

Section 5: What are the concepts and tools for measuring rehabilitation outcomes in HIV in SSA?

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5.1 – What are outcome measures?

Outcome measures refer to tools, questionnaires, or devices that facilitate the assignment of numbers to related concepts of interest.

Outcome measures can be:

- "Objective" whereby a rehabilitation provider conducts an assessment of a person's health status (e.g., range of motion as measured by goniometry)
- "Subjective" (also called "self-report"), whereby a client completes a health questionnaire (e.g., symptom presence and severity as measured by an HIV symptom index).

5.2 – Why should rehabilitation providers use outcome measures?

Evidence-based practice is now a well-accepted component of health and medical care in many parts of the world.

What is evidence-based practice?

- *"the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients"*¹

What is the goal of **evidence-based rehabilitation**?

- To incorporate research findings with clinical wisdom and clients' preferences to inform rehabilitation assessment and treatment.²

Research questions addressed in rehabilitation include:

- the effectiveness and safety of interventions;
- the frequency of diseases and disability;
- aetiology and risk factors;
- prediction and diagnosis;
- diagnostic accuracy and other phenomena including hypothesis generation.³

The evidence base in rehabilitation is growing rapidly, but translating these findings into practice remains a challenge.^{4,5,6,7,8} The goal of this resource is to provide evidence-informed guidance on rehabilitation for adults and children living with HIV.

Rycroft-Malone et al (2004)⁹ describe four types of evidence that can contribute to the delivery of care: 1) research, 2) clinical experience, 3) patient experience, and 4) information from the local context.

Research: The strongest type of research evidence is a blinded, randomized controlled trial (RCT) for testing an intervention.¹⁰ However, other types of quantitative and qualitative research are valuable when used appropriately.

Clinical experience: Knowledge from clinical experience is a crucial component of evidence-based practice to achieve client-centred care. This perspective allows clinicians to work according to their skills and experiences.

Patient experience: Knowledge from clients, family members and carers regarding what works for the client is crucial. Communication of desires and goals are necessary to apply the research-based evidence appropriately.

Information from the local context: Finally, practice can be improved by incorporating knowledge from the local context, including knowledge of an organization's culture and the local health system.

Why use outcome measures?

- As evidence-based practice and initiatives to improve healthcare have grown around the world, there has been increased recognition of the need to measure outcomes.
- Using outcome measures in practice is important because it helps rehabilitation providers:
 - compare a client's function to other people living with HIV, or the general population
 - determine whether changes in a client's health status occur over time
 - facilitate communication about a client's health status among members of the health care team
 - e.g., when a client is transferred from acute to rehabilitation care, the rehabilitation provider in acute care can indicate scores on a symptom index in the chart and the rehabilitation provider in the rehabilitation department will be able to know what they mean
- determine whether a change in health status occurs in response to a particular intervention.

Why are using outcome measures in rehabilitation with people living with HIV important in Sub-Saharan Africa?

- HIV management can be complex, which demands a comprehensive continuum of care.
- Given the complexity of care associated with rehabilitation of people living with HIV, key issues to be addressed include: *'what works?'*, *'how can it be measured?'*, *'what can be used to measure that which works?'*

Table 5.2: Purpose of outcome measures

Purpose	Description
Descriptive	<p>Describes the state of a health construct at a point in time.</p> <p>This description can be used to compare the client to other clients, or the general population.</p> <p>For example, measuring activities of daily living or symptom severity at one point in time.</p>
Predictive	<p>Used to predict outcome or make a prognosis, helps clinicians set treatment goals or discharge plans, and anticipate the need for home adjustments or community support. ^{11,12}</p> <p>For example, using a balance scale to predict whether someone is at risk of falling.</p>
Evaluative	<p>Useful for detecting the magnitude of change over time in an individual or group. ^{13, 14}</p> <p>For example, measuring health-related quality of life (HRQL) at two time points, such as before and after a six week rehabilitation program to see if there are changes (improvement or worsening) in HRQL.</p>
Discriminative	<p>Differentiates between patient groups and identifies differences in patients' abilities ¹⁵</p>

What would rehabilitation providers measure in people living with HIV?

There are many "things" (otherwise referred to as constructs or concepts) that health professionals might measure with clients. These health-related concepts exist at multiple levels:

- **Body structure and function, e.g.,:**
 - [Presence and bothersome nature of symptoms](#): HIV Symptom Index
 - [Fatigue](#): HIV Fatigue Scale
 - [Depression](#): Centres for Epidemiologic Studies Depression Scale
- **Activity, e.g.,:**
 - [Activities of daily living](#): Assessment of Motor and Process Skills (AMPS)
 - [Self-management self-efficacy](#): Perceived HIV Self-Management Scale
 - [Functional Assessment of HIV Infection](#)
- **Social participation, e.g.,:**
 - [Social Support](#): Medical Outcomes Study Social Support Survey (MOS-SS)
 - [Stigma](#): HIV Stigma Scale
 - [Coping Response](#): Brief COPE Scale
 - [Stress](#): HIV Stress Scale
- **Health-related quality of life**
 - [Medical Outcomes Study Short Form \(SF-36\) Questionnaire](#)
 - [Medical Outcomes Study-HIV Health Survey \(MOS-HIV\)](#)
 - [Multidimensional QOL Questionnaire for HIV/AIDS \(MQoL-HIV\)](#)
 - [WHOQOL-HIV](#)
 - [Patient Reported Outcomes Quality of Life-HIV \(PROQOL-HIV\)](#)

5.3 – How do rehabilitation providers know if an outcome measure will be useful in practice?

Measurement properties are characteristics of a measure that can help determine whether the measure will be suitable for use in practice. There are four main measurement properties commonly seen in the literature (see Table 5.3)

Table 5.3: Descriptions of Measurement Properties

Measurement Property	Description
Reliability	<p>Degree of consistency of the measure and whether a measure (or questionnaire) is free from error.¹⁶</p> <p>It is important that measures are reliable (or consistent) and able to differentiate measure scores between clients.</p>
Validity	<p>How well the measure really measures what it is supposed to measure¹⁶</p> <p>Cronbach's alpha is a measure of internal consistency reliability, otherwise referred to as homogeneity of the scale. This is a reflection of how well the items in the scale are measuring different aspects of the same concept.¹⁶ Nunnally suggests that a Cronbach's alpha of >0.9 is defined as acceptable for an instrument used with individual patients and a Cronbach alpha >0.80 is defined as acceptable for a clinical instrument used with a group of patients (i.e. research).¹⁷</p> <p>For example, does the HIV Symptom Index,¹⁸ developed to measure symptom presence and severity, really measure this construct or are there other HIV symptoms that people living with HIV might experience not captured in this questionnaire?</p>
Responsiveness	<p>Ability for a measure to detect change in a client over time if a change has occurred.¹⁶ This property is relevant to evaluative types of measures.</p> <p>A sensitive, or responsive, assessment enables the healthcare provider to detect small to large changes in the construct of interest.</p> <p>For example, a rehabilitation provider might be interested in knowing whether participation in a six-week aerobic exercise program has an impact on the health-related quality of life of a client.</p>
Interpretability	<p>Meaning of the scores or values associated with the outcome measures, i.e., what do the numbers really mean?</p> <p>For example, what does a score of 82 on the Mental Health Summary Score of the Medical Outcomes Study Short Form (SF-36)^{19,20} mean for clients? What does it mean for treatment decisions in clinical practice?</p> <p>Terms such as the minimal detectable change (MDC), or minimal clinically important difference (MCID) refer to interpretability, specifically the minimum</p>

score that reflects an important or clinical change (improvement or worsening) for a given measure.^{16,21}

For example, the MCID for the six-minute walk test is 25 meters among people living with Chronic Obstructive Pulmonary Disease.²² If an individual improves her/his score on the test by 30 metres, this can be interpreted as a clinically important improvement in functional capacity.

Often measures do not have a clear MCID or MDC and rehabilitation providers are left trying to interpret what the scores on a given measure mean for specific clients and what the scores mean for decision-making in clinical practice.

5.4 – What are floor and ceiling effects in outcome measurement?

Table 5.4: Description of Floor and Ceiling Effects

Measurement Property	Description
Floor effect	<p>Floor effect occurs when responses on a measure, questionnaire or scale cluster at the more negative health state end of scale.</p> <p>For instance, if the scale were administered a second time, there would be no room to detect any possible deterioration in health, even if it had occurred.</p>
Ceiling effect	<p>Ceiling effect occurs when responses on a measure or questionnaire cluster at the more positive health state end of the scale.</p> <p>This means that if the scale were administered a second time, there would be no room to detect any possible improvements in health, even if they had occurred.</p>

5.5 – What is the difference between generic and HIV-specific outcome measures?

Table 5.5: Advantages and Disadvantages of Generic versus Disease-specific Measures

Type of Outcome Measure	Advantages and Disadvantages
<ul style="list-style-type: none"> Generic Measures These measures can be used with all individuals in the general population. 	<p>If a generic measure is used with people living with HIV, their scores can be compared with people living with other types of illness who completed that same measure, or even to the general 'healthy' population.</p> <p>Examples of generic measures commonly used in HIV practice and research include:</p> <ul style="list-style-type: none"> Medical Outcomes Study Short Form (SF-36) questionnaire, which measures health-related quality of life (HRQL)^{19,20} Assessment of Motor and Process Skills (AMPS), which is used to measure safety, independence, efficiency and effort when performing daily life tasks within and around the home^{23,24} Centre for Epidemiological Studies for Depression Scale (CES-D), which measures depression²⁵ <p>One drawback with generic measures is that there may be unique aspects related to HIV that are not captured in a generic type of measure (e.g. lipodystrophy, HIV stigma and discrimination, and fear of disclosure).</p>
<ul style="list-style-type: none"> Disease-Specific Measures These can measure a health-related concept within a specific disease group (e.g., people living with HIV). 	<p>To capture disease-specific issues, researchers developed disease or HIV-specific measures to measure the extent of certain health constructs of interest for people living with HIV.</p> <p>Examples of HIV-specific measures are:</p> <ul style="list-style-type: none"> HIV Symptom Index, a 21-item self-reported questionnaire that measures symptom presence and severity¹⁸ Medical Outcomes Study-HIV Health Survey which was adapted from the Short Form 36 (SF-36) to measure HRQL specifically for people living with HIV^{26,27,28}

5.6 – How should you decide which outcomes measure to use?

Table 5.6: Steps to consider when using outcome measures in clinical practice

Steps	Description
1) Identify the "things" or "health-related concepts" you want to measure with the client	For example, pain, symptom severity, disability, health-related quality of life
2) Determine the purpose or reason for measuring this health-related concept	<p>Is the intent to describe, predict, or evaluate change over time?</p> <p>Different outcome measures are developed with different purposes and it is important to choose the measure that is geared towards a specific purpose (see Table 5.2).</p>
3) Search for available outcome measures that can measure a construct with a purpose in mind	<p>Many outcome measures exist to choose from. It is important to review the literature and talk to other health professionals about different outcome measure options available to measure the desired concept.</p> <p>Consider feasibility such as the length of the outcome measure (e.g. number of items in a questionnaire), the amount of time it takes someone to complete the measure, and literacy requirements if the measure is a self-reported questionnaire.</p>
4) Choose the measure	<p>When choosing a measure, consider:</p> <ul style="list-style-type: none"> • Whether a generic measure or an HIV-specific measure is appropriate • Whether an objective or subjective (self-report) measure is appropriate • The measurement properties (psychometric adequacy) of the questionnaire, scale or tool. For instance, has the measure been evaluated for reliability and validity with people living with HIV and/or with people in Sub-Saharan Africa? If evaluating change over time, determine whether this measure is able to detect change over time if change has occurred? And finally, how are the scores on the measure interpreted? What do they mean?

5.7 – How do you access a copy of an outcome measure?

If the outcome measure chosen is a questionnaire, rehabilitation providers may find it available online. However, they may be required to email the authors of the questionnaire to obtain a copy and obtain their permission to use the measure.

In some cases, the questionnaires are copyrighted and there might be a cost associated with using the questionnaire. In other cases, the questionnaires might be available for use in the public domain.

In addition, it is important to obtain clear instructions regarding how to administer and score the measure. Some questionnaires have administration and scoring manuals that help standardize the way in which the tool is administered with clients and will instruct on how to calculate domain and total scale scores and describe what the scores mean (interpretability).

See [Section 5.8](#) for a detailed list of outcome measures.

5.8 – What are rehabilitation-related outcome measures that can be useful for people living with HIV in SSA?

This section provides information about outcome measures that are relevant for rehabilitation providers to use when providing care to people living with HIV in Sub-Saharan Africa. The measures are organized by the construct that they measure. Detailed information about each is provided including a description and how to access it.

[5.8.1 – Activities of Daily Living](#)

[5.8.2 – Coping Response](#)

[5.8.3 – Depression](#)

[5.8.4 – Fatigue](#)

[5.8.5 – Health-related quality of life](#)

[5.8.6 – Presence and bothersome nature of symptoms](#)

[5.8.7 – Self-management self-efficacy](#)

[5.8.8 – Social Support](#)

[5.8.9 – Stigma](#)

[5.8.10 – Stress](#)

5.8.1 – Activities of Daily Living (ADL)

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
Assessment of Motor and Process Skills (AMPS) ^{23,24}	Generic Evaluative and Descriptive	Performance-based/ observation 36 items (16 ADL motor skills and 20 ADL process skills) 2 domains (ADL Motor Ability and ADL Process Ability)	<p>Reliability: Good internal consistency (multi-faceted Rasch equivalent of Cronbach's alpha > 0.90)²⁹</p> <p>High interrater reliability ($r \geq 0.90$)³⁰</p> <p>High test-retest reliability ($r \geq 0.90$)³¹</p> <p>Validity: Construct validity in a sample of people living with HIV³²</p> <p>Numerous studies demonstrating cross-cultural validity.</p>

5.8.2 – Coping Response

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
Brief COPE Scale ^{33,34}	HIV-specific Descriptive	Self-reported questionnaire 28 items 14 domains and 2 summary scores (maladaptive coping and adaptive coping)	Reliability: Adequate internal reliability (Cronbach's alpha \geq 0.50) among general population. Validity: Construct validity demonstrated among general population ³³

5.8.3 – Depression

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
Centres for Epidemiologic Studies Depression Scale (CES-D) ³⁵	Generic Descriptive	Self-reported questionnaire 20 items 8 domains	<p>Reliability: high internal reliability ($\alpha \geq 0.85$) and adequate test-retest reliability on a general adult population.</p> <p>Validity: Concurrent construct validity on a general adult population.</p> <p>Demonstrated predictive construct validity and high internal consistency reliability on a population with Hepatitis C.³⁶</p>

5.8.4 – Fatigue

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
HIV Fatigue Scale ³⁷	HIV-specific Descriptive	Self-reported questionnaire 56 items 3 domains	<p>Reliability: High internal consistency reliability. Cronbach's alpha was >0.90 on all domains among people living with HIV-related fatigue. Cronbach's alpha for the entire tool was 0.94. Test-retest reliability was moderate with a correlation coefficient of 0.43.</p> <p>Validity: Good convergent construct validity among people living with HIV-related fatigue.³⁸</p>

5.8.5 – Health-related Quality of Life

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
Functional Assessment of HIV Infection (FAHI) ³⁹	HIV-specific Descriptive and Evaluative	Self-reported questionnaire 47 items 5 domains	Reliability: Internal consistency reliability (>0.73 Cronbach's alpha for all domains) Validity: Convergent and discriminant validity among adults living with HIV. Responsiveness to change among adults living with HIV. ⁴⁰
Medical Outcomes Study Short Form (SF-36) Questionnaire ^{19,20}	Generic Descriptive	Self-reported questionnaire 36 items 8 domains and 2 summary scores (physical component and mental component)	Demonstrated reliability and validity among people living with HIV. Reliability: Good internal consistency reliability among people living with HIV (all Cronbach alpha values typically > 0.80) and good test-retest reliability. Validity: Demonstrated content validity, criterion validity, construct validity with people living with HIV. ^{41,42}
Medical Outcomes Study-HIV Health Survey (MOS-HIV) ^{43,44,45}	HIV-specific Descriptive	Self-reported questionnaire 35 items 10 domains and 2 summary scores (Mental Component Summary (MCS) and Physical Component Summary (PCS) scores)	Reliability: Good internal consistency (>0.75 Cronbach's alpha) for all dimensions for people living with HIV. Validity: Convergent and discriminant construct validity with people living with HIV. ^{44,46}
Multidimensional QOL Questionnaire for HIV/AIDS (MQoL-HIV) ⁴⁷	HIV-specific Descriptive and Evaluative	Self-reported questionnaire 40 items 10 domains	Reliability: Good internal consistency reliability (>0.70 Cronbach's alpha for 8 out of 10 domains) and test-retest reliability (correlation coefficient >0.70 for all domains except cognitive functioning) among people with asymptomatic and symptomatic HIV infection. Validity: Discriminative construct validity among people with asymptomatic and symptomatic HIV infection.

			<p>Responsiveness: Responsive to change in number of symptoms, viral load and CD4 count during a 3 month period for people living with HIV starting or changing an antiretroviral therapy regimen.⁴⁶</p>
WHO QOL-HIV ^{48,49}	HIV-specific Descriptive	Self-reported questionnaire 120 items 6 domains	<p>Reliability: Good internal consistency reliability for all domains with Cronbach's alpha between 0.70 and 0.90 among people living with HIV from seven culturally diverse centres.</p> <p>Validity: Good discriminant validity among people living with HIV in diverse cultural settings.^{49,50}</p>
Patient Reported Outcomes Quality of Life-HIV (PROQOL-HIV) Questionnaire ^{51,52}	HIV-specific Descriptive	Self-reported questionnaire 43 items 8 domains and 1 global health item	<p>Reliability: Good internal consistency reliability with Cronbach alphas on domains ranging from 0.77–0.89. Test–retest reliability demonstrated consistency of the measure over time (intraclass correlation coefficient = 0.86).</p> <p>Validity: Good convergent and discriminant validity. Correlations with EQ-5D and Medical Outcomes Study–HIV questionnaires complied with concurrent validity expectations; as well as correlations with self-reported symptom and depression questionnaires.</p>

5.8.6 – Presence and nature of symptoms

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
HIV Symptom Index ¹⁸	HIV-specific Descriptive	Self-reported questionnaire 20 items No domains	Validity: Good construct validity among people living with HIV on combination antiretroviral therapy. ¹⁸

5.8.7 – Self-management self-efficacy

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
Perceived HIV Self-Management Scale (PHIVSMS) ⁵³	HIV-specific Descriptive	Self-reported questionnaire 8 items 1 domain	<p>Reliability: Good internal consistency reliability with Cronbach's alpha 0.78 with adults (primarily men) living with HIV.</p> <p>Validity: Construct validity demonstrated in adults living with HIV with correlations to criterion measures of HRQL and depression ranging from 0.37-0.66.⁵³</p>

5.8.8 – Social Support

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
Medical Outcomes Study Social Support Survey (MOS- SS) ⁵⁴	Specific to chronic disease Descriptive	Self-reported questionnaire 19 items 5 domains	<p>Reliability: High internal consistency reliability (Cronbach's alpha ≥ 0.90) among people living with HIV.</p> <p>Validity: Convergent and discriminant construct validity demonstrated among people living with HIV.</p>

5.8.9 – Stigma

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
HIV Stigma Scale ⁵⁵	HIV-specific Descriptive	Self-reported questionnaire 40 items 4 domains	<p>Reliability: Good internal consistency reliability (Cronbach's alpha \geq 0.90 for subscales and 0.96 for the summary scale) among people living with HIV.</p> <p>Validity: Construct validity in a sample of people living with HIV.</p>

5.8.10 – Stress

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
HIV Stress Scale ⁵⁶	HIV-specific Descriptive	Self-reported questionnaire 29 items 3 domains	Validity: Convergent construct validity among men living with HIV. ⁵⁶

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