

HIV-Related Disability in HIV Hyper-Endemic Countries: A Scoping Review*

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ABSTRACT

Background: In the era of enhanced access to ART, many people live longer lives but with episodes of disability resulting from HIV, HIV-related conditions, and/or as side-effects of ART. It is crucial to understand the extent of disability among people living with HIV in high-prevalence settings to inform choices regarding care, policy and research. This article presents the results of the first scoping review to examine the extent, nature and range of disability among people living with HIV in HIV hyper-endemic countries. **Methods:** This scoping review used the World Health Organization's International Classification of Functioning, Disability and Health (ICF) to conceptualize "disability". A systematic search of electronic databases was conducted using specific keyword and subject heading combinations. Identified publications were screened and reviewed according to inclusion/exclusion criteria. Data were systematically extracted and reviewed for quality. Extracted data were reviewed for patterns related to methods or results. Results were aligned with the corresponding ICF code. **Results:** Forty-one articles were included, reporting data from 38 unique studies. Most (78%) of the studies were conducted in South Africa; five in Botswana, one in Zimbabwe and Lesotho, and none in Swaziland. Almost all studies recruited more females than males. All studies except two were in adults. The studies indicate that people living with HIV experience a variety of disabilities. Impairments in body structure/function comprise the majority of data, with particular focus on mental function. Data on activity limitations and participations restriction were limited, however were recorded it indicates severe impact on peoples life's and possible adherence. **Conclusions:** We argue that the time has come to elevate the focus holistically on health and life-related consequences of living with HIV and to integrate disability into the discussions and approaches to HIV care.

Keywords: Public Health; Disability; HIV/AIDS; Africa; Morbidity

1. Background

The experience of HIV is shifting in hyper-endemic countries now that access to free antiretroviral therapy (ART) is becoming more widespread [1,2]. Many people living with HIV who can access and tolerate ART are living longer lives [3]. However, increased longevity can be accompanied by a diverse range of health-related challenges [3], which may be termed disability [4-7]. This changing experience calls for a shift in how we con-

ceptualize HIV in order to inform responses within this new era [4,8].

Disability and rehabilitation frameworks became useful for HIV policy-makers, advocates and researchers upon the advent of ART in resource-rich countries in the mid-1990s [9]. In particular, the World Health Organization's International Classification of Functioning, Disability and Health [10] is a framework that has proven helpful in understanding and taking action on HIV [8-14]. The ICF has also been used for better understanding the disability dimensions of other health conditions in Southern Africa [7,15-17]. As such, the ICF offers a potentially useful framework for considering the experience of HIV in the era of enhanced access to ART in Southern Africa.

In the ICF framework, disability is understood as a

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“complex phenomenon that manifests itself at the body, person and social level” [18]. The ICF is concerned with function at three levels, which are termed structure/function (or impairment), activity (or activity limitation), and participation (or participation restriction) [10]. According to this framework, these three levels are outcomes of interactions between health conditions, intrinsic contextual features of the individual and extrinsic contextual features of the social and physical environment (see **Figure 1**). Impairments of body structure or functioning are understood to be problems with the anatomical structure of the body (e.g., a missing limb) or its functioning (e.g., memory loss). Activity limitations are understood as difficulties with executing a task or action (e.g., getting dressed). Participation restrictions are problems relating to involvement in life situations (e.g., being employed). The ICF schematic (see **Figure 1**) is complemented by an extensive ICF Checklist, which assigned “codes” to specific dimensions of functioning and disability at three increasingly focused levels [19] (see column entitled “ICF Checklist Code” in **Tables 1** and **2**).

The one population-based study assessing prevalence of disability among people living with HIV was conducted in British Columbia, Canada, using an earlier version of the ICF [12,13]. The study revealed extraordinarily high rates of disability: over 90% of the population experienced one or more impairments, with one-third reporting over ten. Prevalence of activity limitations and participation restrictions was 80% and 93%, respectively. In Southern Africa, the ICF has been used to study HIV in four studies [7,16,17,20], each of which describes a diverse experience of disability among people living with HIV.

A population-based study using the ICF to evaluate the

extent of disability among people living with HIV in the world’s most hard hit countries would provide extremely useful data to inform health and social service needs. In the absence of such a study, however, the ICF may be used as a lens for reflecting on the results of other studies collecting data that fit within this broad conceptualization of disability. Using this framework, it is possible to examine HIV studies that are not based on the ICF, but which have investigated particular outcomes that can be located within the ICF concepts of impairment, activity and participation. As such, one could develop a preliminary picture of the disability experienced by people living with HIV by systematically reviewing various HIV-related outcome studies using the ICF as an organizing framework.

This approach would be particularly salient in the HIV hyper-endemic countries of Botswana, Lesotho, Zimbabwe, South Africa and Swaziland where, by definition, over 15% of the country’s population is HIV-positive [1,2]. Given the enormous burden of HIV plus the growth of access to ART in these settings, many people can expect to live longer lives but with diverse experiences of disability [3,4]. The policy and practice implications of the shift could be profound. As such, it is imperative to understand the extent of disability experienced by people living with HIV in high-prevalence settings.

The purpose of this article is to present the results of a scoping review that examined the extent, nature and range of disability (as conceptualized by the ICF) among people living with HIV in HIV hyper-endemic countries. By systematically reviewing data from HIV studies that may be understood within the ICF framework, we seek to demonstrate how a disability framework can complement

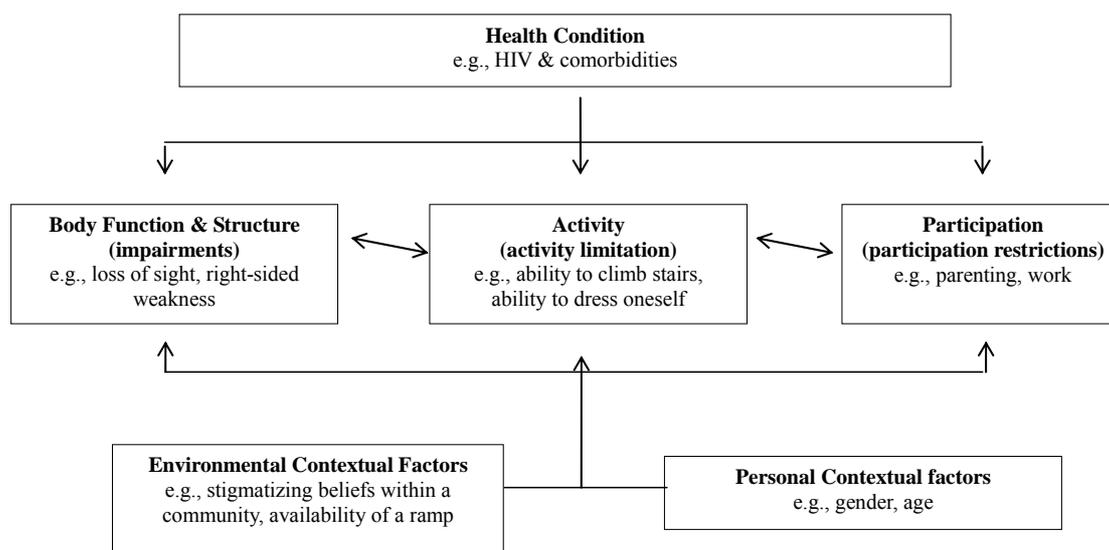


Figure 1. The World Health Organization’s International Classification of Functioning, Disability and Health (ICF) with examples related to living with HIV.

other approaches to HIV. Results can inform directions for future disability-oriented research based on the empirical gaps revealed by this analysis.

2. Methods

2.1. Study Design

We conducted a scoping study to examine the state of the literature on the extent, nature and range of disability experienced by people living with HIV in hyper-endemic countries. The study design followed the scoping study methodology outlined by Arksey & O'Malley and further developed by Levac *et al.* [21,22]. This approach was complemented by the systematic review methodology described by Denyer and Tranfield [23,24] to inform our use of the ICF as a lens for classifying outcomes within the HIV literature.

2.2. Search Strategy

This scoping study identified peer-reviewed journal articles published between January 2005 and July 2011 reporting on any disability outcome (as understood within the ICF) among people living with HIV in hyper-endemic countries. Studies were identified using keyword searches of electronic databases. The databases sourced were: EBSCOhost (including Academic Search Complete, Africa-Wide Information, Health Source, PsycARTICLES, PsycINFO, eBook Collection, Medline, and Social Science Citation Index); Science Direct; ISI Web of Science; Cochrane Library; Anthropology Index; Abridged Index Medicus (AIM); and African Journals OnLine (AJOL). The search string used synonyms and variations of the following terms: HIV/AIDS, disability, prevalence studies and HIV hyper-endemic countries. The search string for disability was developed using the first level of the ICF checklist, which identifies particular impairments, activity limitations and participation restrictions [10,19]. Details of the search strings for each of the databases are outlined in Additional File 1.

2.3. Inclusion and Exclusion Criteria

Articles were assessed according to six inclusion criteria:

- 1) Study participants are people living with HIV.
- 2) Outcomes include data on the extent of disability, as defined by the International Classification of Functioning, Disability and Health (ICF).
- 3) Study designs are cross-sectional, case-control, or other approaches that allow for assessment of frequency, severity and/or type of disability.
- 4) Studies used standardised and validated instruments
- 5) Study locations include one or more HIV hyperendemic country, *i.e.*, Botswana, Lesotho, South Africa, Swaziland and/or Zimbabwe.

6) Data were collected after 2004 and published between January 1, 2005 and July 31, 2011, in order to reflect experiences of HIV since the growth of access to ART in these settings.

The search excluded newspaper articles, case studies, literature reviews, narrative papers, and papers not written in English.

2.4. Procedure for Article Selection

The procedure for selecting articles consisted of four steps: identification of relevant literature; screening of abstract for inclusion and exclusion criteria; assessing eligibility on the basis of full text; and, final inclusion of articles. See **Figure 2** for the number of records retrieved and included in each of these steps.

Studies retrieved from the initial search were imported into a single Endnote file and duplicates were removed. Each abstract was reviewed independently by two research team members for inclusion and exclusion criteria. Full articles were downloaded for each abstract that met inclusion criteria. Hard-to-find papers were acquired by contacting the authors. All full-text articles were then reviewed again by a research team member to assess eligibility. This process resulted in 41 articles based on 38 different studies.

2.5. Data Extraction

Data were extracted from included studies using a data extraction sheet created for this study [21], which recorded: authors; title; year of publication; year of data (see **Figure 2**). **Table 1** presents the measurement tools used in the included studies. **Table 2** reports on how particular items in the measurement tools correspond with codes in the ICF Checklist and, thus, may be understood as reflecting disability. **Table 2** first presents the items aligned with the ICF concepts of “body function and structure (impairments)”, followed by “activity limitations and participations restrictions” and, lastly, according to “environmental and personal contextual factors”.

Table 3 presents details of each of the 41 included articles. The final column in **Table 3** presents the specific ICF dimensions of disability addressed by each study. Below we summarize findings related to the extent, nature and range of disability reported across the studies. Overall, the included studies predominately reported data at the disability level of impairment. We first present a summary of these data according to the following ICF categories: mental, sensory/perception, cardiovascular/respiratory, digestive/metabolic/endocrine, genitourinary and reproductive, and muscle. We then summarize the lesser amount of data in the included studies related to the disability levels of activity and participation. Finally,

Table 1. Measurement tools used in included studies that corresponded with dimensions of the ICF.

Measurement tool	Included studies using each measurement tool
ADL—Activities of Daily Living Scale	Lawler <i>et al.</i> 2011
AIDS-related Stigma Scale	Simbayi <i>et al.</i> 2007
AUDIT—Alcohol Use Disorders Identification Test	Joska <i>et al.</i> 2009, Myer <i>et al.</i> 2008
BDI—Beck Depression Inventory	Do <i>et al.</i> 2007, Lawler <i>et al.</i> 2011, Moosa <i>et al.</i> 2005
BPNS—Brief Peripheral Neuropathy Score	Kagee <i>et al.</i> 2010, Maritz <i>et al.</i> 2005
BAVLT—Botswana Auditory Verbal Learning Test	Lawler <i>et al.</i> 2011
BSID—Bayley Scales of Infant Development, Second Edition	Ferguson <i>et al.</i> 2009, Jelsma 2007, Jelsma 2005
Carver Brief COPE	Olley <i>et al.</i> 2006, Olley <i>et al.</i> 2005
CESD—Centers for Epidemiological Studies Depression Scale	Myer <i>et al.</i> 2008, Fincham <i>et al.</i> 2008, Simbayi <i>et al.</i> 2007
CIDI—Composite International Diagnostic Interview	Freeman <i>et al.</i> 2007
DAP—Goodenough Draw a Person	Zeegers <i>et al.</i> 2010
DDS—Dietary Diversity Score	Oketcha <i>et al.</i> 2010
DSC—Neuropsychological Test Battery Digit Symbol	Lawler <i>et al.</i> 2011
EPDS—Edinburgh Postnatal Depression Scale	Rochat <i>et al.</i> 2006
DSM-IV – Diagnostic and Statistical Manual of Mental Disorders IV	Schlebusch <i>et al.</i> 2010
EUROQoL—Euro Group Quality of Life Instrument	Wouters <i>et al.</i> 2009, Wouters 2007
EQ-5D—Five Domain Index of Health Status	Booyson <i>et al.</i> 2007
GPT—Grooved Peg Board Test	Gupta <i>et al.</i> 2010, Lawler <i>et al.</i> 2011
HDS—HIV Dementia Scale	Joska <i>et al.</i> 2009
HIV Stigma Scale	Petel <i>et al.</i> 2009
HR-QOL—Health Related Quality of Life Survey	Friend-du Preez <i>et al.</i> 2009, Kabore <i>et al.</i> 2010, Nair <i>et al.</i> 2009
HFIAS—Household Food Insecurity Assess Scores	Kagee <i>et al.</i> 2010, Oketcha <i>et al.</i> 2010
HSCL-D—Hopkins Symptom Checklist for Depression	Kagee <i>et al.</i> 2010
HTS—Harvard Trauma Scale	Joska <i>et al.</i> 2009
HTQ—Harvard Trauma Questionnaire	Myer <i>et al.</i> 2008
ICF—World Health Organization International Classification of Functioning, Disability and Health	Myezwa <i>et al.</i> 2009, Van As <i>et al.</i> 2009
IHDS—International HIV Dementia Scale	Lawler <i>et al.</i> 2010
LEC—Life Events Checklist	Joska <i>et al.</i> 2009
Mann-Whitney Test	Rochat <i>et al.</i> 2006
MINI—Mini-International Neuropsychiatric Interview	Fincham <i>et al.</i> 2008, Joska <i>et al.</i> 2009, Myer <i>et al.</i> 2008, Olley <i>et al.</i> 2006, Olley <i>et al.</i> 2005
MAS—Morisky Adherence Scale	McInerney <i>et al.</i> 2008
MOS-SS—Medical Outcomes Study Social Support Scale	McInerney <i>et al.</i> 2008,
MOS-HIV QAL—Medical Outcome Study HIV and Quality of Life	Oketcha <i>et al.</i> 2010, Petel <i>et al.</i> 2009
MPSS—Multidimensional Scale of Perceived Social	Nair <i>et al.</i> 2009

Continued

UNAIDS General Survey and the Department of Health Services AIDS module	Gupta <i>et al.</i> 2010
OHIP—Oral Health Impact Profile	Yengopal <i>et al.</i> 2008
Prime-MD—Primary Care Evaluation of Mental Disorders	Lawler <i>et al.</i> 2011(a), Lawler <i>et al.</i> 2011(b)
PNASACTG—Perceived Non-Adherence	McInerney <i>et al.</i> 2008
RSRCI—Retrospective Self-Report of Childhood Inhibition	Fincham <i>et al.</i> 2008
Sheehan Disability Scale	Olley <i>et al.</i> 2006
SSC-HIVrev—Sign and Symptom Checklist for Persons with HIV Disease	Peltzer <i>et al.</i> 2008
SCC—Subjective Cognitive Complaints Questionnaire	Lawler <i>et al.</i> 2010
SSQ14—Shona Symptom Questionnaire	Friend-du Preez <i>et al.</i> 2009, Petel <i>et al.</i> 2009, Simbayi <i>et al.</i> 2007
SF-36—Medical Outcomes Survey Short Form	McInerney <i>et al.</i> 2008, Nair <i>et al.</i> 2009
SNAP-IV—Swanson, Nolan and Pelham questionnaire	Zeegers <i>et al.</i> 2010
SM—Suicidality Measure (adapted from Sheehan)	Nair <i>et al.</i> 2009
TNSr—Total Neuropathy Score-Reduced	Maritz <i>et al.</i> 2005
UCSF CAPS HIV—University of California at San Francisco Center for AIDS Studies HIV Counseling and Testing Questionnaire	Patel <i>et al.</i> 2009
WHOQOL-HIV BREF (HRQoL) World Health Organisation's Quality of Life Instrument Module for HIV	Friend-du Preez <i>et al.</i> 2009, Peltzer <i>et al.</i> 2008
WHO staging	Jao <i>et al.</i> 2011
WAIS—Wechsler Adult Intelligence Scale (third edition)	Lawler <i>et al.</i> 2010
Medical records	Franey 2009, Julius <i>et al.</i> 2011, Van Marle <i>et al.</i> 2009
Self-designed questionnaire	Bhat <i>et al.</i> 2010, Kabore <i>et al.</i> 2010, Kakinami <i>et al.</i> 2010

Table 2. Constructs in measurement tools corresponding with ICF Checklist codes.

ICF Checklist code	Measurement tool used in the included studies	Sample items
Body Function and Structure (impairments)		
b1. MENTAL FUNCTIONS		
b110 Consciousness	MINI-Neuro	feeling dizzy, unsteady, faint
	SSC-HIVrev	experiencing dizziness
b114 Orientation (<i>time, place, person</i>)	WHODAS	understanding, cognition
b117 Intellectual (<i>incl. retardation, dementia</i>)	SRQ-20	trouble thinking
	HIV-dementia scale	measuring constructing a cube
	Bayleys scales	cognitive development tasks
b130 Energy and drive functions	SSC-HIVrev	experiencing fatigue
	SRQ-20	experiencing loss of energy, fatigue
	CES-D	being tired, exhausted, feeling tired, without energy, not get going
	HOP25/HCL	feeling low energy, everything is an effort

Continued

b130 Energy and drive functions	Hamilton Inventory	feeling physically slowed down
	SCID-CV	experiencing low energy, tired, fatigue
	MOS-HIV (QOL)	being tired out, enough energy, worn out
	WHO QOL—HIV BREF	low energy
b134 Sleep	BDI	having sleeping problems
	SRQ-20	sleep badly
	MINI-Neuro	trouble sleeping
	CES-D	trouble sleeping
	HOP25 / HCL	difficulty falling asleep, staying sleeping
	Hamilton Inventory	waking up , sleep problems
	SCID-CV	sleep problems, waking
b140 Attention	BDI	experiencing concentration problems
	SNAP-ADHD	experiencing low attention (impulsivity, hyperactive behavior, restlessness, day dreaming)
	WHODAS	ability to concentrate
	HIV-dementia scale	keeping attention
	MINI-Neuro	concentration, keeping attention, restlessness
	SCID-SC	thinking and concentrating problem
	MOS-HIV (QOL)	keeping attention, concentrating and thinking
	WHO QOL—HIV BREF	concentrating
b144 Memory	SSC-HIVrev	experiencing concentration problems
	HIV-dementia scale	remembering
	MOS-HIV (QOL)	experiencing memory, forgetting
b152 Emotional functions	SSC-HIVrev	experiencing memory loss
	EQ-5D	being depressed or anxious
	SSC-HIVrev	having fear, being upset
	BDI	experiencing sadness, crying, temper, self-dislike
	HIV stigma scale	being emotional affected, self-dislike
	Edward depression scale	stop laughing, being sad or happy, blaming, being anxious, panicking, feeling depressed
	SNAP ADHD	being emotionally affected
	WHODAS	worried, ending life, unhappy, joy, crying, no interest
	SRQ-20	being worried, panicked, fear being in public, feeling sad, depressed, empty, bad mood, grouchy, losing joy
	CIDI	feeling worthless, suicidal, guilty, hopeless

Continued

	MINI-Neuro	being worried, sad
	CES-D	crying, lonely, nervous, fearful, lonely, no interest, ending life
	HOP25/HCL	experiencing emotions, feeling depressed, moods, crying, anxious, nervous
b152 Emotional functions	Hamilton Inventory	losing interest, pleasure, feeling depressed, thinking about death, feeling nervous an afraid, downhearted
	MOS-HIV (QOL)	experiencing joy, fear, worry, self-blame& acceptance, being depressed anxious
	WHO QOL—HIV BREF	experiencing fear and worries
	DSM IV	experiencing fear, being afraid, scared, having nightmares, being upset
	SSC-HIVrev	experiencing numbness
	Neuropathy diagnostic tool	feeling pin and needles, numbness
b156 Perceptual functions	MINI-Neuro	tingling
	Hamilton Inventory	feeling pins and needles
	SSC-HIVrev	having numbness and tingling
	BPMS and TNSr	having numbness and tingling
b164 Higher level cognitive functions		
b167 Language	MINI-Neuro	having trouble with language
	Bayleys scales	understanding and expression
b2. SENSORY FUNCTIONS AND PAIN		
	EQ-5D	feeling pain
	SSC-HIVrev	having headaches
	Neuropathy diagnostic tool	feeling pain
	SRQ-20	feeling headache
b280 Pain	MINI-Neuro	feeling pain
	HOP25 / HCL	feeling headache
	Hamilton Inventory	feeling pain
	MOS-HIV (QOL)	feeling pain
	WHO QOL—HIV BREF	feeling physical pain
b3. VOICE AND SPEECH		
b4. FUNCTIONS OF THE CARDIOVASCULAR, HAEMATOLOGICAL, IMMUNOLOGICAL AND RESPIRATORY SYSTEMS		
b420 Blood pressure	Medical lab tests	
b5. FUNCTIONS OF THE DIGESTIVE, METABOLIC AND ENDOCRINE SYSTEMS		
b515 Digestive	SRQ-20	having digestion problems

Continued

	SSC-HIVrev	having abdominal pain, diarrhea
b525 Defecation		
	CIDI	losing or gaining weight
	Hamilton Inventory	losing weight
b530 Weight maintenance	SCID-CV	losing or gaining weight
	SSC-HIVrev	gaining weight
b555 Endocrine glands (<i>hormonal changes</i>)	Lab tests	having metabolic diseases
	BDI SRQ-20 CIDI	having no appetite, experiencing appetite disturbance
b6. GENITOURINARY AND REPRODUCTIVE FUNCTIONS		
b620 Urination functions	ADL-score	having problems with bladder control
	Medical records and lab tests	having renal impairments
b7. NEUROMUSCULOSKELETAL AND MOVEMENT RELATED FUNCTIONS		
b730 Muscle power	WHODAS	being able to stand
	SSC-HIVrev	having skinny arms, thump on back
b735 Muscle tone	Hamilton Inventory	having stiff muscle
b8. FUNCTIONS OF THE SKIN AND RELATED STRUCTURES		
	SSC-HIVrev	being itchy (numbness)
	Neuropathy diagnostic tool	feeling pin and needles, numbness
Any other body functions		
Activity (activity limitations) and Participation (participation restrictions)		
d1. LEARNING AND APPLYING KNOWLEDGE		
d115 Listening	WHODAS	following conversations
	WHODAS	problem solving
d175 Solving problems	HIV-dementia scale	constructing a cube
	MOS-HIV (QOL)	solving problems
	Bayleys scales	performing cognitive development tasks
d2. GENERAL TASKS AND DEMANDS		
d3. COMMUNICATION		
d4. MOBILITY		
d430 Lifting and carrying objects	Neuropathy diagnostic tool	lifting objects
	MOS-HIV (QOL)	lifting
d440 Fine hand use (<i>picking up, grasping</i>)	HIV-dementia scale	psychomotor speed with hand
	Bayleys scales	conducting fine motor tasks
d450 Walking	Neuropathy diagnostic tool	climbing a hill, walking 50 meters
	WHODAS	walking

Continued

	MOS-HIV (QOL)	walking
	EQ-5D	walking
	Bayleys scales	conducting gross motor tasks
d465 Moving around using equipment (<i>wheelchair, skates, etc.</i>)	ADL-score WHODAS	transferring from positions moving around
d5. SELF CARE		
d510 Washing oneself (<i>bathing, drying, washing hands, etc.</i>)	EQ-5D	having problems with washing
	ADL-score	bathing, transfer yourself
d520 Caring for body parts (<i>brushing teeth, shaving, grooming, etc.</i>)		
d530 Toileting	ADL-score	going on toilet
	MOS-HIV (QOL)	toileting
d540 Dressing	EQ-5D	having problems with dressing
	ADL-score	dressing
	WHODAS	dressing
	MOS-HIV (QOL)	dressing
d550 Eating	MOS-HIV (QOL)	eating
d6. DOMESTIC LIFE		
	Sheehan Disability scale	disrupted work
	EQ-5D	performing “usual activities” e.g. housework
d640 Doing housework (<i>cleaning house, washing dishes laundry, ironing, etc.</i>)	WHODAS	doing housework
	MOS-HIV (QOL)	doing housework and social activities
	WHO QOL—HIV BREF	doing daily living activities
d8. MAJOR LIFE AREAS		
d810 Informal education		
d820 School education	Sheehan Disability scale	having disrupted school
d830 Higher education		
	EQ-5D	performing “usual activities” e.g. work
d850 Remunerative employment	Sheehan Disability scale	having disrupted work
	WHODAS	doing work
	MOS-HIV (QOL)	working
d9. COMMUNITY, SOCIAL AND CIVIC LIFE		
d910 Community Life	Sheehan Disability scale	having “disrupted social life”
	HIV stigma scale	stopping to socialize
d920 Recreation and leisure	WHO QOL—HIV BREF	participating in leisure activities
Environmental and Personal Contextual Factors		
e1. PRODUCTS AND TECHNOLOGY		
e2. NATURAL ENV'T AND HUMAN MADE CHANGES TO ENVIRONMENT		

Continued

e3. SUPPORT AND RELATIONSHIPS		
e310 Immediate family	Multi Scale of perceived Social Support	emotional support from family
	WHO QOL—HIV BREF	having relationships
e320 Friends	Multi Scale of perceived Social Support	having support friends
	WHO QOL—HIV BREF	having support from friends
e340 Personal care providers and personal assistants	Multi Scale of perceived Social Support	having support from career
e4. ATTITUDES		
e460 Societal attitudes	HIV-stigma scale	feeling treated like an outcast, experiencing rejection by people
e465 Social norms, practices and ideologies	HIV-stigma scale	keeping HIV secret
E5. SERVICES		

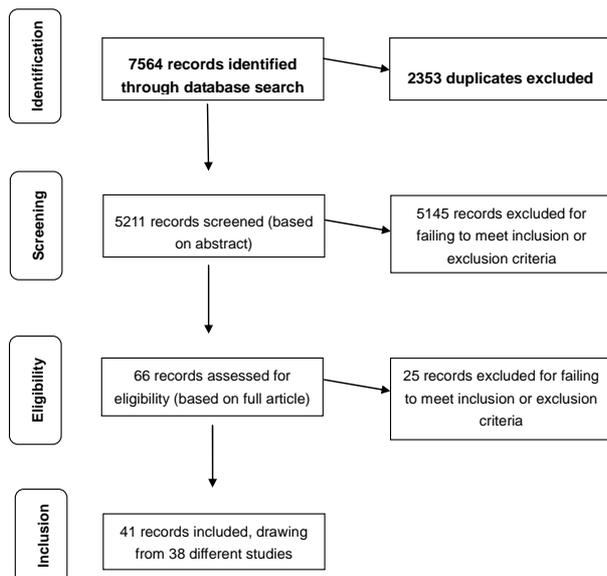


Figure 2. Flow of citations through article selection process.

we review the few studies that examined interlinkages collection; country and context (rural, peri-urban or urban); sample size; target group; sampling method; study design; concepts/constructs measured; scales/tools used; study results in general; results relevant to disability as defined in the ICF; study limitations; and authors' recommendations. Extracted data were reviewed by a second research team member to ensure quality control and consistency of extraction process. Inconsistencies were resolved through consensus.

3. Analysis

Once data were extracted from the 41 included articles (38 studies), we reviewed the findings for patterns related

to study methods (e.g., approaches to sampling or study tools) and study results (e.g., data related to particular impairments). To analyse study results according to the ICF, we first aligned each study's findings with the corresponding ICF code. For articles that identified specific outcomes (e.g., difficulty getting dressed), we were able to directly align the outcome with the corresponding dimension of the ICF framework (e.g., ICF code "d540 Dressing"). For studies that identified research measurement tools (e.g., the Hamilton Inventory), we reviewed each tool to clarify whether and how certain items within the tool corresponded with particular dimensions of the ICF (e.g., the item "sleep problems" in the Hamilton Inventory corresponds with ICF code "b134 Sleep"). **Table 1** outlines the measurement tools used in the included studies.

Table 2 illustrates how constructs in each measurement tool corresponded with the ICF Checklist codes. Once study results were organized according to the ICF, we reviewed these findings for patterns and gaps related to the extent, nature and range of disability described across the studies.

4. Results

4.1. Characteristics of Included Studies

Forty-one articles met inclusion criteria, which reported data from 38 different studies. **Table 3** presents the characteristics of included studies. Of the five hyper-endemic countries considered in the scoping study, 78% of the included articles were studies conducted in South Africa (32 articles), 5 in Botswana and 1 in Zimbabwe; no studies were conducted exclusively in Lesotho or Swaziland. Two studies were conducted in more than one country, one including a site in Lesotho.

Fifty one per cent of articles (21) took place exclusively in urban areas; 17% (7 articles) only in rural areas; 12% (5 articles) in both urban and rural settings; and 10% of studies (4 articles) in semi and peri-urban areas. Study setting was unclear in four articles.

In terms of study design, most studies were cross-sectional (30 articles). Three studies also used either a prospective or retrospective study design. In terms of sample size, 85% of the articles (35 articles) included more than 100 participants. Three articles (7%) used a random sampling technique and 3 articles (7%) used stratified sampling. Nineteen articles (47%) used convenience sampling, 2 articles (5%) used purposive sampling, and 14 articles (34%) did not specify their sampling strategy. Almost all studies recruited more females than males. In 61% (25 articles), more than 70% of the sample was female; 20% (8 articles) recruited roughly equal numbers of males and female; 17% (7 articles) did not describe the sex of their participants (see **Figure 3**). All studies included adults except for two, which included youth below the age of eighteen [25,26].

4.2. Extent, Nature and Range of Disability

This scoping review investigated the state of literature on disability (as conceptualized by the ICF) experienced by people living with HIV in HIV hyper-endemic countries among ICF levels.

4.3. Impairments Related to Body Structure and Function

Mental Function (b1): Twenty articles presented data focusing on mental functioning and an additional 8 articles presented mental functioning as part of a wider inquiry into participants' health or quality of life. Using the ICF, Myezwa *et al.* [25] reported impairments in mental function in 72.6% of their sample of 80 people living with HIV. They also reported energy and drive impairments in 75% and sleep impairments in 71% of the sample. Also using the ICF, van As *et al.* [26] reported mental functions impairments in 69% of their sample of 45 adults visiting an HIV outpatient clinic. Disorders such as depression, anxieties and post-traumatic stress disorder (PTSD) were identified in a number of studies, with percentages of the sample showing symptoms of mental health condition as follows: Kagee 38% (depression), Myer 19%, Moosa 56%, Freeman 43% (depression), Rochat 41%, Olley 2006 48% (depression, post-traumatic stress disorder—PTSD), Olley 2005 14.8% (PTSD), Lawler 38% (depression), Gupta (28% (depression) and Finchman 13.1% (anxiety) [27-31]. Wouters *et al.* reported anxiety or feelings of depression in 30% of their sample [32,33]. Two studies [32-34] reported improvements in the area of emotional functions, energy and

drive while being on treatment; however, one study highlighted how activity limitations continued to affect the patient's life when on ART [33].

Other mental function domains reported in the literature were consciousness, intellectual functions, memory and language. Lawler *et al.* (2010) reported that 38% of their 120 participants were diagnosed with HIV-dementia. Joska *et al.* reported that 23.5% of their 536 participants in urban South Africa were diagnosed with HIV-associated neurocognitive disorder (HAND). Lawler *et al.* (2011) reported that 37% of people living with HIV were described as cognitively impaired [35-37] and Bhat *et al.* identified significant loss of memory in 17.9% of their sample of 168 patients at a rural health centre in South Africa [38]. The study by Lawler *et al.* which used a control group, reported that HIV-positive participants were more impaired on neuropsychological measures when compared to demographically-matched controls for all cognitive-motor ability areas, which included processing speed, verbal learning/memory, language, psychomotor speed, executive function, and fine motor speed [37].

Sensory and perception functions (b2): The sensory or perception functions reported most frequently were tingling or numbness. Maritz *et al.* reported 49% of their sample on HAART was diagnosed with peripheral neuropathy, and 30% with severe neuropathic symptoms [39]. Data were also reported on sensory function problems and pain. Bhat *et al.* [38] reported that 20% of their sample experienced pain, Van As *et al.* [26] reveals that 71% of their sample experiencing sensory functions problems and pain, and Myezwa *et al.* [25] reported 83.5% experienced sensory functions disorders. Similarly pain and discomfort were reported in 37% of participants in the study by Wouters *et al.* [32]. One study [40] reported on changes in ability to taste while being on treatment. No data were reported on other sensory functions, such as visual, hearing or voice impairments.

Cardiovascular and respiratory function (b4): Four articles reported data in regards to functions of the cardiovascular and respiratory system. Myezwa *et al.* [25] described problems in 82.5% of the participants related to the haematological, immunological and respiratory systems. Similarly, the study by van As *et al.* of 45 clinic patients found hypertension in 33% of the sample, respiratory problems in 22% (which they attributed largely to TB), and at least one haematological problem in 96% of the sample. High blood pressure was also recorded Maritz *et al.*, and problems with breathing and breathlessness in 13% of the sample in Bhat *et al.*

Digestive, metabolic and endocrine function (b5): Six studies reported data on impairments in digestive, metabolic or endocrine function, on or off treatment. Data were presented regarding increase or loss in weight as well as diagnostic of obesity [38,41,42]. Additionally,

Table 3. Characteristics of included studies.

Author	Title	Study site	Study design	Population	Study Instruments	ICF Checklist Code
Bhat <i>et al.</i> (2010)	Factors associated with poor adherence to antiretroviral therapy in patients attending a rural health centre in South Africa	South Africa: rural	Cross-sectional	N = 168 PLHIV on ARV 60% females	Self-designed pre-structured questionnaires	<ul style="list-style-type: none"> • B130: "side effects", fatigue • B144: memory • B280: pain • S120 or B156: tingling • B530: weight loss • B440: breathing problems • B152: depression, sadness, anxiety b152 • B640: sexual dysfunction • B8: skin rash and hair changes
Booyesen <i>et al.</i> (2007)	The heart in HAART: quality of life of patients enrolled in the public-sector antiretroviral treatment programme in the Free State Province of South Africa	South Africa: rural	Case-control study	N = 371 PLHIV waiting for ART and ART Almost $\frac{2}{3}$ females	EQ-5D	<ul style="list-style-type: none"> • D4: quality of life • B: mobility (not specified) • D5: self care (not specified)
Do <i>et al.</i> (2010)	Psychosocial Factors Affecting Medication Adherence among HIV-1 Infected Adults Receiving Combination Antiretroviral Therapy (cART) in Botswana	Botswana: urban	Cross-sectional	N = 300 PLHIV on ART 76.3 % females	BDI	<ul style="list-style-type: none"> • B152: alcohol abuse and depression • B144: forgetting ART
Ferguson <i>et al.</i> (2009)	The prevalence of motor delay among HIV-Infected children living in cape Town, South Africa Also Jelsma, J. & Ferguson, G., 2007, Motor Development in Children Living within Resource Poor Areas of Western Cape	South Africa: urban	Disability prevalence	N = 86 (HIV infected children and non-infected children)	BSID	<ul style="list-style-type: none"> • B 7 and d4: motor development delay
Fincham <i>et al.</i> (2008)	The relationship between behavioural inhibition, anxiety disorders, depression and CD4 counts in HIV-Positive adults: a cross-sectional controlled study	South Africa: rural	Cross-sectional	N = 456 PLHIV 75 % females	RSRCL, CES-D, MINI	<ul style="list-style-type: none"> • B152: GAD, depression and PTSD • D7: social fears associated to depression (not specified)
Franey <i>et al.</i> (2009)	Renal Impairment in a Rural African Antiretroviral Programme	South Africa: rural	Retrospective review and prospective study	N = 2189 patients on ARV 68.8 % females	Review of medical records	<ul style="list-style-type: none"> • B8: skin irritations • B620: renal dysfunction
Freeman <i>et al.</i> (2007)	Factors Associated with Prevalence of Mental Disorder in People Living with HIV/AIDS in South Africa.	South Africa: rural	Cross-sectional	N = 900 PLHIV some on ART 74 % females	CIDI, Point-prevalence	<ul style="list-style-type: none"> • B152: mental health disorder (mainly depression) • D7: discrimination by community/ family and isolation

Continued

Friend-du Preez et al. (2009)	HIV Symptoms and Health-Related Quality of Life Prior to Initiation of HAART in a Sample of HIV-Positive South Africans	South Africa: rural	Cross-sectional	N = 612 PLHIV prior HAART 70.3 % females	SSC-HIVrev, WHOQOL-HIV BREF (HRQoL)	<ul style="list-style-type: none"> • B530: weight loss • B8: dry mouth • B280: headaches • B144: memory loss • B130: weakness • B280: painful joints
Gupta et al. (2010)	Depression and HIV in Botswana: A population-based study on gender-specific socioeconomic and behavioral correlates	Botswana: rural	Cross-sectional	N = 1168 PLHIV Not known gender distribution	HSCL-D, UNAIDS General Survey and the Department of Health Services AIDS module	<ul style="list-style-type: none"> • B152: emotional e.g. depression • D7 and D770: lack of control in sexual relationships and stigma
Jao et al. (2011)	Factors associated with decreased kidney function in HIV-infected adults enrolled in the MTCT-Plus Initiative in Sub-Saharan Africa	Multicounty including, South Africa	Prevalence study	N = 2495 PLHIV on ART > 70 % females	WHO staging, CD4 cell count, Cockcroft-Gault (CG) equations for creatinine clearance, Diet in Renal Disease Equation (MDRD) and CKD Epidemiology Collaboration (CKD-EPI)	<ul style="list-style-type: none"> • B620: Urination functions
Jelsma et al. (2005)	An investigation into the health-related quality of life of individuals living with HIV who are receiving HAART	South Africa: urban	Cross-sectional	N = 83 PLHIV on HAART 74.5 % females	EQ-5D	<ul style="list-style-type: none"> • B280: pain, discomfort • B152: emotional e.g. anxiety and depression • D4 mobility • D5: self care activities
Joska et al. (2009)	Clinical Correlates of HIV-Associated Neurocognitive Disorders (HAND) in South Africa	South Africa (SA): urban	Cross-sectional	N = 536 PLHIV 73.3 % females	HDS, MINI, AUDIT, HTS, LEC	<ul style="list-style-type: none"> • B114, B117, B140, B144: HAND • B152: PTSD
Julius et al. (2011)	The Burden of Metabolic Diseases Amongst HIV Positive Patients on HAART Attending The Johannesburg Hospital	South Africa: urban	Cross-sectional	N = 304 PLHIV on ART >1 year) 78 % females	Patient clinical records, blood tests and anthropometric measurements.	<ul style="list-style-type: none"> • B4: metabolic diseases (diabetes, hypertension...)
Kabore et al. (2010)	The Effect of Community-Based Support Services on Clinical Efficacy and Health-Related Quality of Life in HIV/AIDS Patients in Resource-Limited Settings in Sub-Saharan Africa	South Africa, Lesotho and Botswana	Cross-count ry incl. Observational cohort study	N = 377 PLHIV on ART 72% females	Self designed questionnaires, HRQOL	<ul style="list-style-type: none"> • D4: ART and/or community support improved physical • D9: social • B1 or B117: cognitive • B152: emotional functioning • B130: energy drive (all at baseline lower)
Kagee et al. (2010)	Psychological Distress among Persons Living with HIV, Hypertension, and Diabetes	South Africa: semi-urban	Cross-sectional	N = 124 PLHIV receiving treatment for diabetes or hypertension, 79% females	HSCL-25	<ul style="list-style-type: none"> • B152: emotional distress
Kagee et al. (2010)	Symptoms of Depression and Anxiety among a Sample of South African Patients Living with HIV	South Africa: semi-urban	Prevalence study	N = 85 PLHIV some on ART 75.3% females	HSCL-25, BDI	<ul style="list-style-type: none"> • B152: depression and anxiety

Continued

Kakinami et al. (2010)	The Impact of Highly Active Antiretroviral Therapy on Activities of Daily Living in HIV-Infected Adults in South Africa	South Africa: urban and rural	Cross sectional	N = 4328 PLHIV 71% - 78% women	Self developed questionnaires	<ul style="list-style-type: none"> D4-6 activity assistance needs
Lawler et al. (2011)	Neurobehavioral effects in HIV-positive individuals receiving highly active antiretroviral therapy (HAART) in Gaborone, Botswana	Botswana: urban	Cross-sectional	N = 140 PLHIV on ART (60 intervention group and 80 control group), gender not provided	DSC, BAVLT, GPT, Primary Care Evaluation of Mental Disorders, ADL	<ul style="list-style-type: none"> B117, B144, D140, B3: cognition and/or fine motor speed, language B152: anxiety disorder
Lawler et al. (2010)	Neurocognitive impairment among HIV-positive individuals in Botswana: a pilot study	Botswana: urban	Cross-sectional	N = 120 PLHIV 50% females	IHDS, Verbal Learning Test, WAIS Digit Symbol Coding, Mood Module of the primary care evaluation of mental disorders, Activities of Daily Living Scale, SCC	<ul style="list-style-type: none"> B117: dementia
Lawler et al. (2011)	Depression among HIV-positive individuals in Botswana: a behavioral surveillance	Botswana: urban	Mental health prevalence	N = 120 PLHIV (random) 50% women	BDI-FS, Mood Module (MM) of Prime-MD, ADL	<ul style="list-style-type: none"> B152: emotional e.g. depression
Maritz et al. (2010)	HIV Neuropathy In South Africans: Frequency, Characteristics, And Risk Factors	South Africa: urban	Cross-sectional	N = 598 PLHIV on ART 76% females	BPNS, TNSr, CD4 counts, ART status	<ul style="list-style-type: none"> B156 or B7: neuropathy B420: blood pressure
McInerney et al. (2008)	Quality of life and physical function in HIV-infected individuals receiving antiretroviral therapy in KwaZulu-Natal, South Africa	South Africa: area not described	Descriptive exploratory design	N = 149 PLHIV on ART N = 95 females	MOS-SSS, SF-36, MOS-SF36HS, PNASACTG, MAS	<ul style="list-style-type: none"> D4: mobility D2: general tasks and demands E3: social support
Moosa et al. (2005)	HIV in South Africa - depression and CD4 count	South Africa	Prevalence of depression	N = 41 PLHIV 71% females	BDI - Beck Depression Inventor, CD4 count test	<ul style="list-style-type: none"> B152: emotional e.g. depression
Myer et al. (2008)	Common Mental Disorders among HIV-Infected Individuals in South Africa: Prevalence, Predictors, and Validation of Brief Psychiatric Rating Scales	South Africa: semi-urban	Cross-sectional study	N = 465 PLHIV with >24 on the MMSE 75% females	MINI, CES-D, HTQ, AUDIT	<ul style="list-style-type: none"> B152: depression PTSD and alcohol dependence
Myezwa et al. (2009)	Assessment of Classification of Functioning, Disability and Health (ICF) at Chris Hani Baragwanath Hospital, Johannesburg	South Africa: urban	Cross-sectional study with ICF checklist	N = 80 PLHIV some on ART Gender not specified	ICF checklist	<ul style="list-style-type: none"> All ICF domains

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Nair et al. (2009)	Psychological Well-Being and Health Related Quality of Life among a Group of Low-Income Women Living with HIV/AIDS in South Africa	South Africa: urban	Cross-sectional study	N = 133 PLHIV > 70% females	MPSS, SM, HRQOL, SF-36	<ul style="list-style-type: none"> D4: physical functioning B130: vitality B152: mental health B280: bodily pain D8: normal work E3: perceived social support
Oketcha et al. (2010)	Too little, too late: Comparison of nutritional status and quality of life of nutrition care and support recipient and non-recipients among HIV-positive adults in KwaZulu-Natal.	South Africa: semi-urban	Cross-sectional study	N = 300 PLHIV, 97 in intervention N = 252 females	DDS, HFIAS, malnutrition: assessment screening tool for HIV-positive adults, nutritional status: Anthropometry with ISAK and BMI, QAL: MOS-HIV	<ul style="list-style-type: none"> B530: obesity B8: skin infection D5: self care
Olley et al. (2006)	Persistence of psychiatric disorders in a cohort of HIV/AIDS patients in South Africa: A 6-month follow-up study	South Africa: urban	Cross-sectional study	N = 65 PLHIV N = 56 females	MINI, INI, Carver Brief COPE, the Sheehan Disability Scale and exposure to negative life events and risk behaviors	<ul style="list-style-type: none"> B152: depression and PTSD D8: work D9: social D7: family life
Olley et al. (2005)	Post-traumatic stress disorder among recently diagnosed patients with HIV/AIDS in South Africa	South Africa: urban	Cross-sectional study	N = 149 PLHIV, N = 105 females	MINI, the Carver Brief COPE coping scale and the Sheehan Disability Scale, previous exposures to trauma and past risk behaviours	<ul style="list-style-type: none"> B152: emotional e.g. depression and PTSD D8: work D9: social D7: family life
Patel et al. (2009)	Quality of life, psychosocial health, and antiretroviral therapy among HIV-positive women in Zimbabwe	Zimbabwe: urban	Cross-sectional study	N = 200 PLHIV on ART > 70 % females	HIV Stigma Scale, UCSF CAPS HIV Counselling and Testing, SSQ14, MOS-HIV QOL	<ul style="list-style-type: none"> B130: general health perception/vitality D4: physical functioning B280: bodily pain B152: mental health
Peltzer et al. (2008)	Health-related quality of life in a sample of HIV-infected South Africans	South Africa: rural	Prevalence study	N = 607 PLHIV 78 % females	SSC-HIVrev; WHOQOL-HIV BREF, HIV symptoms and medical variables, socio-economic variables	<ul style="list-style-type: none"> B130, B280, B152: low energy, pain E1, D9: low environmental domain decreases participation (transport, participation accessibility)
Rochat et al. (2006)	Depression among pregnant rural South African women undergoing HIV testing	South Africa: rural	Depression prevalence study	N = 242 pregnant women	EPDS, Mann-Whitney test	<ul style="list-style-type: none"> B152: depression D9 perception of discrimination E1: health care and finance
Schlebusch et al. (2010)	HIV-infection as a self-reported risk factor for attempted suicide in South Africa	South Africa: urban	Quantitative study	N = 112 PLHIV who committed suicide, gender not specified	Self designed against DSM-IV-TR12 criteria	<ul style="list-style-type: none"> B152: emotional e.g. depression
Simbayi et al. (2007)	Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa	South Africa: urban	Survey	N = 1063 PLHIV N = 643 females	AIDS related Stigma scale, self developed discrimination scale, CESD, SSQ self designed substance abuse questionnaire	<ul style="list-style-type: none"> B152: internalized AIDS stigma and depression (cognitive and affective [CESD]) E4: HIV discrimination E3: social support "B152": substance abuse: alcohol abuse and drug abuse

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Van as et al. (2009)	The international classification of function disability and health (ICF) in adults visiting the HIV outpatient clinic at a regional hospital in Johannesburg, South Africa	South Africa: urban	Cross-sectional descriptive study	N = 45 PLHIV 64% females	WHO ICF checklist, dynamometry, Oxford muscle testing, goniometry	<ul style="list-style-type: none"> • All ICF domains
Van Marle et al. (2009)	HIV-occlusive vascular disease	South Africa: urban	Prospective clinical survey	N = 154 PLHIV admitted to vascular unit, N = 20 females	CD4 and CD8 T-cell counts, viral load, screening for other sexually transmitted infections; arterial Duplex Doppler scans, patient questionnaire	<ul style="list-style-type: none"> • B430: lifting and caring objects
Wouters et al. (2009)	Physical and emotional health outcomes after 12 months of public-sector antiretroviral treatment in the free state province of South Africa: a longitudinal study using structural equation modelling	South Africa: urban and rural	Longitudinal cross-sectional study	N = 268 PLHIV ready for ART 67% females	Euro QoL 5D, subjective well-being (<i>i.e.</i> self-report)— assess five generic aspects of current health (mobility, self-care, limitation of activities, pain, and mood)	<ul style="list-style-type: none"> • B280: pain
Wouters et al. (2007)	Short-term physical and emotional health outcomes of public sector ART in the free state province of South Africa	South Africa: urban and rural	Cross sectional/prevalence study	N = 371 PLHIV ready for ART Gender unspecified	EuroQoL 5D	<ul style="list-style-type: none"> • B152: physical health • D4: mobility
Yengopal et al. (2008)	Do oral lesions associated with HIV affect quality of life?	South Africa: urban	Cross-sectional analytic study	N = 150 PLHIV with and without oral manifestations of HIV, gender unspecified	HIV Adult Oral Health Status Data Capture Sheet, OHIP	<ul style="list-style-type: none"> • B8: skin and others • B280: pain • B515: oral function problems related to problems with digesting food • B3: speaking • B2: looks, smell, taste • B515: digestion
Zeegers et al. (2010)	Attention deficit hyperactivity and oppositional defiance disorder in HIV-infected South African children	South Africa: urban	Retrospective medical record review	N = 100 HIV-infected children (≥ 5 years), 49% girls	SNAP-IV, Goodenough draw-a-person (DAP)	<ul style="list-style-type: none"> • B140: concentration/attention

Myezwa *et al.* revealed impairments related to digestive, metabolic or endocrine systems in 83.9% of their sample. Similarly in the study by van As *et al.*, 44% of the sample experienced digestive, metabolic or endocrine problems [25,26]. Julius *et al.* indicated a prevalence of diabetes of 20.4%, with 16.8% obese and 28.6% overweight in the sample [43], although these data were not compared to HIV-negative controls.

Genitourinary and reproductive function (b6): Four studies reported data on functions of the genitourinary and reproductive systems. Van As *et al.* [26] showed that 31% of the sample experienced genitourinary or repro-

ductive problems. Bhat *et al.* [38] reported problems with sexual functions in 8.9% of their sample of 168 participants. Renal function was explored in larger trials. Franey *et al.* reported renal problems in 1.3% of their sample of 2189 PLHIV who are on treatment. Both Franey *et al.* and Jao *et al.* [44,45] found increased renal impairment at ART onset with men more affected than women.

Muscle function and related tissue (b7): Nine articles (describing eight studies) provided data on the extent of impairments related to muscle tone, power and motor development as well as the functions of the skin and related structures. Myezwa *et al.* revealed neuromuscu-

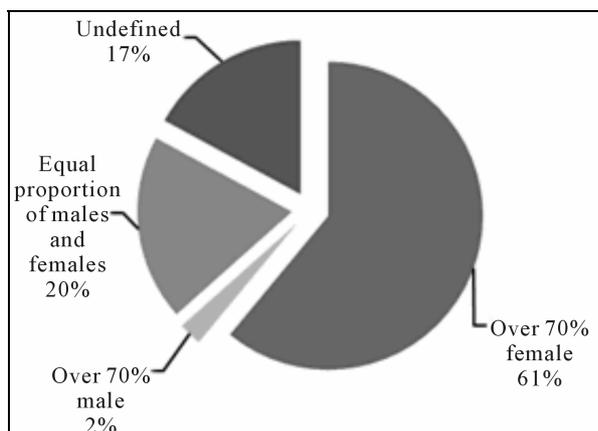


Figure 3. Proportion of women and men in included studies.

loskeletal movement impairment in 73.8% and muscle power loss in 75% of their sample [25]. Van As *et al.* reported that 31% of the sample experienced skin impairments and for 27% the most common neuromuscular problem was loss of muscle power. Focusing on fine and gross motor skills, Ferguson *et al.* [46,47] reported motor delay in their study of 86 HIV-positive children with matched controls. Significant motor delay was 66.7% in the HIV-positive sample, which was significantly higher than the age-matched compared. Bhat *et al.* reported problems with skin rashes in 8.3% and with hair loss in 7.7% of the sample. Franey *et al.*, Friend-du Preez *et al.* Oketcha *et al.* and Yengopal *et al.* also reported problems associated with the function of skin and related structures [40-42,44].

4.4. Activity Limitations and Participation Restrictions

In contrast to the level of *impairment*, far less data were reported on the ICF levels of *activity* or *participation*. Studies that did report on these concepts are described below according to the ICF domains of mobility, self-care, and community, social and civic life. Several studies also reported elements of “learning and applying knowledge”, which includes problem-solving, or “communication”. There was little information related to contextual factors, such as access to services, technology, support and relationships and attitudes.

Mobility (d4): Eight studies reported problems with mobility, mainly for PLHIV on treatment. Myezwa *et al.* [7,25] found mobility limitations in 56.4% of the sample, while van As *et al.* [26], using the same framework, found mobility limitations in 40% of the sample, especially lifting and carrying. These complaints were associated with mild difficulty undertaking multiple tasks without assistance. Similarly, Nair and Patel reported decreased physical functioning as measured by mobility. The studies by Wouters *et al.*, Booysen *et al.*, Kakinami

et al., and McInnerney *et al.* [32,33,48-50] reported improvement in mobility upon initiating ART, with participants followed for the first 12 or 18 months. The study by Karbore *et al.* [51] showed that among participants not receiving community services (*i.e.*, food and home-based care), the mean physical functioning score increased by 1.6 points to 11.2 at 12 months but then decreased to 10.6 at 18 months, while the group which received community services improved continuously.

Self-care (d5): Three studies described data on self-care. Oketch *et al.* [42] reported minor (80.6%), moderate (14%), or severe (5.4%) problems with self-care. The studies by Booysen *et al.* [48], Jelsma *et al.* [15] and Kakinamis *et al.* [49] each showed improvements in the domain of self-care during the first year of ART. Data over a longer period were not available.

Community, social and civic life (d9): Two studies reported data in this domain. Myezwa *et al.* reported that activity limitations were present in major life areas (55.1%), and community, social and civic life (50%), and that many of those activity limitations were associated with impairments [25]. They also reported that activity limitations or participation restrictions, including difficulties with general tasks and demands, interpersonal relationships, domestic life, and community, social and civic life, were closely associated with barriers in obtaining products for personal use and in using technology. Van As *et al.* [26] showed that participants had challenges in major life areas (58%), and that interpersonal interactions and relationships (56%) were most common. Of these, challenges related to school, higher education and remunerative employment were specifically problematic.

4.5. Linkages among Impairment, Activity and Participation Levels

Few studies explored how the different domains might be associated with each other. Nair *et al.* [52] reported that Perceived Social Support was correlated with vitality ($r = 0.28$, $p < 0.01$) and mental health ($r = 0.26$, $p < 0.01$), suggesting that high levels of social support from family and friends are related to good mental health in the participants. Gupta *et al.* [53] reported that depression was associated with stigma and relationship problems. Nair *et al.* also reported how a low score on the SF-36 Bodily Pain Scale was associated with compromised ability to work.

The four studies that addressed contextual factors reported that certain impairments or activity limitations were associated with domains such as access to products and technology [25,31,54]. Simbavi *et al.* demonstrated how challenges within the ICF domain of emotional functions were related to problems with support and relationships [55].

Finally, linkages between dimensions of disability and

ART adherence received little attention in the available literature. Bhat *et al.* [38] reported that reasons given by participants for ART adherence problems included that they “simply forgot” (41.3%) or were attributed to the “side effects” of ART (50.8%). They also reported that HIV-related impairments or “side effects” were greatly increased in the portion of the sample that did not adhere to treatment, and that the reason for skipping the dose was often because of these side effects.

5. Discussion

This is the first analysis to systematically review the literature on HIV-related outcomes among people living with HIV in hyper-endemic countries within a disability framework. In the era of enhanced access to ART, many people will be living longer lives but with potential episodes of disability resulting from HIV, HIV-related conditions, and/or as side effects of ART. It is crucial to understand the extent of disability among people living with HIV in high-prevalence settings in order to inform choices regarding care, policy and research. These findings add to the growing body of literature that calls for attention to disability in high HIV-prevalence settings [4-7,16,56-59]. In particular, this scoping review demonstrates that much is already known about impairments, activity limitations and participation restrictions experienced by people living with HIV in hyper-endemic countries, but that key gaps in understanding remain.

5.1. What Is Known and Unknown about HIV-Related Disability in Hyper-Endemic Countries?

This review identified literature that reports data on all concepts within the ICF schematic of disability (see **Figure 1**), but in vastly unequal ways. By far, impairments in body structure and function comprise the majority of data available on disability experienced by people living with HIV in hyper-endemic countries. Most of the included studies report on some form of impairment, and all of the first level ICF impairment codes were addressed except for one (“b3 Voice”). Particularly striking is the extent of data reported on impairments related to mental functions, which is an area of disability that can be overshadowed by physical concerns. This mirrors the findings of the population-based disability prevalence study of people living with HIV in British Columbia, in which the prevalence of mental impairments was 78% [12].

Rusch *et al.* also reported a high prevalence of concurrent impairments, with a median of 7 impairments and approximately one-third of the sample experiencing more than ten impairments in the past month [12]. Similarly, our scoping study found multiple diverse impairments

being reported. However, a striking finding is that none of the included articles reported data on the sensory functions of hearing and seeing, despite the fact that HIV and its opportunistic diseases can cause these impairments [60]. Furthermore, few studies addressed functions of the cardiovascular and respiratory systems, even though tuberculosis and lipodystrophy are well-described health conditions associated with HIV.

Whereas Rusch *et al.* also reported high rates of activity limitations (80%) and participation restrictions (93), few studies included in this review addressed these levels of concern. Studies that did attend to these issues focused primarily on self-care, mobility and engagement in community. While some studies indicated improvement of these areas following onset of ART, [15,48-50] others reported that a large number of PLHIV continue to experience challenges related to these areas [61,62]. A longitudinal study using a comprehensive disability measure could enhance understanding of the shifting experience of activity limitations and participation restrictions over time. In addition to these areas, future research is needed to better understand domains not commonly included in outcome studies, such as communication, domestic life, and education.

The review also found very little data on contextual factors, which include availability of assistance devices, rehabilitation and social support in the context of HIV. The importance of these environmental factors can be crucial in mitigating activity limitations and participation restrictions. We note that data on contextual factors may more commonly be found in qualitative studies; however, the adage that “what gets counted counts” emphasizes the importance of quantifying outcomes across the holistic experience of disability in order to inform action.

A key direction for future research is investigation of linkages between HIV-related disability and ART adherence. The multi-faceted challenge could gain from better understanding how various dimensions of disability contribute to ART adherence or attrition. We also note the dearth of data related to disability among HIV-positive children and youth, indicating another priority for future research.

5.2. Contributions of a Disability Framework to HIV Research

An issue that arises from this review relates to the biomedical emphasis in HIV outcomes studies. The articles with the largest samples and thus the greatest opportunity to draw conclusions (at least within this research paradigm) typically focused on particular clinical concerns, without taking into account how these diagnoses might influence or be connected to other areas of health or life. It is therefore unsurprising that responses to HIV care are

largely medicalized and often do not include or privilege rehabilitation [3] or other services that could significantly improve quality of life. This is not to diminish the importance of biomedical approaches, and medicines in particular, to the experience of living with HIV. However, we argue that the time has come to elevate the health and life-related consequences of living with HIV to the status given to surrogate markers of disease progression.

Lack of data can lead to lack of responses that could strengthen HIV care. An advantage of the ICF is the way that each concept in the schematic can influence and be influenced by the other concepts, as illustrated by the double-headed arrows (see **Figure 1**). This framing acknowledges the complexity of life and challenges researchers to consider not only the concepts but their interactions. Only a few studies explored interactions between concepts, yet these findings provide important insights not only on the experience of disability but also on opportunities for providing support. For example, Nair *et al.* reported on links between pain and ability to work, pointing to the potential that pain management might play in reducing attrition from work. A more comprehensive approach to HIV care that includes broader concerns with function and activity is needed to inform other responses, such as rehabilitation and community interventions that could complement ART. Using a disability lens in the context of HIV has the potential to connect the medical field to others that address opportunities to promote human activity and participation.

By far the most comprehensive approach to disability and HIV in this scoping review was undertaken in the studies by Myezwa *et al.* and van As *et al.* Both studies used the ICF checklist as a tool of investigation. As a result, these two articles provide data across impairment, activity limitations and participation restriction levels like no other study in this review. Myezwa *et al.* were able to demonstrate that difficulties with general tasks and demands, interpersonal relationships, domestic life and/or community, social and civic life are associated with barriers in obtaining products for personal use and using technology. This highlights the importance of assessing contextual factors as well. Studies that used the ICF provide a more holistic understanding of the experience of living with HIV, and a link between the diagnoses of health conditions on the one hand, and the identification of impairments, activity limitations and participation restrictions on the other.

5.3. Limitations

The extent to which our review's findings can be generalised to reflect HIV-related disability in hyper-endemic countries is limited in three important ways: geographic and location issues, constraints of sampling approaches,

and concerns with sample sizes.

First, 78% of the studies were conducted in South Africa in contrast to just one study in Zimbabwe and none in Lesotho or Swaziland. Furthermore, all studies were conducted in public health care settings, which are more likely to include participants with lower socioeconomic status and less access to education and resources. As such, study results related to experiences of disability could be influenced by factors other than HIV. Future research needs to include matched control groups to clarify the degree to which disability is HIV-related.

Secondly, most studies in this sample used convenience sampling; only three studies (7%) used random sampling. As such, findings are likely to reflect the kinds of individuals who more frequently attend the recruitment settings. Most of the studies in this review included more women than men. HIV prevalence in Southern Africa is higher in women, and women may be more likely than men to seek health services. As such, results may erroneously give the impression of certain experiences being more common among women than men. Conversely, the study by van Marle *et al.* included more males than females [63]. However, the study focused on HIV-occlusive vascular disease, which may be more prevalent in men in the general population. Therefore, it would be inappropriate to make claims about gendered differences in the extent of disability related to this condition.

Thirdly, the studies in this review with the largest sample sizes ($n > 1000$) focused on particular health conditions, such as renal failure or neurological disorders. Studies that took a broad view of disability had relatively small samples ($n < 100$). As such, we may draw only limited conclusions about the extent of disability in PLHIV. A population-based prevalence study of disability (understood comprehensively, as in the ICF) would mitigate each of these methodological concerns.

6. Conclusion

This scoping review described the literature on disability experienced by people living with HIV in hyper-epidemic countries since expanded access to ART in the mid-2000s. A key innovation in this study is the way that we have conceptualized HIV-related disability in Southern Africa using the World Health Organization's ICF. We hope that this review will prompt consideration of disability issues and inclusion of people with disabilities in our collective thinking about HIV in the region.

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List of Abbreviations

ARV: Antiretroviral
ART: Antiretroviral therapy
HAART: Highly active antiretroviral therapy
HAND: HIV-associated neurocognitive disorders
ICF: International Classification of Functioning, Disability and Health
IHDS: International HIV dementia scale
PLHIV: People living with HIV
PTSD: Post traumatic stress disorder
SF-36: Short Form 36
STD: Sexual Transmitted Disease
SRQ-20: Self Reported Questionnaire 20
QAL: Quality of Life