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Patient-reported outcome measure of the quality of life in Ugandans living with autoimmune rheumatic diseases

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ABSTRACT

Aim of the work: To assess the patient reported outcome measure (PROM) of the quality of life (QoL) of patients with autoimmune rheumatic diseases (RDs) attending two tertiary care rheumatology clinics in Uganda.

Patients and methods: Patients with a confirmed diagnosis of RD and receiving disease modifying anti-rheumatic drugs (DMARDs) were studied. Health index and overall self-rated health status were assessed using the EuroQol 5-dimension (ED-5D-5L) questionnaire tool.

Results: 74 patients were studied: 48 (64.9%) had rheumatoid arthritis (RA), 14(18.9%) systemic lupus erythematosus (SLE), and 12(16.2%) had other RDs; spondyloarthritis (n = 5), systemic sclerosis (n = 3), juvenile idiopathic arthritis (n = 2), and idiopathic inflammatory myositis (n = 2). Their mean age was 45 ± 17 years and 69 (93.2%) were female. 14(18.9%) were on concomitant herbal medication and 26 (35.1%) self-reported at least 1 adverse drug reaction. Any level of problem was reported by 54(72.5%) participants for mobility, 47(63.5%) for self-care, 56(75.6%) for usual activity, 66(89.1%) for pain and discomfort, and 56(75.6%) for anxiety/depression. The mean health index of the patients was 0.64 ± 0.16 and the overall self-rated health status was 58.1 ± 16.7. Patients with SLE (0.74 ± 0.12) had higher health index compared to those with RA (0.60 ± 0.17) or other RDs (0.70 ± 0.1) ($p < 0.007$). Overall self-rated health status was comparable across clinical diagnoses ($p = 0.23$). Both the index and self-reported status were better for patients who received private hospital care compared to public hospital ($p < 0.0001$ and $p = 0.01$).

Conclusion: There is a substantial negative impact of autoimmune rheumatic diseases on quality of life of patients, especially those receiving care from a public facility in Uganda.

1. Introduction

Autoimmune rheumatic disorders such as rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE) are associated with pain, disability and several co-morbid conditions thus significantly impacting on quality of life (QoL) and overall wellbeing of the affected individuals and their families [1]. Consequently, higher morbidity and mortality rates are observed among these individuals compared to the general population [1,2]. Also, there are significant individual differences in the day-to-day variability of pain, fatigue, and well-being in patients with rheumatic disease [3]. Therefore, QoL is central in the care of patients with autoimmune rheumatic disease and is an important target in therapeutic advances in rheumatology while evaluating or managing these patients with disease modifying anti-rheumatic drugs (DMARDs) [4].

Patient-reported outcomes (PROs) are patient's perspectives on their disease activity, functional status, and QoL [5]. Patient-reported outcome measures (PROMs) are a set of widely available tools that directly capturePROs. PROMs are increasingly being used in clinical rheumatology practice and in research to help inform patient-centered care and clinical decision-making even among vulnerable rheumatic disease (RD) patients such as those with low health literacy or English proficiency [6].

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There are no locally validated RD specific PROMs in Africa and data on PROs of patients with rheumatic diseases in Africa is scanty, even though these diseases, especially RA and SLE are increasingly being reported in Africa [7-9]. This study aimed to describe the QoL of patients with autoimmune RD in two tertiary care centers in Uganda.

2. Patients and methods

This descriptive, cross-sectional clinical study recruited consecutive outpatients attending two rheumatology clinics at Mulago National Referral Hospital (Mulago Hospital), Kampala, Uganda and St. Francis's Hospital-Nsambya, Kampala, Uganda (Nsambya Hospital) between September and December 2020. Mulago Hospital is the largest national public specialized health facility in Uganda with over 1,000-bed capacity. Nsambya Hospital is a private-not-for-profit hospital also located in Kampala. Patients $\geq$ 16 years with an autoimmune RD: RA, SLE, spondyloarthritis (SpA), systemic sclerosis (SSc), juvenile idiopathic arthritis (JIA) and idiopathic inflammatory myositis (IIM) diagnosed by experienced rheumatologists (AM and MK) according to the corresponding classification criteria [10-15] for whom at least one of the DMARDs was prescribed in their last clinic visit constituted the study population. All patients provided written informed consent and the study protocol was approved by the hospitals ethical committees and was in compliance with the *Declarations of Helsinki*.

Data were collected using semi-structured questionnaires administered by the treating physicians (the authors) during routine clinical care. This audit was anonymous, consisting of semi-structured questions, which were available only in English. Data was collected on the following parameters: (1) patient sociodemographic characteristics: age, gender, marital status, level of education, current employment status, monthly income and financial support from family members; (2) Clinical diagnosis: duration of illness, self-reported disease severity, disease flares, hospitalization and family history of autoimmune disease; (3) Medication: DMARDs used, duration of therapy, source of DMARDs, monthly expenditure on DMARDs, satisfaction with treatment, concomitant use of herbal medication, adverse drug reactions; (4) Number of additional medications used daily; and (5) Charlson co-morbidity index.

Patient-reported outcome measure: The EuroQol 5-dimension 5-level (EQ-5D-5L) questionnaire, a standardized instrument for

Table 1
Sociodemographic and clinical characteristics of the rheumatic diseases patients.

Variable n (%), mean ± SD or median (range)			74 RD patients
Age (years)			45 ± 17
Female: male			69:5 (13.8:1)
Marital status	Single		31 (41.9)
	Married		22 (29.7)
	Widow/er		13 (17.6)
	Divorced		8 (10.8)
Education	Informal		6 (8.1)
	Primary		21 (28.4)
	Secondary		18 (24.3)
	High		29 (39.2)
Formal employment			25 (33.8)
Financial support			55 (74.3)
Disease duration (months)			48 (2–420)
Self-reported disease severity	Controlled		10 (13.5)
	Mild		18 (24.3)
	Moderate		29 (39.2)
	Severe		12 (16.2)
	Very severe		5 (6.8)
Satisfaction with medical treatment			65 (87.8)
Use of herbal medication			14 (18.9)
Adverse drug reactions			26 (35.1)
Charlson co-morbidity index			2 (1–11)
Co-morbidity		Hypertension	23 (31.1)
		CHF/diabetes/HIV	3 (4.1) each
Treatment regimen by clinical diagnosis	RA	MTX alone	23 (47.9)
	(n = 48)	HCQ alone	8 (16.7)
		HCQ + MTX	8 (16.7)
		MTX + LFN	6 (12.5)
		HCQ + AZA	2 (4.2)
		HCQ + MTX + LFN	1 (2.1)
	SLE (n = 14)	HCQ + AZA	8 (57.1)
		HCQ alone	4 (28.6)
		HCQ + MMF	2 (14.3)
	Other	AZA or SAZ alone	3 (25) / 3 (25)
	RDs	MTX or HCQ alone	1 (8.3) / 1 (8.3)
		HCQ + MTX or AZA or SAZ	1 (8.3) each
		MTX + SAZ	1(8.3)
DMARD source	Private pharmacies		54 (73)
	Nsambya hospital		16 (26.6)
	Hospital or private pharmacy		4 (5.4)
Uninterrupted DMARD therapy (months)			12 (1–240)
Off DMARDs in the last one week			21 (28.4)

CHF: Chronic heart failure, HIV: human immunodeficiency virus, RA: rheumatoid arthritis, SLE: systemic lupus erythematosus, MTX: methotrexate, HCQ: hydroxychloroquine, LFN: leflunomide, AZA: azathioprine, MMF: mycophenolate mofetil, SAZ: sulfasalazine. Other rheumatic diseases (RDs): SpA (n = 5), SSc (n = 3), JIA (n = 2), IIM (n = 2). DMARDs; disease modifying anti-rheumatic drug.

use as a measure of health outcomes consisting of 5 dimensions and 5 levels was administered to the participants [16]. The tool has been previously used in sub-Saharan Africa and is being validated in Ethiopia [17,18]. The 5 dimensions assessed were mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has five levels (no problems, slight problems, moderate problems, severe problems, extreme problems/unable to). Health state profile was generated from these dimensions and levels. Overall self-rated health status was assessed using the visual analogue scale (VAS) on which the patient rates his/her perceived health from 0 (the worst imaginable health) to 100 (the best imaginable health).

Statistical analysis: Baseline characteristics were summarized using medians and ranges or means and standard deviations (SD) for continuous variables and frequencies and percentages for categorical variables. Comparisons for variables were performed using Student's *t*-test or Mann-Whitney U (for two group comparisons) and the one-way analysis of variance or Kruskall-Wallis (for more than two group comparisons) for continuous numerical data. Categorical data were compared using either χ^2tests or Fisher's exact tests as appropriate. Health state index scores generally range from <0 (where 0 is the value of a health state equivalent to dead; negative values representing values as worse than dead) to 1 (the value of full health) were calculated from individual health profiles using crosswalk value sets for Zimbabwe [16]. Statistical analyses were performed using STATA 16.0 and GraphPad Prism 8.0. A $p < 0.05$ was considered to indicate statistical significance.

3. Results

A total of 74 eligible RD patients were studied: 41 (55.4%) from Mulago Hospital and 33 (44.6%) from Nsambya Hospital. None of the participants dropped out of the study. Sociodemographic and clinical characteristics of the rheumatic diseases patients are presented in table 1. 39 (52.7%) of the patients were $\leq$ 45 years old and 40 (54.1%) had a disease duration of $\leq$ 48 months. 49 (66.2%) were not formally employed. The median (range) monthly income was 300,000 (30,000 – 1,000,000) Ugandan shillings (UGX).

Forty-eight (64.9%) patients had RA, 14 (18.9%) had SLE, and 12 (16.2%) had other RDs namely SpA (n = 5), SSc (n = 3), JIA (n = 2), and IIM (n = 2). The median (range) episodes of disease flares in the preceding 3 months was 1 (range: 0–2). Thirty-two (43.2%) patients had at least one co-morbidity; of these, 23 (71.9%) were RA patients, 4 (12.5%) SLE and 5 (15.6%) had another RD.

None of the patients was on biologic DMARDs. Majority of the patients with RA were on monotherapy of methotrexate (MTX) (n = 23, 47.9%), those with SLE were mostly either on monotherapy of hydroxychloroquine (HCQ) or in a combination with azathioprine (AZA) (n = 12, 85.7%), and half of patients with other RDs were either on AZA or sulfasalazine (SAZ) (n = 6, 50%), Table 1. Uninterrupted DMARD therapy for > 12 months was reported by 29 (39.2%) of the patients. The monthly cost of DMARDs was 120,000 (12,800 – 2,000,000) UGX. Most adverse drug reactions (ADRs) were observed with MTX (10/26; 38.5%) and 4 patients reported dizziness, 3 weakness, 2 gastrointestinal (GI) disturbances and 1 pulmonary fibrosis. ADR due to HCQ was reported in 8/26 (30.8%); 1 visual impairment, 2 rashes and 5 dizziness, for SAZ was in 4/26 (15.4%); 1 nightmare and 3 GI disturbance, for AZA 3/26 (11.5%) reported weakness, and 1 reported diarrhea while on mycophenolate mofetil.

18/21(86%) of the patients off DMARDs in the week prior to clinic visit were attending Mulago Hospital Rheumatology Clinic *vs*. 3/21 (14%) from Nsambya Hospital (p = 0.01).

Regarding the health profiles of the participants, 71 (96%) participants reported at least one activity limitation. Any level of problem was reported by 54 (72.5%) participants for mobility, 47 (63.5%) for self-care, 56 (75.6%) for usual activity, 66 (89.1%) for pain and discomfort, and 56 (75.6%) for anxiety/depression (Table 2). Table 3 summarizes the health indices and overall self-rated health status of patients across sociodemographic and clinical characteristics.

4. Discussion

Understanding PROs influence treatment decisions and inform clinical care in patients with autoimmune rheumatic disease [19,20]. In the present study, among Ugandan patients with autoimmune rheumatic diseases, over 95% of the patients reported at least one activity limitation. This finding is consistent with the 2020 American College of Rheumatology (ACR) patients survey, where about 83% of people living with a RD reported at least one activity limitation as a result of their disease, including ability to exercise, work, and perform physical activities [21]. The present findings suggest that patients with SLE have a better QoL compared to patients with other autoimmune RDs which is in line with prior investigation [22]. Contrastingly, a recent study from Kenya showed that patients with SLE had significantly low health-related QoL [23]. This is probably because the Kenyan patients were much younger age compared to the current participants. Consistent with the Kenyan study, a recent study among Egyptian patients with SLE also reported a substantial negative impact of disease on QoL [24]. Remarkably, participants with duration of illness of 4 years or less and those who were on DMARDs for <1 year had higher health indices. Equally remarkably, overall self-rated health status was comparable across groups and sub groups of illness duration and duration of uninterrupted DMARDs therapy.

Age, disease severity and co-morbidities are important predictors of QoL of patients with autoimmune diseases [19,23,25]. Thus it was not surprising that patients who reported controlled or mild disease and those who reported satisfaction with DMARDs had higher health indices and high self-rated health status. Current rheumatic management guidance emphasizes the treat-to-target approach, as patients in remission or low disease activity tend to have better QoL indices [20]. However, access and affordability of both conventional and biologic DMARDs remains a challenge worldwide [21,26]. Indeed, none of the present participants was

Table 2
EuroQol 5-dimension 5-level (EQ-5D-5L) questionnaire frequencies and proportions reported by rheumatic disease patients.

Degree of affection n (%)	5 EuroQoL dimensions in RD patients (n = 74)				
	Mobility	Self-care	Usual activity	Pain/discomfort	Anxiety/Depression
Level 1 (*no problem*)	20 (27)	27 (36.5)	18 (24.3)	8 (10.8)	18 (24.3)
Level 2 (Slight)	26 (35.1)	23 (31.1)	26 (35.1)	23 (31.1)	26 (35.1)
Level 3 (Moderate)	15 (20.3)	15 (20.3)	20 (27.0)	26 (35.1)	20 (27.0)
Level 4 (Severe)	12 (16.2)	8 (10.8)	6 (8.1)	17 (23)	8 (10.8)
Level 5 (Extreme)	1 (1.4)	1 (1.4)	4 (5.4)	0 (0)	2 (2.7)

RD: rheumatic disease.

Table 3
Health index and overall self-rated health status of the rheumatic disease patients across sociodemographic and clinical characteristics.

Variable mean ± SD	RD patients (n = 74)			
	Health index	p	Self-rated health status	p
Total score	0.64 ± 0.16	–	58.1 ± 16.7	
Hospital				
Mulago *vs* Nsambya	0.59 ± 0.18 *vs* 0.72 ± 0.11	**<0.0001**	53.7 ± 17.2 *vs* 63.6 ± 14.3	**0.01**
Age ≤ 45 *vs* > 45 y	0.66 ± 0.14 *vs* 0.63 ± 0.19	0.52	58.6 ± 15.6 *vs* 57.7 ± 17.8	0.82
Female *vs* male	0.64 ± 0.16 *vs* 0.74 ± 0.18	0.16	57.6 ± 16.6 *vs* 65 ± 18	0.34
Marital status				
Single	0.67 ± 0.17		57.1 ± 18.9	
Married	0.63 ± 0.14	0.63	59.8 ± 15.7	0.87
Widow/er	0.61 ± 0. 21		59.6 ± 15.9	
Divorced	0.63 ± 0.11		55 ± 12.8	
Education level				
Informal	0.68 ± 0.14		60.8 ± 20.1	
Primary	0.59 ± 0.16	0.23	55.5 ± 14	0.85
Secondary	0.63 ± 0.17		59.4 ± 16.2	
High	0.69 ± 0.16		58.6 ± 18.6	
Employment				
Formal *vs* Informal	0.67 ± 0.17 *vs* 0.63 ± 0.16	0.3	61 ± 16.6 *vs* 56.6 ± 16.7	0.29
Finance support: y *vs* n	0.64 ± 0.16 *vs* 0.67 ± 0.67	0.53	58.2 ± 16.9 *vs* 57.9 ± 16.4	0.95
Clinical diagnosis				
RA	0.60 ± 0.17		55.7 ± 17.4	
SLE	0.74 ± 0.12	**0.007**	63.9 ± 17.0	0.23
Others	0.70 ± 0.1		60.8 ± 11.4	
DD. ≤ 48 *vs* > 48 mo	0.68 ± 0.13 *vs* 0.60 ± 0.19	**0.03**	61.3 ± 15.4 *vs* 54.4 ± 17.5	0.08
Disease severity				
Controlled	0.74 ± 0.11		72.5 ± 14.4	
Mild	0.72 ± 0.12		65 ± 13.1	
Moderate	0.65 ± 0.16	**<0.0001**	55.5 ± 15.2	**<0.0001**
Severe	0.47 ± 0.09		45 ± 15.5	
Very severe	0.57 ± 0.23		51 ± 15.6	
ttt satisfaction: y *vs* n	0.67 ± 0.15 *vs* 0.47 ± 0.19	**0.001**	60.8 ± 15 *vs* 38.9 ± 16.4	**<0.0001**
Herbal ttt: y *vs* n	0.56 ± 0.23 *vs* 0.66 ± 0.14	**0.03**	47.9 ± 23.2 *vs* 60.5 ± 14	**0.01**
ADR: y *vs* n	0.63 ± 0.18 *vs* 0.65 ± 0.16	0.52	57.9 ± 13.4 *vs* 58.2 ± 18.3	0.93
Co-morbidity: y *vs* n	0.64 ± 0.17 *vs* 0.65 ± 0.16	0.91	58.6 ± 17.7 *vs* 57.7 ± 16.1	0.05
Source of DMARDs				
Private pharmacy	0.64 ± 0.16		55.7 ± 17.0	
Nsambya hospital	0.71 ± 0.1	0.2	66.3 ± 14.9	0.83
Both	0.65 ± 0.1		58.8 ± 10.3	
Therapy ≤ 12 *vs* > 12 mo	0.68 ± 0.13 *vs* 0.59 ± 0.2	**0.04**	57.8 ± 15.4 *vs* 58.2 ± 20	0.92
Off ttt last week: y *vs* n	0.62 ± 0.19 *vs* 0.65 ± 0.18	0.77	58.1 ± 21.5 *vs* 59.4 ± 11	0.82

RD: rheumatic disease, RA: rheumatoid arthritis, SLE; systemic lupus erythematosus, DD: disease duration, ttt: treatment, ARD: adverse drug reaction, DMARD: disease modifying anti-rheumatic drug.

on a biologic DMARD. Lack of access to and non-affordability of DMARDs have negative association with disease activity and a poorer QoL [26]. This is evident in this work where patients attending care in a private hospital with better access to DMARDs had better health indices and overall self-rated health status. DMARDs are expensive and are unaffordable by most patients. In the 2020 ACR patient survey, the median annual out-of-pocket spending on treatment for RDs was $1,000 per year [21]. On average, out-of-pocket expenditure on DMARDs of our patients was about $400 per year. This is quite high and explains the high proportion of patients not being on their DMARDs the week prior to their scheduled clinic appoints. In Uganda, many DMARDs such as MTX that are on the essential medicine list, are not routinely available for the care of patients with RDs. The heavy financial burden of these diseases and their management explains the huge need for financial support observed in over 70% of the patients. Consequently, patients in private settings have better adherence and health outcomes as observed in one of the centres in the present study.

One in every 5 patients with RD reported concomitant use of herbal medication. Regrettably, this was associated with lower health index and lower overall self-rated health status. Despite the fact that ADRs were similar among those who were on herbal medications and those not, these findings should encourage clinicians to always assess for herbal medication use among these patients and provide appropriate counseling. However, it is unclear whether the poor QoL of patients on concomitant herbal medication was truly due to negative impacts of herbal medicines on RDs or because patients who showed poor response while on DMARDs had uncontrolled disease and therefore sought for herbal remedy for a better disease control. Herbal medication use remains an area of further research among these patients. Known beneficial add-on therapy in patients with RDs revolves around optimization of the management of underlying co-morbidities, physical and occupational therapies [21,27].

Our study has some important limitations. Firstly, we were unable to assess disease specific severity for the different RDs. However, we were able to elicit patients-reported disease severity which fairly correlates with disease severity scores [27-29]. Secondly, we were unable to formally assess for medication adherence using validated tools due to lack of access to license. Thirdly, we were unable to use disease specific health-related outcome measures such as Lupus QoL [22]. However, ED-5D-5L has been shown to be a reliable tool for these group of patients [30]. Lastly, measurements of test–retest reliability were not done because patients were assessed on only one clinic visit. However, this the first study

from Uganda and one of the few in the region to report on QoL of patients with autoimmune RDs receiving DMARDs. Future studies would aim at correlating health indices with disease severity and medication adherence in our setting. At policy level, we need to identify strategies to widely increase availability; accessibility and affordability of DMARDs in Uganda. It's timely to welcome clinical trials on biologic DMARDs for our patients to evaluate short- and long-term outcomes.

In conclusion, over 95% of Ugandan patients with autoimmune RDs on DMARDs have at least one activity limitation. SLE patients have better QoL compared to patients with other RDs. Concomitant use of herbal medication is common and associated with lower health index and lower overall self-rated health status.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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