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

Felix Bongomin\textsuperscript{a,b,*}, Maria Sekimpi\textsuperscript{a}, Barbra Natukunda\textsuperscript{a}, Anthony Makhoba\textsuperscript{c,d}, Mark Kaddumukasa\textsuperscript{a}

\textsuperscript{a}Department of Medicine, College of Health Sciences, Makerere University, Kampala, Uganda
\textsuperscript{b}Department of Immunology and Medical Microbiology, Gulu University Medical School, Uganda
\textsuperscript{c}Department of Medicine, St. Francis’s Hospital- Nsambya, Kampala, Uganda
\textsuperscript{d}Department of Medicine, Mother Kevin Postgraduate Medical School, Uganda Martyrs University, Kampala, Uganda

Abstract

\textbf{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.

\textbf{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.

\textbf{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).

*Corresponding author at: Department of Immunology and Medical Microbiology, Gulu University Medical School, Gulu, Uganda. dbongomin@gmail.com (F. Bongomin).

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.
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.

Keywords
Autoimmune rheumatic diseases; SLE; Rheumatoid arthritis; Health index; Patient-reported outcomes; DMARDs; 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 capture PROs. 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].

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-Nsamba, Kampala, Uganda (Nsamba Hospital) between September and December 2020. Mulago Hospital is the largest national public specialized health facility in Uganda with over 1,000-bed capacity. Nsamba Hospital is a private-not-for-profit hospital also located in Kampala. Patients ≥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

Egypt Rheumatol. Author manuscript; available in PMC 2022 August 23.
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 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 χ² tests 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 ≤ 45 years old and 40 (54.1%) had a disease duration of ≤ 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 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.

Acknowledgement

Mark Kaddumukasa was supported by a grant from the National Institute of Health (K43TW010401), The National Institute of Neurological Disorders and Stroke (NINDS) and Fogarty International Center (FIC). Felix Bongomin was supported by the Fogarty International Center of the National Institutes of Health, U.S. Department of State’s Office of the U.S. Global AIDS Coordinator and Health Diplomacy (S/GAC), and President’s Emergency Plan for AIDS Relief (PEPFAR) under Award Number 1R25TW011213 to Prof. Sarah Kiguli. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The administrative support from the 2 participating hospitals is appreciated.

Funding

This work did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

References

[1]. Zochling J, Braun J. Mortality in rheumatoid arthritis and ankylosing spondylitis. Clin Exp Rheumatol 2009;27:S127–30. [PubMed: 19822059]

[2]. Gabriel SE, Michaud K. Epidemiological studies in incidence, prevalence, mortality, and comorbidity of the rheumatic diseases. Arthritis Res Ther 2009;11(3):229. doi: 10.1186/ar2669. [PubMed: 19519924]

[3]. Schneider S, Junghaenel DU, Keefe FJ, Schwartz JE, Stone AA, Broderick JE. Individual differences in the day-to-day variability of pain, fatigue, and wellbeing in patients with rheumatic disease: Associations with psychological variables. Pain 2012;153:813–22. [PubMed: 22349917]

[4]. Burmester GR, Bijlsma JWJ, Cutole M, McInnes IB. Managing rheumatic and musculoskeletal diseases – past, present and future, Nat Rev Rheumatol 2017;13(7):443–8. [PubMed: 28615732]

[5]. US Food & Drug Administration. Patient-reported outcome measures: use in medical product development to support labeling claims 2009. https://www.fda.gov/regulatory-information/search-fda-guidance-documents/patient-reported-outcome-measures-use-medical-product-development-support-labeling-claims (accessed December 13, 2020).

[6]. Carvajal Bedoya G, Davis LA, Hirsh JM. Patient-reported outcomes in rheumatology patients with limited english proficiency and limited health literacy. Arthritis Care Res (Hoboken) 2020;72(S10):738–49.

[7]. Phuti A, Schneider M, Makan K, Tikly M, Hodkinson B. Living with systemic lupus erythematosus in South Africa: A bitter pill to swallow. Health Qual Life Outcomes 2019;17(1). doi: 10.1186/s12955-019-1132-y.
[8]. Usenbo A, Kramer V, Young T, Musekiwa A, Nurmohamed M. Prevalence of arthritis in Africa: A systematic review and meta-analysis. PLoS One 2015;10(8):e0133858. [PubMed: 26241756]

[9]. Bongomin F, Sekimpi M, Kaddumukasa M. Clinical and immunological characteristics of 56 patients with systemic lupus erythematosus in Uganda. Rheumatol Adv Pract 2020;4.

[10]. Aleataha D, Neogi T, Silman AJ, Funovits J, Felson DT, Bingham CO 3rd, et al. 2010 rheumatoid arthritis classification criteria: an American College of Rheumatology/European League Against Rheumatism collaborative initiative. Ann. Rheum. Dis 2010;69(9):1580–8. [PubMed: 20699241]

[11]. Petri M, Orbai A-M, Alarcon GS, Gordon C, Merrill JT, Fortin PR, et al. Derivation and validation of the Systemic Lupus International Collaborating Clinics classification criteria for systemic lupus erythematosus. Arthritis Rheum 2012;64(8):2677–86. [PubMed: 22553077]

[12]. Dougados M, Linden SVD, Juhlin R, Huifeldt B, Amor B, Calin A, et al. The European Spondylarthropathy Study Group preliminary criteria for the classification of spondylarthropathy. Arthritis Rheum 1991;34(10):1218–27. [PubMed: 1930310]

[13]. van den Hoogen F, Khanna D, Fransen J, Johnson SR, Baron M, Tyndall A, et al. classification criteria for systemic sclerosis: an American college of rheumatology/European league against rheumatism collaborative initiative. Ann Rheum Dis 2013;72(11):1747–55. [PubMed: 24092682]

[14]. Petty RE, Southwood TR, Manners P, Baum J, Glass DM, Goldenberg J, et al. International League of Associations for Rheumatology classification of juvenile idiopathic arthritis: second revision, Edmonton, 2001. J Rheumatol 2004;31:390–2. [PubMed: 14760812]

[15]. Bohan A, Peter JB. Polymyositis and dermatomyositis (first of two parts). N Engl J Med 1975;292(7):344–7. [PubMed: 1090839]

[16]. EuroQol - a new facility for the measurement of health-related quality of life. Health Policy (New York) 1990;16:199–208.

[17]. Sibhat SG, Fenta TG, Sander B, Gebretekle GB. Health-related quality of life and its predictors among patients with breast cancer at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia. Health Qual Life Outcomes 2019;17:165. [PubMed: 31690327]

[18]. Welie AG, Gebretekle GB, Stolk E, Mukuria C, Krahn MD, Enquoselassie F, et al. Valuing health state: An EQ-5D-5L value set for Ethiopians. Value Heal Reg Issues 2020;22:7–14.

[19]. Fanouriakis A, Kostopoulou M, Alunno A, Aringer M, Bajema I, Boletis JN, et al. 2019 Update of the EULAR recommendations for the management of systemic lupus erythematosus. Ann Rheum Dis 2019;78(6):736–45. [PubMed: 30926722]

[20]. Aringer M, Costenbader K, Daikh D, Brinks R, Mosca M, Ramsey-Goldman R, et al. 2019 European League Against Rheumatism/American College of Rheumatology classification criteria for systemic lupus erythematosus. Ann Rheum Dis 2019;78(9):1151–9. [PubMed: 31383717]

[21]. American College of Rheumatology. 2020 Rheumatic Disease Patient Survey Results. Access, Affordability & Lifestyle Challenges for Americans Living with Rheumatic Disease. http://simpletasks.org/wp-content/uploads/2020/09/ACR-Survey-2020.pdf (accessed 1st January 2021).

[22]. Greenfield J, Hudson M, Vinet E, Fortin PR, Bykerk V, Pineau CA, et al. A comparison of health-related quality of life (HRQoL) across four systemic autoimmune rheumatic diseases (SARDs). PLoS One 2017;12(12):e0189840. [PubMed: 29261752]

[23]. Nyambane E, Genga E, Achieng L, Oyoo O, Otieno FC. Assessment of disease activity and health related quality of life in patients with systemic lupus erythematosus at Kenyatta national hospital. African. J Rheumatol 2020. A121.2–A122.

[24]. Gaballah NM, El-Najjar AR. Clinical characteristics and health related quality of life (HRQoL) in Egyptian patients with systemic lupus erythematosus. Egypt Rheumatol 2019;41(2):117–21.

[25]. Wadiee S, Tikly M, Hopley M. Causes and predictors of death in South Africans with systemic lupus erythematosus. Rheumatology 2007;46(9):1487–91. [PubMed: 17681980]

[26]. Bergstra SA, Branco JC, Vega-Moraes D, Salomon-Escoto K, Govind N, Allaart CF, et al. Inequity in access to bDMARD care and how it influences disease outcomes across countries worldwide: results from the METEOR-registry. Ann Rheum Dis 2018;77(10):1413–20. [PubMed: 29980576]

[27]. Abu Al-Fadl EM, Ismail MA, Thabit M, El-Serogy Y. Assessment of health-related quality of life, anxiety and depression in patients with early rheumatoid arthritis. Egypt Rheumatol 2014;36(2):51–6.
[28]. Nikiphorou E, Radner H, Chatzidionysiou K, Desthieux C, Zabalan C, van Eijk-Hustings Y, et al. Patient global assessment in measuring disease activity in rheumatoid arthritis: a review of the literature. Arthritis Res Ther 2016;18(1). doi: 10.1186/s13075-016-1151-6.

[29]. Gamal RM, Mahran SA, Abo El Fetoh N, Janbi F. Quality of life assessment in Egyptian rheumatoid arthritis patients: Relation to clinical features and disease activity. Egypt. Rheumatol 2016;38(2):65–70.

[30]. Zhang Le, Luan W, Geng S, Ye S, Wang X, Qian L, et al. Lack of patient education is risk factor of disease flare in patients with systemic lupus erythematosus in China. BMC Health Serv Res 2019;19(1). doi: 10.1186/s12913-019-4206-y.
Table 1

Sociodemographic and clinical characteristics of the rheumatic diseases patients.

| Variable                             | 74 RD patients |
|--------------------------------------|----------------|
| Age (years)                          | 45 ± 17        |
| Female: male                         | 69:5 (13.8:1)  |
| Marital status                       |                |
| Single                               | 31 (41.9)      |
| Married                              | 22 (29.7)      |
| Widower/widower                      | 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      |
| (n = 48)                             | 23 (47.9)      |
|                                      | HCQ alone      |
|                                      | 8 (16.7)       |
|                                      | HCQ + MTX      |
|                                      | 8 (16.7)       |
|                                      | MTX + LFN      |
|                                      | 6 (12.5)       |
| Variable n (%), mean ± SD or median (range) | 74 RD patients |
|-------------------------------------------|----------------|
| SLE (n = 14)                              |                |
| HCQ + AZA                                 | 2 (4.2)        |
| HCQ + MTX + LFN                           | 1 (2.1)        |
| 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.
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          | Health index | Self-rated health status |
|-------------------|--------------|--------------------------|
|                   | RD patients (n = 74) | p       |                         |
| Total score       | 0.64 ± 0.16 | –          | 58.1 ± 16.7             |
| Hospital          |              |            |                         |
| Mulago vs Nsambya | 0.67 ± 0.18 vs 0.62 ± 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           | 0.68 ± 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 |
| Variable mean ± SD | RD patients (n = 74) |  |
|-------------------|----------------------|---|
|                   | Health index         | p | Self-rated health status | p |
| Severe            | 0.47 ± 0.09          |   | 45 ± 15.5                |   |
| Very severe       | 0.57 ± 0.23          |   | 51 ± 15.6                |   |
| Current treatment: 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 treatment: 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  | 66.3 ± 14.9 | 0.83 |
| Both              | 0.65 ± 0.1  | 58.8 ± 10.3 |
| Therapy ≤12 mo 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 treatment 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.