poor HRQOL was significantly associated with high CHAQ scores (functional status) and high pain scores ($p = 0.003$ and $p = 0.042$, respectively) (Table VII). Other variables like low socioeconomic class, duration of symptoms before diagnosis, and perceived social support were not significantly associated with poor HRQOL.

Table VII: Univariate analyses of factors associated with impaired HRQOL in children with rheumatic diseases

Variables	Children with poor HRQOL (n = 27) n (%)	Children with good HRQOL n = 28 n (%)	f/ χ^2	p-value
Socioeconomic status				
Lower	8(29.6)	10(35.7)	0.381 (f)	0.911
Middle	17(62.9)	16(57.1)		
Upper	2(7.4)	2(7.1)		
Functional status				
CHAQ score (0–3)	2(7.4)	12(42.9)	9.103 (χ^2)	0.003*
No difficulty (0)	25(92.6)	16(57.1)		
Difficulty (> 0)	9 (33.3)	17 (60.7)	4.134 (χ^2)	0.042*
Pain VAS (1–10)	18 (66.7)	11 (39.3)		
<3				
≥3				
Duration of symptoms before diagnosis				
<6months	11 (40.7)	14 (50.0)	0.475 (χ^2)	0.491
≥6months	16 (59.3)	14 (50.0)		
	n = 5	n = 3	f	p-value
	n (%)	n (%)		
Disease activity (0–10)				
cJADAS				
≤1	2 (40.0)	2 (66.7)	0.036	1.000
>1	3 (60.0)	1 (33.3)		
	n = 11	n = 16	f	p-value
	n (%)	n (%)		
SLEDAI-2K (0-105)				
≤6	2	1	0.940 (f)	0.549 (f)
>6	9	15		

	n = 24	n = 23	f	p-value
	n (%)	n (%)		
Perceived social support (0–4)				
<2	2	2	0.002	1.000 (f)
≥2	22	21		

CHAQ: childhood health assessment questionnaire, **VAS**: visual analogue scale, **JADAS**: juvenile arthritis disease activity score, **SLEDAI-2K**: systemic lupus erythematosus disease activity index 2000.

Note 8, 27, and 47 children were eligible for c**JADAS**, **SLEDAI-2K**, and perceived social support assessment, respectively.

χ^2 = Chi square, **f** = Fisher's exact

Upon logistic regression analysis, a high CHAQ score remained an independent predictor of poor HRQOL (OR = 7.38, CI = 1.38–39.42, p = 0.019).

Discussion

This study has documented patterns of PRDs and HRQOL of children with rheumatic diseases compared to a healthy age- and sex-matched control group.

The predominance of female children observed is similar to earlier reports from Nigeria [6], Ghana [11], Tanzania [9], and South Africa [10]. This contrasts with findings from Bangladesh and Kenya, where male children were predominant [8, 23]. This difference might be due to health-seeking behaviour (where boys are more likely to seek medical attention in certain cultures), in addition to innate disease factors. It has been documented that the sex hormones oestrogen and prolactin are pro-inflammatory, and the increased exposure in females may explain the high female: male ratio [46].

We found JSLE to be the commonest PRDs among our participants, followed by JIA. This contrasts with earlier studies in which JIA was reported as the most common PRD, followed by JSLE or other connective tissue diseases [6, 9–11, 23]. One possible explanation is that some children with JIA may be managed by other specialists, such as orthopaedic surgeons or physiotherapists, and may therefore not be referred to paediatric rheumatology services. Furthermore, JSLE has more systemic symptoms that are quite worrisome to the parents, thus necessitating early presentation in the hospital, unlike the subtypes of JIA except systemic JIA.

However, the median ages of children with JSLE (14.0 years) and JIA (10.5 years) at diagnosis were higher than (12.3, 12.6 years) and (6.6, 9.1 years), respectively, than in well-described cohorts in Egypt [25], Japan [47], and the United Kingdom [48]. This may be due to late presentation and delayed

diagnosis as a result of poverty, ignorance, and inadequate healthcare infrastructure and personnel [49]. Late presentation and delayed diagnosis have been associated with high morbidity and mortality in children with rheumatic diseases [5].

The current study reflected a longer duration of symptoms before diagnosis for JSLE and JIA compared to one month for JSLE and 1.8 months for JIA in a study by Narazaki et al [47]. A plausible contributor is the fact that constitutional symptoms such as fever, anorexia, loss of appetite, and weight loss are also found in other childhood conditions like malaria, sepsis, sickle cell disorders, and leukaemia. These symptoms create confusion for a physician making the diagnosis of PRDs, to be delayed. This delay not only provides room for worsened clinical presentation but also drains caregivers' resources such that they may be unable to subsequently afford the investigations required for definitive diagnosis and treatment. A delayed diagnosis was identified as a poor prognostic factor in a cohort study of patients with JSLE in South Africa [50].

Although, there was prolonged time to diagnosis across our PRDs population, we observed that children with JSLE had shorter median time to diagnosis than JIA and then others. A similar pattern had been earlier reported in a Japanese study [47]. The symptoms of JSLE and then JIA are generally more straightforward and recognizable by general practitioners than those of other rheumatic diseases. This might have expedited relatively earlier referral of children with JSLE and then JIA to our specialist clinic, compared to the 'others' group which have more varying subtle presentation and more likelihood of diagnostic delays.

Our finding of significant impairment of HRQOL in patients with paediatric rheumatic diseases across all four domains compared to the controls (76.9 versus 87.5; $p < 0.001$) is consistent with previous report [51]. It has been documented that living with the daily impact of a chronic disease like PRDs constitutes a great challenge for children and their families [52].

Similar to previous studies [31, 32, 51], functional disability (high CHAQ scores) was an independent determinant of impaired health-related quality of life in the current study. This is likely because the 30 items assessed in the functionality questionnaire (CHAQ) are everyday activities like dressing, eating, and walking. A child who experiences difficulties in performing these functions is unlikely to have a good health-related quality of life. Functional ability is an important issue in the management of paediatric rheumatic diseases, and its assessment helps to evaluate a patient's current state and the efficacy of treatment [51]. Clinically, our finding makes case for integration of routine serial assessment of HRQOL into the outpatient care of children with PRDs as well as rehabilitation care.

The strengths of the current study are its comparative cross-sectional design and the use of a variety of validated tools to evaluate the health-related quality of life of children living with PRDs.

Paediatric rheumatology is still an evolving field in Africa, and more robust studies are needed to compare with most of the findings from the present study.

Conclusion

JSLE appears to be relatively more common among patients attending the paediatric rheumatology clinic in Lagos when compared with reports from several other countries, highlighting the growing burden and clinical relevance of PRDs within our environment.

Furthermore, this study demonstrates that children living with PRDs experience significantly poorer HRQOL compared with healthy controls. The impact of these diseases extends beyond physical symptoms, affecting emotional well-being, social interactions, school participation, and overall daily functioning. Importantly, functional disability emerged as the independent predictor of poor HRQOL among children with PRDs. This emphasizes the critical role of functional status in determining the overall well-being of a child living with PRDs.

Overall, the findings of this study highlight the urgent need for comprehensive, multidisciplinary, and patient-centred approaches to managing PRDs in Nigeria and similar settings. Strengthening early diagnosis, optimising treatment strategies, improving rehabilitation services, and integrating psychosocial support into routine care are essential steps towards improving long-term outcomes and quality of life for affected children.

Limitations of the study

The single-centred nature, sampling bias, and tertiary setting of the current study may not be representative of the pattern and health-related quality of life of children with paediatric rheumatic diseases in Nigeria.

Abbreviations

PRDs

paediatric rheumatic diseases

HRQOL

health-related quality of life

JSLE

juvenile systemic lupus erythematosus

JIA

juvenile idiopathic arthritis

PedsQL

Pediatric Quality of Life Inventory

CHAQ

Child Health Assessment Questionnaire

cJADAS

Clinical Juvenile Arthritis Disease Activity Score

SLEDAI

Declarations

Ethical approval and consent to participate

The study has received approval from the Ethics Committee of LASUTH (reference number: LREC/06/10/1582). Consent/assent was obtained from the participants and their parents, as applicable. Patient confidentiality was maintained throughout the study.

Consent for publication

Not applicable.

Conflicting interests

There were no conflicts of interest during this study

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None.

Author Contribution

AF, IA, OA, FN, and OO contributed to the conceptualization and design of this work. AF contributed to data acquisition, formal analysis, and manuscript drafting. All authors revised the manuscript and approved the final version.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

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