STUDY PROTOCOL

Functioning problems associated with conditions with greatest disease burden in South Africa and Zimbabwe: a scoping review protocol [version 1; peer review: awaiting peer review]

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Abstract

Background: A notable rise in health-related disability for which evidence-based rehabilitation is beneficial is evident in low-to-middle income countries. This scoping review aims to summarize and synthesize the status of peer-reviewed literature regarding the most common functioning problems associated with health conditions that contribute most to disability in South Africa and Zimbabwe.

Methods: The scoping review will be conducted according to the framework developed by Arksey and O’Malley and corresponding guidance contained in the Joanna Briggs Institute Reviewers’ Manual. Peer-reviewed studies of all designs published from January 2006 onwards will be systematically searched from five databases. Studies reporting on functioning problems (impairments, activity limitations, and participation restrictions) in South African and Zimbabwean adults (>18 years) related to the top 10 health conditions contributing most to years lived with disability in South Africa and Zimbabwe according to the Global Burden of Disease Study 2019 will be included. Two reviewers will screen titles, abstracts, and full texts and chart data. The International Classification of Functioning, Disability and Health (ICF) framework will be used to map identified functioning problems. A narrative approach will be used to synthesize results.

Discussion: This scoping review will provide a comprehensive mapping of functioning problems affecting adults in South Africa and Zimbabwe. Understanding the local rehabilitation needs may be a first step in strengthening primary care rehabilitation in low-resource settings.

Registration: This scoping review protocol was registered with the Open Science Framework (doi: 10.17605/OSF.IO/FJM7W) on 31/12/2020.
Introduction
The global epidemiological transition of disease has been paralleled by an exponential increase in disability within the population. This has resulted from the increasing prevalence of chronic diseases and the improving life expectancies due to advances in healthcare and technology. The trend has been more markedly evident in recent years in low-to-middle income countries (LMICs). Moreover, the rise in trauma-related injuries and the persistence or re-emergence of infectious diseases in these resource-constrained settings continues to contribute to health-related disability. The notable rise in disability levels, will strain the national health systems and accentuate the need for rehabilitation services, especially at primary health care where rehabilitation service delivery remains largely inaccessible, inadequate and uncoordinated. It is important to understand which health conditions (disorders or diseases) or injuries contribute most to disability within a local context in order to plan and implement functional rehabilitation policy frameworks and delivery models as part of universal health coverage.

The burden of disability at country and global levels is commonly depicted by metrics developed by the Global Burden of Disease (GBD) consortium, such as years lived with disability (YLDs). Disability impacts the functional capacity of a person resulting in low quality of life (QoL), poor return to work potential or poor work performance. The YLDs are weighted to reflect the extent of the reduction of QoL due to diseases and thus can be used as a proxy indicator of rehabilitation need. A rise in YLDs is particularly evident in LMICs; the total YLDs due to conditions for which evidence-based rehabilitation can ameliorate disability having increased thrice more in LMICs compared with high-income countries (HICs) over the last three decades. According to the top 10 causes of YLDs in 2019 reported on GBD Compare, similar health conditions cause the most disability in LMICs. These include human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), headache disorders, depression, low back pain, diabetes mellitus, and chronic obstructive pulmonary disease (COPD).

Rehabilitation is a key health strategy for reducing disability by optimizing functioning and participation. Rehabilitation occurs across the life-span and along a continuum of care. A disease-focused model may no longer be effective in meeting rehabilitation needs especially of people with complex health conditions including multimorbidity. Two people with the same disease may have different functioning profiles and therefore have different rehabilitation needs. A person-centred rehabilitation approach may be more useful in tailoring rehabilitation interventions that are not solely based on an individual’s disease profile to address the underlying functioning problems, although knowledge of the underlying disease/s and prognoses affects the timing and type of rehabilitation interventions. Using this approach, the person’s needs and perspectives underpin the rehabilitation service delivery and improved functioning is what patients receiving rehabilitation care value most. Moreover, diagnosis of the underlying disease/s alone does not provide sufficient information for monitoring a population’s health state or the impact of health interventions. The World Health Organization now recognises functioning as the third indicator of health, thus information on functioning is essential.

Collective data regarding functioning problems at the population level in LMICs are incomplete and incomparable. Most of the data emanate from grey literature on population censuses and national disability surveys rather than academic studies. The increasing use of various tools based on the most internationally accepted disability framework, the International Classification of Functioning, Disability and Health (ICF), such as the Model Disability Survey (MDS), the Washington Group Short Set (WG-SS) and the Extended Set (WG-ES), has allowed comparability of disability statistics collected during population censuses and national disability surveys. However, these national censuses use a relatively narrower definition of disability that focuses on people with relatively more significant and/or chronic disabilities. Yet the scope of rehabilitation is broader, including persons with less severe disabilities or needing rehabilitation temporarily at certain points in life such as after a sports injury. A more comprehensive understanding of population disability in LMICs is required to inform rehabilitation service planning.

The ICF in its entirety is comprehensive and comprises 1495 categories of functioning problems, but is not applicable to a specific context. Wide variation exists in how the ICF is used to measure disability within a specific context, in whether the focus is on a specific functioning problem (impairments, activities limitations or participation restrictions) or a specific health condition (for some of which ICF Core Sets have been developed). As a result, studies carried out in LMICs provide silos of impairment- and/or condition-specific prevalence data and not all health conditions have received the same degree of research-related efforts. The ICF core sets consist of succinct, priority ICF categories that are relevant for specific health conditions or care contexts. However, none of these ICF core sets, including the generic rehabilitation core set, which can be used across health conditions, have been validated in African countries. There is need for a composite and comprehensive mapping of functioning problems at country level in populations living in lower resource settings to develop congruous rehabilitation interventions as one of the first steps towards improving rehabilitation service delivery.
The main aim of this review will be to summarize and synthesize the status of peer-reviewed literature regarding the most common functioning problems presenting in the adult population in two LMICs, South Africa and Zimbabwe. To achieve this aim, we will complete the following objectives:

1. Describe the spectrum (type and prevalence) of the most reported types of functioning problems (impairments, activity limitations and participation restrictions) associated with the top 10 conditions contributing most to YLDs in South Africa and Zimbabwe and for which evidence-based rehabilitation interventions to address associated disability exist. The cut-point of 10 top conditions was arbitrarily selected to keep the study manageable.

2. Map the reported functioning problems to the ICF framework.

3. Report on associations between activity limitations and impairments and between activity limitations and participation restrictions.

Methods

The study will involve a broad and comprehensive scoping review of the current evidence regarding functioning problems associated with the priority conditions in South Africa and Zimbabwe following the methodological framework first developed by Arksey and O’Malley. Corresponding guidance contained in the Joanna Briggs Institute Reviewers’ Manual will also be considered. The identified functioning problems will be coded to the ICF framework. This will allow a standardised analysis of the types and prevalence of identified impairments, activity limitations, and participation restrictions associated with priority conditions in South Africa and Zimbabwe to determine which are most common. The anticipated heterogeneity of studies reporting on functioning problems deems a scoping review design most appropriate for the proposed study (versus a more precise systematic review). This scoping review was registered on the Open Science Framework website (https://doi.org/10.17605/OSF.IO/FJM7W) on 31/12/2020.

Review framework

We will use the ICF framework to guide our review. The ICF provides a consistent language for assessing and describing health-related function and disability. The ICF’s bio-psychosocial model broadens the perspective of disability proposing that every person experiences disability at some point in their life. Functioning problems refer to the aspects of disability that affect what one can do or not do at individual level. These include impairments of body function and structure at body level, activity limitations at person level, and participation restrictions at society level. Functioning problems may result from a pathology, secondary/associated conditions or side effects of medications. Thus, we will be able to systematically code and compare concepts referring to impairments, activity limitations and/or participation restrictions used in different outcome measures in studies from different countries, health care settings, periods of publication, and regardless of the discipline. The ICF appropriately recognizes that functioning and disability are etiologically neutral, enabling us to objectively assess functioning problems that have been obtained from condition-specific studies. By looking through the lens of the ICF’s bio-psycho-social model framework we hope to identify functioning problems that may be prevalent in these settings, but that may have been missed with the use of the biomedical model of disability.

The ICF model (Figure 1) conceptualizes a person’s level of functioning as an interplay between health conditions and contextual factors (environmental and personal factors). As such, activities may relate to the interplay of multiple functions, structures, and participations. The ICF uses a coded system to indicate such interactions. To illustrate (with ICF codes in brackets), a person with stroke may experience an activity limitation such as difficulty with lifting and carrying objects (d480) resulting from the following upper limb impairments: pain (b280), reduced muscle tone (b735), reduced muscle power (b730) related to structures of the shoulder region (s720). This makes it difficult for the individual to find employment (d845). The extent of functioning or disability within an ICF domain is recorded by means of qualifiers. For the domains under body function and structure, the primary qualifier indicates the presence and location of an impairment and, on a five-point scale, the degree of impairment (no impairment, mild, moderate, severe, and complete). For activity limitations, the capacity qualifier is used to describe an individual’s ability to carry out a task or action, while the performance qualifier is used for participation restrictions.

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1 According to the ICF coding system, functioning and disability is divided into four components: body function (coded ‘b’), anatomical structures (coded ‘s’), activities and participation (coded ‘d’). Therefore, impairments of body function would begin the coding with ‘b’, impairments of body structure would begin the coding with ‘s’, while activity limitations and participation restrictions begin with ‘d’.24
Identifying the research question
The main research questions for this review will be: (i) “What is the spectrum of functioning problems associated with conditions contributing most to YLDs in South Africa and Zimbabwe?”, (ii) “Which impairments are associated with reported activity limitations?” and (iii) “Which participation restrictions are associated with reported activity limitations?”.

Eligibility of the research questions was determined using the Population Exposure Context Outcome design (PECoD) framework. (Table 1).

Table 1. Eligibility criteria for the research question.

| Criteria   | Determinants                                                                 |
|------------|-----------------------------------------------------------------------------|
| Population | Adults (aged 18 years and older) diagnosed with one or more of conditions contributing to the greatest years lived with disability (YLD) as indicated by Global Burden of Disease (GBD) data. |
| Exposure   | One or more of the top 10 conditions contributing to the greatest YLD in South Africa and Zimbabwe. |
| Context    | South Africa and Zimbabwe.                                                  |
| Outcome    | Impairments of body function and structure; Activity limitations; Participation restrictions. |
| Design     | Peer-reviewed studies of all designs.                                       |

Inclusion and exclusion criteria
Type of evidence sources
This systematic scoping review will include Zimbabwean and South African, peer-reviewed studies of all designs examining functioning problems associated with one or more of the top 10 health conditions resulting in the greatest burden of YLD. The studies will be considered eligible if information regarding type and prevalence of the impairments, activity limitations or participation restrictions associated with the condition is reported.

Studies will need to be published from 1 January 2006 to the date of final search commencement. This date limit will enable us to focus on current functioning problems, considering that constant improvements in clinical care, public health and technology may affect rates of disability. Eligible studies will need to be available in English and Afrikaans, the most common languages for scholarly communication in South Africa and Zimbabwe.
Grey literature, including theses and dissertations, will not be reviewed as we are looking for complete, peer-reviewed published data only. Studies will be excluded if they do not provide data on functioning problems in the sample diagnosed with the defined condition, and if full-length texts are not available.

Type of participants

Participants will include adults (18 years and older) diagnosed with any of the priority conditions listed from the GBD 2017 data published on the Institute for Health Metrics (IHME) website. Manifestations and outcomes of most health conditions in children and adolescents differ from adults, therefore, this study focuses on adults. No other limitations will be applied (including gender and ethnicity) as our intent is to retrieve all articles on adults’ functioning problems associated with a given condition without restriction based on population characteristics. Studies involving control participants will be considered if subgroup data for impairments, activity limitations or participation restrictions in the diagnosed participants are provided. Studies on animals will be excluded.

Type of outcome measures

Studies will be eligible if at least one of the following types of outcome measure was used to evaluate function or dysfunction:

— Impairment-based measures, which measure any dysfunction in a body region or system e.g., findings of reduced joint range of motion by goniometry.

— Patient-reported outcome measures, which include body region or condition specific questionnaires and scales e.g., Barthel Index for stroke.

— Physical performance-based outcome measures, which are used by a clinician while an individual performs a functional task e.g., balance, gait speed and aerobic endurance tests.

— Functional performance testing, which incorporates all the above.

— Participation-based outcome measures with outcomes that can be linked to the ICF.

Some outcome measures will report on functioning problems that can be directly linked to the ICF components. However, other outcome measures will require the use of linking rules to link reported concepts regarding functioning problems to the ICF components. We will exclude impairments that are not indicated for rehabilitation, for example, neck stiffness in tuberculous (TB) meningitis or internal impairments such as vomiting, constipation, or diarrhoea.

We will exclude health related QoL assessments as they focus on the individual’s values and expectations following disease or injury rather than functioning problems in terms of impairments, activity limitations and participation restrictions.

Search strategy

We shall identify all studies relevant to this review by carrying out a comprehensive search of PubMed/MEDLINE (PubMed, RRID:SCR_004846), Web of Science (Clarivate Analytics, RRID:SCR_017657), EbscoHost (CINAHL and Africanwide Information), ScienceDirect and SCOPUS by Elsevier (Elsevier, RRID:SCR_013811) and African Journals Online (AJOL) for relevant South African and Zimbabwean studies. An initial search in PubMed using key search terms including “activity limitation”, “functional impairment”, “functional loss”, “functional deficit”, “dysfunction”, “disability”, “handicap”, “disablement” and “participation restriction” will be used in varying combinations with the medical subject headings (MeSH) (MeSH, RRID:SCR_004750) and terms and keywords for the listed conditions. This will be followed by an analysis of text words contained in the title and abstract, and of index words selected to describe key articles. A subsequent search of the remaining databases will be done using the various combinations of identified keywords. We will use a wide search to include Title, Abstract and Keywords fields to avoid missing important articles that may not reflect the content of the article. Articles will be excluded by limiting the search to adult, humans, articles published since January 2006 and available in the English or Afrikaans languages. A provisional electronic search strategy made in PubMed that will be adapted to the different databases is available on Open Science Framework. Any additional search strategies that may be incorporated as the review progresses will be documented.
Data collection

Selection of studies

After deduplication, two independent reviewers will screen all the titles and abstracts retrieved and select studies for possible inclusion in the study. Titles and abstracts that meet the pre-determined criteria will be included for full-text review. We will also conduct a secondary search by manually reviewing reference lists of eligible studies for studies that may have been missed during the initial database searches.

Disagreements at any phase of the review process will be resolved by discussion and consensus. In the case where a consensus is not reached, a third independent reviewer will determine eligibility. Ineligible studies will be excluded from the review and reasons for exclusion will be recorded. Authors of the included studies will be contacted directly if further data clarification is needed during the eligibility assessment.

Charting the data

The reviewers have held discussions to determine the variables, nature, and extent of the information to be extracted from the eligible studies to ensure consistency and clarity. The data extraction forms were developed in Microsoft Excel (Microsoft Excel, RRID:SCR_016137) and have been piloted on a sample of 33 full text articles on stroke and revised iteratively (available on https://doi.org/10.17605/OSF.IO/FJM7W). Two reviewers will independently extract data from the studies using the final version of the data extraction form. Information obtained will include the first author and year of publication, study design, study aim, setting (rural, urban, or semi-urban), level of care (rehabilitation centre, primary, secondary, or tertiary hospital), condition, multimorbidity (the co-existence of two or more chronic health conditions in an individual), sampling method and description of sample population, including sex, age group/age (mean ± standard deviation and/or range), and socio-economic status.

Details regarding outcome measures used to evaluate function, the type and prevalence of functioning problems will also be recorded. In the case of unclear or incomplete data, authors will be contacted for further details.

Prevalence reporting on different recall periods (point, annual or lifetime) of functioning problems will be extracted. In longitudinal studies where both baseline and post intervention prevalence are reported, the baseline will be considered since this is when the patient potentially begins to receive rehabilitation. In cases where a range is reported, e.g., 10-25%, the highest prevalence will be extracted to represent the worst-case scenario.

Quality assessment

We will not appraise methodological quality or risk of bias, in line with guidance on scoping review methodology.22

Data analysis

Type of functioning problems

One reviewer will deductively code the impairments, activity limitations and/or participation restrictions identified in the included studies using the ICF framework. A second reviewer will check for completeness and accuracy of the coding. Where the impairments, activity limitations and/or participation restrictions are not explicitly reported in the study, the main concepts from the assessment tool or outcome measures used to evaluate functioning and vulnerability will be used to derive the activity limitation or impairment using ICF linking rules.27 An ICF code will include not only the domain but also a measure on the domain (the qualifier). It will be germane to the purpose of the paper to attempt to code to the second or third level of ICF categories in our analysis. The coding will be checked by an expert in the use of ICF.

Prevalence of functioning problems

Data on prevalence will be taken from cross-sectional studies with randomized sampling only, representing a close representation of the target population. The pooled point, annual and lifetime prevalence of the various impairments, activity limitation and/or participation restrictions (grouped according to the ICF domains and health condition) will be
calculated to provide summary estimates. The 95% confidence intervals (CI) will be calculated to enable a meta-analysis of the observational data. Sub-group analyses will be conducted for age groups (younger, middle-aged, and older adults), setting (rural, urban, semi-urban and hospital level of care), sex/gender (male and female) and the health conditions.

We anticipate that this synthesis process will additionally identify gaps in the existing literature and reveal potential areas for further research.

**Presenting and reporting of results**

We will report the scoping review according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines and the Meta-analyses Of Observational Studies in Epidemiology (MOOSE) guidelines for observational studies in epidemiology. A modified PRISMA flow diagram will be used to summarize the selection of articles at each phase and display reasons for excluding articles. Narrative text and summary tables will be used to present the study characteristics and findings related to the outcomes. We will report any gaps that might require further research.

**Ethics and dissemination**

This proposed study will not require research ethics approval since it does not involve human participation. Following scoping review methodology, this study will use only published literature. Results will be disseminated through publications in open access peer-reviewed scientific journals and presentations at scientific meetings and conferences.

**Patient and public involvement**

This scoping review plans to analyse published scientific literature. Patients and/or the public will not be involved in the design, or conduct, or reporting or dissemination of this study. A validation of results from the scoping review will be provided through a proposed mixed methods study involving adult patients presenting for primary health care in selected regions of South Africa and Zimbabwe. Any gaps in knowledge regarding prevalence and type of functioning problems existing in these populations may be addressed during the quantitative phase. The qualitative phase will determine which functioning problems are perceived to impact most on their life roles. The functioning problems reported to be prevalent in literature may not have the most impact on the lives of adults (what matters most to them with regards to what they can or cannot do) in the selected low-resource settings.

**Study status**

We are currently developing and piloting a data extraction tool.

**Discussion**

This proposed scoping review will establish the current evidence from peer-reviewed literature on the prevalence and associations between functioning problems contributing to most disability in South African and Zimbabwean populations. To our knowledge, this proposed scoping review will be the first on this topic. The results of the scoping review will guide the development of primary care rehabilitation guidelines, helping to ensure that the scope of such guidelines will be suited to the context and needs of Zimbabwean and South African populations. Guidelines may subsequently be adapted in similarly poorly resourced settings. This scoping review may inform future systematic reviews on the prevalence of impairments in Zimbabwe and South Africa, in terms of the adequacy of the numbers of available relevant primary studies. Furthermore, establishing the prevalence of functioning problems associated with health conditions contributing most to disability, and describing associations between the functioning problems, may complement YLD measures as useful indicators of rehabilitation need. It is anticipated that mapping the scope of rehabilitation need will be a first step in determining the rehabilitation capacity of the public health care system in the selected regions. This will improve transparency in the rehabilitation policy and service planning process to improve health services delivery and access to rehabilitation services especially at primary care. More specifically these findings will prove valuable in building a rehabilitation investment case for funders, healthcare managers and policymakers to make informed decisions with regards to providing adequate finance in support of strengthening rehabilitation at primary health care.

**Strengths and limitations of the proposed study**

- The proposed scoping review will allow a comprehensive mapping of functioning problems reported in published scientific literature for adult populations in low resource settings.

- The ICF, which is a standard framework for reporting health and functioning states, will be used.
The yield of literature search might not be extensive enough to allow a comprehensive analysis of functional burden associated with the broad selection of health conditions required in this review.

Data availability

Underlying data

All data underlying the results are available as part of the article and no additional source data are required

Extended data

Open Science Framework: ‘Functioning problems associated with conditions with greatest disease burden in South Africa and Zimbabwe’. https://doi.org/10.17605/OSF.IO/FJ7W.

This project contains the following extended data:
- Provisional search strategy.docx
- Stroke-related impairments data extraction pilot.xlsx

Data are available under the terms of the Creative Commons Attribution 4.0 International license (CC-BY 4.0).

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