How Rehabilitation Can Help People Living with HIV in sub-Saharan Africa:

An Evidence-Informed Tool for Rehab Providers

Partners:

University of Toronto

University of Zambia

Realize (formerly CWGHR)

The DSP Kenya Project

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About this Resource

What is this resource about and who is it for?

What is this resource about?

The aim of this e-module is to enhance knowledge about HIV care among rehabilitation providers in Sub-Saharan Africa to help address the needs of people living with HIV.

What do we mean by “rehabilitation”?

In this resource, **rehabilitation** is defined as any service or activity that addresses or prevents body impairments, activity limitations, and social participation restrictions experienced by an individual.[1]

Rehabilitation is concerned not only with physical well-being, but also with mental and spiritual dimensions of health.

Who is this resource for?

This resource is primarily for rehabilitation providers practicing in Sub-Saharan Africa.

Rehabilitation providers include occupational therapists, physiotherapists, speech-language therapists, and physiatrists.

Others who may benefit from this resource include:

- other health and social service providers;
- community rehabilitation workers, community health workers or home-based carers; and,
- people living with or affected by HIV

A description of the many people who can provide rehabilitation for individuals living with HIV is provided in Section 1.5

Why was this resource created?

Treatment advances have improved survival for people living with HIV who have access to care. HIV disease is now considered chronic and cyclical, with periods of wellness and illness. [2,3,4]

As many people with HIV in Sub-Saharan Africa are now living longer, they face a number of health challenges related to HIV, concurrent health conditions, and side effects of treatment.

A 2004 survey in Canada was the first to document the high prevalence of disablement among people living with HIV. At least 80% of respondents experienced a minimum of one impairment (e.g. fatigue, pain, memory problems), activity limitation (e.g. difficulty carrying out daily activities) or social participation restriction (e.g. employment, financial independence) in the previous month.[5]

More recently, research has been conducted in Sub-Saharan Africa that illustrates the various forms of disablement that may be experienced by adults and children living with HIV.[6,7,8,9]

These findings highlight the role for rehabilitation to help people meet the challenges of living and aging with HIV.

How can this resource be used?

This resource is designed for use either:

- as a *whole* or
- by *section* depending on the specific learning needs of the user.

Each section can be used online or downloaded as a PDF file.

The online format allows readers to navigate around the resource to find specific content as needed. Links to additional resources are provided throughout so that readers can access further information.

Can this resource be used for teaching?

- Yes!
- This resource is designed to be used widely for teaching others, including:
  - Rehabilitation students
  - Practicing rehabilitation providers
  - Community rehabilitation workers, community health workers or home-based carers
  - Other health or social service providers
  - People living with HIV and their caregivers

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This resource is intended to be shared with as broad a range of stakeholders as appropriate. Use of these materials is encouraged!

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Permission must be obtained to excerpt and/or edit/adapt the content or to use the resource for commercial purposes. For further information, please contact ***Realize*** at info@realizecanada.org.

How is this resource organized?

This resource is divided into 5 sections as follows:

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How was this resource developed?

This resource is a comprehensive adaptation of the 2014 version of the "*e-Module for Evidence-Informed HIV Rehabilitation" (e-Module)*,[10] which was designed for *Canada*. This resource was adapted for rehabilitation providers in *Sub-Saharan Africa.*

What is the history of the 2014 version of the "e-Module for Evidence-Informed HIV Rehabilitation"?

In 1998, "*A Comprehensive Guide for the Care of Persons with HIV Disease (Module 7)*", was published by Health Canada and the Wellesley Central Hospital in Toronto, Canada.[11]This version was updated by ***Realize*** (formerly the Canadian Working Group on HIV and Rehabilitation) in 2013 and 2014.

> Founded in 1998, ***Realize*** is a national multi- sector, multi-disciplinary, charitable organization of stakeholders involved in rehabilitation in the context of HIV in Canada. ***Realize*** works to bridge the traditionally separate worlds of HIV, disability and rehabilitation to promote quality of life through research, education, and cross- sector partnerships (www.hivandrehab.ca).

In 2013, the 1998 'Module 7' was updated to address the changing profile, emerging issues and new evidence related to HIV and rehabilitation.[12]The 2013 adaptation was led by ***Realize*** and was a collaboration among a dedicated team of authors, editors, and external reviewers including: people living with HIV, clinicians, researchers, and advocates representing fields spanning medicine (family medicine and physiatry), nursing, occupational therapy, psychology, physical therapy, speech-language pathology, social work, pediatrics, midwifery, and policy.

In 2014, the resource was further updated by a large team of volunteers who participated as content experts, advisory committee members, writers and reviewers. The final resource was called the 2014 version "*e-Module for Evidence-Informed HIV Rehabilitation".*[10]

How was the Canadian 2014 e-Module adapted for Sub-Saharan Africa?

This current resource is a comprehensive adaptation of the 2014 Canadian e-Module for rehabilitation providers in Sub-Saharan Africa. This adaptation was led by collaborators at:

- Realize (Canada)
- Disability Service Programme (Kenya)
- International Centre for Disability and Rehabilitation at the University of Toronto (Canada)
- University of Zambia (Zambia)

Adaptation involved input from a range of individuals with rehabilitation, disability and/or HIV experience from 5 countries in Sub-Saharan Africa. The adaptation process involved 7 steps:

1) The **2013 e-Module** was carefully reviewed by individuals with experience in HIV and/or disability and/or rehabilitation in Sub-Saharan Africa.
2) Reviewers' feedback was consolidated and an outline for the adapted resource was developed.
3) Content for the adapted resource was developed by drawing on text from the 2014 e-Module and new writing.
4) Drafts were reviewed by all collaborators.

5) The adapted resource was pilot tested with rehabilitation providers and rehabilitation students in Kenya and Zambia.
6) Changes were made to the resource based on feedback from the pilot.
7) The final resource was made available for free in online (ssa.hivandrehab.ca), mobile and downloadable PDF versions.

Who funded the development of this resource?

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Disclaimer

While the content of this resource is, to the best of our knowledge, current and reliable, information is not a substitute for actual health care and treatment. The opinions expressed in this resource do not necessarily reflect the official policy of Realize (formerly the Canadian Working Group on HIV and Rehabilitation) or any of the sponsoring organizations.

Section 1: What is the role of rehabilitation in the context of HIV in SSA?

1.1 – How is "rehabilitation" defined in this resource?

In this resource, **rehabilitation** is defined as any services or activities that address or prevent body impairments, activity limitations, and social participation restrictions experienced by an individual.[13] Rehabilitation is concerned not only with physical well-being, but also with mental and spiritual dimensions of health.

1.2 – How can rehabilitation help people living with HIV in SSA?

The medical community is getting very good at treating HIV disease. However, where is the focus on the impact of HIV and its related conditions on a person's *function* or *participation* in her/his community? This is the focus of rehabilitation.

A focus on function and participation is especially important now that many more people living with HIV are able to access life-extending antiretroviral therapy (ART). For many people on ART, HIV is becoming a chronic and cyclical disease with periods of wellness and illness.[14,15,16]

Since 1995, antiretroviral therapy has averted 4.8 million deaths in sub-Saharan Africa. The greatest declines in AIDS-related deaths in sub-Saharan Africa (2008 – 2013) were in the following countries:

- Rwanda (76%)
- Eritrea (67%)
- Ethiopia (63%)
- Kenya (60%)
- Botswana (58%)
- Burkina Faso (58%)
- Zimbabwe (57%)
- Malawi (51%)
- South Africa (48%)
- Tanzania (44%)[17]

This success in reducing AIDS-related mortality is credited to the rapid increase in the number of people on ART.

Medicine is adding *years to life*. **Rehabilitation aims to add *life* to one's *years*** – by helping people living with HIV to continue to work, keep up parenting roles, go to school, participate in church, feel active and independent, or any other goal related to living life.

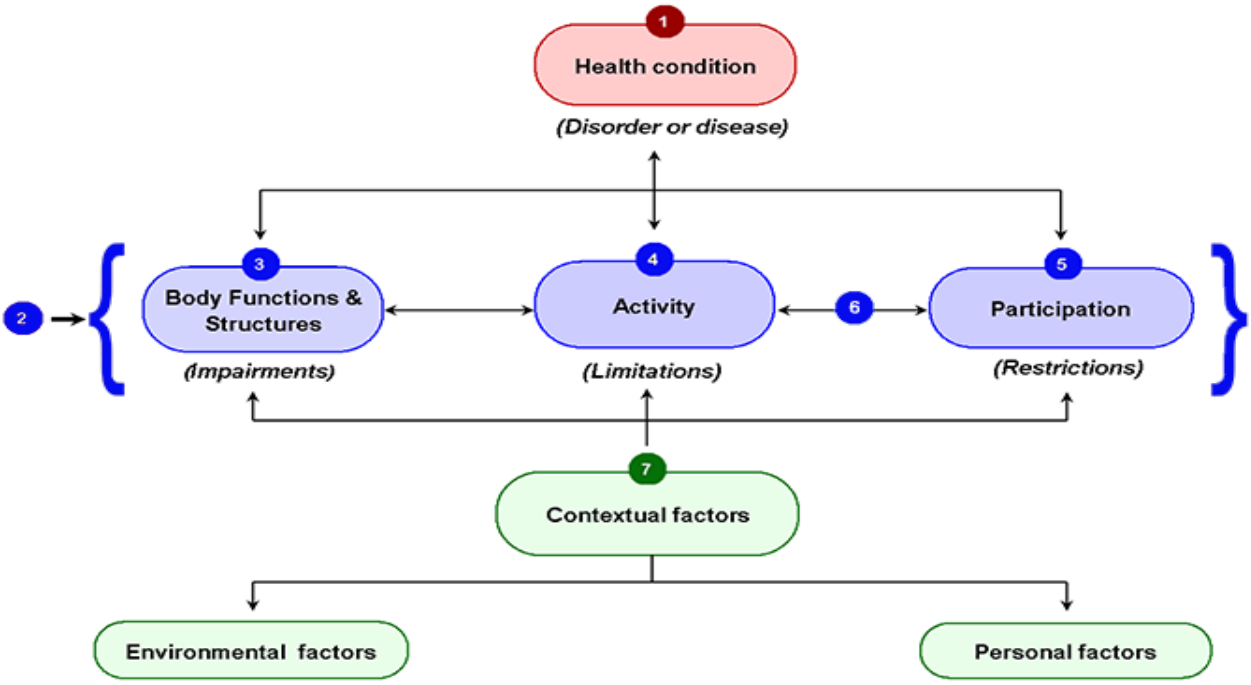
1.3 – How can the World Health Organization's "ICF" help us think about rehabilitation for people living with HIV?

The World Health Organization's International Classification of Functioning, Disability and Health (known as the **ICF**)[18] is helpful for thinking about the role of rehabilitation in HIV.[19,20,21]

Health conditions (the top box) are often the focus of HIV care and treatment, whereas the ICF calls attention to the wide range of the **life-related** challenges resulting from health conditions that can be addressed by rehabilitation (boxes 3-5).

The model was designed for all types of diseases and functioning, not just HIV. It offers a common language for clinicians, managers, policy makers or others interested in HIV models of care.

Figure 1.3: The ICF Model



The ICF Model (Figure 1.3) Explained	
1	This box describes the medical diagnoses, diseases or injuries that a person can experience. For a *person living with HIV*, this could be any combination of: • HIV (e.g., the virus directly targeting the immune or neurological systems) • HIV-related conditions (e.g., TB, pneumocystis carinii pneumonia, Kaposi's sarcoma) • Diagnoses related to ART (e.g., peripheral neuropathy) • Diagnoses unrelated to HIV (e.g., multiple sclerosis, trauma resulting from a motor vehicle accident)

2	This row describes the **life-related impacts** that result from health conditions. Rehabilitation addresses these impacts.
3	**Impairments** are problems in **body function** (physiological or psychological functions of body systems) or **structure** (anatomical body parts), e.g., weak abdominal muscles, memory loss, right-sided hypertonicity, congested lungs
4	**Activity limitations** are problems executing a task or action (e.g., getting dressed, walking to a clinic, carrying one's child, communicating with a neighbor)
5	**Participation restrictions** are problems an individual may experience with involvement in life situations (e.g., being excluded from school, difficulty participating with one's church, feeling stigmatized at work, challenges with parenting)
6	Note the arrows are bi-directional. This means that a challenge at one level can affect any other level. For example: • Peripheral neuropathy (**health condition**) causing bilateral leg pain (**impairment**) can limit one's ability to walk to one's bank (**activity limitation**) which in turn can limit one's ability to manage her/his household finances (**participation restriction)**. • Stigmatization for being HIV-positive can result in being excluded from one's football team (**participation restriction**) which results in less physical activity (**activity limitation**) which results in decreased endurance and strength (**impairments**)
7	**Contextual factors** influence or shape people's experiences with these life-related impacts of health conditions. • **Environmental factors** are the physical, social and attitudinal environment in which people live and conduct their lives (e.g., stigmatizing attitudes about HIV, stairs vs. ramp outside a health clinic, laws that criminalize certain HIV-related behaviors). These contextual factors include the social determinants of health[22](e.g., housing, food security, access to employment). • **Personal factors** are internal to each individual (e.g., gender, age, coping styles, education, past medical history).

1.4 – How can the Episodic Disability Model help us think about rehabilitation for people living with HIV?

For people who can access and tolerate ART, HIV is becoming a chronic and cyclical disease. These cycles of wellness and illness over time are not well captured in the ICF. Therefore, the Episodic Disability Model was developed with adults in Canada to describe the unpredictable nature of living with HIV.[23,24]

There is reason to expect that women, men and children on ART in sub-Saharan Africa will also experience episodes of wellness and illness related to their HIV.

The framework recognizes that each individual with HIV has her/his own disease course.

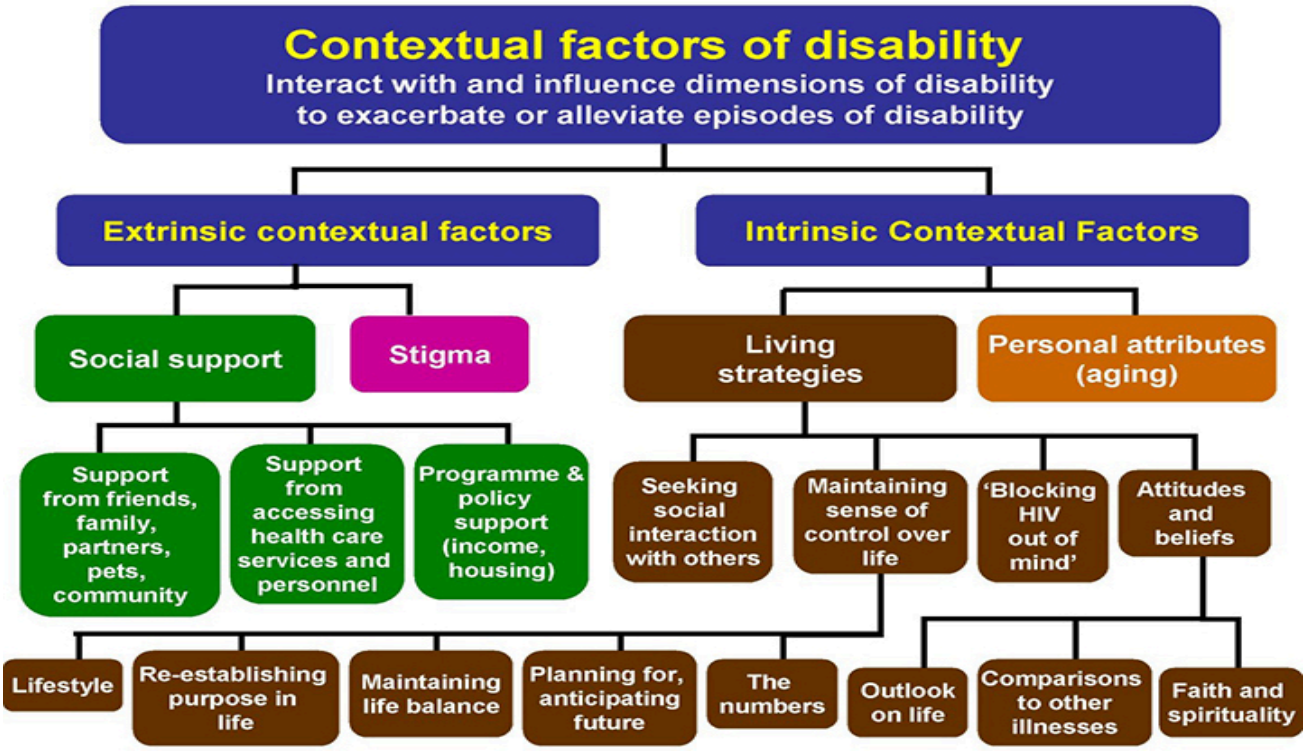
The Episodic Disability Model has 3 features:

- **Dimensions of episodic disability** which describe four dimensions of episodic disability and their sub-components that may be experienced by adults living with HIV (see Figure 1.4.1)
- **Contextual factors of disability** which describe the context in which disability is experienced. Extrinsic and intrinsic contextual factors could exacerbate or alleviate each of the four dimensions of disability for adults living with HIV (see Figure 1.4.2)
- **Triggers** or life events that can mark a major episode of disability (e.g., first receiving an HIV diagnosis, starting or changing medications, suffering the loss of a family member or friend) (see Figure 1.4.3)

Figure 1.4.1: Dimensions of Episodic Disability

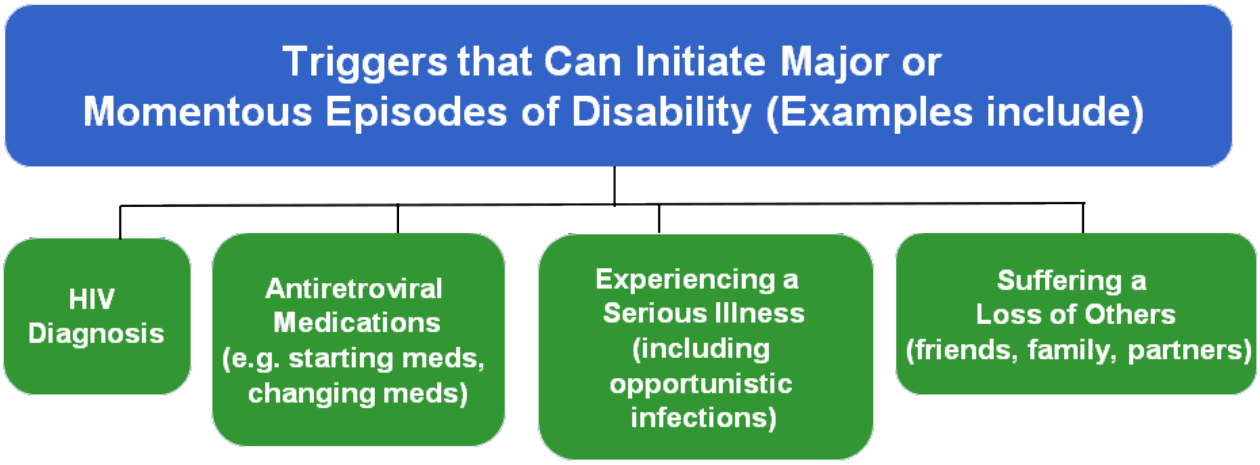
O'Brien *et al. Health and Quality of Life Outcomes* 2008 **6**:76 doi:10.1186/1477-7525-6-76

Figure 1.4.2: Contextual factors of disability



O'Brien *et al. Journal of the International AIDS Society* 2009 **12**:30 doi:10.1186/1758-2652-12-30

Figure 1.4.3: Triggers



O'Brien *et al. Health and Quality of Life Outcomes* 2008 **6**:76 doi:10.1186/1477-7525-6-76

Why is it helpful to think about HIV as an episodic disability?

As people with access to ART live longer, the long-term impacts of HIV and its treatments (in combination with aging itself) may lead to increased prevalence of concurrent conditions, such as arthritis, fractures from osteoporosis, diabetes, some forms of cancer, and depression or other mental illnesses.[25]

- The common feature of these other conditions is that they can all be **episodic** both in nature and impact.
- As such, people living with HIV may experience several episodic conditions concurrently, all with different fluctuations in their functioning and health.
- Thus, the need for rehabilitation is expanding to prevent or manage such disabling impacts and promote quality of life.

This approach also helps to identify policy models that promote more flexible employment or school programs that enable people with episodic illnesses to participate when their health permits without losing the opportunity when they get sick again.

1.5 – Who provides rehabilitation for people living with HIV?

Rehabilitation is defined as any service or activity that addresses or prevents body impairments, activity limitations, and social participation restrictions experienced by an individual. This includes physical, mental and spiritual dimensions of health.[26] Therefore, there are *many* people who can provide rehabilitation for people living with HIV, including:

- Rehabilitation professionals, such as physiotherapists, occupational therapists, speech-language therapists and physiatrists[27]
- People providing rehabilitation in the community, including community rehabilitation workers, other community-based rehabilitation (CBR) workers, HIV home-based care workers, or family/friends focused on improving an individual's function and participation
- Doctors, nurses, social workers, psychologists, nutritionists or others working in health care who are focused on enhancing an individual's function and participation
- Complementary therapies focused on function and participation, including the work of chiropractors and massage therapists
- Traditional healers and spiritual leaders may also contribute to rehabilitation when they promote function and social participation (see Section 3.4)
- Anyone else in the multidisciplinary team who is focused on improving the function and participation of a person living with HIV

1.6 – Do rehabilitation providers need special skills or training to care for people living with HIV? If so, what?

Most rehabilitation providers **already** have the clinical skills they need to help people living with HIV (e.g., rehabilitation assessment of patients and treatment techniques that are used for musculoskeletal, cardiorespiratory and neurological conditions).

Many diseases affect only one body system. However, HIV and its related conditions can affect every body system (e.g., neurological, musculoskeletal, cardiorespiratory). While the underlying HIV-related pathology may be new, the resulting *impairments* (e.g., muscle weakness, impaired memory)*, activity limitations* (e.g., difficulty climbing stairs or getting dressed) and *participation restrictions* (e.g., being able to work, participating in a community group) tend to be the same as other conditions.

The rehabilitation assessment and treatment techniques for these challenges also tend to be the same.

Examples

- A pneumonia may result from HIV, but the chest physiotherapy assessment and treatment techniques are the same as other pneumonias.
- A stroke may result from HIV, but the rehabilitation assessment and treatment techniques are the same as other patients with stroke
- Cognitive dysfunction may occur as a result of HIV, but the rehabilitation assessment and treatment techniques for assisting that individual to cope with daily tasks are the same as other patients with cognitive decline

However, there is *some* new information that rehabilitation providers need to know about HIV, including:

- That HIV can simultaneously affect multiple body systems
- The side effects of HIV treatments that may cause disability
- The unique forms of HIV-related stigma that may disable people as much as the virus itself
- Psychosocial aspects of living with HIV and where to refer for counselling

Another concern is that rehabilitation providers may not feel skilled enough to care for people living with HIV.[28,29,30] This is the primary purpose of this resource: to equip rehabilitation providers with guidance on the care of people living with HIV, in order to improve quality of life.

1.7 – What roles do rehabilitation providers have related to HIV in SSA?

Table 1.7: Roles of Rehabilitation Providers

Roles of Rehabilitation Providers	Examples
Clinical care	From promotion, to prevention, to referral, to acute care, to rehabilitation, to habilitation and to palliation. E.g., see Section 1.8 for details of clinical roles for rehabilitation.
Advocacy	Using one's knowledge and status in the community to advocate for change in support of the needs of people living with or at risk for HIV. E.g., advocating for inclusion of rehabilitation in HIV National Strategic Plans, advocating for HIV physicians to refer to rehabilitation, advocating for people living with HIV who are marginalized to receive equitable care, advocating for food security and feeding schemes.
Capacity-building	Providing training to others to enhance the inclusion and participation of people living with HIV in their communities. E.g., education to teachers about how to ensure inclusion of children living with HIV in their classrooms, education to employers about how to support employees living with HIV, education to parents or other family members about appropriate HIV precautions and how to combat HIV-related stigma, education of spiritual leaders and traditional healers about the importance of individuals living with HIV taking ARV
Research	Many rehabilitation researchers are leading the way conducting studies to better understand how to address HIV/ART-related disability. E.g., research to develop a tool to assess HIV-related disability,[31] research on when and how people with disabilities may be excluded from HIV care and how to address this,[32] research on non-pharmacological treatment of peripheral neuropathy or lipodystrophy,[33,34] research on rehabilitation with children living with HIV,[35] rehabilitation on pain management in HIV,[36] research on safe and effective exercise prescription for people living with HIV[37, 38]

1.8 – When is rehabilitation clinical intervention useful along the HIV care continuum?

Rehabilitation has important contributions to make throughout the care continuum. Although people often present for care late in their HIV disease, rehabilitation also has an important role to play in preventing disability when someone with HIV is feeling well and is asymptomatic.

Table 1.8: Rehabilitation along the HIV care continuum

	Status of the person living with HIV				
	Feeling well, asymptomatic	**Minor symptoms**	**Acute illness**	**Recovering from acute illness**	**Palliative**
Goal of rehabilitation	Prehabilitation to prevent future disability	Address specific impairments with goal of optimizing function and participation in typical roles	Address acute cardiorespiratory, neurological, musculoskeletal or other impairments to recover from acute illness	Improve function and independence to return to typical function and participation	Pain management, maintaining function to optimize comfort
Settings for rehabilitation	Community, Work place, Home	Rehabilitation clinic, Community Home	Hospital, Home	Hospital, Rehabilitation clinic, Community	Home, Hospice, Hospital
Examples	Aerobic and progressive resistance exercise prescription	Interventions to help manage impairments related to peripheral neuropathy in feet	Chest physiotherapy	Stroke rehabilitation	Specific pain management techniques, providing adaptive equipment to assist with function while patient becomes weaker

1.9 – What is the relationship between disability, poverty, HIV and rehabilitation?

Disability, poverty and HIV are linked in a vicious cycle

People with disabilities are more likely to experience poverty, and people in poverty are more likely to develop disabilities. This also extends to the families of people in poverty.[39]

HIV can also become part of this cycle – that is, HIV can result in disability, and HIV can also exacerbate poverty for many people.

Similarly, having a disability or being in poverty can make a person more vulnerable to HIV or AIDS.

Examples

For example, if a person living with HIV is the main breadwinner in a family, her/his illness and resulting disability can worsen the poverty of that household. Worsened poverty can result in poor nutrition for the entire family, and also for the person living with HIV – which can be especially challenging if that person is also taking medications that require good nutrition.

Most countries in sub-Saharan Africa do not have strong financial support systems to help people living with disabilities. This worsens the cycle.

Rehabilitation offers a strategy for breaking this cycle by reducing disability and supporting people to optimize their function, participation and independence. In addition to **clinical** roles, rehabilitation providers also have an **advocacy** role to play in addressing the wider determinants of health that can exacerbate disability.

Is HIV itself a disability?

The answer to this question depends on what you mean by disability. In this resource, we consider people with disabilities to include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.[40] This is the definition in the Convention on the Rights of Persons with Disabilities (CRPD) so we do not consider HIV to be a disability in this resource.

However, in certain social support systems, being HIV-positive may qualify people for a "disability grant" or other forms of financial benefit.[41, 42] In these unique instances, people may consider HIV to count as itself a disability.

Section 2: What do rehabilitation providers need to know about HIV in SSA?

2.1 – What do rehabilitation professionals need to know about the stages of HIV infection?

Rehabilitation providers have a role in caring for people living with HIV throughout the course of their illness. In this section we introduce the stages of HIV infection. To learn more about the role of rehabilitation in HIV disease please see *Section 1.7*.

2.1.1 Acute Infection

When a person first becomes infected it is called viremia, a term used for all viral infections. During this initial phase, the virus replicates rapidly and people commonly experience flu-like symptoms (e.g. fever, fatigue, aching muscles, headache, and rash). Many of these symptoms can go unrecognized.

A person is most infectious during this phase.

Within the first 2 to 6 weeks, the CD4 count decreases rapidly as the virus attacks these cells.

After 6 to 8 weeks, antibodies are developed as part of the immune response (seroconversion) and the viral load (amount of HIV in the blood) drops.

HIV tests are designed to detect if these antibodies are present so a person will have a positive HIV test ***after*** seroconversion.

The antibodies for HIV are measurable within 3 months of initial infection for most people. During this time, people may not show any signs of being infected.

2.1.2 Clinical latency

During the clinical latency phase, an HIV-infected person may be symptom free and unaware of his or her HIV status. This phase varies in length and depends on many factors including pre-existing health status, genetic factors, social determinants of health, and stress.

When the CD4 count drops below 200 cells/mm^3, the immune system struggles to fight off the virus, the viral load increases and the body is susceptible to opportunistic infections and HIV-related illnesses.

If the person is not treated with HIV medications at this point (i.e., once the CD4 count has dropped below 200 cells/mm^3), the natural history of HIV has shown high mortality levels within 2 to 3 years.

It is important to note, however, that most individuals with HIV can now have a life expectancy that is close to normal if they can access and adhere to lifelong antiretroviral therapy.[43]

2.1.3 AIDS (Acquired Immunodeficiency Syndrome)

In advanced stages of HIV, a person may be diagnosed with Acquired Immunodeficiency Syndrome (AIDS).

AIDS is not a disease. AIDS is a category developed in 1993 by the U.S. Centre for Disease Control as a way of identifying advanced HIV progression (CDC 1993). A person is said to have AIDS if:

- they are HIV-positive, **and**
- their CD4 count is less than 200 cells/mm^3, **or**
- they have one of the 26 clinical conditions that are considered to be AIDS-defining illnesses.

Given advances in HIV care, the AIDS classification system is used less often.

For rehabilitation providers, the focus is on diagnosing and addressing the challenges (i.e., impairments, activity limitations, participation restrictions) resulting from HIV and/or HIV-related illnesses (which may or may not constitute "AIDS"). See Section 1.3 for further details.

2.2 – What do rehabilitation providers need to know about CD4 count and viral load?

CD4 count and viral load are two of the surrogate markers (clues) used to understand disease progression in HIV. These measures will help a rehabilitation provider understand a patient's immune system at a single point in time as well as changes in immune status over time.

2.2.1 CD4 count

Cells in a person's body with CD4 receptors on their surface are the primary targets destroyed by HIV.

CD4 count is the most important surrogate marker for health status and strongest predictor of disease progression.

How to interpret CD4 count:

- A normal CD4 count level is between 500 to 1500 cells/mm^3.
- CD4 count in a healthy individual varies over time.
- In a person living with HIV, the CD4 count will become lower as her/his HIV disease worsens.
- Most opportunistic infections occur when a CD4 count is less than 200 cells/mm^3.

The CD4 count is influenced by a number of factors (e.g., stress, illness, time at which it was measured) and therefore, the **trend** in CD4 counts is more important versus one test at a single point in time.

2.2.2 Viral load

Viral load reflects the amount of virus (HIV) within the body. Viral load is used to predict the rate of progression of HIV disease and to initiate, monitor, and change antiretroviral therapy.

How to interpret viral load levels:

- The HIV viral load test measures the amount of HIV virus, in each ml or cubic centimeter of blood (e.g., from 50 to 500,000).
- The higher the viral load, the more viral reproduction (HIV copying itself) is taking place, and the more active (worse) the disease.
- Viral load tests struggle to measure fewer than 50 HIV viruses in each ml of blood and so the test may say that the viral load is "undetectable."
    - This does not mean that a person is cured of HIV.
    - An undetectable viral load means that a person's HIV disease is well controlled (but not gone).
    - It is also important to note that it is still possible to transmit the virus when the viral load is 'undetectable'.
    - It also does not mean that the patient should discontinue taking their treatment, unless advised by the health care team.

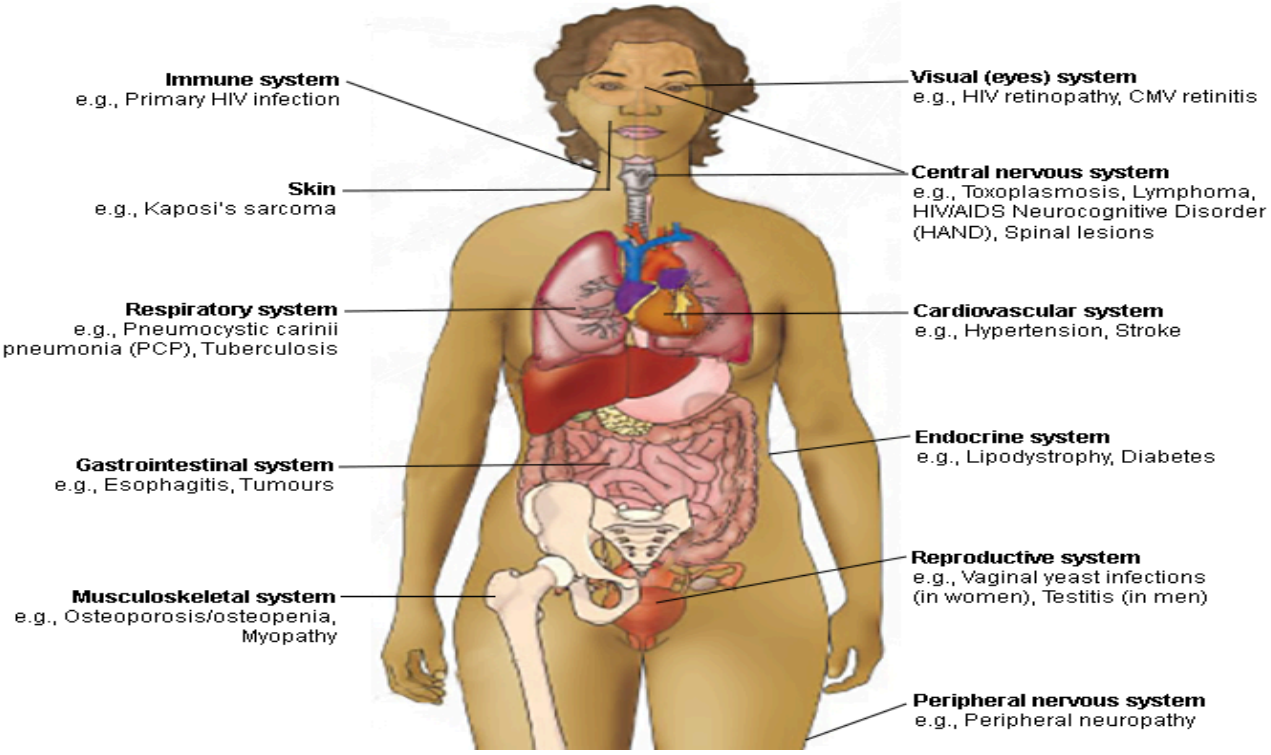
The goal of ART is to reduce viral load to the lowest possible level for the longest possible time.

2.3 – What is the impact of HIV on body systems and why does this matter for rehabilitation providers?

HIV is a complex and multi-system disease that causes a range of conditions that can affect almost every body system. However, antiretroviral therapy has contributed to HIV-positive people living longer and having better quality of life.

Despite these improvements, Van As et al.[2] found that physical impairments, activity limitations and participation restrictions have had a negative effect on people living with HIV. They highlighted the need for rehabilitation providers to have detailed knowledge of the effects of HIV on the patient so that appropriate interventions can be made. They recommend the International Classification of Functioning, Disability and Health (ICF),[45] developed by the World Health Organization, as a useful framework for evaluating impairments and life-related challenges resulting from HIV and HIV-related conditions (see Section 3 to learn more about HIV-related disability).

Examples of diagnoses affecting different body systems in people living with HIV



2.4 – Who might rehabilitation providers treat in SSA?

Sub-Saharan Africa (SSA) has the highest HIV infection rate in the world and is home to more than 2/3 of all people worldwide living with HIV.[46] Gender inequality and economic disparity are the leading root causes of high HIV prevalence in SSA.

HIV is a generalized epidemic in many countries in SSA: it can be present in anyone and across all ages.

However, there are some populations that are at higher risk for HIV infection including young adults, truck drivers, migrants, people with disabilities, commercial sex workers, men who have sex with men, prison inmates and injection drug users.

Table 2.4: Estimated prevalence and incidence of HIV infection and mortality in Sub-Saharan Africa and globally, 2016[46]

	Sub-Saharan Africa 2016 Estimates	Global 2016 Estimates
Number of People Living with HIV (all ages)	25 500 000	36 700 000
New HIV Infections (all ages)	1 160 000	1 800 000
AIDS Deaths	730 000	1 000 000

2.4.1 Encouraging trends

Despite these alarming figures, progress has been made in Sub-Saharan Africa in recent years, including:[47]

- a decrease in the number of new infections
- a decrease in AIDS-related deaths
- a decrease in children newly infected
- increases in the prevention of mother-to-child transmission (PMTCT)
- increases in HIV testing rates
- increased uptake of HIV treatment among eligible HIV-positive people

2.4.2 Persistent gender inequities

Women are more likely to be infected than men. They account for approximately 57% of people living with HIV in Sub-Saharan Africa.[48] This increased risk is due to both physiologic differences and socio-economic factors including poverty, marginalization, gender power inequalities, and violence.[49]

2.4.3 HIV and aging

There are limited data available on older people living with HIV in Sub-Saharan Africa. However, it has been projected that the number of people living with HIV who are 50 years or older in SSA will climb

from approximately 1 in 7 in 2011 to 1 in 4 in 2040.[50] While people with HIV are living longer, many are challenged by comorbidities related to aging.

2.5 – What do rehabilitation providers need to know about ARTs in SSA?

Although rehabilitation providers do not prescribe drugs, the effects of pharmacological treatments (both good and bad) experienced by people living with HIV can impact rehabilitation goals.

The goals of HIV drug therapy are:

- maximal and sustained suppression of viral load
- reduction of morbidity (illness) and mortality (death)
- improvement of quality of life

In 2015, the World Health Organization (WHO) recommended that all people living with HIV receive ART. In the Africa WHO Region in 2016, 54% of people living with HIV were receiving treatment.[51]

2.5.1 Benefits of Antiretroviral Therapy (ART)

Advances in the treatment of HIV with effective, more convenient and more tolerable ART have dramatically changed the course of HIV infection. This has led to a sharp reduction in morbidity and mortality among patients who have access to treatment.[52]

Antiretroviral drugs are **not a cure** for HIV. However, with lifelong adherence most individuals can achieve close to normal life expectancy.[53]

Benefits of Antiretroviral Therapy[54]

Saves lives. Antiretroviral therapy averted 7.6 million AIDS-related deaths globally from the peak in 1995 until 2013. Sub-Saharan Africa accounted for 63% of those lives saved.[55]

Prevents new HIV infections. Antiretroviral therapy reduces the risk of HIV transmission by up to 96%.[56]

Prevents illness. Antiretroviral therapy reduces the risk of tuberculosis infection among people living with HIV by 65%.[57]

Saves money and promotes development. HIV treatment can generate economic savings within five years.[58] Spending on antiretroviral therapy also generates economic returns of double or more than the initial investment.[59]

Keeps people productive. Working-age adults living with HIV can return to work earlier when they receive treatment, boosting labour productivity and reducing hardship among affected households.

2.5.2 Treatment Guidelines

The World Health Organization (WHO) publishes recommendations on the diagnosis of HIV, the care of people living with HIV and the use of antiretroviral drugs for treating and preventing HIV infection from a global perspective.

These treatment guidelines address specific populations and provide guidance on how best to use ART to maximize success of drug therapy. **The 2016 WHO Consolidated Guidelines on the use of Antiretroviral Drugs for Treating and Preventing HIV Infection** are available at http://www.who.int/hiv/pub/arv/arv-2016/en/

2.5.3 ART Adherence

For best results, individuals with HIV need to take their medications every single day, in the proper way and at the same time for the rest of their lives.

When there is only partial adherence, suppression of HIV may not be achieved and there is increased risk of developing drug resistance.

Table 2.5: Examples of facilitators and barriers to adherence

Facilitators to Adherence	Barriers to Adherence
• Social support • Reminders • Dosing frequency and pill burden (e.g. one pill per day) • Experiences with health improvement on treatment • Decreased HIV-related stigma and discrimination	• Unreliable drug supply • Transportation cost • Access to food and water • Polypharmacy (taking multiple treatments at the same time) • Homelessness or unstable housing • Long clinic queues • Stigma/fear of disclosure • Depression • Fatigue • Other co-morbidities • Side effects

2.5.4 Side Effects of ART

As with other medications, antiretroviral medications have both short and long term side effects. These side effects can affect many different body systems, and can range from bothersome to fatal.

Rehabilitation providers can assist patients with impairments that are the result of side effects of HIV medication. For example, several drugs can cause a condition called **distal symmetrical polyneuropathy**, which presents as bilateral pain, tingling and numbness in both lower legs and feet.

Other drugs can cause a condition called **lipodystrophy**, which causes metabolic changes as well as changes in body composition. The body changes can present as reduced fat in arms and legs, and added fat around the waist or back of neck.

There are many drugs used to treat HIV, and therefore many different types of side effects. For side effects associated with specific drugs, see up-to-date websites such as:

- https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/22/63/hiv-medicines-and-side-effects
- https://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-arv/31/adverse-effects-of-arv

2.5.5 ART for Prevention

Emerging pharmacologic advances include the use of ART for prevention.[60] This includes testing of pre-exposure prophylaxis (PREP) with oral or mucosally delivered antiretroviral medications to reduce an individual's risk of acquiring HIV infection.[61]

Microbicides are products that may reduce HIV risk when applied vaginally. Although there seems to be an overall acceptance by women of microbicides, they are not yet available on the market.[62]

While significant research has been completed on HIV vaccines, the development of a safe and effective vaccine remains a medium to long-term prospect.[63]

2.6 – What are the precautions that all rehabilitation providers should take regarding HIV and other related co-infections?

When working with people living with HIV, **standard precautions** (often called **universal precautions)** should be used.

- Standard precautions require **frequent hand washing** between all client interactions.
- Standard precautions also include using a barrier device (e.g. **gloves**) whenever contact with blood or body fluids is anticipated.
- When handling clients whose skin is intact, gloves are not needed. However, if there are open lesions or breaks in the skin and/or contact with bodily fluids is likely, gloves and long-sleeved gowns are appropriate.
- Use needles and other sharps safely, and dispose of them safely in biological waste (without any attempt to recap them)
- For more detailed information see the World Health Organization's standard precautions in health care http://www.who.int/csr/resources/publications/EPR_AM2_E7.pdf

These are the *same* precautions that should be used with *all* patients, regardless of whether or not they are HIV-positive. This is because HIV is a blood borne disease.

Table 2.6: Which body fluids are infectious for HIV?

Body Fluids Potentially Infectious for HIV	Body Fluids Not Infectious for HIV
• Blood • Cerebrospinal • Amniotic • Pericardial • Peritoneal • Pleural • Synovial • Seminal • Vaginal • Penile secretions • Breast milk • Inflammatory exudate • Human tissue • Any other body fluids which contain visible blood	• Stool • Urine • Tears • Saliva However, if these non-infectious body fluids contain blood, they may be infectious.

While universal precautions are appropriate for protecting oneself from HIV, a person living with HIV may also have **other diseases that require a higher level of precaution**, such as:

- Pulmonary TB – precautions would include wearing an appropriate mask

- Hepatitis B – precautions would include vaccination

Health care workers in developing countries, including those in Sub-Saharan Africa, are at increased risk of occupational exposure to blood borne diseases for a number of reasons, which make **adherence to universal precautions** even more important. Reasons for increased risk of occupational exposure include:[64]

- Increased disease prevalence in the population
- Greater disease severity of patients seeking care
- Higher number of needle stick injuries
- Culture of using injections versus other methods
- Use of hazardous equipment and procedures (e.g. glass capillary tubes, non-retracting finger stick lancets)
- Number of informal workers
- Lack of vaccination coverage against hepatitis B
- Lack of availability of post-exposure prophylaxis (PEP)
- Lack of adherence to standard precautions

Post-exposure prophylaxis (PEP)

In the case of a significant occupational exposure (e.g., exposure to blood or bloody body fluids through a hollow bore needle which has been in an artery or vein of a person known to be infected with HIV), individuals should immediately wash the area with warm soapy water and directly seek medical care (e.g., at an emergency department).

Significant exposure may require post-exposure prophylaxis (PEP), which is a form of antiretroviral treatment that is most effective when taken within 72 hours of exposure. Although reasonably successful, PEP is not a guaranteed prophylaxis and should only be used in extreme cases.[65]

Section 3: What are the rehabilitation interventions that can help people living with HIV in SSA?

3.1 – What are the rehabilitation interventions that address impairments common among people living with HIV?

This section is organized according to the categories of **impairment** in the World Health Organization's International Classification of Functioning, Disability and Health (see Section 1.3).

3.1.1: Mental impairments

People living with HIV commonly experience mental impairments. These impairments include (but are not limited to) difficulties related to consciousness, orientation, intellect, energy and drive, sleep, attention, memory, emotion, perception, cognition and language.

These impairments may be caused by the HIV infection itself, one of the many opportunistic infections associated with HIV or side effects of various HIV-related medications. Pre-existing mental impairments may also be present which further impacts the rehabilitation of people living with HIV.

Rehabilitation interventions for these mental impairments include specific psychosocial techniques as well as general exercise and education. Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.1.1: Clinical Aspects of Mental Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[66] (for details, see Section 3.3)
HIV Cognitive-Motor Complex (also known as AIDS Dementia Complex or HIV Dementia)	HIV (the virus itself) Opportunistic infections Side effects of medication	• Exercise prescription – aerobic • Exercise prescription – strength • Fatigue management • Psychosocial rehabilitation • Relaxation techniques
Cognitive impairment (including memory loss)	Hypoxia Cryptococcal meningitis TB meningitis Syphilis Neurovascular disease (stroke) Focal cerebral disease Vitamin deficiency (e.g., B12, B6) Electrolyte abnormalities Pain-related	• Exercise prescription – aerobic • Exercise prescription – strength • Fatigue management • Psychosocial rehabilitation • Relaxation techniques
Psychological disorders (including depression, mood disorders, anxiety and delirium)	Related to cognitive impairment	• Exercise prescription – aerobic

	Side effects of medication Psychosocial factors (e.g., stigma) Premorbid psychiatric disorders Post-traumatic stress disorder Pain-related	• Exercise prescription – strength • Fatigue management • Psychosocial rehabilitation • Relaxation techniques
Substance-related disorders	Prescription medications (e.g., narcotics) Over-the-counter medications Street drugs: premorbid or current Alcohol: premorbid or current	• Psychosocial rehabilitation • Referral to drug or alcohol treatment
Fatigue (including low energy and poor sleep)	Nutritional deficiencies Chronic diarrhea (malabsorption) Anemia (pre-existing, HIV or medication-related) Side effects of medication Hormone-related (e.g., thyroid, adrenal) Psychological (e.g., depression, anxiety) Chronic pain	• Exercise prescription – aerobic • Exercise prescription – strength • Fatigue management • Psychosocial rehabilitation

3.1.2: Sensory functions and pain

Pain is commonly experienced by people living with HIV at all stages of the disease process. Pain prevalence ranges from 54% to 83%. This pain is often of moderate to severe intensity which has a negative impact on physical functioning.[67]

Pain rehabilitation techniques include electrotherapy modalities, cryotherapy and massage, as well as exercise prescription and education. Other sensory impairments, including difficulties related to sight, hearing and vestibular control are also experienced by people living with HIV. These may be managed by environmental modifications, provision of assistive devices and education.

These impairments may be caused by the HIV infection itself, one of the many opportunistic infections associated with HIV or toxicity or side effects of various HIV-related medications. Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.1.2: Clinical Aspects of Sensory Impairment

Impairments	Possible Etiologies	Rehabilitation Interventions[68] (for details, see Section 3.3)
Visual loss (including retinitis, retinal detachment, retinal vascular disease and blindness)	Viral (e.g., CMV, HSV, VSV) Parasitic (e.g., Toxoplasmosis) Fungal (e.g., PCP) Bacterial (e.g., Cryptococcus) Malignancy (e.g., Kaposi's sarcoma, Burkitt's lymphoma) Ischaemia Cranial nerve involvement Diabetes-related Side effects from medication Pre-existing (e.g., cataracts)	• Assistive devices • Environmental adaptation • Psychosocial rehabilitation • Visual Loss - meal preparation, shopping and medication
Auditory impairments (including hearing loss, tinnitus and otalgia)	HIV (the virus itself) Opportunistic infections Lesions in the central nervous system Medication-related Pre-existing	• Assistive devices • Auditory training • Education on managing conversations and communication, cued speech, use of visual clues, learning strategies • Environmental adaptation

Vestibular impairments (including dizziness and poor balance)	Otitis media Side effects of medication Visual impairment	• Environmental adaptation
Pain (acute and chronic)	Musculoskeletal pain (inflammatory or non-inflammatory) Secondary processes, inactivity or deconditioning Joint pain caused by bacterial infections, arthritis and medication Central nervous system lesions (parasitic, fungal, bacterial, fungal or malignant) Peripheral neuropathy (HIV or medication-related) Myelopathy (e.g., secondary to CMV) Systemic pain (e.g. malignancies, pleurisy, esophagitis, myocarditis, colitis) Exacerbation of pain by lack of sleep, anxiety or depression Impact of life situation (stress, finances, etc.)	• Cryotherapy • Desensitisation techniques • Electrotherapy Modalities (e.g., TENS, IFT) • Environmental adaptation • Exercise prescription – aerobic • Exercise prescription – strength • Exercise prescription – stretching and passive movement • Heat therapy • Massage therapy • Psychosocial rehabilitation • Relaxation techniques • Splinting and joint support
Sensation changes (including numbness, burning or tingling)	HIV Peripheral neuropathy	• Desensitization • Exercise prescription – aerobic • Exercise prescription – strength • Exercise prescription – stretching and passive movement

3.1.3: Voice and speech functions

People living with HIV experience impairments relating to voice and speech function caused by infection of the viral pathogen or secondary sarcomas and bacterial or fungal infections. In some cases, voice and speech impairments are associated with neurological impairments.

Rehabilitation interventions for voice and speech functions include exercise related to articulation, fluency, resonance, language as well as adaptation of the communication environment. Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.1.3: Clinical Aspects of Voice and Speech Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[69] (for details, see Section 3.3)
Dysphagia	Kaposi's sarcoma of mouth, pharynx, larynx Viral, bacterial or fungal infection	• Articulation, fluency, resonance, language advice and exercises • Swallowing studies and trial feeding
Phonatory dysfunction	Kaposi's sarcoma of mouth, pharynx, larynx Viral, bacterial or fungal infection	• Articulation, fluency, resonance, language advice and exercises
Dysarthria	Viral pathogen Neurogenic anomalies of viral infection	• Articulation, fluency, resonance, language advice and exercises • Psychosocial rehabilitation

3.1.4: Functions of the cardiovascular, hematological, immunological and respiratory systems

People living with HIV experience impairments related to the heart, blood pressure, hematological system (blood), immune system (including allergies, hypersensitivity) and respiration (breathing).

Possible causes of these impairments include primary HIV infection or secondary bacterial and fungal infections such as cytomegalovirus, Pneumocystis Carinii Pneumonia (PCP) or Tuberculosis (TB). Malignancy such as Kaposi's sarcoma and Non-Hodgkin's Lymphoma are also secondary complications which affect the cardiovascular, hematological, immunological and respiratory systems. These impairments can also be caused by side effects of medications.

Rehabilitation interventions include chest physiotherapy, aerobic and strength exercise, pain management and adaptation of environment. Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.1.4: Clinical Aspects of Cardiovascular, Hematological, Immunological and Respiratory Impairments

Impairment	Possible Etiologies	Rehabilitation Interventions[70] (for details, see Section 3.3)
Impairments related to cardiac dysfunction (e.g., angina pain, anxiety, decreased endurance)	Myocarditis or endocarditis (e.g., from bacterial or fungal infection) Cardiomyopathy (e.g., from viral pathogens or side effects of medication) Pericarditis or pericardial effusion (e.g., resulting from infections from multiple pathogens) Coronary artery disease (e.g., resulting from side effects of medication) Peripheral vascular disease (e.g., resulting from viral pathogens)	• Exercise prescription – aerobic • Exercise prescription – strength • Nutritional advice • Pain management • Psychosocial rehabilitation • Relaxation techniques • Return to work strategies
Shortness of breath and other respiratory impairments	Acute lung disease (e.g., pneumonia) Malignancies (e.g., Kaposi's sarcoma, Non-Hodgkins Lymphoma)	• Assistive devices • Chest physiotherapy techniques • Exercise prescription – aerobic • Exercise prescription – strength

		• Nutritional advice • Pain management • Psychosocial rehabilitation

3.1.5: Functions of the digestive, metabolic and endocrine systems

People living with HIV may have impairments related to digestion, endocrine function and weight maintenance (both excessive weight loss and weight gain). These impairments may be caused by the HIV infection itself, one of the many opportunistic infections associated with HIV, or side effects of various HIV-related medications.

Dietary advice and exercise prescription can be utilized as methods to assist people living with HIV with both weight gain and weight loss. Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.1.5: Clinical Aspects of Digestive, Metabolic and Endocrine Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[71] (for details, see Section 3.3)
Digestive dysfunction	HIV enteropathy Secondary infections (e.g., MAC, cryptosporidium) Obstruction (e.g., tumour) Food intolerances Medication-related	• Exercise prescription – aerobic • Nutritional advice
Endocrine dysfunction	Malignancy Adrenal insufficiency Hypogonadism Hypothyroidism Medication-related Food intolerances	• Nutritional advice • Pain management
Weight loss	Anorexia secondary to physiological (e.g., oesophagitis, candida) or psychological causes Dysphagia (e.g., due to candida, KS or CMV) Malnutrition Malabsorption Malignancy	• Exercise prescription – aerobic • Nutritional advice • Psychosocial rehabilitation • Weight loss interventions

	Infection and fever-related Side effects of medication	
Weight gain	Inactivity and deconditioning Constipation Side effects of medication	• Exercise prescription – aerobic • Exercise prescription – strength • Exercise prescription – stretching and passive movement • Nutritional advice • Psychosocial rehabilitation • Weight gain interventions
Weight redistribution	HIV-infection Side effects of medication Lipodystrophy	• Exercise prescription – aerobic • Exercise prescription – strength • Nutritional advice • Psychosocial rehabilitation

3.1.6: Genitourinary and reproductive functions

People living with HIV can experience impairments of genitourinary and reproductive functions. These impairments are related to urination functions and sexual functions and may be directly caused by the viral pathogen or secondary bacterial and fungal infection. Side effects of medications also have an effect on urinary and sexual functions. Sexual impairments can also result from psychosocial etiologies.

Rehabilitation interventions include psychosocial rehabilitation, electrotherapy modalities and exercise. Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.1.6: Clinical Aspects of Genitourinary and Reproductive Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[72] (for details, see Section 3.3)
Urination dysfunction	Urinary tract infection Viral pathogen affecting the nervous system Side effects of medication Opportunistic infections Other fungal or bacterial infections	• Exercise prescription - pelvic floor • Nutritional advice
Sexual impairments including loss of libido, pain during sex and male erectile problems	Viral pathogen Emotional issues (e.g., anxiety, stress, grief and depression) Smoking Side effect of medication Alcohol use Recreational drug use Hormone dysfunction (e.g., testosterone deficiency and thyroid dysfunction in men and women, early menopause in women with HIV) Autonomic and/or peripheral neuropathy Sexually transmitted infections	• Exercise prescription – aerobic • Exercise prescription – strength • Psychosocial rehabilitation • Referral to sex therapy

3.1.7: Neuromuscular and movement related structures

People living with HIV commonly experience neuromuscular and movement-related impairments. These impairments include (but are not limited to) difficulties related to joint mobility, muscle power and involuntary movements.

These impairments may be caused by pathology in the central nervous system, spinal cord or peripheral nervous system. Neuromuscular rehabilitation techniques include massage therapy, passive movements, proprioceptive neuromuscular facilitation (PNF) and Bobath techniques, and exercise prescription. Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.1.7: Clinical Aspects of Neuromuscular and Movement Related Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[73] (for details, see Section 3.3)
Reduced joint mobility	Disuse Inflammation Fluid retention	• Assistive devices • Electrotherapy Modalities • Exercise prescription – aerobic • Exercise prescription – strength • Exercise prescription – stretching and passive movement • Heat therapy • Massage therapy • Pain management
Muscle tone (increased or decreased tone including flaccidity, spasticity and rigidity)	Deconditioning Central nervous system lesions (including stroke, malignancy or infection) Spinal cord pathology (including myelitis, TB) Lower motor neuron lesions	• Exercise prescription – aerobic • Exercise prescription – strength • Exercise prescription – stretching and passive movement • Neurological rehabilitation • Psychosocial rehabilitation
Reduced muscle strength, power and endurance	Inactivity or deconditioning due to prolonged bed rest or illness Central nervous system	• Exercise prescription – aerobic • Exercise prescription –

	lesions (including stroke, malignancy or infection) Spinal cord pathology (including myelitis, TB spine) Acute inflammatory demyelinating polyneuropathy Inadequate nutritional intake Anemia Electrolyte abnormalities	strength • Neurological rehabilitation • Psychosocial rehabilitation
Involuntary movements (including dystonia and ataxia)	Central nervous system lesions Side effects of medication Electrolyte abnormalities	• Neurological rehabilitation • Psychosocial rehabilitation
Decreased bone density (including osteoporosis and osteopenia)	Inactivity or deconditioning Severe weight loss Malnutrition Hormonal imbalances	• Exercise prescription – aerobic • Exercise prescription – strength • Nutritional advice
Osteonecrosis (avascular necrosis)	Etiology unknown but associated with HIV infection	• Exercise prescription – aerobic • Exercise prescription – strength

3.1.8: Functions of the skin and related structures

People living with HIV may experience impairments related to the skin and related structures. Impairments may be caused by viral, fungal or bacterial infections. Kaposi's sarcoma commonly affects the skin.

Rehabilitation interventions include psychosocial rehabilitation, advice on skin care and exercises. Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.1.8: Clinical Aspects of Skin Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[74] (for details, see Section 3.3)
Skin lesions (including cold sores, rashes, and warts)	Herpes simplex and other viral infections Kaposi's sarcoma	• Psychosocial rehabilitation • Skin care, clothing and environmental advice • Assistive devices
Skin infections	Molluscum contagiosum, folliculitis,seborrheic dermatitis, psoriasis and tinea, caused by viral, bacterial and fungal infections	• Psychosocial rehabilitation • Skin care, clothing and environmental advice • Assistive devices

3.2 – What are the rehabilitation interventions that can address the activity limitations and participation restrictions common among people living with HIV?

The impairments described in Section 3.1 may result in a variety of **activity limitations** and restrictions to an individual's **participation** in education, vocational, family and social pursuits.

A broader and more holistic rehabilitation approach should take into account the activity limitations and participation restrictions faced by people living with HIV. Rehabilitation providers have important roles to play in addressing these challenges at multiple levels. For example:

- Clinical interventions
- Education to family and community
- Advocacy efforts to address the circumstances that create these challenges

It is vital that rehabilitation providers see that they have a role across the spectrum of the disease process from acute hospital care to long-term follow-up in the community. When rehabilitation providers are working with people living with HIV, they should consider both the individual's personal characteristics (e.g., age, gender, economic status), as well as the environment in which they live, socialise and work.

Rehabilitation providers should also, where possible, be involved in **advocacy** efforts to ensure the efficient and effective provision of rehabilitation services to people living with HIV, particularly those from marginalized groups (e.g., unemployed, people with disabilities). Advocacy efforts can be strengthened by active involvement in community-based research initiatives focusing on rehabilitation for people living with HIV.

This section is organized according to the categories of *activity* and *participation* in the World Health Organization's International Classification of Functioning, Disability and Health (see Section 1.3). Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 3.2: Rehabilitation Interventions for Activity Limitations and Participation Restrictions

Activity Limitations and Participation Restrictions	**Rehabilitation interventions**[74] (for details, see Section 3.3)
Learning and applying knowledge	• Adult-based education programmes • Assistive devices • Environmental adaptation • Provision of visual education materials
General tasks and demands	• Energy conservation and pacing • Environmental adaptation

	• Exercise prescription – aerobic • Exercise prescription – strength • Home-based rehabilitation • Return to work strategies
Communication	• Adaptation of communication environment • Articulation, fluency, resonance, language advice and exercises • Education on managing conversations and communication • Environmental adaptation • Psychosocial rehabilitation
Mobility	• Assistive devices • Community-based rehabilitation • Energy conservation and pacing • Environmental adaptation • Ergonomic interventions • Exercise prescription – aerobic • Exercise prescription – strength • Exercise prescription – stretching and passive movement • Home-based rehabilitation
Self-care	• Advice on personal hygiene • Advice and exercises related to transfers • Assistive devices • Energy conservation and pacing • Environmental adaptation • Ergonomic interventions • Home-based rehabilitation
Domestic life	• Advice on meal preparation and nutrition • Assistive devices • Energy conservation and pacing • Environmental adaptation • Home-based rehabilitation

Interpersonal interactions and relationships	• Couple counseling • Family support groups and parenting programmes • Involvement and education of family and friends • Psychosocial rehabilitation
Major life areas including work and employment	• Education and advice on social grants/ employment legislation • Energy conservation and pacing • Environmental adaptation • Ergonomic interventions • Extramural education and activities for learners • Involvement and education of employers, colleagues and educators • Psychosocial rehabilitation • School education programmes • School feeding programmes
Community, social and civic life	• Community-based rehabilitation • Education and advice on human rights • Energy conservation and pacing • Involvement and education of spiritual, political and community leaders

3.3 – More information on the rehabilitation interventions available for people living with HIV in Sub-Saharan Africa?

Articulation, fluency, resonance, language advice and exercises

Advice and exercises can be given to individuals to address challenges with speaking. These include rehabilitation to improve fluency, resonance, phonation, producing sound, intonation, variance of pitch, and voice and language, as well as aeromechanical components of respiration. Individuals may be assessed by a speech language therapist and work in collaboration with the multidisciplinary team to implement therapy.

Assistive devices

The provision of assistive devices can help people with disabilities address and adapt to their environment, promoting normal lifestyle and facilitating employment and education participation. Examples of assistive devices are mobility devices, home modification devices, respiratory devices, hearing aids, and self-care equipment. In resource-poor settings, assistive devices can range from low cost to high cost and some devices can be no cost. For example, individuals experiencing memory loss may set a reminder on their phone to alert them when medication needs to be taken. Other examples of low cost devices are spacers modified from plastic bottles or cups, which are used to administer medication for children. Cardboard boxes can also be used to make appropriate seats for infants with developmental delay. Non-governmental organisations in Africa can be a valuable source of assistive devices.

Auditory training

For auditory impairments and assistive devices, referrals should be made to an audiologist or the specific country's association for deaf people (e.g., the South African National Deaf Association (SANDA)). Rehabilitation providers can give advice to individuals with auditory impairments, including: environmental modifications, auditory training and cued speech.

Chest physiotherapy techniques

Chest physiotherapy techniques are used to treat individuals with respiratory impairments. The goals of treatment are to mobilise secretions to clear lungs, improve the work of breathing and improve oxygenation of the lungs. There are a variety of chest physiotherapy techniques including (but not limited to) deep breathing exercises, active cycle of breathing techniques (ACBT), positioning to encourage postural drainage, and manual techniques such as percussion, vibrations and shaking. Respiratory devices such as positive expiratory pressure masks, incentive spirometers and flutter devices can be used to assist chest physiotherapy techniques.

Community-based rehabilitation (CBR)

The aim of CBR is to promote inclusion of people with disabilities, by establishing community-based programs for social integration, equalization of opportunities, and rehabilitation programs.[10] Leadership in CBR is not dependent on professionals in healthcare, education, vocational or social services but involves community leaders, families and people with disabilities. It is a multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services. CBR is delivered within the community using predominantly local resources. CBR ranges from providing assistive devices for people with disabilities to coordinating with local schools to include vocational rehabilitation for adult education as well as family support and counselling.

Community-based rehabilitation has been shown to be beneficial for individuals with a number of impairments. For example, rehabilitation of stroke patients in the community can lead to improved recovery, with regaining of independence and improved abilities to perform activities of daily living.[76] While there is a growing body of research related to CBR interventions in low and middle-income countries,[77] there is limited evidence on CBR interventions for people living with HIV, particularly in sub-Saharan Africa.

It is important that rehabilitation providers are aware of community organisations operating within their local areas and collaborate with these organisations, where possible. People living with HIV throughout the world have been proactive in developing and managing community-based responses related to education, food security and advocacy efforts. Examples of these organisations in sub- Saharan Africa include the Treatment Action Campaign, The Hunger Project and Stay Alive for Us All (SAFUA), an NGO working with widows of HIV in Kenya.

Cryotherapy

Cryotherapy is the use of low temperatures such as cold water or ice to reduce pain, inflammation and spasm. In acute injuries, cryotherapy is used to promote vasoconstriction of blood vessels and reduce the effects of inflammation and cell damage. Cyrotherapy is not recommended for children under three years of age or for children with severe sensory or communication disorders.

Desensitisation techniques

Desensitisation techniques can be employed to assist people living with HIV who suffer from hypersensitivity, hyperalgesia and allodynia related to conditions such as peripheral neuropathy and polyneuropathy. These techniques include advice regarding adaptation of clothing, such as wearing seamless clothing or wearing socks inside out. Rubbing of the skin with variously textured materials (from smooth to rough) can help desensitise skin. As individuals become less sensitive, contrast bathing (the alternating use of cold and hot water bathing) can be used to treat affected areas of the body.

Electrotherapy modalities

Interferential Therapy (IFT)

IFT is the use of low frequency electrical stimulation created by the interference of two medium frequency currents passing through tissues simultaneously. These result in the stimulation of nerve endings. IFT is applied using 2-4 surface electrodes that are metal plate and pads with water-soaked sponges, carbon rubber electrodes with conducting gel, or suction cup electrodes. IFT is used to manage pain, elicit muscle contraction, decrease oedema, increase blood flow, and stimulate soft tissue healing and repair. IFT devices are becoming more portable and practitioners are able to use them easily in community settings. IFT is not recommended for use with children.

Transcutaneous electrical nerve stimulation (TENS)

TENS is a battery-operated electrical device that is used to relieve pain. It has surface electrodes (2 or more) that transfer electrical current to the surface of the skin and cause nerve stimulation. A TENS unit modulates pulse width, frequency and intensity.

There are a variety of other electrotherapy modalities that may benefit people living with HIV, including ultrasound therapy, pulsed shortwave diathermy (PSD), laser therapy and infrared therapy.

Energy conservation and pacing

Pacing and energy conservation techniques assist individuals to balance work, social and leisure pursuits by ensuring they have the necessary energy levels when required. Various strategies can be taught to people living with HIV by rehabilitation providers to achieve optimum energy levels. Education includes the collaborative setting of achievable goals, advice on the planning of errands to minimise fatigue, and teaching correct posture and biomechanics to ensure efficiency of activity. Adaptation of the physical environment can also assist with energy conservation, as can the prescription of assistive devices, where required. Rehabilitation and exercise sessions should be timed when individuals typically have the highest levels of energy and where necessary, to ensure the optimal effect of any medication (e.g., analgesics) that the individual may take prior to exercise.

Environmental adaptation

Environmental adaptation refers to changing or restructuring the environment to meet the needs of people with impairments. The change could involve home, work, community and/or study environments e.g., adapting the environment of the home to accommodate a person using a wheelchair by clearing passages and widening doorways.

Ergonomic interventions

Ergonomics involves the re-design of the physical environment and the use of equipment to better complement the individual living within that environment. Practical examples of applying ergonomic principles include the re-positioning of furniture in the home, school and/or workplace to decrease musculoskeletal overuse injuries, and advising regular rest intervals during sustained activities. Advice on posture and biomechanics when working or studying can also reduce undue strain and fatigue. Task analysis of an individual's daily activities can ascertain priority areas for intervention. Knowledge of one's country's specific occupational and safety acts is also important to ensure that employers make the necessary adaptations for all workers, particularly those who may have physical and/or cognitive impairments. Knowledge of inclusion policy within a country can also determine adaptations to be made in schools.

Exercise

Exercise is a key strategy that may be used by people living with HIV and by rehabilitation professionals to address or prevent disability and improve or sustain the health of people living with HIV.[78] Exercise is defined as any physical activity involving bodily movement produced by skeletal muscles that requires energy expenditure including (but not limited to) aerobic, resistance, flexibility and neuromotor activity beyond activities of daily living to improve and maintain physical fitness and health.[79, 80]

Regular exercise is widely accepted as an important part of optimal health.[81] In HIV, exercise has been shown to:

- Improve cardiovascular fitness
- Increase body weight
- Improve body composition
- Increase strength

- Improve quality of life, improve mood and decrease stress

Exercise prescription – aerobic

Aerobic (also known as cardiovascular) exercise includes activities such as walking, jogging, stepping, swimming and cycling. Aerobic exercise has been shown to be beneficial for people living with HIV,[82] including interventions conducted in sub-Saharan Africa,[83, 84, 85, 86] conferring physical benefits as well as improving mental health and quality of life, and reducing symptoms of depression. These exercises can be done at little or no cost and can be performed with fellow patients, friends and family members. Although few studies investigate the role of aerobic exercise in children living with HIV, preliminary results suggest that it is an appropriate intervention provided the child is not acutely ill.

Exercise prescription - pelvic floor

Pelvic floor exercises (e.g., kegels) can be used to strengthen the muscles beneath the uterus, bladder and bowel. These exercises can be taught to men or women who have any problems with bladder or bowel incontinence. Individuals should initially be taught how to contract these muscles when the bladder and bowel are empty and then progress to building the endurance of these muscles and finally using these exercises to limit or prevent incontinence. Individuals should be encouraged to continue with these exercises even when the incontinence has resolved.

Exercise prescription – strength

Strength (or resistance) training involves exercises that overcome either internal or external forces using body weight or a variety of equipment including free weights (dumbbells and barbells), machine weights, resistance bands/tubing and hydrotherapy. When correctly taught, these exercises can improve muscle strength, power, endurance and coordination, and also improve daily functioning and quality of life. This form of exercise has been shown to be safe and beneficial for people living with HIV.[87] Although few studies investigate the role of strengthening exercise in children infected with HIV, preliminary results suggest that it is an appropriate intervention if the child is not acutely ill.

Exercise prescription – stretching and passive movement

Passive movement is the movement of separate parts of an individual's body by the rehabilitation provider or by another external force. Passive movements and stretching exercises can help improve flexibility and circulation, normalise muscle tone and reduce the risk of contractures and pressure sores. Family members and friends can be taught to assist with these exercises, providing both a therapeutic intervention as well as an opportunity for interaction and involvement with others. Static stretching exercises can be taught to individual patients while proprioceptive neuromuscular facilitation (PNF) techniques should always be instructed by a trained professional.

Fatigue management

The exercise prescription described above should incorporate principles of task analysis, pacing of activities, efficiency of tasks and the suitable timing of therapy/exercise so as to improve levels of energy, rather than exacerbate fatigue. An assessment of the workplace and home environment, including ergonomic considerations (see above), should be conducted in order to assist the individual, where possible, to conserve energy. It is also vital to assess the individuals' nutritional requirements, so

as to time exercise suitable around meals. Where individuals cannot afford adequate nutrition, as is common in many resource-poor communities, individuals should be referred to community-based/NGO feeding schemes if available.

Heat therapy

Heat therapy (also called thermotherapy) is the application of heat to the body to relieve pain. Methods of application include warm water, hot packs (hydrocollator or microwave heated), ultrasound, infrared lamp, and hot cloth. In some facilities, whirlpool baths and hot thermal wraps are available. Heat is also used to reduce joint stiffness and oedema, aid healing, and relieve muscle spasms. Great care should be taken when using heat therapy with young children, the elderly, or anyone with altered sensation.

Home-based rehabilitation (HBR)

HBR is a rehabilitation strategy that is usually coordinated by rehabilitation providers and may be supplemented by non-governmental organisations. It provides care for patients in their own homes. It is used for patients post-discharge from the acute healthcare setting or when patients are unable to access healthcare services. A review of HBR programmes demonstrated that this model can be based on evidence-based practice, support task shifting to lay personnel, enable patient-centred care and maximize function and independence of PLHIV.[88] In some cases, rehabilitation providers are able to provide HBR care, but often due the scarcity of rehabilitation providers, healthcare workers and community-based carers are trained to provide HBR services. A home stimulation programme taught to the caregiver can significantly improve cognitive and motor development in young children infected with HIV. [89]

Massage therapy

Massage is the use of physical techniques or manipulations such as Swedish strokes, deep tissue work, myofascial release and neuromuscular techniques. It is used to relieve pain, improve circulation, reduce oedema, increase mobility of connective tissue, relieve stress and improve quality of life. Massage is also believed to have a positive effect on immune function through stress mediation and enhanced with the use of other stress modalities.[90]

Neurodevelopmental therapy (NDT)

NDT therapy is typically provided by a physiotherapist, occupational therapist or speech therapist. It is used to treat children or adults with neurological disorders, and is potentially useful in treating children with HIV encephalopathy. The aim is to optimize functional abilities by improving postural tone and co-ordination. The family is very important in providing continued treatment at home.

Neurological rehabilitation

Neurological rehabilitation interventions are designed to reduce the symptoms of people with neurological impairments and improve their functional ability. These include activities to improve mobility and gait, exercises to improve movement and strength (active, passive and proprioceptive neuromuscular facilitation and neurodevelopmental therapy), techniques to minimise disorders of muscle tone (such as Bobath or Motor Relearning techniques), assistance with activities of daily living (e.g., washing, dressing, feeding), speech therapy to assist with speaking and swallowing, and advice

on assistive aids to promote independence. Involvement of family and friends in this rehabilitation and the referral to community support groups, where possible, should be central to these interventions. Appropriate psychosocial interventions may also enhance the success of this form of rehabilitation.

Nutritional advice

Poor diet has a direct effect on the immune system. Advice on nutrition must be tailored to the individual and her/his circumstances. People living with HIV may suffer from weight loss or weight gain. Individuals need to eat a balanced diet with fat, carbohydrates and protein. Individuals could be advised to eat several small meals per day using what is available to supplement all food groups. Individuals may be further advised, to keep logbooks on their weight and diet, with education on warning parameters for weight loss or gain. Dieticians or nutritionists may recommend daily multivitamins. It is important however to consider possible interactions of dietary supplements and ARVs.[91] Referral can be made to a dietician (when available) who may conduct a nutritional assessment, counsel individuals, or assist with food provision through referral to nutrition supports. Alternatively, rehabilitation providers can encourage people living with HIV to begin subsistence farming and set up vegetable gardens or small animal rearing projects to produce food. Any advice on nutrition must include information on adequate hydration level for each individual.

Pain management

Up to 15% of people living with HIV may develop peripheral neuropathy characterized by distal, symmetric anesthesia and/or painful dysesthesia.[92] Although peripheral neuropathy is present in untreated HIV infection, exposure to Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTI), places individuals at an increased risk.[93] Interventions to address peripheral neuropathy include transcutaneous electrical nerve stimulation (TENS) or interferential current (IFC) for symptomatic management, adapted footwear, night ankle splints and bed tents to keep sheets off of feet and desensitization techniques (e.g., rubbing hands and feet with varying textures of material).

Medication can assist in pain management, but this intervention should be directed by a qualified practitioner. Pharmacological interventions for pain include topical analgesics, opioids, non-steroidal anti-inflammatory drugs (NSAIDs) and corticosteroids.

Research also shows there is a psychological component of pain and the importance of chronic pain behavioural interventions that include treatment of depression and substance use.[94]Education, thus, is vital in helping minimize the experience of pain. Furthermore, aerobic exercise (see above) can also be an effective means of reducing pain. Furthermore, aerobic exercise (see above) can also be an effective means of reducing pain.[95] Other non-pharmacological interventions for pain management include relaxation techniques, increased rest, balance diet, acupuncture and TENS (see above).

Positioning

Advice on positioning can be provided to individuals who may suffer from a number of impairments related to HIV. Correct positioning can help with the drainage of respiratory secretions, limit postural deformities, improve the function of individuals with neurological impairments, decrease swelling and minimise secondary complications of disuse such as pressure sores and contractures. Additional devices such as pillows, splints and gel pads can further limit these complications.

Psychosocial rehabilitation

More specialised psychological rehabilitation services can be offered by specifically trained professionals, including psychiatrists, psychologists, psychotherapists and occupational therapists. However, primary prevention, in the form of exercise, adequate nutrition and maximizing quality of life falls within the scope of all rehabilitation providers. Social support structures, such as support groups,[96] friends, family, cultural, religious and other community organisations, can also provide emotional and practical support.

Relaxation techniques

Relaxation techniques (including stress reduction techniques, visualization and imagery, progressive muscle relaxation, and the use of music) can improve name and face recall, short-term memory and incidental learning, reduce anxiety and depression, and strengthen immune function. Where possible, family members, friends and caregivers should also be taught these techniques as they have been shown to increase caregivers' self-efficacy. Singing and rocking infants and small children can be very effective in promoting relaxation.

Return to school strategies

These strategies are similar to those discussed in Return to Work Strategies (see below). The rehabilitation provider can work together with the child, family and educators to prepare a child for return to school. This is particularly important after long absences, when the child has been extremely ill, or is returning with a new disability. The peers of the returning child should be prepared and given strategies to support their friend.

Return to work strategies

Return to work strategies are aimed at rehabilitating people with impairments to facilitate their return to work. It prepares both the employer and employee for what is involved in their return so optimal function is resumed. The employer and employee work together to tailor the work to suit the needs of the employee. The rehabilitation provider, employee and employer work hand in hand to develop and implement strategies for return to work. All employees should be trained to prevent injury and provide an environment that is supportive toward people living with disabilities.

Skin care, clothing and environmental advice

Individuals living with HIV in sub-Saharan Africa need advice on environmental influences on skin. Direct sun avoidance during high intense midday sun (i.e., 10 am to 3 pm) is essential. Individuals should be advised to plan outdoor activities around these times. Protective clothing (sunglasses, long sleeved shirts and pants that block the sun, broad brimmed hats) needs to be worn to protect the skin from the harsh climate in SSA. Dermatologically tested sun care products with a Sun Protection Factor (SPF) that is tailored to suit individual needs should be used to protect the skin from sun damage. Some medication can increase the risk of skin sensitivity and sun damage, making prevention even more important.

Swallowing studies and trial feeding

Swallowing studies and trial feeding as directed by a speech-language therapist in collaboration with the wider healthcare team, are typically used to ensure a nutritionally adequate diet for people living with HIV based on texture and consistency. They can also assist in evaluating an individuals' ability to safely ingest oral food.

Visual loss - meal preparation, shopping and medication

Individuals with visual impairments and visual loss can be assisted with advice and education on meal preparation such as organizing work space and materials, adequately labeling dials and controls on appliances and, with the assistance of occupational therapists, on the safe use of assistive devices with kitchen utensils.

Similarly, shopping can be made easier by organizing lists according to store layout, asking store personnel for assistance, contacting caregivers to assist with shopping, getting items delivered, and using magnifiers or penlights for reading labels.

Individuals can be educated about administration of medication by organizing them by time of day, identifying containers by shape and size, or using elastic bands, magnetic tape, coloured tape, or marked contrasts in labels. The local pharmacy can also assist with alternative packaging (e.g., bubble packs).

Visual loss - referrals

For visual loss and assistive devices, referrals can be made to the specific country's association for blind/visually impaired people (e.g., The South African National Council for the Blind (SANCB)). Rehabilitation providers can give advice to individuals with visual impairments, including: ensuring the physical environment is free from obstacles, ergonomic advice, organising clothing according to texture, and advice on food storage and meal preparation. Support should be provided for visually impaired children returning to school.

Weight gain interventions

Individuals suffering from acute digestive and endocrine-related impairments should be referred for appropriate medical care. There are rehabilitation interventions that can assist individuals who want to put on weight, including: exercise (particularly strength training to build muscle mass), nutrition, rehydration and supplementation. Referral to community feeding schemes may be necessary in instances where individuals cannot afford adequate nutrition. Psychosocial rehabilitation or referral may be necessary when excessive weight loss is primarily related to psychological causes.

Weight loss interventions

Individuals suffering from acute digestive and endocrine-related impairments should be referred for appropriate medical care. There are rehabilitation interventions that can assist individuals who want to lose weight, including: exercise (particularly aerobic exercise to facilitate weight loss) and dietary advice. Referrals to community feeding schemes may be required for individuals who cannot afford alternatives to low-cost, high-caloric foods.

Characteristic features of protease inhibitor-associated lipodystrophy include increases in abdominal visceral adipose tissue, loss of facial fat, development of dorsocervical and supraclavicular fat pads and enlargement around the breasts in women.[97] Adipose cells are not lost but are redistributed to areas around the viscera and within blood vessels. This redistribution, in addition to elevated triglycerides, increases the risk of developing cardiovascular disease and its complications. A combination of aerobic and strength exercise has proven beneficial in reducing the effects of body fat redistribution and improving the quality of lives of people living with HIV and this condition.[83,84]

3.4 – What do rehabilitation providers need to know about their patients' beliefs and use of traditional healers, spiritual leaders and alternative therapies outside the formal medical system?

There is great diversity of ethnic, cultural, language and religious groups throughout sub-Saharan Africa. Health beliefs are closely interwoven with communities' cultural and religious practices. It is vital that rehabilitation providers are aware of the influence of these beliefs on understandings of health and illness, which can affect uptake of (and adherence to) rehabilitation and medical advice.

Traditional healers

Sub-Saharan Africa is the region of the world most affected by HIV; it is also a region in which most people turn first to traditional healers when they fall ill. In this region, traditional healers outnumber medically qualified doctors eighty-to-one.[98] Traditional healers play an important role in responding to the HIV epidemic. Although few traditional remedies have been scientifically tested, it is possible that some of the advice and remedies given by traditional healers are effective in treating HIV-related opportunistic infections and drug side effects. However, like all medicine, these therapies may also do harm through side effects, drug interactions, or delaying use of conventional treatment (ARVs).

When ill, individuals in sub-Saharan Africa will often visit a traditional healer before, during or after seeking help from doctors or other health care professionals. Furthermore, when they do receive Western treatment such as ARTs, adherence can be compromised due to conflicting messages they may receive from a traditional healer. Lack of understanding of HIV pathology is a further concern, in one study 21% of 233 traditional healers in KwaZulu-Natal, South Africa, wrongly believed there is cure for HIV.[99]

It is important that rehabilitation providers work with traditional healers, where possible, both to understand what they do and to educate them regarding the importance of adherence to both medication and rehabilitation for people living with HIV. Collaboration between traditional healers and rehabilitation providers has the potential to improve safety (e.g., by encouraging better hygiene, and adherence to prescribed treatment). Training can also assist traditional healers in identifying illnesses beyond their capacity to treat, hastening referral to a clinic when necessary. A number of organisations (e.g., THETA in Uganda, TAWG in Tanzania, PATF in Zambia, and the iTeach Programme in South Africa) have demonstrated the benefits of collaborating with traditional healers in HIV prevention and care.

Spiritual leaders and religious beliefs

Throughout sub-Saharan Africa, spiritual leaders are revered by large sections of the population and their advice and teachings are often strictly followed. There is an extremely wide array of both indigenous and orthodox religious belief systems throughout Africa many of which work in harmony with the health care system. However, many may be in conflict with Western medical advice. Some spiritual leaders may advocate that patients avoid or cease medical treatment and rehabilitation and instead, adhere only to the beliefs of their religious sect in order to be "healed" of the virus. This may result in issues of non-adherence to ARVs and associated exacerbation of patients' impairments. For example, among a prospective cohort of 442 people living with HIV in Tanzania, 56% sought a cure from a religious healer and their adherence to (ARVs) dropped greatly after the visit.[100] Rehabilitation

providers must collaborate with spiritual leaders, providing advice and education where appropriate, in order to maximise the outcomes of treatment and rehabilitation.

Alternative therapies

Alternative therapy practitioners (excluding traditional healers) are less widespread in sub-Saharan Africa than elsewhere, particularly outside of urban areas. Alternative therapies can be divided into five main categories:[101]

- Whole medical systems (such as Ayurvedic medicine and homeopathy)
- Mind-body medicine (such as yoga and tai-chi)
- Biologically based practices (such as herbal remedies, vitamins and minerals)
- Manipulative and body-based practices (such as chiropractic and reflexology)
- Energy medicine (such as Reiki and acupuncture)

Rehabilitation providers may employ several of these techniques (including tai-chi, yoga and acupuncture) and similarly, alternative therapists may employ techniques used by rehabilitation professionals. It is vital that rehabilitation providers and alternative therapists collaborate wherever possible, to ensure the best possible treatment for people living with HIV.

Who pays for these therapies?

The spiritual, traditional and alternative healers described above, in most cases, fall outside of public healthcare systems in sub-Saharan Africa. Additionally, private healthcare institutions and insurers often provide little or no coverage for these practices. This can place additional financial strain on people living with HIV who seek advice and treatment from these healers.

Section 4: What do rehabilitation providers need to know about caring for children and youth living with HIV?

4.1 – What is the role of rehabilitation for children and youth living with HIV and their families?

As more children infected with HIV get access to antiretroviral therapy, they are living longer, relatively healthier lives. As they live longer, children may experience many challenges resulting from HIV disease as well as the side effects of long-term medication. Studies have shown that up to 50% of children infected with HIV experience some form of disability, even when they are on antiretroviral medication.[102, 103] Rehabilitation providers can help to identify these problems and in many cases can provide treatment or advice to lessen their impact.

In this resource, **rehabilitation** is defined as any services or activities that address or prevent body impairments, activity limitations, and social participation restrictions experienced by an individual.[104]Rehabilitation is concerned not only with physical well-being, but also with mental and spiritual dimensions of health.

Rehabilitation addresses issues that affect a person's overall quality of life. It is important to remember that children are part of a family and community and that their needs should be viewed within their context.

HIV can affect many different body systems. The challenges that a child may face will change as they get older, and so it is very important that children and youth get assessed holistically at different times as they grow up.

4.2 – What is the ICF-CY and how can it help us think about the role of rehabilitation for children and youth living with HIV?

The International Classification of Functioning, Disability and Health–Children and Youth Version (ICF-CY) was developed by the World Health Organization in response to the need for a tool that could be used across the world to record the characteristics of developing children and the impact of their environment. It can be used in health, education and social sectors. It provides a common language to measure and record the health and disability of children and youth.

The ICF-CY is based on the ICF, which was developed for adults (see Section 1.3). It uses the same concepts to understand challenges that may be present in infancy, childhood and adolescence:

- impairments in body functions and structures
- activity limitations, and
- participation restrictions

It also records important environmental and personal factors.

The ICF-CY can help health workers, teachers, researchers, administrators, policymakers and parents to document the characteristics of children and youth that are important in promoting their growth, health and development throughout childhood.

In 2012, a resolution was proposed for adoption by the WHO Family of International Classifications Advisory Council to merge the ICF-CY with the ICF so that there is a "streamlined, comprehensive ICF which adequately addresses all aspects of functioning across the lifespan".[105]

4.3 – What are the rehabilitation interventions that address the impairments common among children and youth living with HIV?

This section is organized according to the categories of **impairment** in the World Health Organization's International Classification of Functioning, Disability and Health.

4.3.1 – Mental Functions

Many children living with HIV have problems with learning and concentration, especially if they did not start ART at an early age. These problems can occur as the virus gets into the brain tissue of infants and causes inflammation and destruction of neural tissue. This damage to the central nervous system can be irreversible. Children in resource-poor settings who are infected with HIV are at great risk for developing HIV encephalopathy.

The presentation of children with neurologic involvement varies significantly and is influenced by social as well as clinical differences. If possible children should be referred to a psychologist and occupational therapist.

Some of the clinical signs which have been seen in children with neurocognitive problems include:

- Microcephaly
- Cognitive delays
- Cerebral atrophy
- Calcification of the basal ganglia
- Delay or loss of developmental milestones
- Abnormal reflexes
- Electroencephalogram (EEG) abnormalities.

Additional factors which may contribute to a child's learning or behavioural problems include:

- Secondary infections
- Poor prenatal care
- Repeated hospitalizations
- Social isolation
- Neglect and lack of stimulation at home
- Malnutrition e.g. marasmus and kwashiorkor, micronutrient deficiencies
- Lack of structure and security at home
- Side effects of medication
- Maternal substance abuse (including alcohol abuse)

In children who are not infected perinatally (e.g., those who are infected through blood transfusions or sexually active teenagers), the cognitive problems tend to be similar to those experienced by adults.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.1: Clinical Aspects of Mental Functions

Impairments	Possible Etiologies	Rehabilitation Interventions[106]
Developmental delay	HIV encephalopathy Other infections e.g., cytomegalovirus, meningitis	Slow acquisition of developmental milestones in babies and toddlers • Consider developmental testing using standardized psychological measures • Use infant stimulation programs using bright, interesting toys or household objects to stimulate the infant to participate in play • Provide play materials that stimulate a variety of senses (e.g., toys that feel different; toys that roll, bounce, and make noises; water and sand play) • Provide a variety of play opportunities both within the home and in settings where the child is exposed to other people, environments, and situations (e.g., playgroup or creche) • Consider enrollment in crèche, early childhood development centres or pre-school to provide opportunities for peer modelling, as well as rest for parents
Increased or decreased muscle tone	Basal ganglia calcification HIV encephalopathy	• Encourage active movement of affected muscles using functional activities through full range of movement
Poor or absent expressive language (speech)	HIV encephalopathy Hearing loss from chronic ear infections Lack of stimulation	• Administer standardized language measures • Provide many speech examples by talking to the baby/child about everything around you • Pause in conversations with the baby/child to allow her/him to respond with some kind of verbal utterance • Provide names for everything and encourage the baby/child to copy the sounds you make • Do not anticipate the baby/child's every wish. Allow the baby/child to use what language she/he does have (e.g., if the baby/child gestures and grunts, do not immediately hand the baby/child what she/he wants; first try to encourage her/him to use a word or sound) • Expand on the baby/child's use of words (e.g., when the baby/child says "juice," the caregiver can say "Do you want some juice?") • As the baby/child learns words, ask open-ended questions instead of those requiring only a yes or no response • Look at picture books or magazines with the baby/child and

		talk about the pictures • Sing songs and play games with the baby/child • Assess for hearing loss, a common cause of language delay in children • Initiate assessment by a speech-language pathologist
Poor memory	HIV encephalopathy Fatigue	**Poor memory in children** • Conduct neuropsychological assessment • Repeat instructions and verbal reminders • Present materials in various forms (e.g., visual, verbal) • Support verbal information with written information • Use cues to help remember (e.g., use of a watch alarm to remind child when to take pills). However it is important to determine whether or not the child is ready for this step and depends upon his or her cognitive abilities and other variables • Use lists when more than one thing is required of the child • Use a daily diary book containing all important information for the day (for older children) • Give the child simple, one-step instructions and ask the child to repeat the directions to be certain that he or she has understood the instructions accurately
Poor learning and/or attention	Pre-existing learning problems HIV encephalopathy Fatigue Pain Fatigue Attention deficit disorder	• Administer standardized tests • Seek remedial classes or extra help in areas of difficulty • Set aside specific time (e.g., 30 minutes every night after dinner) to work on homework and projects in a quiet environment (if there is no homework, the child can use the time for a quiet activity such as reading) • Set short-term goals and use reward system when the child reaches goals (e.g., stickers, stars) • Revise learned material frequently • Have preferential seating to avoid distractions (e.g., away from windows, doors, and noisy classmates and at the front of the class near the teacher) • Allow for sufficient rest times during the day to ensure maximum alertness and ability to participate in the school day
Poor visuomotor skills	HIV Lack of stimulation	• Allow the child to draw and color • Practice cutting out shapes with scissors

		• Do puzzles with the child • Look at books and talk about the colors and shapes in the pictures
Depression or behavioural problems e.g. aggression and fighting	HIV Side effects of medication Social problems at home and /or school	• Provide a safe place for children to talk • Refer for psychological assessment and counselling

4.3.2 – Sensory functions and pain

Pain is a complex and multifaceted issue in every child living with HIV. All children infected with HIV should be assessed for pain. If available a pain specialist and physiotherapist should be consulted.

Both pharmacological and non-pharmacological treatments should be considered. Ensuring the child's comfort is also an important component of pain management, including using a gentle touch when moving or supporting a client and providing cushioning and supports.

Pain is associated with a lower quality of life, a low CD4 count, more significant immunosuppression and mortality. Girls and younger children describe higher pain levels, specifically gastrointestinal and limb related, than older children and boys. Any pain is important to note, but of particular importance is pain that is **new or different**.

Pain can be measured using modified visual analogue pain scales and rating measures, e.g., the Wong and Baker Faces Pain scale. These measures can be adjusted according to age, degree of illness and other factors, such as cultural background and beliefs.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.2: Clinical Aspects of Sensory Functions and Pain

Impairments	Possible Etiologies	Rehabilitation Interventions[107]
Pain (acute and chronic)	HIV HIV-related infections Side effects of medication Resulting from diagnostic and therapeutic interventions	Non-pharmacological Interventions for pain • Screen for peripheral neuropathy • Relaxation techniques • Massage therapy • Distraction • Free play time • Music • Sleep • Rest • Balanced diet • Warm bath • Transcutaneous Electrical Nerve Stimulation (TENS) • Weight bearing exercises • Deep pressure

Pharmacological interventions are also important and can include:

- Topical analgesics
- Local anaesthetics
- Non-steroidal anti-inflammatory drugs (NSAIDs)
- Corticosteroids
- Anticonvulsants with analgesic effects
- Selective serotonin reuptake inhibitors (SSRIs)
- Narcotics

4.3.3 – Hearing

Children living with HIV are prone to getting ear infections and many suffer from chronic otitis media.

- Otitis media is especially common in the first two years of life. Low socio-economic status, attendance of day care, absence of breastfeeding, and winter season are all risk factors for developing otitis media.[108]

Acute otitis media presents with pain, fever and irritability.

- Examination of the ear will reveal typical otoscopic findings of inflammation and infection.
- Many children go on to develop chronic otitis media. These children may be asymptomatic or only mildly symptomatic.
- They may present with pain, hearing loss, dizziness and ringing in the ears.
- The hearing loss may impact on their speech development and the dizziness may affect their balance and gross motor development.

Complications of chronic otitis media include tympanic membrane perforation, meningitis, mastoiditis and hearing loss. Children with painful ears should see their doctor. Children with chronic ear infections should be referred for a hearing test.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.3: Clinical Aspects of Hearing Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[108]
Hearing loss	Otitis media	• All children living with HIV should have their ears examined by a doctor regularly • Ear infections should be treated promptly with appropriate medication • Children should have their hearing screened once a year • Any child whose caregiver reports that they are not listening or hearing well should be sent for a full assessment by an audiologist • Any child whose balance has suddenly deteriorated and who does not like to move through space (e.g., play on swings) should have her/his ears checked • Children with hearing loss should be referred to a speech and language therapist • Children with poor hearing should be seated in the front of their class and the teacher should be made aware of their challenges

4.3.4 – Vision

Children have immature visual systems, which makes them more vulnerable to the neuropathic effects of HIV. This vulnerability is present until the child is approximately eight years old and their visual system is more mature.

Few children will complain about visual loss, especially if the problem starts when they are very young. It is very important that all infected children are screened regularly for visual problems.

By the time they reach their early teens, children are likely to experience similar ocular problems to adults.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.4: Clinical Aspects of Visual Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions
Infections	Cytomegalovirus Toxoplasmosis TB	• All children should have their vision screened once a year • Eye infections should be treated promptly and appropriately • Children with visual problems should be referred for proper visual assessment • Children with visual problems should receive the necessary support at school e.g., sit near the front, large text books • Encourage them to wear their glasses
"Cotton wool spot"	Microvascular infarct of nerve fibre leading to retinal oedema	
Blindness/loss of vision	Retinal haemorrhage Retinal arterial/ vascular occlusion Optic nerve atrophy	
Strabismus	HIV	
Peripheral retinopathy	Drug toxicity (ddI)	

4.3.5 – Sensation

Children can get peripheral neuropathies in the same way as adults living with HIV. Recent studies in sub-Saharan Africa have shown that peripheral neuropathy is much more common than had been thought and may affect as many as 24% of children.[109]

Peripheral neuropathy in adults has been linked to the use of nucleoside reverse transcriptase inhibitors (NRTIs) and this class of drug is still included in some paediatric ART regimes in Africa.[109]

Children may present with numbness, burning and tingling sensations in their feet. They may have decreased sensation and reduced or abnormal ankle reflexes.[110] Children with sensory problems should be referred to a physiotherapist.

Many children who have been on ART since they were very young will not complain of symptoms as they have grown up with these abnormal sensations and do not consider them out of the ordinary.

Table 4.3.5: Clinical Aspects of Sensory Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[111]
Sensation changes, including numbness, burning or tingling	HIV Peripheral neuropathy	• All children should be screened for peripheral neuropathy. Do not wait for complaints about altered sensation. • Assess children's balance and proprioception • Monitor children's gait pattern • A programme consisting of deep pressure and/or vibration, balance and gait re-education as well as proprioceptive training is advised.

4.3.6 – Voice and speech functions

Expressive and receptive speech may be affected by HIV encephalopathy. Children may speak in short sentences and not make use of many descriptive words.

Children who have cardiac or respiratory disease may become breathless even with normal speech. They may speak very quietly and may also use very short sentences with long pauses between sentences. Children with speech problems should be referred to a speech and language therapist if possible.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.6: Clinical Aspects of Voice and Speech Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions [112]
Challenges with speech	HIV encephalopathy	• Provide opportunities for children to talk i.e., engage them in conversation even if they are very young • Encourage children to describe what they are seeing and doing • Use descriptive words • Sing songs and rhymes • Read books with children. Even toddlers and preschool children should look at picture books and talk about the story and pictures. • If children are breathless and become tired talking, do not pressure them. Allow them to point to what they want and help them find a position in which they can breathe most easily.

4.3.7 – Functions of the cardiovascular, haematological, immunological and respiratory systems

Cardiovascular

As children with HIV are living longer, cardiovascular complications are becoming more prevalent and contribute significantly to the morbidity and mortality. It is estimated that over 90% of children with HIV will have some form of cardiovascular problem.[13]

Most children are initially asymptomatic and may present with a range of diagnoses. Children most at risk for cardiovascular problems are those who present with encephalopathy, wasting and low CD4 counts.

Cardiovascular symptoms may be missed or thought to be due to respiratory or other infections. Regular screening of children, a healthy diet and regular exercise can help cardiac disease.

Haemotological

- Most children living with HIV have problems with their haemotological systems.
- These can be caused directly by HIV but may also be due to poor nutrition or side effects of medication.
- These conditions are usually asymptomatic but may become life threatening.

Immunological

- The primary problem resulting from HIV infection is dysfunction of the immune system.
- HIV affects the infected immune cells directly and causes damage.
- It also damages cells which are not directly infected and causes a generalized response to host cell infection.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.7: Clinical Aspects of Cardiovascular, Haematological, Immunological and Respiratory Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[114]
Cardiovascular	HIV Left ventricular abnormalities Dilated cardiomyopathy Myocarditis Pericarditis	• Assess heart rate and blood pressure before and after any exercise • Monitor levels of dyspnea (breathlessness) during exercise • Take complaints of dizziness and chest pain seriously • Refer to a doctor for a full cardiac assessment including echocardiograms if symptoms persist

	Rhythm disturbances	
Immunological	HIV	• Rehabilitation cannot directly improve the immunological status of a patient. However there are aspects of rehabilitation that must be taken into consideration: ◦ Maintain strict infection control in order to protect the immunocompromised child from secondary infections ◦ Be aware of the degree of immunocompromise and adapt your treatment according to how ill the child is at this time. As with adults, children may present with periods of decreased immunity and episodic disability (see Section 1.4).

4.3.8 – Respiratory Impairments

Respiratory tract problems are among the most frequent complications in children living with HIV.[115]

A common form of pneumonitis in children is **lymphoid interstitial pneumonia (LIP)**, a chronic disease characterized by spontaneous exacerbations, intermittent wheezing, and chronic cough.[116] The chest x-ray pattern varies often, showing migrating interstitial infiltrates. In some cases, the pattern is difficult to distinguish from tuberculosis.

Pneumocystis jerovecii pneumonia (PJP) remains one of the most common presenting infections in children not previously diagnosed with HIV infection, and in children unable to tolerate prophylactic treatment.

Red Flag: Any acute changes in respiratory status (such as increased respiratory rate, difficulty breathing during minimal exertion, change in sputum colour, or fever) may indicate a significant infection requiring urgent medical assessment and treatment.

Co-infection with HIV and TB is extremely common in sub-Saharan Africa.

- Children with HIV and TB tend to have lower CD4 counts and severe illness and a higher mortality rate than children without TB.
- It is extremely important that the TB is treated properly and that treatment is adhered to.

Health care workers must take the necessary steps to protect themselves from TB especially in areas where multi-drug resistant TB is common.

Manual physiotherapy techniques should be used only if there is a clear indication that a superimposed acute or chronic lung disease process is present with evidence of lower airway secretions. Those patients with only upper airway secretions do not require manual physiotherapy techniques. These children/youth may benefit from deep breathing exercises or cough assist techniques to aid in optimizing ventilation. Suctioning is only required if they are unable to clear their own secretions with coughing.

Red Flag: Special note for hemophiliacs: Manual techniques such as percussion and vibration are a relative contraindication in hemophiliacs due to their underlying bleeding disorder. Their bleeding problems are often compounded by low platelets. Active Cycle of Breathing (ACBT) techniques could be used instead for those children over five years of age. Positioning and suctioning (if necessary) are recommended for younger children. The risks and benefits of manual techniques need to be considered for each individual.

Respiratory muscle function

- Respiratory muscles may be weak especially if the child has been very ill and is severely immunocompromised

Exercise tolerance and additional functions

- Children who have chronic lung disease and even those who appear to be healthy may have decreased exercise tolerance. This may affect their functional ability and the way in which they participate in school and community activities.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.8: Clinical Aspects of Respiratory Impairments

Impairments	Possible Etiologies	Rehabilitation Interventions[117]
Respiratory problems	Bacterial pneumonia Tuberculosis Pneumocystis jerovecii pneumonia CMV pneumonitis Bronchiectasis Viral pneumonia Lymphoid interstitial pneumonia	**General** • Positioning to maximize ventilation perfusion matching • Relaxation techniques • Breathing control exercises for example Active Cycle of Breathing (ACBT) **Deep Breathing Exercises** • Diaphragmatic and lateral costal breathing • Bubble blowing • Use of an incentive spirometer (if available) for children over five years of age **Manual Techniques** • Postural drainage • Percussion • Vibration • Neuro-facilitation techniques **Expiratory Techniques** • Forced expiratory technique (FET) **Strengthening** • Strengthening of the muscles of respiration can be very effective in improving respiratory function. **Endurance** • Test children over 5 years of age using a standardized test for example the Six Minute Walk Test

		• Prescribe a graded aerobic exercise programme for children with decreased endurance • Encourage all children to be physically active and to participate in sports.

4.3.9 – Functions of the digestive, metabolic and endocrine systems

Feeding Problems and Poor Growth

There are important feeding and growth issues unique to infants and children:

- Proper nutrition is one of the easiest ways to facilitate good immune function.
- Although antiretroviral therapy has helped reduce poor growth, it is still extremely important to attend to the nutritional needs of infants and children living with HIV.
- Malnutrition can have a negative effect on immune function and make it more difficult to fight infections.
- Interventions should be focused on preventing malnutrition as well as careful nutritional assessment and targeted interventions. This can be achieved if there is early detection of either weight loss or a falling off from age- and sex-corrected growth percentiles.
- The height and weight of children and infants living with HIV should be plotted on appropriate growth curves at regular intervals.

Breastfeeding

For most babies, breastfeeding is by far the best way to be fed. However, it is possible for breastfeeding to transmit HIV from an HIV-positive mother to her baby. Therefore, the risks and benefits of breastfeeding must be carefully considered by HIV-positive mothers and their supporters. We encourage readers to review up-to-date, easy-to-understand descriptions of advice (e.g., see http://avert.org/hiv-and-breastfeeding.htm) and about ART for pregnant mothers and infants (e.g., see https://www.avert.org/hiv-transmission-prevention/pregnancy-childbirth-breastfeeding). We note some (but not all) key points about breastfeeding for HIV-positive mothers here.

The WHO 2013 guidelines recommend that HIV-positive mothers in low-income countries:

- breastfeed exclusively for 6 months if they do not have access to clean water and sanitation and if they are unable to afford formula. Note: In some areas, mothers may qualify for free formula for the first 6 months of their infant's life.
- continue breastfeeding for 6 months, then introduce complementary foods and wean baby at 12 months
- administer appropriate ART to the infant
- breast milk versus formula: The immunological and nutritional benefits of breastmilk far outweigh those gained from formula feeding. Consequently, the World Health Organization recommends exclusive breastfeeding for 6 months for all infants around the globe. However, for HIV-positive mothers, formula feeding is the next best alternative if they have the means to do it safely.

For WHO guidelines:

The **2016 WHO Consolidated Guidelines on the use of Antiretroviral Drugs for Treating and Preventing HIV Infection** are available at http://www.who.int/hiv/pub/arv/arv-2016/en/.

Feeding Problems and Poor Growth

- Infants and children living with HIV are at high risk for malnutrition, which can have a negative effect

on immunity and make it harder to fight infections.
- Malnutrition causes a lack of weight gain, poor growth, and even weight loss.

Other important factors that put an infant or child with HIV infection at risk for malnutrition include:

- Feeding problems
- Anorexia due to acute or chronic infection and illness
- Financial resources of the family
- Stigma

The infant's rehabilitation providers need to address all of these issues. Nutritionists, speech- language pathologists or speech therapists and occupational therapists are some of the specialists who can play important roles in this context particularly.

Red Flag: Any change from previously stable growth curves requires immediate medical assessment and intervention with supplemental nutritional strategies.

Red Flag: Any new gastrointestinal symptoms such as mouth sores, vomiting, or diarrhoea require prompt referral for medical assessment.

Any infant or child with "feeding problems" requires a comprehensive feeding history to be taken to help guide the assessment and interventions. Feeding problems may be multi-factorial.

An infant or child's feeding abilities may change with time and with their medical status (e.g. new mouth sores, acute infection, new medications, encephalopathy). Caregivers need to monitor their child's feeding closely and have it reassessed quickly if issues arise.

Before starting an intervention, a feeding assessment is required to identify the specific areas of concern. The assessment is important, as the history or presentation may appear similar in children with very different feeding issues. For example, an infant who is reported to have a "poor suck" and "fall asleep" while feeding may have poor oral motor skills and decreased endurance. However, he or she may also be demonstrating adaptive or protective techniques to limit intake due to an underlying swallowing problem and aspiration or due to discomfort (e.g., reflux or nausea) with oral feeds. Children with feeding difficulties should be referred to a speech therapist for a feeding assessment if possible.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.9: Clinical Aspects of Feeding Problems and Poor Growth

Impairments	Possible Etiologies	Rehabilitation Interventions
Inadequate feeding	Poor oral motor skills Poor coordination of breathing or swallowing Tires easily/decreased endurance	• Position to maximize efficiency of bottle and spoon feeding • Modify flow rate of liquids when bottle feeding (flow rate may need to be decreased or increased depending on the child's needs). An Occupational Therapist or Speech-Language Pathologist can assist with determining the correct bottle and flow rate for an infant • Spoon liquid if the baby cannot suck • Use higher caloric infant formula as prescribed by a registered dietitian or physician • Use infant cereal or maize meal mixed with formula instead of water. It is important to avoid adding formula to cereals that are labelled "add water" as these cereals contain powdered milk. If formula is added, the caloric content can be excessive and dangerous. Ensuring the cereal is labelled "add formula or breastmilk" is very important. • Use oral stimulation techniques taught by a therapist to improve suck strength and the coordination of the suck, swallow, and breathe sequence
Self-feeding problems	Poor fine motor and visual-motor skills Tires easily/ decreased endurance Developmental delay or regression	• Use cups with a spout that make it easier to drink • Use easy-to-hold finger foods • Use a spoon that is not too big or too small • Encourage finger feeding • Provide opportunities with no stress or expectations on the child for children to experiment and practice self-feeding • Improve fine motor/visual motor skills through activities other than feeding
Swallowing problems (including choking with feeds/aspiration)	Mouth/throat sores or pain Structural abnormalities	• Conduct a comprehensive feeding assessment regarding safety of different textures and consistencies and related aspiration risks

	Swallowing incoordination Developmental regression Encephalopathy or neurologic changes Anorexia, nausea, vomiting, fatigue, pain Decreased taste acuity Abnormal taste Side-effects of medication Psychosocial and emotional distress (e.g., separation, anxiety, depression, parent-child interaction, over/ underfeeding)	• Avoid foods/textures that the feeding assessment has identified as being a risk for aspiration (e.g., provide thickened liquids if thin liquids are found to cause choking/ aspiration) • Maintain good dental hygiene. Children should brush their teeth twice a day • Avoid foods that are too salty, spicy, or acidic • Give soft, smooth, easy-to-chew foods if chewing is difficult or immature • Use a straw for drinking if mouth sores are present • Use food that is cold or at room temperature, if mouth sores are present • Provide verbal or gestural cues to facilitate swallowing • Use a dry swallow after a normal swallow to clear any residue
Diarrhea	Malabsorption Medication side-effects HIV enteropathy Altered gastric motility Infections (viral, bacterial, or parasitic)	• Treat infections • Assess gastrointestinal motility and use appropriate medications as required • Use dietary interventions as recommended by a registered dietician, often low-fat, low lactose foods
Poor appetite	Nausea Side effect of medication	• Use small, frequent meals • Use a higher caloric diet by choosing high-fat dairy products (if tolerated) and adding extra fat foods to table (e.g., butter, margarine, gravy, peanut butter) • Give oral nutritional supplements • Give nutritional supplements via gastrostomy tube for anorexia

4.3.10 – Endocrine disorders

Although children with HIV often present with failure to thrive and poor growth, this is seldom as a direct result of endocrine disorders.[118]

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.10: Clinical Aspects of Endocrine Disorders

Impairments	Possible etiologies	Rehabilitation Interventions
Poor growth	Secondary infection of endocrine glands Malignancy Protease inhibitors	• Regular growth monitoring and appropriate referral to a doctor

4.3.11 – Neuromusculoskeletal and movement-related functions

A number of important and unique issues are involved when caring for children with impairments related to movement and coordination. The rehabilitation provider needs to consider:

- Presence of encephalopathy and developmental delay
- Spinal and corticospinal tract degeneration in children
- Peripheral neuropathy in children
- Muscle weakness due to atrophy
- Joint pain due to infection (e.g., septic arthritis)

Children with motor difficulties should be referred to a physiotherapist and occupational therapist if possible.

Red Flag: Any acute loss of previously mastered skills or fluctuations in levels of consciousness require urgent medical assessment.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.11: Clinical Aspects of Movement and Coordination Impairments 18

Impairment	Possible etiologies	Rehabilitation interventions
Generalized Hypotonia (low tone) and Delayed Achievement of Motor Milestones	Cerebral vascular disease Vasculitis	• Promote motor activity through play, positioning, and handling (e.g. neurodevelopmental therapy) • Develop muscle strength and transitional movements • Use infant seats or chair inserts or a cardboard box (to promote sitting) • Have infant in a variety of physical positions with only enough support to provide appropriate positioning (e.g. sitting, supine, lying prone, on side, supported standing)
Hypertonicity HIV encephalopathy	Cerebral vascular disease Vasculitis HIV-related spinal or corticospinal tract degeneration Wallerian degeneration	• Use tone-inhibiting positioning and handling • Use splints or ankle foot orthoses • Promote motor activity through play, positioning, and handling (e.g. neuro-developmental therapy) • Develop muscle strength and transitional movements • Refer to a specialist for specific appropriate therapies, e.g. Botulinum toxin A, oral anti-tone treatments, surgical interventions Problems of Limited Mobility

	from white matter disease Stroke Spinal cord infections (e.g., CMV, HSV) Malignancies (e.g., lymphoma)	• Use of a wheelchair (with seating insert if required) • Practice selective muscle strengthening, maintaining range of motion • Practice gait re-training • Practice balance re-education • Practice transfers and transitional movements • Assess for walking aids, splints, orthoses • Use hot packs/ice packs as indicated for stiff painful joints (use with caution with children) Loss of Independence in Self-Care • Install adaptations to home or school (e.g. bath seat, ramps, handrails) • Use diapers or special toilet seat
Weakness	Myopathy AZT-related HIV infection-related Peripheral neuropathy Drug-induced (e.g., AZT, ddI, d4T)	• All children should be screened for peripheral neuropathy. Do not wait for complaints about altered sensation. • Assess children's balance and proprioception • Monitor children's gait pattern • A programme consisting of deep pressure and/or vibration, balance and gait re-education as well as proprioceptive training is advised.

Legend: AZT: zidovudine; **CMV**: cytomegalovirus; **CNS**: central nervous system; **ddI**: didanosine; **HSV**: herpes simplex virus

4.3.12 – Functions of the skin and related structures

Children with HIV are very prone to **skin problems** including infections, inflammation and neoplasms of the skin.[120] All health care workers must be aware of the possible skin complaints that children may have and should refer them for medical attention as soon as a problem is noted. As with many other conditions children with a greater degree of immune suppression are at greater risk of having skin problems. Children with skin problems should be referred to a dermatologist or their doctor.

Skin infections are the most common clinical skin problem. Skin infections may be fungal, viral or bacterial. Scabies is extremely common in HIV infected children and is caused by the mite *Scabies sarcoptei.* Scabies is spread very easily through contact with an infected individual. It presents as itchy areas with small papules. It usually starts on the hands and wrists.

Non-infectious skin problems include reactions to medication and dermatis.

Potential causes of these impairments and rehabilitation interventions are shown in the table below.

Table 4.3.12: Clinical Aspects of Skin Problems

Impairments	Possible Etiologies	Implications for Rehabilitation
Skin problems	Neoplasms Infections	• Rehabilitation workers must be aware of skin conditions and should refer children with any new problems to a doctor for assessment. • Care should be taken with infection control until the cause of the skin condition is known. • Use gloves when handling children with scabies and skin infections • Wash hands thoroughly after every treatment session • Place a clean sheet over mats or plinths for each patient

4.4 – What are the rehabilitation interventions that can address the activity limitations and participation restrictions common among children and youth living with HIV?

Rehabilitation encompasses much more than just treating impairments.

A broader and more **holistic rehabilitation approach** should take into account the activity limitations and participation restrictions that affect children living with HIV.

- **Assessment and early treatment** of impairments can prevent secondary complications from developing. This can help prevent potentially disabling conditions from getting to a point where they limit a child's ability to go to school and participate in age appropriate activities.
- **Referral** to appropriate medical and social structures to address concerns quickly and effectively can help ensure that children spend as little time as possible in hospital and remain an active member of their families and communities.

It is crucial that rehabilitation providers understand their roles across the spectrum of the disease process from acute, in-hospital care to long-term follow-up in the community. Each child should be viewed within her/his individual context. Their age, developmental status, and family situation are very important. Furthermore their role in school, sports and social activities must be considered when planning a holistic rehabilitation strategy.

Potential causes of these impairments and rehabilitation interventions are shown in the table below. This table is organized according to the categories of **activity** and **participation** in the World Health Organization's International Classification of Functioning, Disability and Health (see Section 1.3).

Table 4.4: Activity Limitations and Participation Restrictions

Activity Limitations and Participation Restrictions	**Rehabilitation interventions** (for details, see page 32-34)
Learning and applying knowledge	• Environmental adaptation • Assistive devices • Provision of visual education materials • Additional support for children in their classrooms
General tasks and demands	• Environmental adaptation • Advice on appropriate games and activities • Exercise prescription – aerobic • Exercise prescription – strength • Return to school and sport strategies

Communication	• Environmental adaptation • Education of family and educators on how to optimize communication • Education on managing conversations and communication • Articulation, fluency, resonance, language advice and exercises • Adaptation of communication environment
Mobility	• Advice on appropriate games and activities • Exercise prescription – aerobic • Exercise prescription – strength • Assistive devices • Environmental adaptation • Exercise prescription – stretching and passive movement • Advice on appropriate games and activities
Self-care	• Advice on personal hygiene including oral hygiene • Advice and exercises related to transfers • Assistive devices • Environmental adaptation • Ergonomic interventions • Energy conservation and pacing
Domestic life	• Assistive devices • Environmental adaptation • Energy conservation and pacing • Advice for the caregiver on meal preparation and nutrition
Interpersonal interactions and relationships	• Psychosocial rehabilitation • Family support groups and parenting programmes • Involvement and education of family and friends • Adolescent groups • Reduce stigma by providing clear, unambiguous messages to the public

Major life areas including work and employment	• School education programmes • Extra-mural education and activities for learners • School feeding programmes • Environmental adaptation • Ergonomic interventions • Energy conservation and pacing • Involvement and education of educators • Education and advice on social grants/ employment legislation
Community, social and civic life	• Advice on appropriate games and activities • Community activities and programmes • Involvement and education of spiritual, political, education and community leaders • Education and advice on human rights
Policy advocacy	• Advocate for policies and programmes to support food security • Advocate for equitable, affordable access to health care • Advocate for equal access to education for girls and boys • Advocate for safe, sanitary living conditions • Advocate for better services for children across all sectors of society including health, education and social services
Health and wellness	• Getting involved in **prevention** programmes at a number of different levels. This can include education to support prevention of mother to child transmission, exercise programmes for children and youth to prevent complications associated with HIV. • **Promoting** good health through wellness programmes for young people designed to encourage healthy living and lifestyle choices.

Articulation, fluency, resonance, language advice and exercises

Advice and exercises can be given to individuals to address challenges with speaking. These include rehabilitation to improve fluency, resonance, phonation, producing sound, intonation, variance of pitch, and voice and language, as well as aeromechanical components of respiration. Individuals may be assessed by a speech language therapist and work in collaboration with the multidisciplinary team to implement therapy.

Assistive devices

The provision of assistive devices can help people with disabilities address and adapt to their environment, promoting normal lifestyle and facilitating employment and education participation. Examples of assistive devices are mobility devices, home modification devices, respiratory devices, hearing aids, and self-care equipment. In resource-poor settings assistive devices can range from low cost to high cost and some devices can be no cost. For example, individuals experiencing memory loss may set a reminder on their phone to alert them when medication needs to be taken. Other examples of low cost devices are spacers modified from plastic bottles or cups, which are used to administer medication for children. Cardboard boxes can also be used to make appropriate seats for infants with developmental delay. Non-governmental organisations in Africa can be a valuable source of assistive devices.

Energy conservation and pacing

Pacing and energy conservation techniques assist individuals to balance work, social and leisure pursuits by ensuring they have the necessary energy levels when required. Various strategies can be taught to people living with HIV by rehabilitation providers to achieve optimum energy levels. Education includes the collaborative setting of achievable goals, advice on the planning of errands to minimise fatigue, and teaching correct posture and biomechanics to ensure efficiency of activity. Adaptation of the physical environment can also assist with energy conservation, as can the prescription of assistive devices, where required. Rehabilitation and exercise sessions should be timed when individuals typically have the highest levels of energy and where necessary, to ensure the optimal effect of any medication (e.g., analgesics) that the individual may take prior to exercise.

Environmental adaptation

Environmental adaptation refers to changing or restructuring the environment to meet the needs of people with impairments. The change could involve home, work, community and/or study environments e.g., adapting the environment of the home to accommodate a person using a wheelchair by clearing passages and widening doorways.

Ergonomic interventions

Ergonomics involves the re-design of the physical environment and the use of equipment to better complement the individual living within that environment. Practical examples of applying ergonomic principles include the re-positioning of furniture in the home, school and/or workplace to decrease musculoskeletal overuse injuries, and advising regular rest intervals during sustained activities. Advice on posture and biomechanics when working or studying can also reduce undue strain and fatigue. Task analysis of an individual's daily activities can ascertain priority areas for intervention. Knowledge of

one's country's specific occupational and safety acts is also important to ensure that employers make the necessary adaptations for all workers, particularly those who may have physical and/or cognitive impairments. Knowledge of inclusion policy within a country can also determine adaptations to be made in schools.

Exercise

Exercise is a key strategy that may be used by people living with HIV and by rehabilitation professionals to address or prevent disability and improve or sustain the health of people living with HIV.[121] Exercise is defined as any physical activity involving bodily movement produced by skeletal muscles that requires energy expenditure including (but not limited to) aerobic, resistance, flexibility and neuromotor activity beyond activities of daily living to improve and maintain physical fitness and health.[122, 123]

Regular exercise is widely accepted as an important part of optimal health.[124] In HIV, exercise has been shown to:

- Improve cardiovascular fitness
- Increase body weight
- Improve body composition
- Increase strength
- Improve quality of life, improve mood and decrease stress

Exercise prescription – aerobic

Aerobic (also known as cardiovascular) exercise includes activities such as walking, jogging, stepping, swimming and cycling. Aerobic exercise has been shown to be beneficial for people living with HIV, including interventions conducted in sub-Saharan Africa,[125, 126, 127, 128] conferring physical benefits as well as improving mental health and quality of life and reducing symptoms of depression. These exercises can be done at little or no cost and can be performed with fellow patients, friends and family members. Although few studies investigate the role of aerobic exercise in children living with HIV, preliminary results suggest that it is an appropriate intervention provided the child is not acutely ill.

Exercise prescription – strength

Strength (or resistance) training involves exercises that overcome either internal or external forces using body weight or a variety of equipment including free weights (dumbbells and barbells), machine weights, resistance bands/tubing and hydrotherapy. When correctly taught, these exercises can improve muscle strength, power, endurance and coordination, and also improve daily functioning and quality of life. This form of exercise has been shown to be safe and beneficial for people living with HIV.[129] Although few studies investigate the role of strengthening exercise in children infected with HIV, preliminary results suggest that it is an appropriate intervention if the child is not acutely ill.

Exercise prescription – stretching and passive movement

Passive movement is the movement of separate parts of an individual's body by the rehabilitation provider or by another external force. Passive movements and stretching exercises can help improve flexibility and circulation, normalise muscle tone and reduce the risk of contractures and pressure

sores. Family members and friends can be taught to assist with these exercises, providing both a therapeutic intervention as well as an opportunity for interaction and involvement with others. Static stretching exercises can be taught to individual patients while proprioceptive neuromuscular facilitation (PNF) techniques should always be instructed by a trained professional.

Nutritional advice

Poor diet has a direct effect on the immune system. Advice on nutrition must be tailored to the individual and her/his circumstances. People living with HIV may suffer from weight loss or weight gain. Individuals need to eat a balanced diet with fat, carbohydrates and protein. Individuals could be advised to eat several small meals per day using what is available to supplement all food groups. Individuals may be further advised, to keep log books on their weight and diet, with education on warning parameters for weight loss or gain. Dieticians or nutritionists may recommend daily multivitamins. It is important however to consider possible interactions of dietary supplements and ARVs.[130] Referral can be made to a dietician (when available) who may conduct a nutritional assessment, counsel individuals, or assist with food provision through referral to nutrition supports. Alternatively, rehabilitation providers can encourage people living with HIV to begin subsistence farming and set up vegetable gardens or small animal rearing projects to produce food. Any advice on nutrition must include information on adequate hydration level for each individual.

Psychosocial rehabilitation

More specialised psychological rehabilitation services can be offered by specifically trained professionals, including psychiatrists, psychologists, psychotherapists and occupational therapists. However, primary prevention, in the form of exercise, adequate nutrition and maximizing quality of life falls within the scope of all rehabilitation providers. Social support structures, such as support groups, friends, family, cultural, religious and other community organisations, can also provide emotional and practical support.

Return to school strategies

The rehabilitation provider can work together with the child, family and educators to prepare a child for return to school. This is particularly important after long absences, when the child has been extremely ill, or is returning with a new disability. The peers of the returning child should be prepared and given strategies to support their friend.

4.4.1 – Adolescents and Young Adults

Adolescence is a time of transition and growth during which an individual faces changes on many fronts, including physical, emotional, and mental processes as well as sexual identity.[131]

Responding to an HIV diagnosis may be particularly difficult for youth, especially for those living at the margins as a consequence of sexual orientation, race, ethnicity, abuse, homelessness, precarious living arrangements, and substance abuse.

As with adults, an HIV diagnosis can be traumatic and is frequently associated with depression and low self-esteem. Adolescents infected with HIV face multiple health challenges.[132, 133, 134]

Those who acquire HIV during their youth face decisions under significant time constraints. Rapid adaptation to stigma and living with a chronic disease is imperative for these youth as initiation of antiretroviral therapy is crucial.[131] Unfamiliarity and the associated stigma of HIV make adherence to antiretroviral regimens in youth with behaviourally acquired HIV a challenge.[131]

Disclosure and adherence challenges can be related to fear of hurting family and/or being rejected by family and friends. This can be mitigated by support from friends, family and an interdisciplinary team.[131]

Although HIV has been traditionally associated with malnutrition and rapid weight loss, currently more than half of those with behaviourally acquired HIV are, at least initially, overweight or obese.

Another challenge faced by adolescents with HIV is the pending transition to the adult health care system. In most cases, a pediatric care team has been managing the care of the adolescents since birth or early childhood, allowing for a trusting relationship to develop with the adolescent and also with their caregivers.

Fair et al.[135] describe the need for increased independence by the adolescent in managing his or her health condition as the adolescent nears transition to the adult health system. The transition process can begin a few years before the actual change occurs, allowing for a gradual increase in the responsibility and time for the adolescent to become accustomed to managing his or her health.[135] Often during the transition years, the social worker or other health professional, will accompany the youth to the adult clinic to allow for orientation and support throughout the transition.[135]

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

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*"[136]

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

- To incorporate research findings with clinical wisdom and clients' preferences to inform rehabilitation assessment and treatment.[137]

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.[138]

The evidence base in rehabilitation is growing rapidly, but translating these findings into practice remains a challenge.[139,140,141,142,143] The goal of this resource is to provide evidence-informed guidance on rehabilitation for adults and children living with HIV.

Rycroft-Malone et al [144] 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.[145] 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:
  - Maintain objectivity and standardize assessment when working with clients
  - 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, clients, or policymakers to ensure all stakeholders speak the same language.
    - 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	Describes the state of a health construct at a point in time. This description can be used to compare the client to other clients, or the general population. For example, measuring activities of daily living or symptom severity at one point in time.
Predictive	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.[146,147] For example, using a balance scale to predict whether someone is at risk of falling.
Evaluative	Useful for detecting the magnitude of change over time in an individual or group.[148,149] 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.
Discriminative	Differentiates between patient groups and identifies differences in patients' abilities[150]

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	The consistency of the measure and whether a measure (or questionnaire) is free from error.[151] It is important that measures are reliable (or consistent) and able to differentiate measure scores between clients.
Validity	How well the measure really measures what it is supposed to measure[151] 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.[151] 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).[152] For example, does the HIV Symptom Index,[153] 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?
Responsiveness	Ability for a measure to detect any change in a client over time if a change has occurred.[151] This property is relevant to evaluative types of measures. A sensitive, or responsive, assessment enables the healthcare provider to detect small to large changes in the construct of interest. 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.
Interpretability	Meaning of the scores or values associated with the outcome measures, i.e., what do the numbers really mean? For example, what does a score of 82 on the Mental Health Summary Score of the Medical Outcomes Study Short Form (SF-36)[154,155] mean for clients? What does it mean for treatment decisions in clinical practice? Terms such as the minimal detectable change (MDC), or minimal clinically important difference (MCID) refer to interpretability, specifically the minimum score that reflects an important or clinical change (improvement or worsening) for a given measure.[151,156]

For example, the MCID for the six-minute walk test is 25 meters among people living with Chronic Obstructive Pulmonary Disease.[157] 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	Floor effect occurs when responses on a measure, questionnaire or scale cluster at the more negative health state end of the scale. 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.
Ceiling effect	Ceiling effect occurs when responses on a measure or questionnaire cluster at the more positive health state end of the scale. 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.

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
• Generic Measures These measures can be used with all individuals in the **general population.**	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. Examples of generic measures commonly used in HIV practice and research include: • Medical Outcomes Study Short Form (SF-36) questionnaire, which measures health-related quality of life (HRQL)[158,159] • 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[160,161] • Centre for Epidemiological Studies for Depression Scale (CES-D), which measures depression[162] 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).
• Disease-Specific Measures These can measure a health-related concept within a **specific disease group** (e.g., people living with HIV).	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. Examples of HIV-specific measures are: • HIV Symptom Index, a 21-item self-reported questionnaire that measures symptom presence and severity[163] • Medical Outcomes Study-HIV Health Survey which was adapted from the Short Form 36 (SF-36) to measure HRQL specifically for people living with HIVng the presence, severity and episodic nature experienced by adults living with HIV[164,165,166] • • HIV Disability Questionnaire (HDQ), a 69-item self-administered questionnaire describing the presence, severity and episodic nature experienced by adults living with HIV[167,168,169, 170, 171]

5.6 – How should you decide which outcome measures 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	Is the intent to describe, predict, or evaluate change over time? Different outcome measures are developed for different purposes and it is important to choose the measure that is geared towards a specific purpose (see Table 5.2).
3) Search for available outcome measures that can measure a construct with a purpose in mind	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. 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.
4) Choose the measure	When choosing a measure, consider: • 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. It is important to clarify the process for obtaining copies and the use of a given outcome measure.

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 (ADL)

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
Assessment of Motor and Process Skills (AMPS)[172,173]	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)	**Reliability:** Good internal consistency (multi-faceted Rasch equivalent of Cronbach's alpha > 0.90[174] High interrater reliability ($r \geq 0.90$)[175] High test-retest reliability ($r \geq 0.90$)[176] **Validity:** Construct validity in a sample of people living with HIV[177] Numerous studies demonstrating cross-cultural validity.

5.8.2 – Coping Response

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
Brief COPE Scale[178,179]	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 ≥ 0.50) among the general population. **Validity:** Construct validity demonstrated among the general population[178]

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)[180]	Generic Descriptive	Self-reported questionnaire 20 items 8 domains	**Reliability**: high internal reliability (α ≥ 0.85) and adequate test-retest reliability on a general adult population. **Validity**: Concurrent construct validity on a general adult population. Demonstrated predictive construct validity and high internal consistency reliability on a population with Hepatitis C.[181]

5.8.4 – Fatigue

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
HIV Fatigue Scale[182]	HIV-specific Descriptive	Self-reported questionnaire 56 items 3 domains	**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. **Validity:** Good convergent construct validity among people living with HIV-related fatigue.[183]

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)[184]	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**: responsive to change among adults living with HIV.[185]
Medical Outcomes Study Short Form (SF-36) Questionnaire[186,187]	Generic Descriptive	Self-reported questionnaire 36 items 8 domains and 2 summary scores (physical component and mental component, summary scores)	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.[188,189]
Medical Outcomes Study-HIV Health Survey (MOS-HIV)[190,191,192]	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.[191,193]
Multidimensional QOL Questionnaire for HIV/AIDS (MQoL-HIV)[194]	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. **Responsiveness:** Responsive to change in a 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.[193]
WHO QOL-HIV[195,196]	HIV-specific Descriptive	Self-reported questionnaire 120 items 6 domains	**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. **Validity:** Good discriminant validity among people living with HIV in diverse cultural settings.[196,197]
Patient Reported Outcomes Quality of Life-HIV (PROQOL-HIV) Questionnaire[198,199]	HIV-specific Descriptive	Self-reported questionnaire 43 items 8 domains and 1 global health item	**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). **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.

5.8.6 – Presence and bothersome nature of symptoms

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
HIV Symptom Index[200]	HIV-specific Descriptive	Self-reported questionnaire 20 items No domains	**Validity:** Good construct validity among people living with HIV on combination antiretroviral therapy.[200]

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)[201]	HIV-specific Descriptive	Self-reported questionnaire 8 items 1 domain	**Reliability:** Good internal consistency reliability with Cronbach's alpha 0.78 with adults (primarily men) living with HIV. **Validity:** Construct validity demonstrated in adults living with HIV with correlations to criterion measures of HRQL and depression ranging from 0.37-0.66.[201]

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)[202]	Specific to chronic disease Descriptive	Self-reported questionnaire 19 items 5 domains	**Reliability:** High internal consistency reliability (Cronbach's alpha ≥ 0.90) among people living with HIV. **Validity:** Convergent and discriminant construct validity demonstrated among people living with HIV.

5.8.9 – Stigma

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
HIV Stigma Scale[203]	HIV-specific Descriptive	Self-reported questionnaire 40 items 4 domains	**Reliability:** Good internal consistency reliability (Cronbach's alpha ≥ 0.90 for subscales and 0.96 for the summary scale) among people living with HIV. **Validity:** Construct validity in a sample of people living with HIV.

5.8.10 – Stress

Measure (Authors, Year)	Generic vs Specific, Purpose	Administration, Number of Items, Number of Domains	Measurement Properties
HIV Stress Scale[204]	HIV-specific Descriptive	Self-reported questionnaire 29 items 3 domains	**Validity:** Convergent construct validity among men living with HIV.[204]

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