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Systematic Review

Patient-Reported Outcome Measures in Key Sub-Saharan African Languages to Promote Diversity: A Scoping Review



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ABSTRACT

Objectives: Sub-Saharan Africa is a world region rich and diverse in cultures and languages; yet, it is also challenged with regard to resources that may facilitate the cultural adaptation or development of patient-reported outcome measures (PROMs). Systematic exclusion of patients' "voices," because of gaps in the availability of PROMs, may perpetuate health inequity. Hence, the objective is to describe the availability of PROMs in the non-English, sub-Saharan African languages.

Methods: A scoping review was conducted to identify PROMs that had been translated, validated, or developed for use in 32 selected, non-English, sub-Saharan African languages pertaining to health outcomes. Four databases were searched (May 7, 2021), and additional articles were identified through reference screening and via corresponding authors. Data were extracted in terms of country, language, population, construct, and PROM characteristics (eg, number of items).

Results: A total of 220 unique articles were included from 7451 records, leading to the identification of 126 unique PROMs. Most studies were conducted in either Ethiopia, Nigeria, or South Africa. As such, prevalent languages included Amharic, Yoruba, and non-English languages common to South Africa (eg, Setswana, Xhosa, and Zulu). No PROMs were identified in any of the languages for 27 sub-Saharan African countries or 10 of the 32 included languages.

Conclusions: There are significant gaps in the availability of PROMs across the non-English African languages included. Nevertheless, the PROMs that were identified largely align with core outcome sets relevant to the prevalent disease burden in this world region. Consensus-based priority setting may inform the most pertinent gaps to be addressed.

Keywords: Africa, global health, health equity, language, patient-reported outcome measures.

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Introduction

When implementing access to all types of health services, from health promotion to rehabilitation and palliative care, emphasis is placed on the fact that quality healthcare systems should not only focus on preventing and treating disease but also assist in improving well-being and quality of life (QOL).¹ Aspects of health status, such as symptom experience, well-being, or QOL, are key examples of patient-reported outcomes, often assessed using patient-report outcome measures (PROMs).² PROMs aim to derive information regarding a patient's health status, directly from the patient, without interpretation of the patient's response by anyone other than the patient themselves.³ Hence, as derived directly from the patient, PROMs can be considered a means to capture the patient's voice in a quantitative manner. PROMs can be used in routine clinical practice to assess or monitor patient symptoms and outcomes, are increasingly being used in research and clinical trials,^{4–6} and are imperative in informing economic and health policy.⁷ Nevertheless, it is crucial to appreciate that a "patient's voice" in part, is shaped by experience, learning, and

culture.⁸ As such, the development and translation of PROMs to different languages and settings requires a rigorous process to re-establish their validity and reliability,⁹ as well as to safeguard comparability between outcomes and outcome scores.

Sub-Saharan Africa is a world region rich in diverse cultures and languages, which also faces resource constraints that may affect research that can inform health policy and the implementation thereof.¹⁰ In addition, the region is facing further challenges, such as a rapid shift in the burden of disease,¹¹ geographical constraints, and limited human resources, among others.¹⁰ One could argue that against the background of a world region richly diverse in cultures and languages, resource limitations may hamper the ability to develop or translate PROMs that could be deemed particularly relevant in light of the prevailing disease burden and essential to promoting inclusivity.²

Although English is spoken in around half (46%) of the 48 sub-Saharan African countries, only an estimated ~16% of the total sub-Saharan African population speaks some level of English, either as a first language or second language.¹² Considering that most PROMs originate in languages (eg, English) commonly used

in “developed” countries, this may lead to a meaningful gap in the accessibility and availability of contextually and linguistically valid PROMs within the sub-Saharan context. The potential implications thereof include the systemic exclusion of patient populations based on language or subsequent challenges with respect to the quality (eg, ad hoc translation of PROMs) and generalizability of research (eg, exclusion of relevant populations based on language) and the monitoring of routine clinical practice (eg, exclusion of patients’ voice or selected voices). We therefore set out a 2-phased process of identifying the scope of PROMs available in widely spoken, non-English, sub-Saharan African languages (phase I) while planning a systematic appraisal of the measurement properties for the PROMs identified (phase II).² In the present report, we aim to describe the scope of PROMs available (ie, phase I) in commonly spoken, non-English, sub-Saharan African languages.

Methods

Study Design

A detailed description of this 2-phased review has been described elsewhere² and is reported in adherence to the Preferred Reporting for Systematic Reviews and Meta-Analyses reporting guidelines with scoping reviews extension.¹³ The scoping review methodology departs from the viewpoint that the “scope of evidence” at the start of the review may be largely unknown, and as such, eligibility criteria for inclusion in the review may change over time as knowledge of the scope of evidence increases. Hence, differences between the original protocol and the final review process, incited by our advanced understanding of the scope of literature, are highlighted.

Search Strategy

The search strategy is available as an online supplement to the review protocol published elsewhere.² In short, it comprises a search block for the respective 48 sub-Saharan African countries, the 31 languages, and a search block for the identification of PROMs applied to 4 databases (PubMed, Web of Science, CINAHL, and AfricaWide).² These 31 languages were spoken either by > 10 million people or national languages spoken by < 10 million people.¹² A secondary search was conducted to identify studies specific to the Chichewa language as this language was accidentally omitted from the original search strategy despite being a national language (Malawi). No restrictions applied to the language in which the article was written. References in included articles that referred to specific PROMs were screened (blinded), and all corresponding authors of included articles were requested via email to recommend any additional PROMs not identified during the data extraction process. To enable the latter, the preliminary dataset derived during the review process was shared accordingly.

Inclusion Criteria

A PROM was defined as “any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or other, and assessed using self-administered questionnaires.”¹⁴ Structured questionnaires, although completed by an observer (so-called observer reported outcome measures [ObsROMs]), were also eligible for inclusion. ObsROMs are those in which “observations can be made, appraised, and recorded by a person other than the patient (eg, caregiver) and do not require specialized professional training.”¹⁵ ObsROMs are intended to report the

patient’s voice; however, they are recorded by an “observer,” independent of professional training, and without the intent to add a layer of interpretation to the patient’s response by the observer. We included PROMs developed, translated, or validated in one of the 32 languages (Appendix Table 1 or protocol in Supplemental Materials found at <https://doi.org/10.1016/j.vhri.2022.11.001>) and for which the development or translation process was conducted in 1 of the 48 sub-Saharan African countries. To identify the PROMs, we included original research only, describing one of the measurement properties (eg, reliability, validity, or responsiveness), or interpretability, qualitative research for the development of PROMs, or studies in which the use of a PROM in a specific language was mentioned.

Health Outcomes

Given the scope of literature identified, we felt the need to limit our focus on PROMs directly related to health and used the Wilson and Cleary model of health for guidance.¹⁶ This enabled us to focus on PROMs related to the following:

1. Biological and physiological variables: the function of cells, organs, or organ systems. These are not commonly self-reported.
2. Symptom status: a perception, feeling or belief about the state of our body (physical) or mental health (psychophysical). Common examples are pain, fatigue, and lethargy.
3. Functional status: the ability of the individual to perform particular tasks. Can be stratified into physical function, social function, role function, and psychological function.
4. General health perceptions: integrates symptom status, functional status, and others (mental health) into a subjective interpretation of general health.
5. Overall QOL measures: general measures of how happy or satisfied they are with their life as a whole and in relation to their health status.

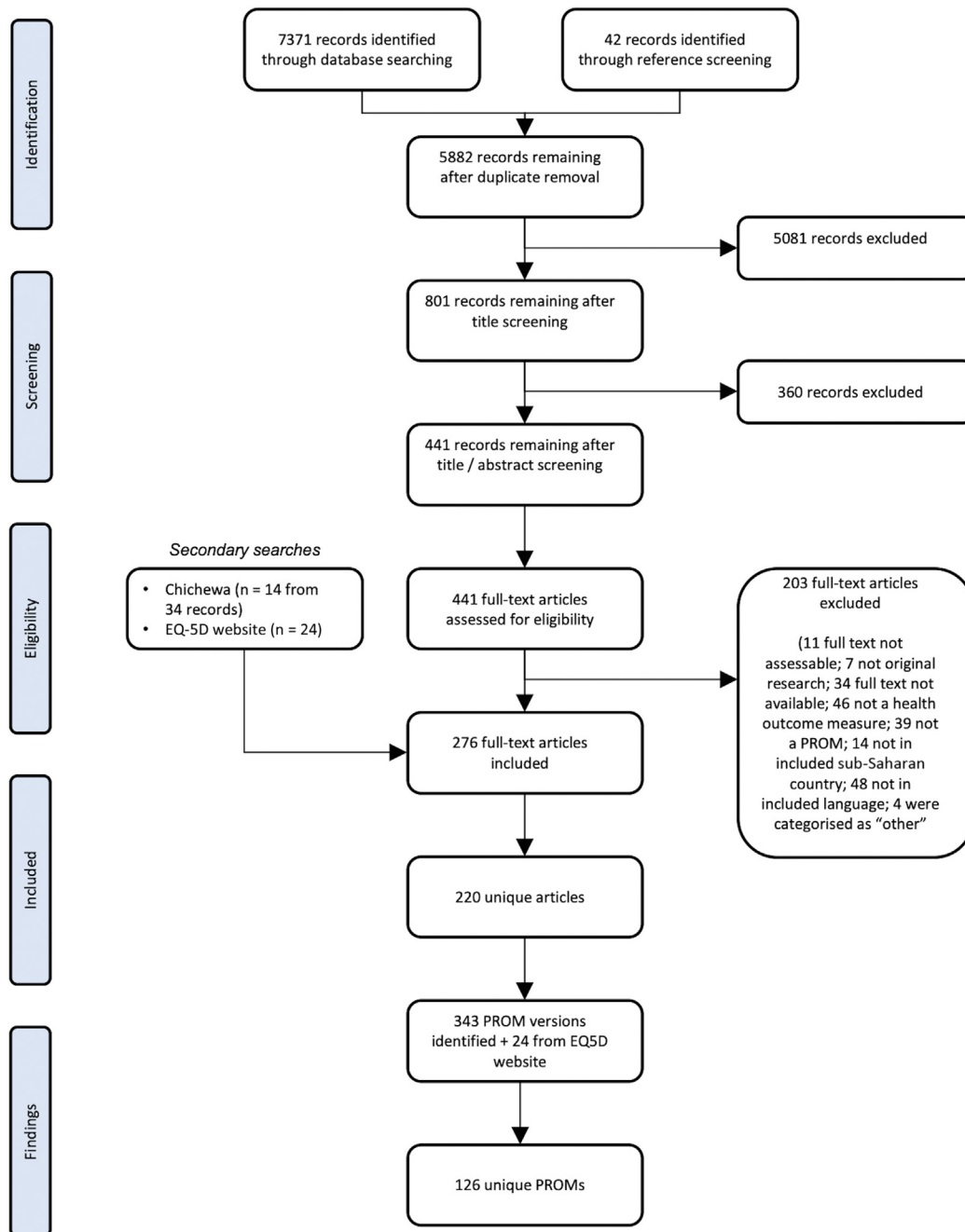
Conversely, PROMs related to individual characteristics that affect symptom experience, personal motivation, or values were therefore excluded.¹⁶ Similarly, environmental characteristics that inform psychological, social, or economic support were also excluded.¹⁶ This was a compromise because clearly, individual characteristics such as health literacy,¹⁷ physical activity,¹⁸ and others are imperative to addressing and understanding health outcomes.

Study Selection

Two reviewers (blinded) independently assessed all titles and abstract for potential eligibility. Where there were disagreements, a discussion between the 2 reviewers was used to reach consensus. The decision to only include outcomes directly related to health was arrived at after the discussion within the entire review team. After title and abstract screening, 2 reviewers (blinded) independently screened the full text articles for the identification of PROMs that met the eligibility criteria. The study selection process was streamlined using the open access platform CADIMA.¹⁹

Data Extraction

A data extraction form was created with key information pertaining to the availability of PROMs in the respective languages, including first author, study type, study population, corresponding burden of disease code, language, PROM long and abbreviated name, number of subscales, items, and construct as stated by the authors. The method of administration (eg, parent

Figure 1. Flowchart of study selection and identification of PROMs.

PROM indicates patient-reported outcome measure.

reported) used was included as part of the data extraction. In addition, we listed whether the PROM was available as part of the publication and whether the article was eligible for the second phase of this project (ie, systematic review of measurement properties).

Results

Study Selection

A total of 7371 articles were identified using the search strategy (May 7, 2021). Of these, 238 articles met the eligibility

criteria (see Fig. 1). The additional search for PROMs in the Chichewa language led to an additional 14 articles (out of 34 for title and abstract screening). Finally, 24 additional articles were identified from the EQ-5D website (<https://euroqol.org>) that were eligible. Hence, in total, 276 articles were identified that report on the development, translation, validation, or use of PROMs in one or more of the stipulated languages. Articles reporting on the same study sample were removed, leading to 220 unique studies. A total of 367 “versions” of PROMs were identified from these 220 studies. These “versions” represent a specific PROM, in a particular language, and patient population.

Description of the Included Studies and Outcome Measures

A detailed description of the included articles is tabulated and available in an online repository.²⁰ A total of 367 PROM versions, available for in-depth review via the online repository, could be consolidated into 126 unique PROMs (see Table 1²⁰). For example, the 36-item Short Form and the 12-item Short Form were considered 2 versions of the same unique PROM for the evaluation of health-related QOL (HRQOL). Most PROM versions (N = 367) originated from cross-sectional studies (n = 282, 76.8%), followed by other designs (n = 41, 11.2%), cohort studies (n = 13, 3.5%), and intervention studies (n = 7, 1.9%). In terms of the burden of disease reported, 30 disease groups were identified (Appendix Table 2 in Supplemental Materials found at <https://doi.org/10.1016/j.vhri.2022.11.001>), the most prevalent being human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) (n = 40, 20.9%), neoplasms (n = 30, 15.7%), low back pain (n = 32, 16.7%), and stroke (n = 12, 6.3%). Nevertheless, the largest proportion of PROMs were studied or used in a healthy population (n = 179, 48.8%). In 137 cases, the study population included children or adolescents (37%). Most measures (~75 out of 126 unique PROMs) were nonspecific (eg, fatigue) rather than disease specific (eg, cancer-related fatigue). In 14 instances (3.8%) the PROM was observer reported (eg, caregiver); however, in 215 instances (58.6%), PROMs were interviewer-administered rather than self-reported; possibly because of literacy-related challenges. Nearly all PROMs were translated from English to the respective language, whereas only 3 PROMs were specifically developed for the African context (in 1 PROM, region-specific items were added).

Constructs

Figure 2 shows the Wilson and Clearly model,¹⁶ populated with a consolidated overview of the key constructs that were identified (not accounting for subscales). We acknowledge that attributing PROMs to a specific Wilson and Clearly health domain (eg, general health perceptions) is not unambiguous and open for interpretation. Nevertheless, cognizant of this limitation, the most symptoms for which PROMs were identified pertained to various “degrees” (eg, psychological distress, clinical depression) and “sources” (eg, post-traumatic depression, cancer-related fatigue) of mental health, pain, or multidimensional symptom experiences. Different measures of functional status (eg, motor function, upper-extremity, and generic disability) were found. Nevertheless, many PROMs that were identified focused on (disease-specific) HRQOL or generic health perceptions, such as activity limitations or participation restrictions. As such, measures of HRQOL were the only PROMs that we allocated to both general health perception and QOL domains (Fig. 2). Measures for general well-being beyond health were scarce.

Geographical Orientation and Languages

Most PROM versions were identified from studies conducted in South Africa (n = 111, 30.2%), Nigeria (n = 81, 22.0%), or Ethiopia (n = 80, 21.7%) (see Appendix Table 3 in Supplemental Materials found at <https://doi.org/10.1016/j.vhri.2022.11.001>). Similarly, the most common languages identified were those spoken in these 3 countries, including Amharic (n = 79, 21.5%), Yoruba (n = 40, 10.9%), Xhosa (n = 38, 10.4%), Setswana (n = 27, 8.0%), and Afrikaans (n = 26, 7.1%) (see Appendix Table 2 in Supplemental Materials found at <https://doi.org/10.1016/j.vhri.2022.11.001>). For 22 of the 32 included languages, at least one or more PROMs were identified (see Appendix Table 4 in Supplemental Materials found at <https://doi.org/10.1016/j.vhri.2022.11.001>). For 10 of the stipulated languages

(representing > 63 million people), no PROMs were identified, and no studies were identified from 27 of the 48 sub-Saharan African countries (see Appendix Tables 5 and 6 in Supplemental Materials found at <https://doi.org/10.1016/j.vhri.2022.11.001>).

Discussion

To our knowledge, this review is the first to map the scope of patient- and observer-reported health outcome measures across 32 non-English, sub-Saharan African languages. A total of 126 unique PROMs were identified, from 367 different versions, that enable a patient perspective on key symptoms, functional status, and HRQOL. Herewith, we discuss our findings and place these in the context of the burden of disease in sub-Saharan Africa,¹¹ as well as recommendations (eg, core outcome sets) for PROMs across key patient populations.

Historically, the burden of disease in sub-Saharan Africa has been dominated by infectious diseases (eg, HIV/AIDS, Tuberculosis, Malaria, and Leprosy) and maternity-related conditions (eg, preeclampsia, malnutrition).¹¹ Therefore, it was no surprise that PROMs being studied in patients with HIV/AIDS (17%), as well as PROMs being studied in pre- or postnatal women, constituted a significant body of the literature identified in this review. Nevertheless, other communicable diseases, or neglected tropical diseases,²¹ were largely absent (eg, Tuberculosis). Given the increasing burden of noncommunicable diseases, as alluded to, the extent to which the availability of PROMs aligns with the shifting research priorities is of particular interest.¹¹ Interestingly, within the realm of various cancer populations, as well as in patients with cardiovascular disease (stroke in particular), a promising availability of PROMs was identified in the respective languages and countries. Nevertheless, possibly one of the most pertinent gaps was the use or study of PROMs in patients with diabetes mellitus (5 unique PROMs identified of which 4 focused on HRQOL). The prevalence of type 2 diabetes in sub-Saharan Africa has increased by 51% between 1990 and 2019, leading to a 136% increase in disability-adjusted life-years during the same period. Nevertheless, although few included studies recruited patients with diabetes specifically, many of the non-disease-specific measures (eg, Short Form 36) may be easily adopted and relevant for both patient and provider. Furthermore, the near infinite combinations of languages, cultures, and health outcomes provides for a difficult conundrum.

Apart from the burden of disease for which PROMs have been translated, one of the primary aims of this review was to explore the hypothesis of gaps in the availability of PROMs in languages other than English, which are widely spoken across the region. For example, screening for PROMs available in 32 of the widely spoken or national languages, we found that for 10 languages no PROMs were found, and very few (≤ 15 PROMs) were found for another 14 languages. Hence, there is a clear gap in terms of PROMs available; yet, it is difficult to value the scale of this gap specifically. It is clearly impossible to translate and validate all pivotal health outcomes into, for example, 525 languages, to use Nigeria as a case example. To further complicate matters, some of these languages may only be spoken (not written) or are sign languages. Nevertheless, on the other hand, we need to be cognizant of the potential effect that the systematic exclusion of patients based on language may have on the external validity of research findings and the subsequent health policy that these research findings ideally inform. One way to prioritize “what” PROMs are being translated is to look at core outcome sets for specific patient populations. For example, the core outcome set for HIV/AIDS studies includes 3 PROMs related to HRQOL, depression,

Table 1. Consolidated overview of the unique PROMs identified.

Measurement tool (Abbreviation)	Construct	N Items	Country (no. of times included)	Language(s)	Population
Adult ADHD self-report scale (ASRS)	ADHD symptoms	32	South Africa	Xhosa	ADHD
Affectometer 2 (AFM)	Level of psychological well-being	20	South Africa	Setswana	Healthy (urban and rural areas)
Beck anxiety inventory (BAI)	Anxiety symptoms	21	South Africa	Xhosa	Patients/students with psychiatric disorders
Beck depression inventory/-II (BDI/-II)	State of depression	21	Kenya; Malawi; Nigeria; South Africa (2)	Chichewa; Swahili; Hausa; Xhosa	Adults with HIV/AIDS and caregivers of adolescents with HIV/AIDS; stroke; community and institutional participants; patients/students with psychiatric disorders; HIV (children)
Body image quality of life inventory (BIQLI)	HRQOL	19	Mozambique	Portuguese	Students
Brief fatigue inventory (BFI)	Cancer-related fatigue	10	Ethiopia	Amharic	Cancer
Brief pain inventory (BPI)	Pain severity	15	Ethiopia; South Africa (2)	Amharic; Xhosa	Cancer; women living with HIV/AIDS
Bristol activities of daily living scale (BADL)	Activities of daily living	UNK	South Africa	Xhosa	Community and institutional participants
Caregiver quality of life index - cancer (CQOL)	Caregivers' QOL	35	Ethiopia	Amharic	Primary family caregivers of patients with cancer
Center for epidemiologic studies depression scale (CES-D)	Rating of depression symptoms	10	South Africa (8); Botswana	Zulu; Xhosa; Afrikaans; Setswana	Participants aged 15 and older - household members; HIV; young women and men from urban informal settlements; multidisciplinary development team; adolescents; healthy
Chichewa pediatric patient-reported outcome measurement information system pediatric (PROMIS-25)	Mental health	6	Malawi	Chichewa	Lymphoma
Children's depression inventory-ii-short (CDI-II-Sii-s)	Depressive symptoms in children	12	Malawi	Chichewa	HIV (children)
Child behavior checklist (CBCL)	Identification of behavioral/emotional problems	9	Kenya; Mauritius; Ethiopia	Swahili; Creole; Somali	Child and caregiver pairs; Parents (mothers, fathers or caretakers) of children aged 1-6 years; children
Child oral health impact profile (COHIP)	Oral HRQOL	38	Ethiopia; Sudan (2)	Amharic; Arabic	Children/adolescents with orofacial clefts; Healthy children
Child post-traumatic disorder symptom scale (CPSS-I)	Post-traumatic disorder symptoms in children	17	Ethiopia	Somali	Child and caregiver pairs
Childhood trauma questionnaire (CTQ)	Trauma-related symptoms	UNK	South Africa	Xhosa	Women living with HIV/AIDS
Children's dermatology life quality index (CDLQI)	HRQOL	10	Nigeria	Yoruba	Atopic dermatitis
Denture Satisfaction Questionnaire (DSQ)	Satisfaction with complete denture treatment	UNK	Sudan	Arabic	Participants with complete dentures for both jaws
Depression, anxiety and stress scale 21 (DASS-21);	Depression, anxiety and stress	42	Sudan	Arabic	Chronic kidney disease

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Table 1. Continued

Measurement tool (Abbreviation)	Construct	N Items	Country (no. of times included)	Language(s)	Population
Dermatologic life quality index (DLQI)	Dermatologic HRQOL	10	Ethiopia (4); South Africa	Amharic; Xhosa	Leprosy; lymphatic filariasis; podoconiosis; skin disorders
Diabetes-39 (D-39)	HRQOL in Diabetes	39	Rwanda	Kinyarwanda	Diabetes Mellitus
Disabilities of the arm, shoulder, and hand (DASH)	Upper-extremity disability	30	Nigeria; South Africa (2)	Yoruba; Afrikaans	Upper-extremity musculoskeletal disorders; hand injury or condition; upper limb conditions
Early childhood oral health impact scale (ECOHIS)	Impact of oral health problems	13	Madagascar; Nigeria	Malagasy; Pidgin	Children 2-5 years old with oral health conditions (and their parents/caregivers); Parents or other adults accompanying children aged 3-5 years
Edinburgh postpartum depression scale (EPDS)	Postpartum depression	10	The Gambia; Ethiopia; Tanzania; Malawi	Wolof; Amharic; Swahili; Chichewa	Pregnant women; postpartum/natal women
Eleven-point box scale (BS-11)	Pain	1	Nigeria (3)	Igbo	Chronic low back pain
Enforced social dependency scale (ESDS)	Measure of the personal and social functional abilities of patients with cancer	UNK	Botswana	Setswana	Cancer
EQ-5D/3L/5L/Y	HRQOL	4/6	Ethiopia (3); Malawi (4); South Africa (21); Botswana; Rwanda; Somalia; Tanzania (2); Kenya; Mauritius; Sudan; Cameroon	Amharic; Chichewa; Afrikaans; Xhosa; Setswana; Kinyarwanda; Somali; Zulu; Swahili; French; Arabic; Sotho; Tsonga	Cervical cancer; adults with a distal radius fracture, an open tibia fracture or hip joint pathology; Patients with disabilities; HIV/AIDS; Healthy adolescents; Breast cancer; idiopathic patients with Parkinson's disease and caregivers; musculoskeletal disorders
EURO-D	Existing depressive symptoms	3	South Africa	Xhosa	Community dwellers aged \geq 60 years
European organization for research and treatment of cancer - cervical cancer module (EORTC QLQ-CX24)	Cancer-specific disability	24	Ethiopia (2); South Africa	Amharic; Afrikaans	Cervical cancer
European organization for research and treatment of cancer quality of life questionnaire (EORTC QLQ-C30)	HRQOL in cancer	30	Ethiopia (8); South Africa (2)	Amharic; Xhosa; Zulu	Cancer (cervical, gynecological, breast); HIV-associated Kaposi Sarcoma
European organization for research and treatment of cancer quality of life questionnaire - breast cancer module (EORTC QLQ-BR 23)	HRQOL in breast cancer	23	Ethiopia (3)	Amharic	Breast cancer
Functional assessment of cancer therapy - breast (FACT-B)	HRQOL in breast cancer	37	Senegal	Wolof	Breast cancer
Functional assessment of cancer therapy - general (FACT-G)	HRQOL in cancer	34	South Africa (4)	Setswana; Zulu	Cancer
Functional assessment of HIV infection (FAHI)	HRQOL in patients with HIV	47	Kenya	Swahili	People living with HIV

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Table 1. Continued

Measurement tool (Abbreviation)	Construct	N Items	Country (no. of times included)	Language(s)	Population
Gastrointestinal symptom rating scale (GSRS)	Gastrointestinal symptom severity	15	South Africa	Afrikaans	Symptoms of heartburn
General health questionnaire (GHQ)	Psychiatric morbidity	12/28	South Africa; Nigeria (3); Botswana; Niger	Setswana; Yoruba; French	Healthy (urban and rural); Schizophrenia patient/caregiver dyads Chronic wounds; General population (clinic attendees); healthy (young refugees and internally displaced people)
General psychological well-being scale (GPWS)	General psychological well-being	20	South Africa	Setswana	Healthy (rural)
Generalized anxiety disorder scale (GAD-7)	Severity of generalized anxiety disorder	7	Kenya	Swahili	People living with HIV
Geriatric depression scale (GDS)	Depression among the elderly	30	Nigeria	Yoruba	Elderly
Geriatric oral health assessment index (GOHAI)	Oral HRQOL	12	Sudan	Arabic	Participants with complete dentures for both jaws
Glaucoma quality of life-15 questionnaire (GQL-15)	HRQOL with regard to perceived visual disability	15	Ethiopia	Amharic	Glaucoma; healthy eyes
Gross motor function classification system family questionnaire (GMFCSFQ)	Motor function/ functional ability	5	Nigeria	Yoruba	Children with cerebral palsy and their primary caregivers
Hamilton anxiety and depression scale (HADS)	Depression and anxiety	UNK	Cameroon	French	Idiopathic patients with Parkinson's disease and caregivers
Harvard trauma questionnaire (HTQ)	Trauma-related symptoms	17	Ethiopia; South Africa (7)	Somali; Xhosa, Zulu; Afrikaans	Adult refugees; healthy; women living with HIV/AIDS
Health assessment questionnaire (HAQ)	ADL activities	UNK	Nigeria	Yoruba	Persons aged 65 years old and over
Hopkins symptom checklist 37 for adolescents (HSCL-37A)	Severity of DSM-IV-based symptoms	37	Congo	Swahili	Adolescents
Hopkins symptom checklist-15 (HSCL-15)	Depressive symptoms	15	Rwanda	Kinyarwanda	HIV/AIDS
Hospital anxiety and depression scale (HADS)	Anxiety and depression	14	Nigeria (2); Ethiopia	Igbo; Yoruba; Amharic	Chronic low back pain; chronic wounds; HIV/AIDS
Ibadan knee/hip osteoarthritis outcome measure (IKHOAM)	Activity limitations and participation restrictions in osteoarthritis	28	Nigeria	Hausa	Knee osteoarthritis
Impact of event scale revised (IES-R)	Prevalence of post-traumatic stress symptoms	22	Congo	Swahili	Adolescents
Infants' dermatitis quality of life index (IDQOL index)	HRQOL	10	Nigeria	Yoruba	Atopic dermatitis
International index of erectile dysfunction (IIEF)	Erectile dysfunction	UNK	Sudan	Amharic	Patients with chronic kidney disease on hemodialysis and those who underwent renal transplant
Juvenile arthritis multidimensional assessment report (JAMAR)	Disease status	UNK	South Africa	Afrikaans	Juvenile idiopathic children with arthritis

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Table 1. Continued

Measurement tool (Abbreviation)	Construct	N Items	Country (no. of times included)	Language(s)	Population
KATZ index of independence in activities of daily living 13	Assessment of activities of daily living	UNK	Nigeria	Yoruba	Persons aged \geq 65 years
KESSLER-6/10 (K-6/10)	Mental/psychological distress	6 / 10	Ethiopia (8); Tanzania	Amharic; Swahili	Mothers; patients with HIV with and without TB; healthy adults; patients attending primary healthcare facilities; podoconiosis; postnatal women; traumatic brain injury
Kidney disease quality of life short form 36 (KDQOL-36)	HRQOL in kidney disease	36	Sudan	Arabic	Chronic kidney disease
King's health questionnaire (KHQ)	Impact of urinary incontinence on QOL	31	South Africa (2)	Afrikaans; Xhosa	Urinary incontinence
Leeds dyspepsia questionnaire short form (SF-LDQ)	Frequency and severity of dyspepsia related symptoms	UNK	Rwanda	Kinyarwanda	Dyspepsia
Lower extremity functional scale (LEFS)	Assessment of lower limb functional ability	20	Rwanda	Kinyarwanda	People living with HIV
M.D Anderson symptom inventory (MDASI)	Symptom severity and impact on daily living	13	Ethiopia	Amharic	Cancer
Major depression inventory (MDI)	Depressive symptoms	12	Kenya	Swahili	Young people (13-24 years) - healthy
Medical outcomes study HIV health survey (MOS-HIV)	HRQOL in HIV	35	Rwanda; South Africa	Kinyarwanda; Zulu	HIV/AIDS; Multidisciplinary development team
Memorial symptom assessment scale - short form (MSAS-SF)	Multidimensional cancer-related symptoms	30	Botswana	Setswana	Cancer
Mental health continuum-short form (MHC-SF)	Mental health	14	South Africa (3)	Setswana	Healthy (urban and rural areas);
Modified BORG scale (MBS)	Dyspnea	1	Nigeria	Yoruba	Asthma
Modified verbal rating scale for pain (MVRS)	Pain	1	Nigeria	Yoruba	Osteoarthritis
Nagi physical performance scale	Instrumental activities of daily living	UNK	Nigeria	Yoruba	Persons aged \geq 65 years
Nepean dyspepsia index-short form (SF-NDI)	Quantification of dyspeptic symptom severity	UNK	Rwanda	Kinyarwanda	Dyspepsia
Numerical pain rating scale (NPRS)	Pain	1	Kenya; Nigeria	Swahili; Hausa	Inpatients (random) > 8 years; Chronic low back pain
Oral health impact profile-14 (OHIP-14)	Oral HRQOL	14	Sudan (2)	Arabic	Outpatient dental clinic patients; Complete dentures for both jaws
Oral impact on daily performance (OIDP) (Child version as well; CHILD-OIDP)	Oral HRQOL	8	South Africa; Tanzania; Madagascar; Sudan (2)	Afrikaans; Swahili; Malagasy; Arabic	General population (relatively well off and socially disadvantaged); Children attending standard 7 in public primary schools/Healthy; Adults; Mucocutaneous diseases (with and without oral mucosal lesions)
Oswestry disability index (ODI)	Functional disability	10	Nigeria (6)	Hausa; Yoruba	Chronic low back pain

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Table 1. Continued

Measurement tool (Abbreviation)	Construct	N Items	Country (no. of times included)	Language(s)	Population
Pediatric quality of life inventory (PEDSQL)	HRQOL in children	23	Nigeria	Yoruba	Healthy adolescents
Pain self-efficacy questionnaire (PSEQ)	Measure a patients' belief in their abilities to perform a number of activities	10	Ethiopia	Amharic	Chronic low back pain
Parkinson's disease screening questionnaire (PDSQ)	Self-reported symptoms of typical of Parkinson's disease	9	South Africa (3)	Afrikaans; Setswana; Zulu	Healthy local residents/ local residents living near a ferromanganese smelter
Parkinson's disease questionnaire (PDQ-39)	Parkinson's Disease-specific HRQOL	39	South Africa (3)	Zulu; Afrikaans; Setswana	Healthy local residents/ local residents living near a ferromanganese smelter
Participation scale (P-SCALE)	Participation restrictions	18	Nigeria (2)	Igbo	Hansen's disease/Leprosy
Patient health questionnaire 2/6/8/9 (PHQ-2/6/8/9)	Psychological distress/ depression	2/6/8/9	Ethiopia (14); Malawi; South Africa (5); Botswana; Kenya (2); Tanzania; Rwanda; Mozambique	Amharic; Chichewa; Zulu; Xhosa; Afrikaans; Setswana; Somali; Swahili; Kinyarwanda; Portuguese; Oromo	Leprosy; Lymphatic filariasis; Podoconiosis; Participants aged \geq 15 -household members; Pregnant women/ pregnant women in the second and third trimester; Adult refugees; Malnourished children between 6 months and 5 years with their primary caregivers; HIV/AIDS; Head and neck cancer; Epilepsy; Postpartum women; Type 2 diabetes; Primary caregivers of children; Patients/patients attending primary healthcare facilities; Adults attending outpatient departments; Female heads of household; Adults in a rural community
Pelvic floor distress inventory-20 (PFDI-20)	HRQOL in pelvic floor disorders	20	South Africa (2);	Afrikaans; Sotho	Pelvic floor dysfunction vs not
Pelvic floor impact questionnaire 7 (PFIQ-7)	Symptom impact in pelvic floor disorders	7	South Africa (2)	Sotho; Afrikaans	Pelvic floor dysfunction vs not
Pelvic organ prolapse quality of life (P-QOL)	HRQOL	20	Ethiopia (2)	Amharic	Pelvic organ prolapse
Pelvic organ prolapse symptom score (POP-SS)	Pelvic organ prolapse symptom severity	7	Ethiopia	Amharic	Pelvic organ prolapse
Perceived health scale (PHS)	Perception of health	5	Angola	Portuguese	Elderly
Perceived wellness survey (PWS)	Perception of wellness	36	South Africa	Setswana	Healthy (South African Police Service personnel) officers
Post-traumatic stress disorder list - civilian version (PCL-C)	PTSD symptoms	17	Kenya	Somali	Refugee youth
Post-traumatic Stress diagnostic scale (PDS)	Post-traumatic stress	UNK	Somalia (2)	Somali	Female caregivers of children and pregnant women; pregnant women; Ex-combatants

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Table 1. Continued

Measurement tool (Abbreviation)	Construct	N Items	Country (no. of times included)	Language(s)	Population
Psychological screening for young children aged 3 to 6 (PSYCa 3-6)	General level of psychological distress	22	Niger	Hausa	Mothers and caregivers of children 3-6 years old
Quality of life in reflux and dyspepsia questionnaire (QOLRAD)	HRQOL in reflux and dyspepsia	25	South Africa	Afrikaans	Symptoms of heartburn
Quick inventory of depressive symptomatology self-report (QIDS-SR)	Depressive symptom severity	UNK	Nigeria	Yoruba	Persons aged \geq 65 years
Reintegration to normal living index (RNLI)	Perceived reintegration to normal living after an incapacitating illness	11	Nigeria	Igbo	Mobility restrictions
Revised fibromyalgia impact questionnaire (FIQR)	Health status in fibromyalgia	UNK	South Africa (2)	Afrikaans; Xhosa	Fibromyalgia
Rhinosinusitis disability index (RSDI)	HRQOL in chronic sinusitis	30	Nigeria	Yoruba	Adults with chronic sinusitis
Roland Morris disability questionnaire (RMDQ)	Disability	24	Nigeria (7)	Igbo; Yoruba; Hausa	Chronic low back pain; rural and urban patients with low back pain
Satisfaction with life scale (SWLS)	General satisfaction with life	5	South Africa (2); Angola (2); Togo	Setswana; Portuguese; French	Healthy (urban and rural areas, elderly, students, school and high-school students, young adults, and adults)
SCOPA - AUT	Presence of autonomic symptoms	UNK	Cameroon	French	Parkinson's disease
SCOPA - SLEEP SCALE	Nocturnal sleep disorders and diurnal drowsiness	UNK	Cameroon	French	Parkinson's disease
Screening of activity limitation and safety awareness scale (SALSA)	Measures activity limitations	20	Nigeria (2);	Igbo	Leprosy/Hansen disease
Self-efficacy for managing chronic disease 6-item scale (SE-6)	Self-efficacy	UNK	South Africa	Xhosa	Women living with HIV/AIDS
Self-reporting questionnaire (SRQ)	Psychological distress	20	Ethiopia (4); Malawi; Sudan; The Gambia; Rwanda; Somalia	Amharic; Arabic; Chichewa; Wolof; Kinyarwanda; Somali	HIV; patients attending primary healthcare facilities; postpartum women; pregnant women; healthy; mental disorders; ex-combatants; general population, people "in non-psychiatric treatment" and people "in psychiatric treatment": urban and rural
Sexual function and influence of urinary incontinence questionnaire (SFIUIQ)	Sexual dysfunction	20	South Africa	Afrikaans	Incontinence
Sheehan disability scale (SDC)	Role impairment due to depression	UNK	Nigeria	Yoruba	Persons aged \geq 65 years
Short form-8/12/36 health survey (SF-8/12/36)	HRQOL	8/12/36	Ethiopia (5); Botswana; Nigeria (5); South Africa (4)	Amharic; Setswana; Hausa; Yoruba; Zulu; Swahili; Afrikaans	HIV/AIDS; chronic low back pain; general rural population and groups with schizophrenia, bipolar and depression; tuberculosis; diabetes; apparently healthy individuals

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Table 1. Continued

Measurement tool (Abbreviation)	Construct	N Items	Country (no. of times included)	Language(s)	Population
Short mood and feelings questionnaire (SMFQ)	Depressive symptoms	13	South Africa (2)	Afrikaans; Xhosa	Healthy (school students)
Short musculoskeletal function assessment questionnaire (SMFA)	Functional disability	48	Malawi	Chichewa	Musculoskeletal disorders
South African pain catastrophizing scale (SAPCS)	Pain catastrophizing	13	South Africa (2)	Xhosa; Afrikaans	Fibromyalgia
Strengths and difficulties questionnaire (SDQ)	Childhood mental health status	25	Ethiopia; Nigeria; Malawi; South Africa	Amharic; Yoruba; Chichewa; Xhosa	Children < 5 years; healthy adolescents grade 8 participants; HIV (children)
Stroke impact scale (SIS)	HRQOL in stroke	59	Nigeria (2)	Hausa	Stroke
Stroke specific quality of life (SS-QOL)	HRQOL in stroke	49	Nigeria (4)	Yoruba; Hausa	Stroke
Symptom checklist revised (SCL-90R)	QOL	7	Nigeria	Hausa	Healthy (internally displaced)
The faces pain scale revised (FPS-R)	Pain	1	Kenya	Swahili	Inpatients (random) > 8 years
University of Washington quality of life questionnaire (UWQOL)	HRQOL	UNK	Kenya	Swahili	Head and neck cancer
Utation quality of life (UQOL)	HRQOL	23	Nigeria	Yoruba	Menopausal women
Verbal rating scale for Pain (VRS-pain)	Pain	1	Nigeria	Yoruba	Osteoarthritis with knee pain
Vertigo symptom scale (VSS)	Vertigo symptoms	22	South Africa	Afrikaans	Vertigo
Visual analog scale (VAS) - pain/dyspnea	Measure of pain, dyspnea, and fatigue	1	Nigeria (10); Cameroon; South Africa	Yoruba; Hausa; Xhosa; Igbo; French	Asthma; idiopathic patients with Parkinson's disease and caregivers; chronic low back pain; community and institutional participants; hip or knee osteoarthritis
Washington group short set of questions on disability	Disability	5	South Africa (2)	Xhosa; Zulu	Healthy
Wisconsin brief pain questionnaire (WBPQ)	Pain intensity and interference	11	South Africa (4)	Setswana; Tsonga; Xhosa; Zulu	Patients who are HIV-positive
World Health Organization disability assessment schedule (WHODAS)	Disability	12/36	Ethiopia (6); South Africa (3); Nigeria (2)	Amharic; Zulu; Xhosa; Afrikaans; Igbo; Yoruba	Leprosy; lymphatic filariasis; podocniosis; participants aged 15 and older - household members; road traffic trauma; people with severe mental disorders and their caregivers; chronic low back pain
World Health Organization disability assessment schedule for children (WHODAS-CHILD)	Disability in children	36	Rwanda (2)	Kinyarwanda	Children and adolescents; caregivers of Rwandan children and adolescents
World Health Organization quality of life for HIV - abbreviated (WHOQOL-HIV-BREF)	HRQOL in HIV	31	Ethiopia (6); Nigeria	Amharic; Hausa; Oromo	HIV; HIV infected adults with and without visceral leishmaniasis; patients with HIV with and without TB; patients with HIV on highly active antiretroviral therapy (HAART)

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Table 1. Continued

Measurement tool (Abbreviation)	Construct	N Items	Country (no. of times included)	Language(s)	Population
World Health Organization's 5 perceived well-being index (WHO-5)	Psychological well-being	5	Kenya; Ethiopia; Nigeria	Swahili; Amharic; Yoruba	HIV; epilepsy; primary caregivers of children; chronic wounds
World Health Organization's quality of life scale - short form (WHOQOL-BREF)	HRQOL	26	Malawi; Nigeria (7); Mozambique; Ethiopia (3)	Chichewa; Yoruba; Portuguese; Amharic; Hausa	Hemiparesis after stroke; Dental patients and students; adults attending outpatient departments; adults with podocniosis; spinal cord injury; type 2 diabetes; persons aged \geq 65 years; elderly persons; healthy adults; ischemic or hemorrhagic stroke; stroke
Zung self-rating anxiety scale (SAS)	Anxiety	19	South Africa (2)	Afrikaans; Xhosa	Healthy (school students)

Note. All abbreviations used, and proposed constructs reported, are based on the reporting in underlying articles from which these data were drawn. A full dataset, including a more in-depth specification of the various populations in which these PROMs were studied can be found elsewhere.²⁰ ADHD indicates attention-deficit/hyperactivity disorder; ADL, activities of daily living; AIDS, acquired immunodeficiency syndrome; ED-5D-3L, 3-level version of EQ-5D; EQ-5D-5L, 5-level version of EQ-5D; HIV, human immunodeficiency virus; HRQOL, health-related quality of life; PROM, patient-reported outcome measure; TB, tuberculosis; UNK, Unknown.

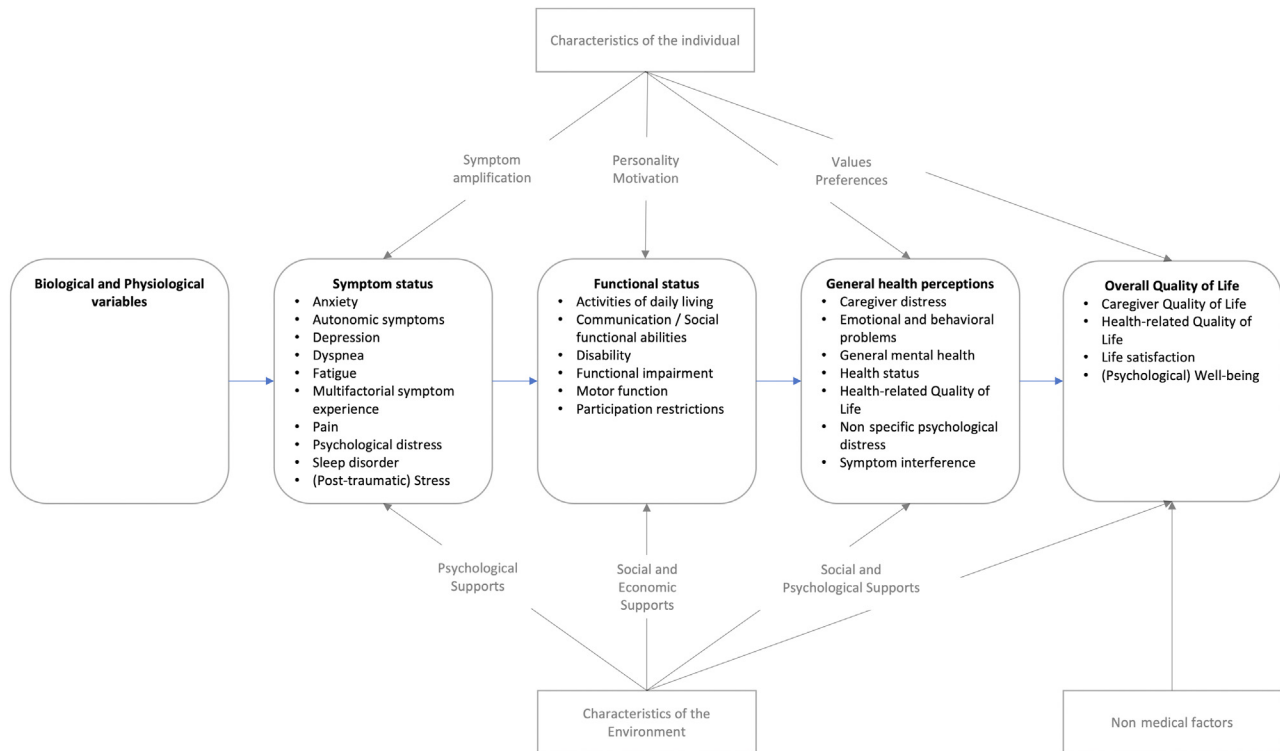
and sexual functioning.²² In addition, a recently published core outcome set for people with diabetes includes PROMs about global QOL and activities of daily living.²³ For patients with cancer, the core set included PROMs such as depression, anxiety, fatigue, and pain.²⁴ Most of these health outcomes were represented in the scope of PROMs identified, albeit with significant gaps in the languages and patient populations in which these PROMs were studied. These core outcomes, however, have been developed with very limited input from African representatives; a mere 17% of the 56 core outcome sets listed in the Core Outcome Measures in Effectiveness Trials database included participation from Africa.²⁵ Hence, there may be crucial region-specific health outcomes that are overlooked when setting priorities moving forward on the basis of these outcome sets.²⁶ Nevertheless, under the assumption that these core outcome sets are applicable to an African context, the remaining question is how “unique” each language is in relation to the “construct” being self-reported? In other words, if we translate measure A into Yoruba and Hausa (both commonly spoken in Nigeria), and no differences persist between the Yoruba and Hausa version, can we then safely translate this version to any of the other written Nigerian languages without compromising construct validity? To prioritize and collaborate toward a set of well-translated and relevant PROMs that can be used by all, and to untangle some of the challenging questions, we call for regional collaboration; how do we acknowledge all voices (do we need to?) in settings where the diversity in language is extensive (eg, Nigeria) or languages are not written (implications on quality of “reporting”?), and how may colonial roots influence the availability, access, and potential quality of reporting on self-reported patient outcomes (or the linguistic literacy in de-facto languages spoken in these settings)? First steps toward such a collaboration have been taken by allowing corresponding authors of included articles in this review to express interest for further collaboration in a sub-Saharan African Network for PROMs. Second, a regional (open access) and living repository of PROMs, or other forms of structured dissemination of PROMs available across languages,

may provide a mechanism for upscaling the use of PROMs in clinical practice and research.

Limitations

This review has some limitations. First, the findings of this review may be partially affected by the resources available for academics and clinicians within African countries to use PROMs in their respective (research) activities and, moreover, to report on these research activities in the peer-reviewed journals. This may partially explain why geographically, South Africa, Nigeria, and Ethiopia contributed significantly to the scope of literature on this topic. Limitations in research capacity have been highlighted as a key theme when low-resourced settings are considered, and as such, these limitations may affect the scope of PROMs identified in this review.¹⁰ In other words, there may be a gap in the PROMs we were able to identify through literature and the PROMs actually available and used “on the ground.” To partly counter this limitation, corresponding authors were actively engaged to identify PROMs that may not have been published or identified through our search. Second, as we focus on non-English languages, for some countries or regions, the availability of PROMs may seem inadequate when in fact English is commonly spoken and PROMs may be more readily available as such. The findings of this review are therefore limited by the way in which we selected the included languages. The implications thereof are mostly unclear. For instance, when using Ghana as an example—a former British colony where English is the national language—most inhabitants are likely more proficient in 1 of the 9 other commonly spoken Ghanaian languages. Hence, our review is by no means exhaustive in the identification of PROMs used in Ghana; it merely highlights the need to consider language as a potential important parameter moving forward in our attempt to promote health equity. Third, this review was limited to health outcomes as defined by Wilson and Cleary,¹⁶ whereas PROMs that indirectly affect health outcomes may be equally important in addressing health equity gaps. For example, some key constructs referred to frequently in relation to

Figure 2. Overview of health outcomes identified in relation to the Wilson and Cleary model.¹⁶



the increasing burden of noncommunicable disease on the African continent, such as health literacy and physical activity, were not part of this review. Moreover, there is only some, although limited, research on the applicability of the Wilson and Cleary model¹⁶ to the African region.²⁷⁻²⁹ Finally, owing to the scope of work identified and included in this review, the time between search and reporting is more than optimal (> 1 year). Hence, some PROMs may have been missed from more recent literature. Nevertheless, it is unlikely that this affects the general findings and conclusions of this review.

Conclusions

The scope of PROMs available in various non-English, sub-Saharan African languages is wide ranging and for some populations and health outcomes, match those identified as possible core outcomes. Nevertheless, the transitioning burden of disease toward chronic noncommunicable disease may be inadequately reflected, and some widely spoken languages and countries were missing within the scope of literature included. Regional collaboration may assist in consensus-driven priority setting, while circumventing pertinent resource limitations, such that key gaps in the availability of PROMs can be addressed. Addressing such gaps may be important in ensuring that the impact of language on both research and clinical practice is limited.

Supplemental Material

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REFERENCES

1. Universal health coverage. World Health Organization. <https://www.who.int/westernpacific/health-topics/universal-health-coverage>. Accessed August 13, 2020.
2. Heine M, Mokkink LB, van Zyl C, Derman W, Hanekom S. Patient-Reported Outcome measures in key African languages to promote Diversity in research and clinical practice (PROUD)-protocol for a systematic review of measurement properties. *Trials*. 2021;22(1):380.
3. Prinsen CAC, Mokkink LB, Bouter LM, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. *Qual Life Res*. 2018;27(5):1147–1157.
4. Calvert MJ, O'Connor DJ, Basch EM. Harnessing the patient voice in real-world evidence: the essential role of patient-reported outcomes. *Nat Rev Drug Discov*. 2019;18(10):731–732.
5. LeBlanc TW, Abernethy AP. Patient-reported outcomes in cancer care – hearing the patient voice at greater volume. *Nat Rev Clin Oncol*. 2017;14(12):763–772.
6. Heine M, Lupton-Smith A, Pakosh M, Grace SL, Derman W, Hanekom S. Exercise-based rehabilitation for non-communicable disease in low-resource settings: a scoping review. *BMJ Glob Health*. 2019;4(6):e001833.
7. Appleby J, Devlin N, Parkin D. *Using Patient Reported Outcomes to Improve Health Care*. Chichester, United Kingdom: John Wiley & Sons; 2015.
8. Peacock S, Patel S. Cultural influences on pain. *Rev Pain*. 2008;1(2):6–9.
9. Rabin R, Gudex C, Selai C, Herdman M. From translation to version management: a history and review of methods for the cultural adaptation of the EuroQol five-dimensional questionnaire. *Value Health*. 2014;17(1):70–76.
10. van Zyl C, Badenhorst M, Hanekom S, Heine M. Unravelling 'low-resource settings': a systematic scoping review with qualitative content analysis. *BMJ Glob Health*. 2021;6(6):e005190.
11. Gouda HN, Charlson F, Sorsdahl K, et al. Burden of non-communicable diseases in sub-Saharan Africa, 1990–2017: results from the Global Burden of Disease Study 2017. *Lancet Glob Health*. 2019;7(10):e1375–e1387.
12. Languages of the world. *Ethnologue*. <https://www.ethnologue.com/>. Accessed August 13, 2020.
13. Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*. 2018;169(7):467–473.
14. Deshpande PR, Rajan S, Sudeepthi BL, Abdul Nazir CP. Patient-reported outcomes: a new era in clinical research. *Perspect Clin Res*. 2011;2(4):137–144.
15. Walton MK, Powers 3rd JH, Hobart J, et al. Clinical outcome assessments: conceptual foundation-report of the ISPOR clinical outcomes assessment – emerging good practices for outcomes research task force. *Value Health*. 2015;18(6):741–752.
16. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life: a conceptual model of patient outcomes. *JAMA*. 1995;273(1):59–65.
17. Heine M, Lategan F, Erasmus M, et al. Health education interventions to promote health literacy in adults with selected non-communicable diseases living in low-to-middle income countries: a systematic review and meta-analysis. *J Eval Clin Pract*. 2021;27(6):1417–1428.
18. Heine M, Badenhorst M, van Zyl C, et al. Developing a complex understanding of physical activity in cardiometabolic disease from low-to-middle-income countries—a qualitative systematic review with meta-synthesis. *Int J Environ Res Public Health*. 2021;18(22):11977.
19. Kohl C, McIntosh EJ, Unger S, et al. Online tools supporting the conduct and reporting of systematic reviews and systematic maps: a case study on CADIMA and review of existing tools. *Environ Evid*. 2018;7(1):1–17.
20. Heine M, van Zyl C, Mokkink L, Hanekom S. Dataset for study on patient-reported outcomes in non-english African languages (V3). *Mendeley Data*. 2022. <https://doi.org/10.17632/g7whxvncn3.3>.
21. Hotez PJ, Kamath A. Neglected tropical diseases in sub-Saharan Africa: review of their prevalence, distribution, and disease burden. *PLoS Negl Trop Dis*. 2009;3(8):e412.
22. Marques-Gomes J, Salt MJ, Pereira-Neto R, et al. Development of the HIV360 international core set of outcome measures for adults living with HIV: a consensus process. *HIV Med*. 2022;23(6):639–649.
23. Harman NL, Wilding JPH, Curry D, et al. Selecting Core Outcomes for Randomised Effectiveness trials in type 2 diabetes (SCORE-IT): a patient and healthcare professional consensus on a core outcome set for type 2 diabetes. *BMJ Open Diabetes Res Care*. 2019;7(1):e000700.
24. Ramsey I, Corsini N, Hutchinson AD, Marker J, Eckert M. A core set of patient-reported outcomes for population-based cancer survivorship research: a consensus study. *J Cancer Surviv*. 2021;15(2):201–212.
25. Gargon E, Gorst SL, Williamson PR. Choosing important health outcomes for comparative effectiveness research: 5th annual update to a systematic review of core outcome sets for research. *PLoS One*. 2019;14(12):e0225980.
26. Ciani O, Salcher-Konrad M, Merzagaglia M, et al. Patient-reported outcome measures in core outcome sets targeted overlapping domains but through different instruments. *J Clin Epidemiol*. 2021;136:26–36.
27. Ojelabi AO, Graham Y, Haighton C, Ling J. A systematic review of the application of Wilson and Cleary health-related quality of life model in chronic diseases. *Health Qual Life Outcomes*. 2017;15(1):1–15.
28. Ade-Oshifogun JB. Model of functional performance in obese elderly people with chronic obstructive pulmonary disease. *J Nurs Scholarsh*. 2012;44(3):232–241.
29. Phaladze NA, Human S, Dlamini SB, et al. Quality of life and the concept of "living well" with HIV/AIDS in sub-Saharan Africa. *J Nurs Scholarsh*. 2005;37(2):120–126.