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

Table of Contents

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.[1, 2] 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.[3]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”.[4]

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[5]
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[6]
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.[7]

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[7]
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.[8]

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.[8]

Children may present with numbness, burning and tingling sensations in their feet. They may have decreased sensation and reduced or abnormal ankle reflexes.[9] 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[10]
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 [11]
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[13]
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

	Rhythm disturbances	symptoms persist
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.[14]

A common form of pneumonitis in children is **lymphoid interstitial pneumonia (LIP)**, a chronic disease characterized by spontaneous exacerbations, intermittent wheezing, and chronic cough.[15] 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[16]
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.[17]

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	• 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

	degeneration from white matter disease Stroke Spinal cord infections (e.g., CMV, HSV) Malignancies (e.g., lymphoma)	Problems of Limited Mobility • 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.[19] 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.[20] 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.[21, 22]

Regular exercise is widely accepted as an important part of optimal health.[23] 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,[24, 25, 26, 27] 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.[28] 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.[29] 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.[30]

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.[31, 32, 33]

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.[30] Unfamiliarity and the associated stigma of HIV make adherence to antiretroviral regimens in youth with behaviourally acquired HIV a challenge.[30]

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.[30]

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.[34] 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.[34] 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.[34]

References

[1]Devendra A, Makawa A, Kazembe P, Calles N, Kuper H. HIV and Childhood Disability: A Case-Controlled Study at a Paediatric Antiretroviral Therapy Centre in Lilongwe, Malawi. PLOS One. 2013;8(1): e84024

[2]Knox J, Arpadi S, Kauchali S, Craib M, Kvalsig J, Taylor M, Bah F, Mellins C, Davidson L .2018 Screening for developmental disabilities in HIV positive and HIV negative children in South Africa: Results from the Asenze Study. PLOS One. 2018;13(7).

[3]Worthington C, Myers T, O'Brien K, Nixon S, Cockerill R. Rehabilitation in HIV/AIDS: development of an expanded conceptual framework. AIDS Patient Care STDS. 2005 Apr;19(4):258-71. PubMed PMID: 15857198. http://www.ncbi.nlm.nih.gov/pubmed/15857198.

[4]Details of the resolution: http://www.who.int/classifications/icf/whoficresolution2012icfcy.pdf?ua=1

[5, 6, 10, 11, 13, 16]Choice of rehabilitation interventions will depend on patient assessment and available resources.

[7]Dashefsky B, Wald E. 1994. Otitis Media and Sinusitis in Patients with HIV Infection. In Pediatric AIDS: the challenge of HIV infection in infants children and adolescents. 2nd edition. Edited by Pizzo P and Wilfert C. Williams and Wilkins

[8]Peters R, Van Ramshorst M, Struthers H, McIntyre J. Clinical assessment of peripheral neuropathy in HIV-infected children on antiretroviral therapy in rural South Africa. European Journal of Pediatrics. 2014; DOI 10.1007/s00431-014-2303-9

[9]Sankhyan N, Lodha R, Sharma S, Menon P, Choudhary A, Kabra S, Gulati S. Peripheral neuropathy in children on Stavudine therapy. Indian Journal of Pediatrics. 2014; DOI 10.1007/s12098-014-1477-5

[12]Dadlani G and Lipshultz S. 2005. Cardiac problems. In :Textbook of Pediatric HIV Care edited by Zeichner S and Read J. Cambridge

[14]Da Cunha NCP, Potterton JL, Humphries CRM. Burden of Respiratory Disease Among Paediatric Patients Infected with HIV. The South African Journal of Physiotherapy. WITS Special edition. 2013; 36-41.

[15]Zar H. Chronic Lung Disease in Human Immunodeficiency Virus (HIV) infected children Pediatric Pulmonology. 2008;43:1-10.

[17]Dreimane D and Geffner M. 2005. Endocrine Disorders. In: Textbook of Pediatric HIV Care. Edited by Zeichner S and Read J. Cambridge

[18] Naik T, Potterton J, Humphries C, Firth G 2018 A comparison of HIV infected to uninfected children with spastic diplegia in South Africa. Vulnerable Children and Youth Studies DOI:10.1080/ 17450128.2017.1417657

[19]Blauvelt A. 2005. Cutaneous diseases. In: Textbook of Pediatric HIV Care. Edited by Zeichner S and Read J. Cambridge

[20]Botros D, Somarriba G, Neri D, Miller TL. Interventions to address chronic disease and HIV: strategies to promote exercise and nutrition among HIV-infected individuals. Curr HIV/AIDS Rep. 2012 Dec;9(4):351-63. doi: 10.1007/s11904-012-0135-7. Review. PubMed PMID: 22933247; PubMed Central PMCID: PMC3492509.

[21]Garber CE, Blissmer B, Deschenes MR, Franklin BA, Lamonte MJ, Lee IM, Nieman DC, Swain DP: American College of Sports Medicine position stand. Quantity and quality of exercise for developing and maintaining cardiorespiratory, musculoskeletal, and neuromotor fitness in apparently healthy adults: guidance for prescribing exercise. Med Sci Sports Exerc 2011, 43:1334-1359.

[22]World Health Organization (WHO). Health Topics: Physical Activity [http://www.who.int/topics/physical_activity/en/] n.d. Accessed Jan 10, 2015.

[23]Stuart M, Chard S, Benvenuti F, Steinwachs S. Community exercise: a vital component to healthy aging. Healthc Pap. 2009;10(1):23-8; discussion 79-83. Review. PubMed PMID: 20057213. http://www.ncbi.nlm.nih.gov/pubmed/20057213.

[24]Maharaj SS, Chetty V. Rehabilitation program for the quality of life for individuals on highly active antiretroviral therapy in KwaZulu-Natal, South Africa: a short report. Int J Rehabil Res. 2011;34:360-365.

[25]Roos R, Myezwa H, van Aswegen H, Musenge E:. Effects of an education and home-based pedometer walking program on ischemic heart disease risk factors in people infected with HIV: a randomized trial. J Acquir Immune Defic Syndr. 2014;67:268-276.

[26]Mutimura E, Stewart A, Crowther NJ, Yarasheski KE and Todd Cade W. The effects of exercise training on quality of life in HAART-treated HIV-positive Rwandan subjects with body fat redistribution. Quality of Life Research. 2008a: 17: 377–385.

[27]Mutimura E, Crowther NJ, Todd Cade W, Yarasheski KE, and Stewart A. Exercise reduces central adiposity and improves metabolic indices in HAART-treated HIV-positive subjects in Rwanda: a randomized controlled trial. AIDS Research. 2008b:24: 5-23.

[28]O'Brien KK, Tynan AM, Nixon SA, Glazier RH. Effectiveness of Progressive Resistive Exercise (PRE) in the context of HIV: systematic review and meta-analysis using the Cochrane Collaboration protocol. BMC Infect Dis. 2017 Apr 12;17(1):268. doi: 10.1186/s12879-017-2342-8. Review. PubMed PMID: 28403830; PubMed Central PMCID: PMC5389006.

[29]Jalloh MA, Gregory PJ, Hein D, Risoldi Cochrane Z, Rodriguez A. Dietary supplement interactions with antiretrovirals: a systematic review. Int J STD AIDS. 2017 Jan;28(1):4-15. doi: .1177/0956462416671087. Epub 2016 Sep 27. Review. PubMed PMID: 27655839.

[30]Spiegel HM, Futterman DC. Adolescents and HIV: prevention and clinical care. Curr HIV/AIDS Rep. 2009 May; 6(2):100-7.

[31]Hazra, R., Siberry, G.K., and Mofenson, L.M. Growing Up with HIV: Children, Adolescents, and Young Adults with Perinatally Acquired HIV Infection. Annual Review of Medicine. 2010;61(1), pp.169–185.

[32]Lowenthal, E.D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., and Ferrand, R.A. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. Lancet Infectious Diseases. 2014;14, pp.629–39.

[33]Sohn, A.H. and Hazra, R. The changing epidemiology of the global paediatric HIV epidemic: keeping track of perinatally HIV-infected adolescents. Journal of the International AIDS Society. 2013;16(1), p.18555.

[34] Fair CD, Sullivan K, Gatto A. Best practices in transitioning youth with HIV: perspectives of pediatric and adult infectious disease are providers. Psychology, Health & Medicine 2010;15:414-29.