

realize

FOSTERING
POSITIVE CHANGE
FOR PEOPLE LIVING
WITH HIV AND OTHER
EPISODIC DISABILITIES

E-MODULE FOR EVIDENCE-INFORMED HIV REHABILITATION

(E-Module)

2020

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E-Module for Evidence-Informed HIV Rehabilitation (E-module)

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The opinions expressed in this publication are those of the authors and do not necessarily reflect the views of the Public Health Agency of Canada.

Disclaimer:

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

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Realize is a national multi-sector, multi-disciplinary, charitable organization of stakeholders involved in rehabilitation in the context of HIV. *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.

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PREFACE

Introduction

With many people with HIV living longer, facing a multitude of health challenges related to HIV, concurrent health conditions, and side effects of treatment, the role of rehabilitation in the context of HIV continues to grow. This E-Module for Evidence-Informed Rehabilitation (e-module) is a comprehensive resource for rehabilitation professionals to respond to the increasing role of rehabilitation in the context of HIV.

This e-module is an update of "A Comprehensive Guide for the Care of Persons with HIV Disease (Module 7)", originally published in 1998 by Health Canada and the Wellesley Central Hospital, Toronto, Canada. The changing profile, emerging issues and new evidence related to HIV and rehabilitation prompted *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) to update this important resource for rehabilitation professionals so that they may better address the current needs of people living with HIV.

Rehabilitation Audience

In this e-module, *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) broadly defines rehabilitation as any services or providers that may address or prevent symptoms and impairments, activity limitations and social participation restrictions experienced by an individual (Worthington et al. 2005). Hence, while the e-module is primarily intended for rehabilitation professionals, other audiences may include other health and social service providers and people living with HIV.

Development of the E-Module

The aim of this e-module is to enhance knowledge about HIV care among rehabilitation professionals so they may better address the needs of people living with HIV. Development of this document involved a multi-staged and interdisciplinary process, led by *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation). Notable characteristics of this e-module include the comprehensive review and incorporation of current best evidence on HIV and rehabilitation and the interdisciplinary approach to its development. This document resulted from 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 psychiatry), nursing, occupational therapy, psychology, physical therapy, speech-language pathology, social work, , midwifery, and policy.

Through the leadership of *Realize* , the e-module team collectively authored, reviewed and revised the document at multiple stages to ensure the content was comprehensive, relevant, readable and applicable for rehabilitation professionals and HIV care. We gratefully acknowledge the financial support for the development of this e-module from the Ontario Ministry of Health and Long-Term Care and the Public Health Agency of Canada.

Content

We made a number of revisions to this e-module, building on the original Module 7. We updated sections with current best evidence on HIV and rehabilitation, removed out-of-date sections from the original module, and added content to address current and emerging issues in HIV and rehabilitation. New sections of the e-module worthy of highlighting include aging and concurrent health conditions, cognitive rehabilitation, evidence-informed rehabilitation interventions, information on accessing rehabilitation and advocacy. Another novel component of the e-module includes six comprehensive case studies developed to facilitate learning through the practical application of knowledge in complex clinical scenarios. Case studies include guiding questions to promote critical thinking among rehabilitation professionals about assessment, analysis and treatment interventions that can be addressed independently or as a group. Guiding questions include discussion notes with embedded links that will direct the reader to applicable sections in the e-module that are addressed in each case.

This E-Module for Evidence-Informed Rehabilitation is divided into eight chapters. Chapter 1 includes an introduction that reviews current approaches to HIV and rehabilitation, HIV pathogenesis, and epidemiology, interacting with communities affected by HIV, and rehabilitation, including traditional rehabilitation professionals (physical therapy, occupational therapy, speech-language pathology and psychiatry), complementary and alternative medicines and therapies, vocational rehabilitation, and psychological rehabilitation. Chapter 2 provides an overview of best practices in rehabilitation. Chapter 3 describes the symptoms and impairments associated with HIV and interventions to address them. Chapter 4 provides an overview of the systemic impacts of HIV. Chapter 5 is dedicated to paediatrics. Chapter 6 provides an overview of interventions (both pharmacological and non-pharmacological) including exercise, modalities, vocational rehabilitation, and self-management. Chapter 7 describes issues related to HIV and rehabilitation such as access to care, advocacy, research priorities, and provides additional resources on national rehabilitation and consumer

organizations. Chapter 8 includes six case studies that encourage the integration of the e-module content and problem solving around practical scenarios that rehabilitation professionals may face in clinical practice. Red flags throughout the e-module highlight important clinical symptoms that indicate the need for immediate referral to a physician.

How to Use the E-Module

While the e-module can be read sequentially from start to finish, the online format allows readers to navigate and seek out specific sections of this resource, depending on their individual learning needs and areas of interest. Links to additional resources on topics addressed in the e-module are interspersed throughout so that readers can immediately access further information.

E-Module for Sub-Saharan Africa

The free website, entitled "How Rehabilitation Can Help People Living with HIV in Sub-Saharan Africa: An Evidence-Informed Tool for Rehab Providers", was adapted from the 2013 and 2014 versions of this E-Module and is also downloadable for use on paper.

<http://ssa.hivandrehab.ca/>

It is designed to be a one-stop resource for physiotherapists, occupational therapists and other health workers who can quickly and easily research the most common HIV-related disabilities, and find evidence-based rehabilitation solutions. Development of this resource was led by Dr. Stephanie Nixon, Director of the International Centre for Disability and Rehabilitation at the University of Toronto and *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation).

This innovation was funded by Grand Challenges Canada.

How to Cite

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Keeping the E-Module Current

The e-module was designed to be a living document, and it will be updated regularly. Updates are completed by a large team of volunteers who participate as content experts, advisory committee members, writers and reviewers. While we strive to modify key findings that may occur in several places throughout the e-module, readers are also asked to inform us when content between sections seems to be conflicted. For further information, to provide feedback, or to suggest updates for this e-module, please contact *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) at <http://realizecanada.org> or info@realizecanada.org.

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March 31, 2018

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ACRONYMS

Acronyms will be defined in each subsection to accommodate e-format. Acronyms will not be used in titles. Where the acronym long form only appears once in a section the long form will be maintained. Long form will not be used for Acquired Immunodeficiency Syndrome (AIDS) or Human Immunodeficiency Virus (HIV).

| | |
|---------------|--|
| Botox: | Botulinum toxin type A |
| BTA: | Botulinum toxin type A |
| cART: | Combination antiretroviral therapy |
| CAD: | Coronary Artery Disease |
| CAMT: | Complementary and Alternative Medicines and Therapies |
| CAS: | Canadian AIDS Society |
| CATIE: | Canadian AIDS Treatment and Information Exchange |
| CBHO: | Community-based HIV Organizations |
| CBT: | Cognitive Behaviour Therapy |
| CCAC: | Community Care Access Centres |
| CES-D: | Centre for Epidemiological Studies for Depression Scale |
| CMV: | Cytomegalovirus |
| CNIB: | Canadian National Institute for the Blind |
| CNS: | Central Nervous System |
| COPD: | Chronic Obstructive Pulmonary Disease |
| DHHS: | Department of Health and Human Services |
| DNA: | Deoxyribonucleic Acid |
| DOT: | Directly Observed Therapy |
| DSP: | Distal Symmetrical Polyneuropathy |
| EDEN: | Episodic Disabilities Employment Network |
| EBV: | Epstein-Barr Virus |
| FES: | Functional Electrical Stimulation |
| FET: | Forced Expiry Technique |
| GI: | Gastro-Intestinal |
| HAD: | HIV-Associated Dementia |
| HAART: | Highly Active Antiretroviral Therapy |
| HALS: | Highly Active Antiretroviral Therapy-Associated Lipodystrophy Syndrome |
| HAND: | HIV-Associated Mild Neurocognitive Disorder |
| HBV: | Hepatitis B Virus |
| HCV: | Hepatitis C Virus |
| HIV: | Human Immunodeficiency Virus |
| HIVAN: | HIV Associated Nephropathy |

| | |
|------------------|--|
| HIVE: | HIV Encephalopathy |
| HPV: | Human Papillomavirus |
| HRQL: | Health-Related Quality of Life |
| HSV: | Herpes Simplex Virus |
| IBS: | Irritable Bowel Syndrome |
| ICF: | International Classification of Functioning, Disability and Health |
| IDP: | Inflammatory Demyelinating Polyneuropathy |
| IDU: | Injection Drug Use |
| IFC: | Interferential Current |
| IPV: | Intimate Partner Violence |
| IRIS: | Immune Reconstitution Inflammatory Syndrome |
| IUD: | Intrauterine Device |
| KS: | Kaposi's Sarcoma |
| LBP: | Low Back Pain |
| LIP: | Lymphocytic Interstitial Pneumonitis |
| MAC: | Mycobacterium Avium Complex |
| MDC: | Minimal Detectable Change |
| MCID: | Minimal Clinically Important Difference |
| MI: | Myocardial Infarction |
| MTCT: | Mother-to-Child Transmission |
| N/NRTI: | Nucleoside/Nucleotide Reverse Transcriptase Inhibitor |
| NNRTI: | Non-Nucleoside Reverse-Transcriptase Inhibitor |
| NRRTS: | National Registry of Rehabilitation Technology Suppliers |
| NSAID: | Non-Steroidal Anti-inflammatory Drug |
| OHL: | Oral Hairy Leukoplakia |
| OT: | Occupational Therapist |
| PCNSL: | Primary Central Nervous System Lymphoma |
| PCP: | Pneumocystis Carinii Pneumonia |
| PCP: | Phencyclidine |
| PEP: | Post-Exposure Prophylaxis |
| PEP mask: | Positive Expiratory Pressure Mask |
| PML: | Progressive Multifocal Leukoencephalopathy |


| | |
|---|---|
| PNF: | Proprioceptive Neuromuscular Facilitation |
| PSE: | Progressive Subacute Encephalopathy |
| PSMP: | Positive Self-Management Program |
| PT: | Physical Therapist/Physiotherapist |
| QOL: | Quality of Life |
| RCT: | Randomized Controlled Trial(s) |
| RNA: | Ribonucleic Acid |
| SD: | Sexual Dysfunction |
| SF-36: | SF-36 Quality of Life Questionnaire |
| SLT/ SLP: | Speech-Language Therapist/Speech-Language Pathologist |
| SSRIs: | Selective Serotonin Reuptake Inhibitors |
| STI: | Sexually Transmitted Infection |
| TB: | Tuberculosis |
| TENS: | Transcutaneous Electrical Nerve Stimulation |
| VZV: | Varicella-Zoster Virus |
| WHO: | World Health Organization |
|  | Red flags located throughout this module highlight particularly important clinical symptoms that indicate the need for immediate direct contact with a physician. |

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CHAPTER 1

Introduction

1_1 Introduction

1.1.1 Current Approaches to HIV and Rehabilitation

1.1.1.1 Realize (formerly the Canadian Working Group on HIV and Rehabilitation)

HIV disease is now considered chronic and cyclical, with periods of wellness and illness. HIV is a complex and multi-systemic disease affecting the cardiorespiratory, neurological and musculoskeletal systems of the body. This situation provides multiple opportunities for disease prevention and rehabilitation interventions.

By the turn of the 21st century, treatment advances improved survival for people living with HIV who had access to care. As a result, health professionals, researchers, and activists turned to rehabilitation and disablement frameworks for insight into how to reconceptualize HIV and its treatment. The World Health Organization's (WHO's) International Classification of Functioning, Disability and Health (ICF 2001) was developed out of previous international work and provided a framework that could highlight the health-related challenges related to living with HIV at the level of the body structure or function (e.g. painful knee or congested lungs), the level of the individual (e.g. difficulty walking or getting dressed), and the level of involvement in life situations (e.g. difficulty with one's job or in parenting roles) (Nixon and Cott 2000). This framework provided the basis for both programming and policy advocacy.

A 2004 survey documented a 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 (Rusch et al. 2004). Results highlighted the role for rehabilitation to respond to the health-related needs of people living with HIV.

Realize (formerly the Canadian Working Group on HIV and Rehabilitation) was founded in 1998 by HIV activists, rehabilitation providers, government policy makers and representatives from the insurance industry to examine and respond to the emerging needs of people living with HIV in this new context (www.hivandrehab.ca). Guided by the ICF framework, *Realize* has four main strategic directions that

encompass four key areas of research, education, policy and practice. Example activities include engaging in research addressing the key research priorities in HIV and rehabilitation, HIV education and mentorship for current and future rehabilitation professionals, and issues surrounding labour force and income support for people with episodic illnesses.

Definition of Rehabilitation:

Realize defines rehabilitation as any services or activities that address or prevent body impairments, activity limitations, and social participation restrictions experienced by an individual (Worthington et al. 2005).

Rehabilitation professionals may include occupational therapists, physical therapists, speech-language pathologists, and physiatrists. Types of rehabilitation professionals are described in [Section 1_3](#). However, there are some providers who may be involved in the broader delivery of rehabilitation services. In the context of this module, these individuals are termed rehabilitation providers and may more broadly include individuals who work in community-based organizations, other health professionals (e.g. physicians, massage therapists, social workers, chiropractors), counsellors, family members, care providers, and others.

In 2005, Worthington et al. advanced the conceptualization of rehabilitation in the context of HIV based on the ICF (Worthington et al. 2005). The HIV Rehabilitation Conceptual Framework heightens the understanding of rehabilitation domains, services and issues in the context of HIV (Worthington et al. 2005). Using the ICF, the framework outlines the multiple life domains affected by HIV and associated treatments, provides a working definition of rehabilitation in the context of HIV (see above), and highlights the expanded role that health providers and services have in the rehabilitation of people living with HIV, including their role in enhancing their participation in the labour force and overall social participation.

1.1.1.2 A New Concept - Episodic Disability

Along with advocacy efforts geared specifically at HIV, *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) also brought together individuals and organizations from other disease groups who were facing similar concerns. For example, those living with multiple sclerosis or arthritis may experience similar types of disablement in an episodic way. An early outcome of this

initiative was the creation of a model that helped identify areas of shared concern across the groups and sparked the notion of "episodic disability".

The model uses medical diagnoses as the basis for illustrating the intersection of issues related to HIV; "permanent" or static disability; and "episodic" disability, which refers to experiences of disablement that are unpredictable and/or intermittent.

Recognition of the unpredictable nature of living with HIV has proven to be a crucial milestone in the Canadian context for advancing policy advocacy. *Realize* has coordinated ongoing efforts in this area. These activities include the development of the Statement of Common Agenda on Episodic Disabilities, joint meetings with government representatives and decision makers involved in income support and employment programs and a national multi-sectoral summit on episodic disabilities in 2006 (<http://www.realizecanada.org/en/our-work/episodic-disabilities/>).

1.1.1.2.1 Episodic Disability in the Context of HIV

The concept of disability was further explored from the perspective of adults living with HIV. O'Brien and colleagues conducted a series of focus groups and interviews with adults living with HIV asking them to describe their health-related challenges living with HIV (O'Brien et al. 2008, O'Brien et al. 2009). Participants perceived disability as multi-dimensional and episodic, characterized by periods of wellness and illness. Participants felt the term disability itself suggested permanency in contrast to their experiences living with the fluctuating periods of health. However, participants recognized the importance of the term disability, which often was required to access crucial social services and supports. As a result, the term, "episodic disability", emerged as a more accurate framing of the variable health-related consequences experienced by adults living with HIV. Episodic disability is reflected in the resultant title of the Episodic Disability Framework (O'Brien et al. 2008).

1.1.1.2.2 The Episodic Disability Framework

The Episodic Disability Framework is a conceptual framework that describes disability experienced by adults living with HIV (O'Brien et al. 2008, O'Brien et al. 2009). Episodic disability is defined as any symptoms and impairments, difficulties carrying out day-to-day activities, uncertainty and worrying about the future and challenges to social inclusion that may fluctuate on a daily basis and over the continuum of living with HIV.

This framework includes three components:

- Dimensions of disability.
 - Dimensions of disability include symptoms and impairments (e.g. physical, mental and emotional health challenges), difficulties carrying out day-to-day activities (e.g. household chores), uncertainty and worrying about the future and challenges to social inclusion (e.g. employment, personal relationships, fulfilling role as parent) that may fluctuate on a daily basis and over the continuum of living with HIV.
- Contextual factors that may exacerbate or alleviate dimensions of disability.
 - Extrinsic contextual factors include social support (support from friends, family, partners, pets and community, support from healthcare services and personnel, and program and policy support) and stigma.
 - Intrinsic contextual factors include living strategies (seeking social interaction with others, maintaining a sense of control over life and the illness, "blocking HIV out of the mind", and adopting attitudes and beliefs to help manage living with HIV) and personal attributes (gender and aging).
- Triggers that are life events that can mark a major or momentous episode of disability
 - Examples of triggers include receiving an HIV diagnosis, starting or changing medications, experiencing a serious illness and suffering a loss of others (O'Brien et al. 2008, O'Brien et al. 2009).

The framework acknowledges the daily fluctuations (or good days and bad days) that a person might experience, such as fluctuations in fatigue, weakness, or diarrhea, superimposed on the major fluctuations in health. The framework suggests that each individual with HIV has his or her own disease course. The Episodic Disability Framework considers the variable nature of disability, acknowledges uncertainty as a key component, describes contextual factors that influence experiences of disability, and considers life events that may initiate a major or momentous episode. This framework can be used as a way to describe disability experienced by adults living with HIV (O'Brien et al. 2008).

Episodic disability has been the basis for several practical applications. First, the identification of policy models that promote more flexible income support and employment programs thereby enabling people with episodic illnesses to work when their health permits, without losing their income support or health benefits if they get sick again. Similarly, the programs aim to help people work part-time on an ongoing basis combined with partial disability income support.

A second application has been the development of educational programs for employers, human resource professionals and vocational counsellors focused on accommodation of people with episodic illnesses in the workplace. This framing has also led to the development of new models of care for people with episodic illnesses whose health status and healthcare needs, by the very nature of their disease process, tend to fluctuate.

As people living with HIV who have access to antiretroviral therapy live longer, the long-term impacts of HIV and its treatments, in combination with aging itself, may include an increased prevalence of concurrent conditions, such as arthritis, fractures from osteoporosis, diabetes, some forms of cancer, and depression or other mental illnesses (Ernst et al. 2008, Kendall et al. 2014).

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 corresponding need for rehabilitation is expanding to prevent or manage such disabling impacts and maintain or promote improved quality of life.

1.1.1.3 Contributions of Rehabilitation to HIV Treatment

Advances in knowledge and expertise, combined with the development of potent antiretroviral drug combinations and better surrogate markers, have dramatically altered the course of HIV infection. Some people living with HIV have experienced marked clinical improvement and increased longevity. The focus on quality of life has become greater than ever.

Rehabilitation can assist people living with HIV in managing disablement such as adverse effects of medications; fatigue, pain, neuropathy, cognitive problems and issues related to income and vocational support. Rehabilitation providers are already familiar with treating many of the common conditions seen in HIV disease. These include pain, fatigue, weight loss, weakness, breathing problems, cognitive problems, peripheral neuropathies, and other central nervous system conditions. Effective HIV care and treatment should address the needs of the individual. In addition, care and treatment should also address the needs of the individual's family, friends, and community.

Delivery of comprehensive HIV care necessitates that the individual is the focus of the care that may be provided by a wide range of professional and non-professional care providers. Evidence-informed treatment options are discussed in [Section 6](#). The approach of rehabilitation providers to client-centred care is compatible with the needs of people living with HIV. *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) provides

expertise and training to rehabilitation providers and other stakeholders while furthering practice, policy, research and education initiatives in HIV and rehabilitation.

Despite the need for rehabilitation, few rehabilitation professionals work with people living with HIV. A Canadian survey documented only 39% of rehabilitation professionals had knowingly worked with people living with HIV (Worthington et al. 2008). Many respondents felt they needed specific knowledge and training in HIV to adequately serve this population.

Hence, the goal of this module is to help bridge this gap and to help increase knowledge among rehabilitation professionals and providers on HIV and to build capacity for rehabilitation professionals to better address the health-related challenges of people living with HIV.

1.1.2 Pathogenesis of HIV Infection

1.1.2.1 HIV Transmission

HIV transmission may occur through several circumstances, and the probability of transmission varies significantly (Aberg et al. 2009). One of the most significant roles of rehabilitation professionals is to provide education to clients as to the modes and means of preventing HIV transmission. It should be noted that transmission through an occupational exposure is rare and rehabilitation providers should be knowledgeable about this. [Section 7.4](#) outlines the risk of exposure as well as guidelines on preventing exposure. The most effective protective measure is the use of universal precautions, which includes a barrier device whenever contact with infectious fluids is anticipated.

1.1.2.1.1 Unprotected Sexual Activities

Unprotected sexual activities include those without a condom or barrier device either through engaging in vaginal, anal or oral intercourse and can include the use of sex toys not cleaned between partners. Condoms have been reported to significantly reduce the risk of transmission when used properly, but have not been shown to eliminate the risk. This is why sex with a condom is referred to as safer sex, not safe sex. According to one systematic review, consistent use of condoms resulted in 80% reduction in HIV incidence between heterosexual serodiscordant couples (of differing HIV status), when condoms were used for all acts of penetrative vaginal intercourse. Because the studies used in the review did not report on the "correctness" of use, namely whether condoms were used correctly and perfectly for each and every act of intercourse, effectiveness, rather than efficacy, is estimated. Also, the estimate refers to the male condom in general (and not specifically to latex condoms) due to differences in reporting between studies (Weller and Davis-Beaty 2002).

Current estimates for risk of infection by male-to-male receptive anal intercourse has been estimated to be as high as 1 in 10, by male-to-female vaginal intercourse has been estimated to be as high as 1 in 200, and by female-to-male vaginal intercourse has been estimated to be as high as 1 in 700 (Aberg et al. 2009).

1.1.2.1.2 Shared Needles or Equipment

Injection drug use (IDU) can transmit HIV. When people inject drugs, some blood is pulled back into the needle and syringe. If the equipment is shared, that blood is then shot into the bloodstream of the next person using the needle. Current estimates for transmission rates by needle sharing is estimated to be 1 in 150 (Aberg et al. 2009).

According to the Canadian AIDS Society (CAS), heroin has traditionally been the focus of discussions around injection drug use. However, in many cities within Canada, cocaine has become the drug of choice. This shift brings with it a new set of problems. Not only does cocaine attract a broader range of users, but people who use cocaine tend to inject far more frequently, increasing both health and safety concerns. Another factor affecting the spread of HIV in the context of shared needles or equipment is that unsafe sex, the primary cause of HIV infection, is more likely to occur when a person is under the influence of drugs. The use of shared needles does not occur only among people who use injection drugs. Unsterilized needles for tattooing, skin piercing or acupuncture also carry a risk for transmission. It is also important to note that when drugs such as cocaine, heroin or steroids are shared, invisible amounts of blood are transmitted in syringes, water for diluting drugs, cotton filters and straws of pipes (<https://www.avert.org/hiv-transmission-prevention/injecting-drugs>).

1.1.2.1.3 Mother-to-Child Transmission

Mother-to-child transmission, also referred to as vertical transmission or perinatal transmission, is the transmission of HIV from an HIV positive pregnant woman to her fetus or newborn child. Infection can occur during the gestation period (in utero), during delivery (due to fetal contact with maternal blood and mucosa in the birth canal) and with breastfeeding. In the absence of any intervention, an estimated 15% to 30% of women with HIV infection will transmit HIV during pregnancy or delivery, and 10% to 20% will transmit the virus to their newborn via breast milk (World Health Organization 2006). Transmission can be significantly reduced with the use of antiretroviral therapies. Recent cohort studies of non-breastfeeding women confirm that full-course combination antiretroviral therapy reduces rates of mother-to-child transmission to less than 2.5% (Chou et al. 2012).

1.1.2.1.4 Occupational Exposure

In healthcare settings, occupational exposure occurs when the HIV virus enters a healthcare worker's bloodstream. For this reason, care is needed when handling equipment and client body fluids. Used needles should be disposed of in an appropriate receptacle without any attempt to recap them. In the case of a significant occupational exposure (e.g. a needle-stick injury from a large needle arising from the vein or artery of a person known to be infected with HIV), immediately washing the area with warm soapy water and going directly to the emergency department is recommended. Significant exposure may require post-exposure prophylaxis in the form of antiretroviral treatment. Transmission by occupational needle stick exposure has been estimated to be 1 in 300 (Aberg et al. 2009).

When working with people living with HIV, standard precautions should be used regardless of serostatus; whether a person tests positive or negative for markers of HIV in their blood. These precautions require frequent hand washing in between all client interactions. 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. It is important to be aware that improper use of protective wear can send a message about transmission risk that is incorrect and inappropriate. It is important to note that outside of the body, HIV is a fragile virus and is not stable. Consequently, it does not survive for very long. HIV does not live on environmental surfaces. Thus, with blood spills, the virus is quickly inactivated and can be cleaned with soapy water. A good rule of thumb to remember about HIV transmission is "if it dries; it dies" (Benn et al. 2011). However, it is very important to remember that there are other blood-borne pathogens that last longer outside the body, such as Hepatitis C.

1.1.2.1.5 Blood and Blood Products

A current estimate of rates of infection by transfusion with contaminated blood or blood products is about 95 in 100 cases (Aberg et al. 2009). Since 1985, Canadian blood services have been conducting screening measures to test for HIV antibodies present in donated blood. As a result, blood and blood products now pose a theoretical risk. Screening includes both blood testing and interviews with donors to identify those who may pose a risk of transmission. It should also be noted that in some developing countries, the infection might occur through medical procedures.

1.1.2.2 Pathogenesis Once Transmission has Occurred

Once the human immunodeficiency virus (HIV) has entered the bloodstream, it attaches to cells bearing a CD4 receptor, especially lymphocytes and monocytes, and replicates in them. Due to initially unchecked viral replication in the

plasma, viral load rises to high levels. At this point, the virus disseminates into lymphoid tissue and other sites throughout the body. Within two to four weeks of exposure to HIV, between 50% and 90% of people experience an acute, short-lived viral-like illness resembling mononucleosis or the flu. This illness includes symptoms such as fever, fatigue, myalgia (aching muscles), headache, and rash. Many of these symptoms go unrecognized. Plasma viral load is often very high at this time. After this "seroconversion illness," the viral load drops to a certain level or "set point" which differs for each individual.

Initially, the immune system appears to contain the effects of the virus, but the relentless production of 10 billion new viral particles per day eventually overwhelms the body, and clinical manifestations occur. The virus destroys CD4 cells and progressively weakens the immune system. The CD4 lymphocyte count reflects the extent of immune depletion. Certain clinical symptoms and conditions can be anticipated at a low CD4 count.

An increase in CD4 count may occur after an individual starts effective antiretroviral therapy. However, this does not always imply the restoration of immune function.

1.1.2.2.1 Viral Load

Viral load is a surrogate marker that measures the amount of virus in plasma. The number in the HIV viral load test report indicates how many HIV viruses there are in each millilitre (ml or cubic centimetre) of blood. It reflects the amount of replicating virus and is used to predict the rate of progression of HIV disease. Viral load is also used to initiate, monitor, and change antiretroviral therapy. The goal of therapy is to reduce viral load to the lowest possible level for the longest possible time.

1.1.2.2.2 CD4 Count

Cells with CD4 receptors on their surface are the primary targets destroyed by HIV. CD4 is measured in cells per millilitre cubed (cells/mm^3) or cells/microLitre. A healthy, normal CD4 count level is between 500 to 1500 cells/mm^3 . CD4 receptor-bearing lymphocytes are measured and used to clinically stage the disease. The loss of CD4 lymphocytes and the rate of loss are associated with the development of characteristic opportunistic infections and malignancies resulting in the clinical manifestations of HIV. Most opportunistic infections occur at a CD4 lymphocyte count of fewer than 200 cells/mm^3 .

1.1.2.2.3 HIV Replication

Understanding the molecular structure of the virus and how it replicates is important because it provides the basis for understanding the nature and the development of drugs that are designed to disrupt the life cycle and thus prevent the spread of the virus. HIV has proteins on its envelope that

are strongly attracted to the CD4+ surface receptor on the outside of T-cells, the target of HIV. When HIV binds to a CD4+ surface receptor, it activates other proteins on the CD4+ cell's surface called coreceptor CXCR4 and CCR5 that allow the HIV envelope to fuse with the outside of the CD4+ cell. Once the HIV envelope has fused with the outside of the cell, the protein matrix, and HIV capsid (the inside of the virus which contains the Ribonucleic Acid (RNA) and important enzymes) is released into the host cell and immediately break down within the host cell's cytoplasmic environment.

The first of the HIV enzymes called Reverse Transcriptase begins to make a copy of the virus's RNA to form a double strand of Deoxyribonucleic Acid (DNA). This process is called "reverse transcription". The new DNA is called "proviral DNA". The proviral DNA is then carried to the CD4 cell's nucleus to meet with the CD4+ cell's own DNA. The second viral enzyme, called "integrase", begins a process known as integration, by hiding the proviral DNA into the cell's DNA. Once the proviral DNA and the cell's own DNA have been combined, the newly formed viral DNA begins the process of "transcribing" viral RNA. The viral RNA then migrates out of the nucleus and back into the CD4+ cell's cytoplasm. There, new viral proteins are built using the viral RNA as a blueprint. More specifically, the RNA is translated into viral proteins using the host's ribosomes, amino acids, and cellular machinery to make these building blocks that can then self-assemble into new virus particles. It is here where the viral RNA and the viral proteins are met by the third key enzyme called "protease." This enzyme packages new viral particles and releases the new virus back into circulation outside of the host cell.

1.1.2.2.4 Surrogate Markers

Because CD4 cells are the targets of HIV, CD4 count is the most important surrogate marker for health status. The CD4 count indicates how healthy the body's immune system is and indicates how much damage the HIV virus has done to the immune system. The CD4 cell count is the strongest predictor of disease progression and is the most important surrogate marker for health status, particularly in drug naïve clients. The CD4 count is an absolute number and may not be a very accurate measure if taken at a single point in time because is influenced by a number of factors and can be variable depending on stressors, illness, time at which was measured and other issues. Therefore, the trend in CD4 measurements is particularly relevant.

CD4 fraction or CD4 percentage is another test used as a health indicator and reflects the number of CD4 cells expressed as a percentage of the total number of lymphocytes. The CD4 percentage is correlated with CD4 counts and is most important if the percentage of CD4 cells drops below 15% when the absolute CD4 counts are between 200 to 350 cells/mm^3 in the absence of AIDS-defining illnesses. In this CD4 count range, a CD4

percentage below 15% is significantly associated with a higher relative risk for mortality and therefore may indicate the need for initiating antiretroviral treatment (Moore et al. 2006).

Viral load reflects how active the virus is within the body. The HIV viral load test measures the amount of HIV virus in the blood. It does not count the virus itself but measures the materials from the virus that are released into the blood when the virus reproduces. The higher the viral load, the more viral reproduction is taking place, and the more active the disease.

Currently, the HIV viral load test measures the number of HIV viruses in ranges from 50 to 500,000 in each ml of blood. If there are fewer than 50 HIV viruses in each ml of blood, the report will say that the viral load is "undetectable." This does not mean that there is no circulating HIV in the blood, and it does not mean that a person is cured of HIV. In fact, the HIV virus can still be found in other places in the body that cannot be as easily measured as in the blood (e.g. in the lymphatic system, organs, brain). The international studies, PARTNER and HPTN 052 published their results showing that there was no sexual transmission of HIV between serodiscordant partners, when the partner living with HIV was on treatment and had an undetectable viral load. The Consensus Statement of the Prevention Action Campaign, an international coalition of HIV activists and researchers states that there is now robust evidence to conclude that "U=U" ("undetectable = untransmittable"). The risk of HIV transmission to a sex partner from a person living with HIV, who is on antiretroviral therapy and has achieved an undetectable viral load in their blood for at least 6 months, is negligible to non-existent. U=U has been endorsed by 990 organizations from over 100 countries.

1.1.2.2.5 Generalized Course of HIV Infection

When a person first becomes infected it is called viremia, which is a term applicable to all viral infections. During this initial phase, the virus is replicating rapidly because the immune system has not had time to mount a response. It is commonly marked by flu-like symptoms. A person who is HIV positive is most infectious soon after contracting the virus, in the primary phase of HIV infection when the virus is very actively replicating. 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 natural immune response, and the viral load will drop. This phase, when the body begins to produce antibodies, is known as seroconversion. Since HIV tests are designed to detect circulating antibodies as evidence of HIV presence, it is post-seroconversion that a person will be found to have a positive HIV test. Simultaneously, T-helper cell numbers will attempt to recover, and a person may enter a period of relatively stable health.

The battle wages on over time between the virus and the immune system and can last for several years. During this time, people may not show any signs of being infected. This phase, known as clinical latency, can be variable in length. Clinical latency is dependent on a number of factors such as the pre-existing health of the person, genetic factors, social determinants of health, and stress. In this phase, an infected person may be symptom-free and unaware of his or her HIV status. There is a critical point in time when T-helper cell levels drop to a critical level. When the CD4 count drops below 200 cells/mm³, the immune system is no longer able to fight off the virus adequately. The viral load rapidly increases, and the body is no longer able to ward off opportunistic infections. This increases susceptibility to AIDS-related illnesses. If the person is left unchecked, that is without the intervention of HIV medications, the natural history of HIV has shown high mortality levels within 2 to 3 years from this point.

1.1.2.2.6 AIDS-Defining Illnesses

In advanced stages of HIV, a person may be said to be living with Acquired Immunodeficiency Syndrome (AIDS). AIDS is not a disease; rather it is a category developed in 1993 by the U.S. Centre for Disease Control (CDC) to identify advanced HIV progression (CDC 1993). A person is said to have AIDS if their CD4 count is less than 200 cells/mm³ and if they present with one or more of the 26 clinical conditions characterizing the AIDS-defining illnesses. Given the evolution and advancements in HIV care, the classification system established to describe the progression towards AIDS is used in fewer and fewer cases. It becomes more important to monitor CD4 counts, viral loads and to consider the number of factors contributing to the health status of the individual. In 2013, 177 AIDS cases were reported in Canada, a 90.4% decrease since 1993, the year with the highest number of reported AIDS cases (1,837). Throughout this module, individuals living with HIV (or HIV which has progressed to AIDS) will be referred to as people living with HIV.

1.1.3 Epidemiology

The World Health Organization estimates that there were 37.9 million people worldwide living with HIV in 2018 (WHO n.d.).

1.1.3.1 HIV in Canada

By the end of 2014, a cumulative total of 80,469 positive HIV tests were reported since testing began in 1985 (Public Health Agency of Canada (PHAC) 2015). By the end of 2016, an estimated 63,110 adults and children were living with HIV in Canada (PHAC 2018). Of these, approximately 9,090 people were unaware of their HIV infection (PHAC 2018). This increases the risk of transmission and contributes to the spread of the virus. Incidence rates – the number of new

cases - were very high in Canada in early 1980s. This is due in large part to the introduction of tests at that time, coinciding with large numbers of people who suspected they were infected wanting to be tested to determine their status. The incidence rates then stabilized and after peaking in 2008, are now slowly declining, despite a slight increase in 2016 (PHAC 2018). The Canadian AIDS Treatment Information Exchange (CATIE 2016) in collaboration with PHAC maintains a comprehensive summary of the Epidemiology of HIV in Canada (<http://www.catie.ca/en/factsheets/epidemiology/epidemiology-hiv-canada>). The most recent estimates are available for 2016 Due to an enhancement in the case surveillance infrastructure for Canada, PHAC is also able to provide more current summary tables to describe those living with newly diagnosed HIV (PHAC 2016).

1.1.3.2 Canadian Impact

The Public Health Agency of Canada identified certain populations are particularly vulnerable to HIV in Canada. People with disabilities may present as another vulnerable group. However, more research in this area is needed. While information is provided about groups most vulnerable in each region, there is a noticeable absence of information related to the vulnerability of people living with disabilities. A lack of research in this area and failure of the global community to include persons with disabilities in epidemiological studies account for the absence and is worthy of acknowledgement (UN, WHO 2009).

Approaches to address HIV in Canada have focused on target populations as defined by certain terminology. This terminology will be used throughout the rest of this module, with certain caveats as addressed under each classification (PHAC 2015).

Population-specific approaches result in evidence-based, culturally appropriate responses that are better able to address the realities and vulnerabilities that contribute to infection and poor health outcomes for these respective groups. These approaches also allow people at risk of infection and those living with HIV to directly shape policies and programs that affect them.

1.1.3.2.1 Gay Men and Other Men Who Have Sex with Men

Terminology can become transient and contentious, and the term men who have sex with men (MSM) is no exception to the rule. Some researchers use the term MSM to encompass all men who have sex with men, while others feel this constitutes a category distinct from those men identifying as gay or bisexual and refers more specifically to men who have anonymous sex with men yet identify as heterosexual. The situation becomes even more complex when research papers do not clarify which grouping of men they are referring to in their populations of study. This can make it somewhat

challenging to present research findings. This report attempts to be as clear as possible but may not always be able to be specific, particularly if a paper being referenced does not explicitly outline their criteria and use of these particular terms. Within Canada, gay men and other men who have sex with men still account for the greatest number of new infections (PHAC 2018). Despite the changes in behaviour that gay and other men who have sex with men have adopted in response to HIV since the beginning of the epidemic, it is often difficult to maintain safer behaviours all the time. Directly raising the question of HIV status (whether positive or negative) with a potential sexual partner continues to be a challenge for many people regardless of orientation.

1.1.3.2.2 People who Inject Drugs

People who inject drugs (injection drug use (IDU)) and share drug use equipment are at high risk for HIV transmission and represent almost 14.6 % of the infected population in Canada (PHAC 2018). Incidence rates may vary when there is a shift in drug preferences, and there is anecdotal evidence regarding the effects of increased access to safe, sterilized needles and other harm reduction measures (Hou and Ouellet 2007, Knittel et al. 2010). PHAC (2015) reports that there appears to be a decreasing trend in new infections attributed to IDU.

1.1.3.2.3 Indigenous Peoples ;

At the end of 2016, just under one in ten (9.6%) of Canadians living with HIV were Indigenous people (PHAC 2018). People who identify as Indigenous (including First Nations, Inuit and Metis people) are overrepresented in ethnically identifiable data relating to HIV prevalence and incidence. A variety of social, economic, and political factors contribute to the vulnerability of the Canadian Indigenous population to HIV infection and limit the ability of communities to give high priority to HIV prevention initiatives. Not only do many Indigenous peoples face disproportionately high and frequent levels of poverty, drug misuse, violence and suicide, they are also overrepresented in the Canadian Criminal Justice System, which constitutes on its own another at-risk category for HIV infection. These social determinants of health may be considered antecedents of HIV infection.

Injection drug use (IDU) is the primary mode of transmission in Indigenous communities, constituting the majority of all HIV infections for Indigenous people for whom exposure category information exists. In 2013, half of all HIV cases attributed to IDU exposure were Indigenous (50.1%) (PHAC 2014). Even though the proportion of cases attributed to heterosexual exposure is similar to non-Indigenous communities in Canada, Indigenous peoples have a higher proportion of HIV infection from IDU and a lesser proportion than the rest of the Canadian population from gay, bisexual and other men who have sex with men (MSM).

Although adolescents constitute the fastest growing group of Canadians acquiring HIV, Indigenous youth are being infected with HIV at an even younger age than non-Indigenous peoples (Spittal et al. 2007). The majority of HIV positive tests can be attributed to this age group to IDU, and then by heterosexual exposure, followed by MSM. Youth are one sub-group of the Indigenous population that is particularly vulnerable to HIV.

Current evidence predicts that the HIV epidemic in Indigenous communities is not slowing down. The HIV situation in Indigenous communities is complicated by challenges commonly encountered in vulnerable populations, including substance misuse, mental health issues, racism and homophobia and is further compacted via the legacy of colonialism and overrepresentation in the prison system in Canada. For many Indigenous peoples, this legacy can contribute to a continued distrust of institutions, including healthcare organizations. Consequently, intervention strategies must take into account the unique needs of Indigenous peoples and their communities. This can include involving members of the Indigenous communities in developing policy and strategies, as well as incorporating a holistic view of health that neither undermines the emotional and spiritual elements of many Indigenous belief systems nor excludes Indigenous peoples as a community. The National Aboriginal Council on HIV/AIDS (NACHA) was formed in 2001 to create a single council for representatives from First Nations, Inuit, Metis and Aboriginal HIV/AIDS groups to work with federal agencies to address the HIV/AIDS challenge in a culturally relevant manner (<http://www.phac-aspc.gc.ca/aids-sida/fi-if/nachacnavs-eng.php>).

1.1.3.2.4 Prison Inmates

Prison inmates in Canadian correctional facilities experience higher rates of infectious diseases than the general population (Correctional Service Canada (CSC) 2003). Many are already infected with HIV when they enter the correctional system. The unique socio-demographic risk profile of inmates and the nature of incarceration itself present specific challenges for HIV prevention and control (CSC 2007). However, the prison environment allows for the opportunity to provide public health education and health promotion to prevent further spread of HIV in a vulnerable population that might otherwise be difficult to access. Harm reduction measures include ways of minimizing the risks of HIV transmission such as providing inmates with condoms, dental dams, lubricant, bleach for cleaning tattooing, piercing and injecting equipment, and methadone maintenance treatment.

A Canadian collaboration of HIV and legal experts have developed recommendations for prison-based needle and syringe programs in Canada that can be implemented immediately (van der Meulan et al. 2016, van der Meulan 2017).

Indigenous peoples are over-represented in the Canadian prison system, comprising 4% of the national population while constituting 23% of the federal prison population (Glauser 2013). Notably, female Indigenous peoples are even more overrepresented in the Canadian Prison System than are their male counterparts (Office of the Correctional Investigator (OCI) 2010). Moreover, Indigenous youth are more likely to be imprisoned than non-Indigenous Canadian youth. Indigenous youth are also more likely to be incarcerated for longer periods of time, beginning at an earlier age (OCI 2010). This indicates the complexity of risk factors and perhaps more importantly, how they intersect.

1.1.3.2.5 Youth at Risk

People between the ages of 15 to 29 years of age still represent a relatively small percentage of the total incidence of people infected with HIV in Canada (CATIE 2015), however the number of new HIV diagnoses among youth increased by 10% from 2013 to 2017 (PHAC 2017). However, the potential for HIV transmission is high among this group based on reported risk behaviours, including sexual behaviour, substance misuse, and perceptions amongst youth. Youth considered to be at high risk for infection include those who engage in unprotected sex and drug use, and/or for whom street involvement, homelessness, mental illness, and sexual abuse are factors of life (PHAC 2007b). Gay and bisexual youth are more vulnerable than their heterosexual peers, and Indigenous youth are at greater risk than non-Indigenous populations.

1.1.3.2.6 Women

By the end of 2016, 23.0% of reported HIV cases were female (PHAC 2018). While HIV affects women and men, a number of socio-economic factors in addition to physiologic differences, place women at increased susceptibility to infection. Issues such as poverty, marginalization, gender power inequalities, and violence, increase the vulnerability of women to HIV infection (Gatali and Archibald 2003). Also, in 2013, females 15 years of age or older, from endemic countries represented 42.7% of heterosexual contact cases compared to 22.9% among males. HIV testing during pregnancy is an option available to women across Canada; however, guidelines around encouraging informed decisions regarding HIV testing during pregnancy vary by province and territory.

Mother-to-child-transmission, also known as vertical transmission, has decreased remarkably in Canada due to prenatal screening policies and measures to provide treatment to reduce the risk of transmission. Prenatal screening guidelines must include informed consent (Boucher et al. 2001). The proportion of infants confirmed to be HIV positive in Canada has decreased from 33.0% in 1996 to < 1% in 2013 (PHAC 2012b, 2014).

Correspondingly, the proportion of HIV positive mothers receiving antiretroviral therapy increased steadily, reaching 96.5% in 2018 (PHAC 2019).

1.1.3.2.7 People from HIV-Endemic Countries

In 2016, people arriving from countries where HIV is endemic accounted for 13.6% of the total number of positive HIV tests reported to the Public Health Agency of Canada (PHAC 2018). The estimated new infection rate among people from countries where HIV is endemic was 6.4 times higher than among other Canadians.

1_2 Interacting with Communities Affected by HIV

This section explores the social dimensions of HIV disease from the perspective of people living with HIV. It covers the following topics:

- Resources available in the communities
- How communities have been affected
- The role of identity in HIV care
- How identity affects the client-provider relationship
- Characteristics of ethnicity and culture
- "Hard to serve" or "hard to reach" populations

This section was written by a panel of people living with HIV for the first edition of this manual (Philips et al. 1998) and has been modified to reflect current findings or changes in terminology.

1.2.1 Introduction

Many years ago, HIV disease in Canada was widely considered to be a disease of gay men and people from countries where the virus was endemic. While thousands of people from these communities continue to live with HIV disease, the faces of HIV are changing. Increasingly, new infections are occurring among people at society's margins, including injection drug users, people of low income, Indigenous peoples, youth, people with mental illness and prison inmates.

To those at the margins of society, becoming HIV positive can easily become a disastrous complication. Due to societal prejudice and/or racism, many are already viewed by society at large with a mixture of trepidation, indifference, and disdain. Fear of disclosure can lead to increased isolation from society, families and friends. These complications can be further compounded by challenges within government support programs. Some programs have faced service cuts, while others are discriminatory. For example, some assistance programs specifically disqualify people whose disability arises from drug or alcohol use.

Despite setbacks, a climate of renewed hope has developed among those for whom drug treatments have been successful. Today, care providers will encounter a broader spectrum of attitudes towards HIV.

1.2.2 Turning to Community Resources

In the midst of devastation and despair, remarkable responses have arisen from within some of the affected communities. A network of grassroots organizations has evolved to provide education, support and services defined specifically by the people using them, people living with HIV. In many ways, Community-based HIV Organizations (CBHOs) serve as the best model for successful HIV care. They have tackled the daunting and complex problems of changing sexual practice, managing profound grief, and enduring apparently unending trauma and loss. They have demanded and often achieved fundamental changes in services to their communities, struggling to overcome sexism, racism and homophobia, as well as resistance to sex education, needle exchange programs, and services in the prison system.

However, there are limits to what these organizations have been able to accomplish. Services remain scarce outside the major urban areas. As well, some groups at risk for HIV infection are less able to organize community-based responses to the epidemic.

Within all groups, knowledge and understanding of HIV disease varies widely. Some people possess an extraordinary degree of medical knowledge, keeping up with the latest developments through the Internet and scientific journals. Some bring an innate understanding of the principles of holistic care to community programs, and some have drawn an array of complementary therapies into the fight against the disease. On the other hand, many affected people lack even elementary information about their infection and find explanations of the HIV disease baffling.

Developing a plan of care for such individuals requires a careful explanation of options and recommendations about choices which otherwise could be overwhelming. Rehabilitation providers will recognize many "rehab-like" services delivered very successfully within existing community programs.

While these services may differ in detail from more structured professional services, their success arises from their "fit" with the people served through self-help, self-care and peer-driven models. Many of these services reflect "people living with HIV helping people living with HIV". The affected communities are often the first to recognize trends and changes in risk behaviours and needs among their members.

Although rehabilitation providers already possess many skills that can be used to treat people living with HIV, it is likely that the context of HIV disease differs from anything else in

their clinical experience. Knowledge and clinical approaches to HIV disease are constantly changing. Advice and interventions, which seem prudent and accurate today, may seem ill-advised or ineffective within a few months. Adaptability has been key to survival for people living with HIV and will be key to ensuring best practices for providers.

1.2.3 Affected Communities

Many of the affected communities and groups are already culturally or economically marginalized. Most importantly, their underlying health as a group tends to be poorer than that of the general population, even before HIV infection. This adversely affects prognosis. Many members of these communities and groups are reluctant to seek health care and do so only in emergencies. Others lack lasting relationships with providers and tend not to follow through with prescribed treatments. These factors combine to affect:

- Vulnerability to infection
- Ability to cope with major illness
- Ability to trust and to seek care
- Ability to access, choose, and pursue effective HIV treatment
- Prospects for survival, even with treatment

HIV infection is likely to worsen and solidify poverty, intensify discrimination and isolation, and make it more challenging to reach and use care services. Caregivers need to be careful not to make assumptions about prognosis, motivation and adherence to treatment based on a person's economic or social status. Cultural and personal values will influence each person's reaction to becoming HIV positive. While some may fear rejection, others will be concerned about unauthorized disclosure of their serostatus or discussion of their sexual identity.

1.2.4 The Role of Identity in HIV Care

The expression of identity is immensely complex and dynamic. For example, an individual can be someone who is Canadian, HIV positive, a woman, mother, wife, breadwinner and care provider, all at once. Notably, in the process of developing an identity, both isolation and relationships are possible. Often, individuals who share certain elements of identity become communities, and from each community, culture emerges as the sum of its shared values and practices. Throughout life, individual components of identity may dominate at different times, depending on circumstances and events. Many people living with HIV report that at times, HIV dominates their identity, superseding other dimensions, while at other times it recedes. At one time, a person may say he is "a person with AIDS," while another time "an Indigenous person," each being true. Furthermore, identity evolves. People change as life unfolds.

As a healthcare professional, it is important to work with an open mind, as free as possible from judgments of clients. This is key, as "labelling" an individual based on a perception of what "that type of person is like" is usually fraught with pitfalls. Often, judgments and generalizations can be imprecise; at their worst, they are the mechanisms of bigotry.

HIV care and experience demonstrates that messages about behaviour may not be heard unless targeted to a specific community. For example, some communities have a long tradition of silence about anonymous sex between married men, reinforced by rigid institutionalized homophobia. Because many of these men adamantly deny being homosexual or bisexual, HIV prevention messages aimed at gay- or bisexual-identified men have been ineffective. This failure has had disastrous consequences, routinely placing the wives and partners of these men at risk, and making it difficult for these men to even consider accessing care.

Rehabilitation professionals may play a key role in helping individuals to attain significant identity milestones. For example, speech-language pathologists play an important role for those undergoing gender confirming surgery by helping people to speak like the gender they are becoming or have become (Carew et al. 2007, Associated Press 2010). Support from rehabilitation professionals may play an even more important role when life course and aging identities are considered, given that people aging with HIV may encounter age-related milestones that may be out of sync with societal norms. For example, functional age does not always equate with chronological age, and those aging with HIV may also have experienced early disengagement from the workforce.

1.2.5 Identity and the Client-Provider Relationship

Every client and provider brings unique identities, cultures, and experiences to an interaction. This influences what options are proposed and what choices are made.

Even when recognizing that each person is unique in his or her blend of identities, there is a temptation to generalize or to stereotype. If people assume that they "know" what injection drug users or transgender women are like or require, the high variability that occurs within identity groups is denied. While a person may identify with a community, it is important to remember that he or she will be distinct from every other member of that group in one or many ways.

A successful provider-client relationship is defined by certain principles:

- Both client and provider have complex identities. For each, identity evolves, and individual components of identity dominate at various times.

- People providing care will inevitably be different from those for whom they care. They will be closer at times, less related at other times.
- All judgments and evaluations are made through the lens of identity, are influenced by community and culture, and are a potential source of error and miscommunication.
- Judgment is a two-way process. Clients and providers are equally likely to misunderstand each other.

The skilled and successful provider possesses personal insight, broad intercultural education, and experience gained through interaction with a range of communities. Central to these skills is a personal commitment to acceptance and respect of differences; traits that help define client-centred care.

1.2.6 Age

The age of an individual invariably affects how he or she sees the world, as well as how others view that person. With the age range of those acquiring HIV ranging from infancy to those aged 60 years and beyond, age is now an increasingly complex issue for people living with HIV. Age should be recognized as part of the identity of people living with HIV.

1.2.7 Chosen Family

Some people living with HIV develop close ties with people from their communities who serve as a "chosen family". This particularly occurs in the gay community. In many cases, this choice represents a profound estrangement from the biological family, often because of rejection due to lifestyle or HIV status. Providers should attempt to determine which family plays a more central role in the client's life.

1.2.8 Ethnicity and Culture

Ethnicity and culture often include components of visibility, language, religion, and spirituality, each of which encompasses values and beliefs on a wide range of issues.

These values and beliefs may influence:

- Work
- Disability
- Disease
- Death and Dying
- Manner of Accessing Care
- Medical Tradition
- Family
- Reproduction
- Parenting
- Sexuality

- Disclosure of Illness
- Substance Use

When people experience cultural rejection or disapproval of an important component of identity, they will be less likely to reveal this aspect of themselves. This can be a powerful barrier to accessing care and developing frank and trusting relationships with care providers.

Also, providers should consider the influence of life experiences, such as living on the street, substance use, and incarceration. These intense experiences may dominate some people's identities and negatively affect their views of institutions, including healthcare settings.

1.2.9 "Hard to Serve" or "Hard to Reach" – For Whom?

Providers have labelled certain communities as "hard to reach" or "hard to serve," yet the affected communities often ask, "Why are we hard to reach and for whom?" Certainly, these communities represent a special challenge to highly structured medical programs, including rehabilitation clinics. For people who lack food or a safe place to live, or whose day is driven by the demands of drug addiction, arriving on time for a 15-minute appointment in a busy provider's clinic schedule may be a low priority. To be successful, these programs must be flexible, adaptable, and accessible.

In deciding that a population is "hard to reach," providers should consider whether this designation is not in fact primarily an expression of cultural difference. "Hard to reach" sometimes means the form provided is inaccessible.

To enhance access, the following actions should be considered:

- Taking the initiative to reach the affected community
- Involving communities in assessing their own unique needs
- Avoiding assumptions about the ability of the community to participate in or benefit from rehabilitation services
- Providing services where the community lives
- Hiring members of the affected communities as providers or peer support workers (e.g. the Centre for Addictions and Mental Health in Toronto uses peer support workers for many of its programs)
- Integrating HIV services into primary care programs
- Delivering rehabilitation services within the continuum of HIV care
- Encouraging the development of personal support systems
- Explaining clearly what services can and cannot be provided

Nevertheless, complications such as severe mental illness, particularly when coupled with homelessness or addiction, make it difficult for some people living with HIV to address their HIV. This highlights the need for comprehensive care programs that emphasize holistic treatment. In this sense, the relationship between a person living with HIV and the rehabilitation professional must be seen as a long-term process, one that might start with accessibility and acceptance and without particular clinical goals. If possible, this relationship may evolve to a point where comprehensive care of multiple issues can begin.

1_3 Introduction to Rehabilitation for Clients, Families and Other Care Providers

1.3.1 Introduction: What is Rehabilitation?

The profile of HIV is changing: today, new drugs can slow disease progression and help people to live longer with improved quality of life. However, while people are living longer, treatments are often very complicated and can cause debilitating side effects. Rehabilitation in the context of HIV can be broadly defined as any services or activities that address or prevent body impairments, activity limitations, and social participation restrictions experienced by an individual (Worthington et al. 2005).

Rehabilitation involves optimizing choices for people living with HIV by providing the tools and support to help people do what is meaningful to them. This includes physical, vocational, and psychological rehabilitation. One of the French translations for rehabilitation, *réinsertion sociale* or, literally translated, social re-insertion, captures a fundamental aspect of the rehabilitation process: a return to active living and participation in society. Three primary goals of rehabilitation are:

- To increase or maintain a person's functional capacity including (re)-engagement in social participation activities and life roles
- To improve or maintain a person's quality of life
- To decrease hospitalizations and increase self-care

Within these goals, rehabilitation can include a range of services, programs and policies that seek to address a variety of issues including:

- Addressing impairments, activity limitations and participation restrictions (see definitions below) related to HIV or to the side effects of medications, including managing pain, weakness or fatigue and increasing mobility and independence

- Supporting the integration of often complex treatment regimens into daily activities, and facilitating toleration of treatments without increasing toxicity and thereby maintaining complex treatment regimens, lower viral loads and reduced resistance
- Staying at or returning to employment, volunteer work and/or household responsibilities
- Improving access to adequate income support programs to enable people to focus on improving their health and participation in society
- Improving self-esteem, maintaining interpersonal relationships and support networks and reducing stress and isolation

The World Health Organization (WHO)'s model, the International Classification of Functioning, Disability and Health (ICF), categorizes health-related experiences beyond those covered by the concept of disease (WHO 2001). The model lays out three categories, from micro-level (body part or individual) to macro-level (community or society):

Impairments: Impairments are problems in body function or structure; they are at the level of the body part. For example, pain or tingling in feet (peripheral neuropathy).

Activity Limitations: These are difficulties an individual may have executing activities; they are at the level of the person. For example, difficulties walking because of pain and sensitivity in the feet.

Participation Restrictions: These are problems an individual may experience in life situations or the social and environmental consequences of impairments and activity limitations; they are at the level of community or society. For example, difficulties working or taking care of children because these activities may require walking. Rehabilitation interventions may be targeted at one or more of these levels. For more information about ICF, go to <http://www3.who.int/icf/icftemplate.cfm>.

While many healthcare providers have been providing rehabilitation treatment and care to people living with HIV since the beginning of the epidemic, developments in the medical management of HIV have changed the role and scope of rehabilitation. Rehabilitation in this context now involves many players, including healthcare professionals who have not traditionally been involved in HIV issues, such as physical therapists, occupational therapists, social workers, speech-language therapists and psychiatrists, as well as specialists in complementary therapies and alternative medicines. To a large degree, people living with HIV initiated the incorporation of complementary and alternative medicines. All care providers have an important role to play in educating clients about rehabilitation services that are available, referring clients to appropriate service providers and making sure that these services are integrated into a client's treatment plan. Health professionals such as family physicians may also participate in rehabilitation by providing

assessments and supporting documentation for insurance purposes. Rehabilitation services, as with primary care, are centred on the needs of the client, where the client is an active member of the rehabilitation team.

An important companion guide for people living with HIV is the resource *Managing Your Health: a guide for people living with HIV* (CATIE 2015), which provides an up-to-date, reliable, plain language resource for living with HIV from the perspective of people living with this disease. This resource manual is regularly updated by the Canadian AIDS Treatment and Information Exchange (CATIE) and can be accessed free of charge on the CATIE website (<http://www.catie.ca/en/practical-guides/managing-your-health>).

1.3.2 Physical Rehabilitation

Interventions designed to prevent or postpone disease progression play an important role in helping people living with HIV cope with the impairments, activity limitations and participation restrictions that arise from HIV disease as well as from the various side effects of HIV medications. Addressing these side effects through rehabilitation interventions may also serve to promote adherence to treatment.

A range of rehabilitation professionals may be involved in the physical rehabilitation process, including physiatrists, physical therapists, occupational therapists, speech-language pathologists and recreation therapists.

Referring clients to rehabilitation providers can sometimes be challenging given the range of issues that a person living with HIV may face, such as unstable housing or minimal social supports. Rehabilitation professionals need to be sensitive to the impact of stigmatization and the need for confidentiality. As well, while some rehabilitation services may be covered by public or private insurance plans, or available free through a community-based organization, many rehabilitation services may not be covered and may be prohibitively expensive for a client. Resources to help locate a rehabilitation professional with expertise treating people living with HIV can be found in [Section 7_6 Resources](#). Some of the challenges faced by people living with HIV may be caused by physical changes in the body.

1.3.2.1 Physical Therapist

A physical therapist (physiotherapist) (PT) is a professional who is trained to plan and carry out individually designed programs of physical treatment to maintain, rehabilitate or augment function or adaptive behaviour. A PT can help to develop strategies that can help with (but are not limited to):

- Managing or reducing pain, numbness or tingling sensations
- Feeling less tired

- Strengthening muscles
- Improving movement in joints
- Maintaining or improving flexibility, balance and coordination
- Building activity tolerance
- Learning to use a walker or other gait aid for walking if needed

1.3.2.2 Occupational Therapist

An occupational therapist (OT) is a professional who is trained to assess function or adaptive behaviour and assist an individual to maintain, rehabilitate or augment function or adaptive behaviour. An OT can help people living with HIV to manage daily activities and make adjustments in the home or workplace to allow for any physical or cognitive changes that are occurring. This could include (but is not limited to):

- Suggesting changes in living or working space to accommodate any physical limitations
- Organizing activities to assist with focus and memory
- Organizing and prioritizing activities to conserve energy and optimize daily function
- Assessing the need and/or functional benefit of assistive devices and equipment
- Strategizing around complex medication schedules
- Determining how family or other services in the community can provide support

1.3.2.3 Speech-Language Pathologist

A speech-language pathologist (speech therapist) (SLP) is a professional who is trained to identify, evaluate, and treat a wide range of speech, language and swallowing disorders. An SLP can be involved with (but not limited to):

- Issues affecting communication and swallowing
- Maximizing oral and written communication skills for staying at or returning to work (e.g. reading, writing and public speaking; including thinking skills such as word memory, thought organization, and reasoning for effective communication)

1.3.2.4 Physiatrist

A physiatrist is a doctor who specializes in physical medicine and rehabilitation. A physiatrist can help with:

- Regaining movement or physical functioning
- Managing chronic pain
- Accessing any special tests or procedures

1.3.3 Complementary and Alternative Medicines and Therapies

Complementary and alternative medicines and therapies (CAMT) fall outside of conventional Western medicine and are also widely used by people living with HIV. Unfortunately, some healthcare providers are unaware of the potential value of these therapies in a treatment repertoire, or they tend to diminish the value. All care providers need to educate themselves on the wide range of complementary therapies particularly now that many have been tested using rigorous scientific study designs ([Section 6_8_1 Self-Management: Complementary and Alternative Medicines and Therapies](#)). It is important to note that vitamins and minerals also fall under the CAMT classification. For more information on regulated complementary therapies see the colleges listed in [Section 7_6 Resources](#).

Some people living with HIV also find that CAMT is helpful to address the many physical, mental or emotional challenges they face. Some of these include:

- Acupuncture
- Massage Therapy
- Homeopathy
- Naturopathy
- Aromatherapy
- Chiropractic treatments
- Yoga, Meditation, Tai Chi, Reiki

The Canadian AIDS Treatment Information Exchange (CATIE) has produced a useful guide on CAMT for people living with HIV (www.catie.ca).

1.3.4 Vocational Rehabilitation

As a result of changes in the treatment of HIV, returning to or remaining in the workforce, despite HIV-related disabilities, is a rapidly emerging issue. Individuals who have left work and are receiving benefits may be concerned about the risk of losing these benefits if they return to the workforce. Unfortunately, current income support programs in both the public and private sectors present many barriers to effective, flexible workforce participation, particularly for people with episodic disabilities such as HIV. Many Community-based HIV Organizations advocate on behalf of individuals with income support programs. Some organizations address the employment needs of individuals living with HIV (via information seminars, benefits information, psychosocial counselling, financial and career planning, and vocational rehabilitation). Also, there are very recent initiatives to improve programs to allow flexible workforce participation.

This area is discussed in detail in [Chapter 6_7 Vocational Rehabilitation](#).

1.3.4.1 Participation Assistance

Some rehabilitation providers specifically target the optimization of active participation in work, home or leisure activities. These include:

1.3.4.1.1 Rehabilitation Nurses

Rehabilitation nurses are professionals who assist and promote the participation of individuals in activities of daily living, with the primary goal being the achievement of the individual's maximum functional potential.

1.3.4.1.2 Vocational and Rehabilitation Counsellors

Vocational and rehabilitation counsellors are professionals who, through assessment, counselling, and training, assist people who have a medically documented disability that interferes with their ability to obtain and maintain employment, and/or to develop and implement a realistic vocational plan.

1.3.4.1.3 Occupational Therapists

Return-to-work and worksite accommodation is a central role for occupational therapists (OTs) who work in the community, hospital and mental health settings. OTs also work with individuals to regain or improve their self-care, home care, and/or leisure activities. OTs may recommend adaptations within the home or community to enhance participation in all areas of life.

1.3.5 Psychological Rehabilitation

Mental health and rehabilitation are linked. Eating well, exercising and accessing social support through a community-based organization may play an important role in the rehabilitation process for people living with HIV. Further, as people living with HIV experience high rates of depression, accessing psychological support may be critical to successful rehabilitation.

Primary prevention, in the form of exercise, adequate nutrition, and maximizing mental health, is a mainstay of HIV care and also falls within the scope of rehabilitation, though it may be less familiar to some physical rehabilitation professionals. Primary interventions tend to be based in the community rather than in medical facilities.

Care providers can help by linking clients up to community-based agencies for support and rehabilitation services. The HIV community has a rich tradition of health promotion activities. Excellent opportunities exist for partnerships between rehabilitation professionals and community-based organizations to address issues of preventive rehabilitation relating to mental health.

1.3.5.1 Mental Health Promotion and Support

People living with HIV can experience stress, anxiety, depression, changes in sleep and appetite and reduced sex drive (libido). Self-esteem and relationships also can be affected. Psychiatrists, psychologists, psychotherapists, occupational therapists, social workers and mental health counsellors can help by:

- Providing therapy or counselling to help cope with the emotional impact of HIV
- Suggesting strategies and techniques to relieve anxiety and stress
- Helping to reduce feelings of stress and isolation
- Connecting with peer-support groups
- Improving self-esteem, maintaining personal relationships and support networks
- Prescribing drugs, if necessary (only doctors and psychiatrists can do this). Pregnant women with HIV may also receive certain prescriptions for nausea and vomiting in pregnancy from midwives depending on whether an obstetrician or a midwife-obstetrician team is attending these women. This can affect appetite, adherence and mood.

Social supports, such as friends, family, cultural and other community organizations, can also provide both emotional and practical support.

The Canadian AIDS Society (<https://www.cdn aids.ca/>) can help identify a Community-based HIV Organization (CBHO) in specific areas. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>). CBHOs offer a range of support services, which may include services such as food banks or community kitchens, individual or group counselling, drop-in programs, and case management, as well as referrals to other safe community services and programs.

1.3.6 Basic Components of a Rehabilitation Program

In rehabilitation, the person living with HIV is a central part of the process and is encouraged to play an active role in his or her care. Rehabilitation is most effective when it includes a team approach that includes the person living with HIV, his/her social network and primary caregivers, rehabilitation providers and professionals, those who pay for rehabilitation services (e.g. insurance program or company) and other agencies he or she may be involved with.

When referred to a rehabilitation service, the person being referred should expect the following:

- The decision to participate is ultimately the decision of the person living with HIV
- A baseline assessment of areas of concern (although assessment should be viewed as an ongoing process)
- A review of available information (e.g. medical notes) from other caregivers, such as primary care or HIV community care providers
- Establishment of short- and long-term rehabilitation goals
- An individualized rehabilitation plan to achieve those goals
- Regular monitoring of progress towards goals
- Referral to other services and agencies as needed or identified

Additional information on client-centred care, health system navigation and advocacy can be found in [Section 7_2](#).

1.3.7 Where Are Rehabilitation Services Provided?

The place where services are provided will depend on the services available, the medical stability of the referred client's illness and his or her desired and expected outcomes.

Some of the more common settings are:

- Hospitals
- Outpatient centres and clinics
- Private practices of healthcare professionals
- Local Community-based HIV Organizations
- A client's own home
- Hospices
- Work settings
- Schools
- Wellness centres
- Community parks and recreation programs (e.g. YMCAs)
- Public health services
- Primary Care Organizations such as Community Health Centres or Family Health Teams

1.3.8 How Can People Living with HIV Access Rehabilitation Services?

In many cases, people living with HIV will need an assessment and referral by a doctor to access many rehabilitation services. This is especially important if the rehabilitation services are being paid for by a provincial health plan or private insurance. If a Community-based HIV Organization (CBHO) provides the service, a referral may not be necessary, and the service may be free. Once at the specific rehabilitation service, the person living with HIV may or may not be assessed again,

depending on the type of assessment conducted by the physician versus the type used at the rehabilitation service, and a number of other factors including insurance requirements and standards of practice for each rehabilitation service being sought. Some CBHOs have been able to successfully partner with professional schools. In one Toronto CBHO, student clinicians and their respective supervisors from the fields of acupuncture, massage therapy and physical therapy provide treatments to CBHO clients.

1.3.9 Who Pays for Rehabilitation Services?

The types of rehabilitation services paid for by public (government) health plans in Canada vary between each province and territory. Private (employer or individual) health insurance plans cover some rehabilitation services, but there is usually a yearly maximum or a maximum number of treatment sessions, which may mean that the individual will have to pay some of the costs.

Ideally, the person living with HIV and his or her care provider will negotiate with local rehabilitation providers, human resource departments, insurance companies and/or their local Community-based HIV Organization to find out what is covered. Some of the possibilities include:

1.3.9.1 Provincial Health Plan or Hospital Program Funding

If rehabilitation services are provided while an individual is in hospital, they are covered by most provincial health plans or by provincial program funding. Rehabilitation services that are continued in an ambulatory or outpatient clinic after leaving hospital may also be covered.

1.3.9.2 Private Insurers

Some rehabilitation services may be covered by employer's group health insurance plan (if the individual is still working or on disability benefits) or by private health insurance purchased independently. However, even if an individual has

a plan through their employer, there are usually yearly maximums, and generally, only a portion of the cost is covered. It is important to check the plan.

1.3.9.3 Sliding Fee Scales and Payments Over Time

Some rehabilitation providers have a sliding fee scale for people without insurance. Sliding scale means that the fee is based on the individual's ability to pay. Some practices also allow individuals to pay over an extended period of time.

1.3.9.4 Community-based HIV Organizations

Local Community-based HIV Organizations (CBHOs) may provide some rehabilitation services for free either on-site or through a referral system to a local provider. Some CBHOs also offer financial assistance to their clients by providing partial or full reimbursement for some healthcare services and expenses.

Despite the importance of rehabilitation for people living with HIV and the increasing number of persons who may require rehabilitation, access to rehabilitation services continues to be a challenge across Canada for those with and without HIV. For example, some provinces have removed certain rehabilitation services from public coverage. This can create a significant burden for those individuals who can only access rehabilitation services through publicly funded channels.

1.3.10 One Stop Resource

Incorporating rehabilitation into the care, treatment and support of people living with HIV is critical to helping them achieve optimal health. *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) is a national, non-profit, multi-sector and interdisciplinary organization, on HIV and rehabilitation. For additional resources, information and links visit the *Realize* website at <http://www.realizecanada.org>.

CHAPTER 2

Rehabilitation Best Practices

2_1 Current Issues in Evidence-Based Rehabilitation and Interprofessional Learning

Evidence-based practice is now a well-known component of health and medical care in most industrialized nations. Sackett et al. (1996) have defined evidence-based medicine as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients". Within rehabilitation, the evidence base is growing rapidly but moving these findings into practice remains a substantial challenge (Salbach et al. 2007, Salbach et al. 2009a, Salbach et al. 2009b, Menon et al. 2009, MacDermid and Graham 2009).

Integrating research findings with clinical wisdom and clients' preferences and values is the goal of evidence-based rehabilitation (Law and MacDermid 2008).

2.1.1 Building Evidence Across Study Designs

The types of research questions that are commonly addressed in human medicine (including the field of rehabilitation) include those related to the effectiveness and safety of interventions; the frequency or rates of diseases or conditions; etiology and risk factors; prediction and diagnosis; diagnostic accuracy and other phenomena including hypothesis generation (Glasziou et al. 2001).

Scientific evidence is the product of appropriately designed and carefully controlled research studies. A single study only provides preliminary evidence for an intervention. The single study, however, can contribute to an overall body of knowledge, and evidence for or against an intervention should ideally be derived from multiple studies investigating the same research question. Evidence-based medicine in human healthcare categorizes different types of clinical evidence and ranks them according to their freedom from the various biases that may occur. For instance, the strongest evidence for intervention efficacy is provided by blinded, randomized controlled trials (RCTs), when it is ethical to conduct one to address the question of interest (Clancy 2002). In contrast, client testimonials, case reports, and even expert opinion have limited value as proof because of the potential biases inherent in observation and reporting of cases, difficulties in ascertaining who is an expert and more. In the human healthcare literature, one way to describe the hierarchy of evidence is through a ranking system commonly known as the pyramid of evidence

(<https://hslmcmaster.libguides.com/ebm>). Some authors suggest that the current evidence hierarchy has limitations and that a broader evidence base is needed to implement client-centred care (Rycroft-Malone et al. 2004, Upshur 2000). These newer models propose a more equitable contribution of four types of evidence in the delivery of care: research, clinical experience, patient experience and information from the local context (Rycroft-Malone et al. 2004). Specifically, knowledge from clinical experience is a crucial component of evidence-based practice if client-centred care is a goal. This perspective allows clinicians to work according to their skills and experiences. Similarly, knowledge from clients, client family members and client carers for what works for the client is often crucial, as communication of desires and goals are necessary to apply the research-based evidence appropriately. Finally, practice may be improved by incorporating knowledge from the local context, including audit data, client narratives and clinician knowledge of an organization's culture. Qualitative research provides insights into how interventions are/are not effective and how they are experienced by clients in various contexts.

2_2 Outcomes and Measurement in Rehabilitation Practice

2.2.1 What is Measurement?

Measurement is the process of assigning numbers to certain characteristics, traits or attributes according to a set of rules. There are many "things" (otherwise referred to as constructs or concepts) that health professionals might be interested in measuring with clients. Health-related concepts can range from the level of body structure and function (e.g. CD4 count, viral load, range of motion, pain, fatigue, symptom presence and severity), activity (e.g. mobility, functional capacity), social participation (e.g. ability to work), to health-related quality of life (HRQL). Outcomes or measures are the tools, questionnaires, or devices that facilitate the assignment of numbers to related concepts of interest. Some examples of concepts include: range of motion of the knee measured with a goniometer, functional capacity measured by the distance walked in six minutes, symptom severity measured with a symptom index, evaluation of a person's ability and safety when performing daily life tasks (e.g. caring for self and/or home), or health-related quality of life measured with a questionnaire called the Medical Outcomes Study Short Form 36 questionnaire (commonly known as the SF-36 questionnaire) (Ware and Grandek 1998, Ware 2000). Measurement occurs every day. Virtually

every decision an individual makes involves some form of measurement – simply asking a client: 'how are you feeling today?' is a form of measurement.

Depending on the response to this measure (or question) a rehabilitation professional can determine whether she/he continues with the assessment or return to it at a later time. Outcome measures can be "objective" whereby a rehabilitation professional conducts an assessment of a person's health status (e.g. range of motion as measured by goniometry) or "subjective" or "self-report", whereby a client completes a health-questionnaire (e.g. symptom presence and severity as measured by an HIV symptom index).

2.2.2 Why Should Rehabilitation Providers Use Outcome Measures?

Using measurement in HIV practice is important because it can assist the rehabilitation provider to maintain objectivity and standardize assessment when working with clients. This can help determine how well a client might be managing in comparison to other people living with HIV, or with the general population. It can also help determine whether changes in a client's health status occur over time. Outcome measures can help facilitate communication among health providers, clients, or policymakers to ensure that all stakeholders are speaking the same language. For example, 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. Finally, outcome measures are commonly used in research studies to determine whether a change in health status occurs in response to a particular intervention.

2.2.3 Why Do Rehabilitation Providers Use Measures in Practice?

There are three main reasons for the use of measures in clinical practice.

2.2.3.1 Descriptive

To describe the state of a health construct at a point in time. This description can then 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.

2.2.3.2 Predictive

To predict a future health state (e.g. using a balance index to predict whether someone is at risk of falling).

2.2.3.3 Evaluative

To evaluate whether a change occurred in the client's health state over time (e.g. 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 any changes (either improvement or worsening) in HRQL

2.2.4 How Do Rehabilitation Providers Know if a Measure Is Useful in Practice?

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

2.2.4.1 Reliability

Reliability refers to the consistency of the measure and whether a measure (or questionnaire) is free from error (Streiner and Norman 2008). It is important that measures are reliable (or consistent) and able to differentiate measure scores between clients.

2.2.4.2 Validity

Validity refers to how well the measure really measures what it is supposed to measure (Streiner and Norman 2008). For example, does the HIV Symptom Index (Justice et al. 2001), 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?

2.2.4.3 Responsiveness

Responsiveness refers to the ability for a measure to detect any change in a client over time if a change has occurred (Streiner and Norman 2008). This property is relevant to evaluative types of measures. 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. A sensitive or responsive assessment enables the healthcare provider to detect small to large changes in the construct of interest.

2.2.4.4 Interpretability

Interpretability refers to the meaning of the scores or values associated with the outcome measures – 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) mean for clients (Ware and Gandek 1998, Ware 2000)? 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 (Streiner and Norman 2008, Beaton et al. 2002). For example, the MCID for the six-minute walk test is 25 meters among people living with Chronic Obstructive Pulmonary Disease (Holland et al. 2010). If an individual improves his/her 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 to specific clients and what the scores mean for decision making in clinical practice.

2.2.5 Other Measurement Characteristics to Consider

2.2.5.1 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.

2.2.5.2 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.

2.2.6 Generic versus HIV-Specific Measures

There are two types of outcome measures used in practice: **Generic Measures** can be used with all individuals in the general population. **Disease-Specific Measures** can measure a health-related concept within a specific disease group.

Both types of measures have advantages and drawbacks. 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 the HIV practice and research include: the Medical Outcomes Study Short Form (SF-36) questionnaire which measures health-related quality of life (HRQL)(Ware and Gandek 1998, Ware 2000), 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 (Fisher and Bray 2010), and the Centre for Epidemiological Studies for Depression Scale (CES-D) which

measures depression (Radloff 1977). 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, stigma and discrimination, and fear of disclosure). To capture these disease-specific issues, researchers developed disease or HIV-specific measures to ascertain the extent of certain health constructs of interest for people living with HIV. An example of an HIV-specific measure is the HIV Symptom Index, a 21 item self-reported questionnaire that measures symptom presence and severity (Justice et al. 2001); and the Medical Outcomes Study-HIV Health Survey (Wu et al. 1991, Wu et al. 1997a, Wu et al. 1997b). This was adapted from the Short Form 36 (SF-36) to measure HRQL specifically for people living with HIV.

The HIV Disability Questionnaire (HDQ) is a 69 item self-administered questionnaire that describes the presence, severity and episodic nature experienced by adults living with HIV (O'Brien et al. 2012b, 2013a, 2014b, 2015a, 2015b). The HDQ was developed using a community-engaged approach. The HDQ measures disability experienced from health symptoms (physical, cognitive and mental-emotional), difficulties with day-to-day activities, uncertainty about the future and difficulties participating in society. The authors assessed internal consistency reliability and construct validity with 235 adults living with HIV in Canada (n=139) and Ireland (n=96). Internal consistency coefficients for both Irish and Canadian participants were greater than 0.90. Of the 40 construct validity hypotheses, 32 (80%) and 22 (55%) were confirmed by the Canadian and Irish participants respectively. Results suggest the HDQ demonstrates internal consistency reliability and construct validity when administered to adults living with HIV in Canada and Ireland.

Uncertainty was the most present and severe dimension of disability reported among a sample of adults living with HIV in Ontario and Ireland. "Physical symptoms and impairments" was the dimension of disability that fluctuated most on a daily basis as indicated by the highest episodic score. The HDQ demonstrates elements of reliability and construct validity among adults living with HIV in Ontario and Ireland.

2.2.7 Steps to Consider in HIV and Rehabilitation Measurement

The following are some steps to consider when using outcome measures in clinical practice:

- Determine the "things" or "health-related concepts" you want to measure (e.g. pain, symptom severity, disability, Health-related Quality of Life (HRQL)) with the client

- **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
- **Search for available outcome measures** that can measure a construct with a purpose in mind. A wealth of outcome measures exists 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
- **Choose the measure.** When choosing a measure, consider:
 - Whether a **generic measure** or an **HIV-specific measure** is appropriate
 - Whether an **objective or self-report measure** is appropriate
 - The **measurement properties** of the questionnaire, scale or tool. For instance, has the measure been evaluated for reliability and validity with people living with HIV? 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?

Table 2.2 provides an overview of some examples of self-reported generic and HIV-specific measures used with people living with HIV in research and clinical practice.

2.2.8 Obtaining a Copy of the Desired Measure

If the outcome measure chosen is a questionnaire, rehabilitation providers may be required to email the authors of the questionnaire to obtain a copy of the measure and

obtain their permission to use the tool. 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).

2.2.9 Summary

Measurement is the process of assigning numbers to certain characteristics, traits or attributes according to a set of rules. Using outcome measures in practice is important because it helps rehabilitation providers compare how a client might be doing in comparison to other people living with HIV, or the general population. Measuring outcomes can also help to determine whether changes in a client's health status occurred over time, and can facilitate communication about a client's health status among members of the healthcare team. Measures can describe, predict, or evaluate a change in health status. Measurement properties such as reliability, validity, responsiveness and interpretability are important to consider when choosing an outcome measure for use in clinical practice.

The **Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC)** is an international research collaborative based in Canada that includes people living with HIV, researchers, clinicians, representatives from community-based HIV service organizations, and policy stakeholders who have an interest in HIV and rehabilitation research. Current research priorities include a priority area targeted to enhancing outcome measurement in HIV and rehabilitation. CIHRRC deliverables can be found at <http://cihrrc.hivandrehab.ca>

Table 2.2 Examples of Outcome Measures Used in HIV Rehabilitation Practice and Research

| Measure | Construct Measured | Generic versus Specific | Purpose | Administration | Number of Items | Number of Domains | Measurement Properties |
|---|--|-------------------------|------------------------|--------------------------------|--|---|--|
| Assessment of Motor and Process Skills (AMPS) (Fisher & Bray, 2010a, 2010b) | Quality of a person's activities of daily living (ADL) performance (i.e., degree of effort, efficiency independence, and safety) | Generic | Evaluative Descriptive | Performance-based/ observation | 36 items (16 ADL motor skills and 20 ADL process skills) | 2 domains – ADL Motor Ability and ADL Process Ability | <p>Reliability: Good internal consistency (multi-faceted Rasch equivalent of Cronbach's alpha > 0.90 (Fisher, 1990) High interrater reliability ($r \geq 0.90$; Fisher, Liu, Velozo, 1992) High test-retest reliability ($r \geq 0.90$; Fisher & Bray, 2010a).</p> <p>Validity: Construct validity in a sample of people living with HIV (Merritt, Gahagan, Kottorp, 2013). Numerous studies demonstrating cross-cultural validity.</p> |
| Centres for Epidemiologic Studies Depression Scale (CES-D) (Radloff 1977) | Depression | Generic | Descriptive | Self-reported questionnaire | 20 items | 8 domains | <p>Reliability: High internal reliability ($\alpha \geq 0.85$) and adequate test-retest reliability on a general adult population.</p> <p>Validity: Concurrent construct validity on a general adult population. Demonstrated predictive construct validity and high internal consistency reliability on a population with Hepatitis C (Clark et al. 2002).</p> |
| HIV Symptom Index (Justice et al. 2001) | Presence and bothersome nature of symptoms | HIV-specific | Descriptive | Self-reported questionnaire | 20 items | Not Applicable | <p>Validity: Good construct validity among people living with HIV on combination antiretroviral therapy (Justice et al. 2001).</p> |
| Functional Assessment of HIV Infection (Cella et al. 1996) | Health-related quality of life | HIV-specific | Descriptive Evaluative | Self-reported questionnaire | 47 items | 5 domains | <p>Reliability: Internal consistency reliability (>0.73 Cronbach's alpha for all domains).</p> <p>Validity: Convergent and discriminant validity among adults living with HIV.</p> <p>Responsiveness to change among adults living with HIV (Peterman et al. 1997).</p> |

| | | | | | | | |
|--|--------------------------------|--------------|-------------|-----------------------------|----------|--|--|
| HIV Fatigue Scale (Barroso and Lynn 2002) | Fatigue | HIV-specific | Descriptive | Self-reported questionnaire | 56 items | 3 domains | <p>Reliability: High internal consistency reliability. Cronbach's alpha was >0.90 on all domains) among people living with HIV-related fatigue. Cronbach's alpha for the entire tool was 0.94. Test-retest reliability was moderate with a correlation coefficient of 0.43.</p> <p>Validity: Good convergent construct validity among people living with HIV-related fatigue (Pence et al. 2008).</p> |
| Medical Outcomes Study Short Form (SF-36) Questionnaire (Ware and Gandek 1998, Ware 2000) | Health-related quality of life | Generic | Descriptive | Self-reported questionnaire | 36 items | 8 domains and 2 summary scores (Physical Component and Mental Component Summary Scores) | <p>Demonstrated reliability and validity among people living with HIV.</p> <p>Reliability: Good internal consistency reliability among people living with HIV (all Cronbach alpha values typically > 0.80) and good test-retest reliability.</p> <p>Validity: Demonstrated content validity, criterion validity, construct validity with people living with HIV (McHorney et al. 1993, McHorney et al. 1994).</p> |
| Medical Outcomes Study- HIV Health Survey (MOS-HIV) (Wu et al. 1991, Wu et al. 1997a, Wu et al. 1997b) | Health-related quality of life | HIV-specific | Descriptive | Self-reported questionnaire | 35 items | 10 domains and 2 summary scores (Mental Component Summary (MCS) and Physical Component Summary (PCS) Scores) | <p>Reliability: Good internal consistency (>0.75 Cronbach's alpha) for all dimensions for people living with HIV.</p> <p>Validity: Convergent and discriminant construct validity with people living with HIV (Wu et al. 1997b, Badia et al. 2000).</p> |

| | | | | | | | |
|--|--------------------------------|--------------|------------------------|-----------------------------|-----------|------------|--|
| Multidimensional QOL Questionnaire for HIV/AIDS (MQoL-HIV) (Avis 1997) | Health-related quality of life | HIV-specific | Descriptive Evaluative | Self-reported questionnaire | 40 items | 10 domains | <p>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.</p> <p>Validity: Discriminative construct validity among people with asymptomatic and symptomatic HIV infection.</p> <p>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 (Badia et al. 2000).</p> |
| Perceived HIV Self-Management Scale (PHIVSMS) (Wallston et al. 2010) | Self-management self-efficacy | HIV-specific | Descriptive | Self-reported questionnaire | 8 items | 1 domain | <p>Reliability: Good internal consistency reliability with Cronbach's alpha 0.78 with adults (primarily men) living with HIV.</p> <p>Validity: Construct validity demonstrated in adults living with HIV with correlations to criterion measures of HRQL and depression ranging from 0.37-0.66 (Wallston et al. 2010).</p> |
| (WHOQOL-HIV)(O'Connell et al. 2003, WHOQOL HIV Group 2004) | Health-related quality of life | HIV-specific | Descriptive | Self-reported questionnaire | 120 items | 6 domains | <p>Reliability: Good internal consistency reliability for all domains with Cronbach's alpha between 0.70 and 0.90 among people living with HIV from seven culturally diverse centres.</p> <p>Validity: Good discriminant validity among people living with HIV in diverse cultural settings. (Fang et al. 2002, WHOQOL HIV Group 2004).</p> |
| HIV Stress Scale (Pakenham and Rinaldis 2002) | Stress | HIV-specific | Descriptive | Self-reported questionnaire | 29 items | 3 domains | <p>Validity: Convergent construct validity among men living with HIV (Pakenham and Rinaldis 2002).</p> |

| | | | | | | | |
|---|--------------------------------|-----------------------------|-------------|-----------------------------|----------|--|---|
| HIV Stigma Scale (Berger et al. 2001) | Stigma | HIV-specific | Descriptive | Self-reported questionnaire | 40 items | 4 domains | Reliability: Good internal consistency reliability (Cronbach's alpha \geq 0.90 for subscales and 0.96 for the summary scale) among people living with HIV. Validity: Construct validity in a sample of people living with HIV. |
| Medical Outcomes Study Social Support Survey (MOS-SS) (Sherbourne and Stewart 1991) | Social Support | Specific to Chronic Illness | Descriptive | Self-reported questionnaire | 19 items | 5 domains | Reliability: High internal consistency reliability (Cronbach's alpha \geq 0.90) among people living with HIV. Validity: Convergent and discriminant construct validity demonstrated among people living with HIV. |
| Brief COPE Scale (Carver et al. 1989, Carver 1997) | Coping response | HIV | Descriptive | Self-reported questionnaire | 28 items | 14 domains and 2 summary scores (Maladaptive Coping and Adaptive Coping) | Reliability: Adequate internal reliability (Cronbach's alpha \geq 0.50) among the general population. Validity: Construct validity demonstrated among the general population (Carver 1997) |
| Patient Reported Outcomes Quality of Life-HIV (PROQOL-HIV) Questionnaire (Duracinsky et al. 2012a, Duracinsky et al. 2012b) | Health-related quality of life | HIV | Descriptive | Self-reported questionnaire | 43 items | 8 domains and 1 global health item | Reliability: Good internal consistency reliability with Cronbach's 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. |

**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 (Steiner and Norman 2008). 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) (Nunnally and Bernstein 1994).

2_3 Guiding Principles for Best Practices in HIV and Rehabilitation

HIV increasingly is experienced as a lifelong, episodic disease, characterized by unpredictable cycles of wellness and illness. There is a need to develop research, clinical practice, and policy for HIV related rehabilitation, to address the range of impairments, activity limitations, and participation restrictions associated with HIV and its treatments.

Clinical practice guidelines are designed to improve client outcomes; they are the translation or implementation of evidence-based medicine into actionable "best practices" (Roudebush et al. 2004). *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) conducted a scoping review of the published and grey literature. This was followed by focus group and interview consultations with stakeholder groups including people living with HIV, researchers, educators, practitioners, and policymakers with expertise in HIV and rehabilitation, across Canada and internationally (O'Brien et al. 2008c). The purpose of this study was to create a framework for developing evidence-informed recommendations for practitioners working in the area of HIV and rehabilitation.

Participants were asked to describe their understanding and perspectives on best practice guidelines in the area of HIV and rehabilitation. A qualitative content analysis was used to identify key emergent themes and other issues.

Seven recommendations related to the process of developing clinical practice guidelines in HIV rehabilitation emerged that spanned areas of flexibility, scope, adopting existing evidence from concurrent health conditions, format, interprofessional approach to development and implementation, terminology, and knowledge translation.

2.3.1 Guiding Principles

Three guiding principles in the development of best practice guidelines were also established. These guiding principles fell into broad categories related to people living with HIV living in society, approaches to practice, education and research, and systems level considerations. Many of these categories overlap across the three themes.

2.3.1.1 Theme One

Theme One includes the unique characteristics and experiences of the people living with HIV living in their social context.

Best practices should:

- Incorporate an understanding of the diversity of people living with HIV

- Understand the social justice issues and challenges people living with HIV may face because of social and economic circumstances, multiple vulnerabilities and stigma or discrimination
- Recognize the importance of self-determination, self-help and support networks

2.3.1.2 Theme Two

Theme Two relates specifically to approaches to rehabilitation practice, education and research.

Best practices should:

- Incorporate a client-centred and holistic approach
- Incorporate the most current knowledge of HIV and its treatments
- Incorporate the principles of evidence-informed rehabilitation

2.3.1.3 Theme Three

Theme Three addresses systems-level issues that greatly impact on the rehabilitation care that may be received by persons living with HIV

Best practices should:

- Address access to care and include strategies to maximize access to rehabilitation services and assisting people living with HIV to navigate their care especially in under-serviced areas
- Acknowledge and address the role of rehabilitation as a component of optimal care
- Acknowledge the role of government policy and advocacy in the provision of services
- Incorporate communication strategies to ensure that all stakeholders understand what rehabilitation is and its role in HIV prevention and care

2.3.2 Additional Considerations

Additional considerations address the terminology of 'best practice' and 'practice guidelines' in the current context of HIV and rehabilitation including:

- That these considerations should include suggestions for alternative terminology to incorporate a range of belief and health systems
- An acknowledgement of the need for high-quality research assessing rehabilitation interventions in HIV to promote the development of guidelines in areas beyond exercise, massage and cognitive behavioural interventions

- That there are concerns among front-line practitioners that clinical practice guidelines are increasingly being used to sanction practice and may influence funding of programs and therefore alternative terminology may increase consideration by practitioners
- Since this is an emerging field, there was also consensus that guidelines should not be discipline-specific and should include an interdisciplinary approach

Merging the current knowledge in the traditionally separate areas of rehabilitation, HIV and disability, will result in **evidence-informed recommendations** that are specific and relevant to rehabilitation in the context of HIV. These guiding principals and additional considerations have informed the development of this resource module.

2.3.3 The Importance of Interprofessionalism in HIV Care

The current research in health sciences education suggests that interprofessional education opportunities are essential for developing effective collaborative practice (D'Amour et al. 2005). By working together, health professionals get an understanding of each other's scope of practice, learn how to collaborate and make joint clinical decisions (Bone et al. 2006). This approach offers the benefits of collaborative practice and addresses any discipline-specific needs that may arise throughout the learning process. This approach to health professional HIV education demonstrates positive outcomes in factual and interprofessional knowledge, rehabilitation insight, sense of confidence and enjoyment (Solomon et al. 2003). There is increasing evidence that an interprofessional focus will improve collaborative practice and ultimately client outcomes (Reeves et al. 2008). Any research aimed at improving healthcare outcomes for clients should involve multiple health disciplines. Due to the complex nature of HIV disease, comprehensive rehabilitation care for people living with HIV requires a team approach; therefore an interprofessional approach to guideline development is mandatory.

2.3.4 Practitioner-Client Relationship

To foster an environment that promotes good communication between the practitioner and client, the practitioner should follow the following recommendations (Moyers 1992):

- Express an empathetic, non-judgmental attitude
- Emphasize client-practitioner confidentiality

- Be aware of the client's readiness to disclose information: It is unlikely that all of the information will be revealed in the first session. The details are more likely to emerge over time, as trust is built in the client-provider relationship. In addition, rehabilitation professionals should be aware of diversity and inclusion issues and the impacts of power inequities on communication processes

Client- or patient-centred care is further discussed in [Section 7.2.2](#).

2.3.4.1 History-Taking and Assessment

In most healthcare settings, history and assessment information is gathered by a number of people, including physicians, nurses and rehabilitation professionals. A thorough client history and assessment should include the following components:

- Medical history
- Cognitive assessment
- Substance use history
- Sexual history
- Information about support networks

2.3.4.1.1 Medical History

The medical history of a person living with HIV should provide the following information:

- Confirmed HIV diagnosis
- Length of time with HIV (if known)
- Psychological effects of positive HIV test
- Symptoms
- HIV-related conditions
- History of past and current HIV treatment, both conventional (e.g. pharmaceutical) and complementary
- Organic effects of substance use or end organ effects (e.g. liver function, kidney function, heart and peripheral circulation, etc.)

2.3.4.1.2 Cognitive Assessment

The cognitive assessment will help clarify the client's ability to participate in ongoing planning of care. This assessment will also determine the needed levels of care and appropriate referrals (Moyers 1992). Both HIV and substance use can cause cognitive impairment.

2.3.4.1.3 Substance Use History

A detailed substance use history is important for the formulation of an effective treatment plan. Without a substance use history, the rehabilitation provider may be unknowingly struggling with complications arising from a client's undisclosed substance use. It is also important to

note that many drug users use more than one substance. Assessment of substance use history is described in detail in [Section 3.10.3.1.3](#).

2.3.4.1.4 Sexual History

A sexual history will permit discussion of the individual's sexual identity, orientation, and risk(s). Assessing the potential for transmission of HIV and other sexually transmitted diseases/infections requires knowledge of unsafe sexual practices. When taking a sexual history from a sex trade worker, caregivers need to be aware that the sexual practices these workers adopt with their clients may differ from those they use with their partners. Sexual Dysfunction may be an issue. Please see [Section 4_13](#).

2.3.4.1.5 Information About Support Networks

Good support networks and relationships can be meaningful, can enhance health-related quality of life, and can prolong survival. Many substance users who decide to stop using will be required to leave their existing relationships and begin building a new support system.

2.3.4.1.6 Activity and Social Participation Restrictions

A client history must necessarily include an occupational history including involvement in work, family, leisure and other social roles. This includes the physical living environment, work environment (if applicable), cultural and spiritual considerations.

2_4 International Forum on HIV and Rehabilitation Research

The Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC) is an international research collaborative based in Canada that includes people living with HIV, researchers, clinicians, representatives from community-based HIV service organizations, and policy stakeholders who have an interest in HIV and rehabilitation research. CIHRRC hosts international forums to discuss research evidence and knowledge on HIV, disability and rehabilitation. More information regarding CIHRRC can be found at <http://cihrrc.hivandrehab.ca>.

Across all represented countries, and at each forum, participants have reported that the demand for rehabilitation services continues to increase due to ongoing disease complexity and despite the success of antiretroviral therapies. Forum reports and other CIHRRC deliverables can be found at <http://cihrrc.hivandrehab.ca>.

CHAPTER 3

Symptoms and Impairments

3_1 Introduction

Red flags located throughout this section highlight particularly important clinical symptoms that indicate the need for immediate direct contact with a physician.

Primary prevention can be defined as an activity or intervention designed to prevent the occurrence of a disease, condition, or injury. Whereas, secondary prevention may involve an activity or intervention designed to prevent or postpone disease progression or death.

Primary prevention, in the form of exercise, adequate nutrition, and maximizing mental health, is a mainstay of HIV care and also falls well within the scope of rehabilitation, though it may be less familiar to rehabilitation providers. Primary interventions tend to be based in the community rather than in medical facilities.

Secondary prevention has recently taken on added importance in HIV care. Successes with the newer drug regimens have focused even greater attention on the role of rehabilitation professionals in maximizing patient function. Although rehabilitation professionals are comfortable in this role when dealing with other chronic diseases such as diabetes mellitus, multiple sclerosis, and brain and spinal cord injuries, HIV disease represents new territory for many of them.

Providing rehabilitation services for people living with HIV is not a new concept. Since the beginning of the epidemic, healthcare professionals and clients have been actively involved in enhancing performance at home and work across the entire continuum of HIV disease.

Fortunately, general rehabilitation philosophy and management principles can be readily applied to rehabilitation services for people living with HIV. This section links basic medical and rehabilitation information to symptoms and impairments, which allows rehabilitation providers to provide appropriate care for people living with HIV. This linkage is illustrated in [Table 3.1](#), which furnishes examples of common medical conditions and potential rehabilitation management interventions within six basic categories. The evidence to support rehabilitation interventions is outlined in [Section 6](#). Every individual living with HIV has a different lived experience of the disease, its treatments and other conditions, which will impact on the care and treatment plan. It is important to note that individualized assessment and treatment options are required as not all clients can or will benefit from these strategies.

Table 3.1 Examples of Rehabilitation Intervention Categories

| General Intervention Category | Examples of HIV-Related Complications | Examples of Possible Rehabilitation Interventions |
|---------------------------------|--|--|
| | Prolonged bed rest from medical illness | Positioning and mobility assessment bedside exercise by a caregiver, volunteer, therapist |
| | Muscular contractures due to hemiparesis from cerebral toxoplasmosis | Passive stretching and active assisted exercises |
| | Dysphagia from a brainstem tumour | Swallowing evaluation and use of nutritionally complete thickened liquid diet |
| Enhancement of affected systems | Right-sided weakness from CNS lymphoma | Neuro-facilitation techniques |
| | Dysarthria from PML | Alphabet picture board for communication oromotor exercises |
| | Generalized weakness from HIV-associated weight loss | Nutritional repletion and functional exercises |
| | Paraplegia due to vacuolar myelopathy | Strengthening of arms for transfers and wheelchair propulsion |
| Use of adaptive equipment | Left-sided weakness following a stroke in a left-hander | Training for writing, buttoning, eating with the right hand |
| | Ankle weakness due to mononeuropathy simplex | Ankle-foot orthosis to facilitate ankle dorsiflexion during gait |
| Environmental modification | Ataxia with poor safety awareness in bathroom | Tub bench, grab bars, raised toilet seat |

| | | |
|---|--|--|
| | Inability to work due to stairs and visual deficits from CMV | Ramp into work, telecommute, Braille |
| Psychological techniques and adjustment to disability | Memory deficits from early HIV Cognitive-Motor Complex | Memory notebook to track appointments and/or work tasks, the association of new tasks with old tasks |
| | Depression from visual loss due to CMV retinitis | Counselling for disability adjustment identification of compensatory strategies at work |
| | Anxiety due to psychological stresses and uncertainty of prognosis | Psychotherapy, hypnosis, visualization stress management, relaxation training |

Legend: CMV: cytomegalovirus CNS: central nervous system
PML: progressive multifocal leukoencephalopathy

While many elements of traditional rehabilitation philosophy and management principles apply to people living with HIV, these individuals are different from other rehabilitation populations in several respects:

3.1.1 Concurrent Medical and Neurological Diagnoses

Especially in late HIV infection, multiple medical and neurological impairments will be common. Examples include:

- Hemiparesis from cerebral toxoplasmosis together with generalized weakness from HIV-associated weight loss
- Shortness of breath from Pneumocystis carinii pneumonia together with pain from HIV peripheral neuropathy

3.1.2 Episodic and Ultimately Progressive Disease Course

As in multiple sclerosis, people living with HIV tend to have fluctuating disability. A client's functional deficits may change over time depending on the underlying complication of HIV leading to the disability. Examples include:

- Fatigue due to severe prolonged episodes of diarrhea
- Chronic pain from progressive peripheral neuropathy

3.1.3 Parallel Primary and Secondary Prevention Efforts

Rehabilitation providers will generally be asked to minimize existing HIV disability; this constitutes secondary prevention. However, rehabilitation providers should provide primary prevention concurrently with treatment of existing limitations by:

- Providing preventive nutritional information before wasting leads to additional fatigue
- Promoting exercise for health maintenance from time of diagnosis
- Encouraging individuals to do home exercises during and after rehabilitation to maintain cardiovascular and musculoskeletal health
- Identifying depression and anxiety

There is also emerging evidence for the use of preventative prophylaxis (PrEP) to reduce transmission rates in high-risk populations (Grant et al. 2010). The daily use of oral PrEP is approved by Health Canada to reduce the risk of sexual HIV transmission in those at high risk for HIV infection, when combined with safer sex practices. While Health Canada's approval does not include injection drug use transmission, it is recommended to be considered for use in people who inject drugs if they are also at high risk for HIV (CATIE, 2

3.1.4 Uniqueness of Persons Served

HIV disease has hit hardest among certain segments of the population, such as gay and bisexual men, people who use injection drugs, the poor, urban minorities, prison inmates and Indigenous peoples. As in all rehabilitation care, eliciting and understanding the identity and psychosocial background of the person with HIV-related disability is essential in collaborating the individual and their communities to plan, institute, and follow up on a rehabilitation program. The HIV population is also unique in that extensive community-based organizations have been developed over the past 30 years.

3.1.5 Importance of Psychological Impairments

Psychological issues accompany all aspects of living with HIV and may well affect rehabilitative efforts. Depression can occur pre- and post-HIV testing and anytime after diagnosis of HIV. Affecting many people living with HIV, depression can manifest as sadness, crying, changes in sleep and appetite, depressed mood, apathy, and lack of pleasure. Depression is sometimes confused with HIV-associated cognitive impairment because they share symptoms such as impaired concentration and judgment, agitation, psychomotor retardation, diminished motivation, and lethargy. The diagnosis of depression is even more complicated when the individual:

- Uses substances in a harmful or hazardous way
- Uses multiple medications
- Has a central nervous system disease
- Has another mental illness in addition to depression

Care management is multifaceted and may include complete psychosocial assessment, psychotherapy, and antidepressant medications. Even "reactive" depression (depression that emerges as a result of HIV status, whether new or worsening) can become a major depression and warrant pharmacological treatment.

Likewise, anxiety is very common and can be related to:

- Vulnerability
- Prejudice
- Dependence
- Concern with body image
- Fear of physical and mental disability
- Isolation
- Unpredictability of HIV
- Prospect of dying
- Medical treatments
- Loss of independence and control

Anxiety can manifest as:

- Agitation
- Insomnia
- Restlessness
- Sweating
- Palpitations
- Hyperventilation
- Panic attacks
- Shaking
- Excessive worry
- Change in appetite
- Socially isolating oneself

Assessment and treatment should be appropriate to the emotional, cognitive and perceptual presentation and to the context of the person and the illness. Reassurance is critical. Rehabilitation providers can teach individuals to relieve anxiety and provide them with therapies such as hypnosis, relaxation, and visualization. Referral for medication or other complementary therapies (e.g. acupuncture, aromatherapy, massage) may be indicated. Systemic impacts of mental health are further discussed in [Section 3_9](#), and evidence-based treatments are discussed in [Section 6](#).

3.1.6 Importance of Community Resources in HIV Rehabilitation

Community-based HIV Organizations (CBHOs) provide a wide range of health promotion services and programs for people living with HIV and their caregivers. Although not usually described as "rehabilitation services," many are designed to enable people living with HIV to regain or maintain optimal physical and psychosocial functioning and are rehabilitative in nature. Linking individuals to local community organizations can reduce the isolation many people feel, and often has a tremendously positive impact on overall rehabilitation outcomes. These organizations can include the many disability organizations that do not specifically target the HIV population but that do provide support to people living with a variety of disabilities. For example, many people living with HIV who have severe vision impairment due to cytomegalovirus retinitis access the Canadian National Institute for the Blind (CNIB) for practical training and emotional support, which helps them adapt to their new disability.

In addition to providing health promotion programs and services, community organizations also maintain extensive referral lists for linking people living with HIV and their caregivers to relevant professional and community resources. CBHOs have been a vital resource and support system for HIV-affected communities throughout the epidemic and can make significant contributions to the rehabilitation program of an individual living with HIV. Rehabilitation providers should be aware of local community resources, both HIV- and non-HIV-specific, that can provide an important complement to traditional rehabilitation services.

3.1.7 How to Use this Section

Each of the subsections in [Section 3](#) discusses an impairment area, starting with a general description of potential contributing disease processes. These descriptions include red flags highlighting particularly important clinical symptoms that indicate the need for immediate direct contact with a physician. A table providing information on the clinical aspects of that impairment area may also be provided.

The information in the table is important because functional changes may indicate the onset or worsening of a medical complication; rehabilitation providers may be in a position to identify new disease complications between medical evaluations. The table is often followed by a detailed description of rehabilitation interventions and a list of resources available in the community. Some of the more straightforward rehabilitation interventions can be provided by non-professionals (such as family members or partners) after appropriate training. The listing of community resources is not exhaustive and not all resources described


may be available in any one community. A review of the research to support the use of many of these interventions can be found in [Chapter 6](#).

Note: The tables and lists of interventions presented in this section are not intended to be exhaustive; they provide a starting point for linking medical and rehabilitation evaluations and treatment.

3_2 Pain

Pain is a common symptom in people living with HIV. The International Association for the Study of Pain defines pain as "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage". This is the working definition of pain that is being taught in many rehabilitation schools. There are a variety of causes for pain (see [Table 3.2](#)). As well, multiple problems (e.g. pain from Achilles tendon tightness, foot pain from peripheral neuropathy) can occur at the same time. The presentation and character of the pain (locations, quality, intensity) can give clues to the etiology.

Musculoskeletal etiologies, such as myofascial pain secondary to inactivity, poor posture, deconditioning, and pre-morbid injury, tend not to be life-threatening. Likewise, rheumatologic etiologies can be quite debilitating, but rarely life-threatening. Pain associated with abnormalities in strength, sensation, and reflexes tends to occur with central or peripheral neurological disease as a pain source. Management of pain in HIV infection often requires both medications and multiple modalities for adequate control. Analgesic medications should be provided in a step-wise approach, using the least invasive route of administration.

 **Red Flag:** New, changed, or poorly controlled pain should result in an immediate medical referral.


 **Red Flag:** New onset of headaches may be serious and should result in an immediate medical referral.

Table 3.2 Clinical Aspects of Pain

| Category | Causes and Considerations |
|--|---|
| Myofascial pain (including headache) syndromes | <ul style="list-style-type: none"> • Inactivity, poor posture, deconditioning • Exacerbation of pain by anxiety or depression • Inadequate sleep |

| | |
|---|--|
| Joint pain | <ul style="list-style-type: none"> • Joint destruction due to secondary processes, malignancy, drug effects, or repetitive strain due to over-use • Psoriatic arthritis, recurrent hemarthrosis, bacterial and TB joint infections, malignancy • Damage to "unaffected" joints (e.g. left knee pain due to compensating for pain in the right knee) |
| Myopathy | <ul style="list-style-type: none"> • Inflammatory (e.g. polymyositis) • Non-inflammatory • Toxic |
| Respiratory tract disease | <ul style="list-style-type: none"> • Infection (e.g. PCP, TB) • Tumour (e.g. KS) • Pneumothorax • Pulmonary embolus • Pleural infarction |
| Pain associated with CNS lesions (including headache) | <ul style="list-style-type: none"> • Possible CNS lesions: toxoplasmosis, fungal or bacterial abscess, CNS lymphoma • Headache from abscess, cryptococcal meningitis, CNS lymphoma • Meningismus (e.g. cryptococcal meningitis) |
| Distal symmetrical polyneuropathy | <ul style="list-style-type: none"> • HIV-mediated • Vitamin deficiency (e.g. B12) |
| Mononeuropathy simplex and multiplex | <ul style="list-style-type: none"> • Primary effect of HIV • Secondary immune complex • CMV (in late disease) |
| Progressive polyradiculomyelopathy | <ul style="list-style-type: none"> • CMV infection of the cauda equina |
| Esophageal and abdominal pain | <ul style="list-style-type: none"> • Infections (e.g. esophagitis) • Malignancies • Renal colic • Hepatitis • Drug-induced (e.g. narcotics) • Obstructions • Biliary tract disease • Pancreatitis • Colitis • Enteritis • Malabsorption |

| | |
|---|---|
| Somatization, psychological pain disorder | <ul style="list-style-type: none"> Psychological factors have a major role in onset, exacerbation, severity, and maintenance of pain |
| Other sources of neuropathic pain | <ul style="list-style-type: none"> Acute herpes zoster, post-herpetic neuralgia |

Legend: CMV: cytomegalovirus, CNS: central nervous system, KS: Kaposi's sarcoma, PCP: Pneumocystis carinii pneumonia, TB: tuberculosis.

3.2.1 Rehabilitation Interventions

3.2.1.1 Peripheral Neuropathic Pain

Kietrys et al. (2014a) performed a systematic review to explore the effectiveness of physical therapy in individuals with HIV-associated distal sensory neuropathy. Unfortunately, there is a paucity of studies in the area. However, interventions that may improve symptoms, function, disability, and quality of life in individuals with HIV-DSP include:

3.2.1.1.1 Physical Modalities

- Electrotherapeutic agents such as transcutaneous electrical nerve stimulation (TENS) or interferential current (IFC) for symptomatic management

3.2.1.1.2 Adaptive Equipment

- Footwear: supportive, well-fitting, nonslip sole, and minimal seams to minimize irritation
- Orthotics: ankle-foot orthoses for foot drop associated with pain
- Foot orthoses: inserts for shoes to minimize pain by providing support and cushioning
- Bed cradle or boxes to keep sheets off feet
- Resting splints to hold ankles in dorsiflexion, especially helpful in relieving pain at night

3.2.1.1.3 Desensitization Techniques

- Alternate hot and cold contrast baths
- Rub skin with various textured materials, soft to rough
- Wear socks inside-out to avoid seams against feet

3.2.1.1.4 Psychological Counselling and Interventions

- Counselling to facilitate coping and adjustment regarding symptoms, pain management
- Visualization
- Meditation
- Biofeedback

3.2.1.1.5 Environmental Assessment

- Reduce tripping hazards (e.g. no loose scatter rugs)

- Use a non-slip bath mat
- Eliminate clutter
- Install handrails around periphery, especially up and down stairs

3.2.1.2 Medication Management

- Trial of analgesics, anti-inflammatories, antidepressants, antispasmodics and other co-analgesics, and adjuvant medications
- The International Association for the Study of Pain has released a review of interventions for painful HIV-associated sensory neuropathy and concludes that a strong placebo response has complicated attempts to identify treatments that are superior to placebo. There is a lack of evidence to support the use of many drugs shown to be beneficial in other neuropathic pain states. Only the high-dose capsaicin patch has some evidence of efficacy superior to placebo (International Association for the Study of Pain (IASP 2014))

3.2.1.3 Miscellaneous

- Assess need for a mobility aid if balance and safety become a concern with severe pain
- Monitor skin integrity of feet that are severely numb
- Carefully check the temperature of bath water with unaffected limb
- Use caution when trimming toenails

3.2.2 Musculoskeletal and Joint Pain

3.2.2.1 Exercise

- Stretching of **tight** muscles (muscles commonly affected by prolonged inactivity include calf, thigh, and chest)
- Strengthening of **weak** muscles, especially stomach, back, and thigh
- Passive and active range of motion exercises to maintain mobility of joints if non-ambulatory due to pain

3.2.2.2 Positioning

- Encouragement of proper posture and body mechanics in lying, sitting and standing to maximize function and avoid secondary complications
- Splints to prevent joint deformities and rest acutely inflamed joints
- Education on joint protection strategies
- Regular change of positioning to avoid pressure ulcers, if decreased or no activity due to pain
- Gel pads to reduce risk of skin breakdown from shearing forces
- Dense foam or air-inflated cell cushions, which may reduce risk of pressure ulcer development (especially at bony prominences)

3.2.2.3 Physical Modalities

- Hydrotherapy to maximize joint protection, improve flexibility, and improve exercise tolerance
- Bath or shower in the morning to help alleviate pain and stiffness before dressing and self-care activities
- Whirlpool to help relieve pain
- Application of ice for acute pain management and either hot or cold for chronic pain (based on individual preference)
- Transcutaneous electrical nerve stimulation (TENS) or interferential current (IFC) for symptomatic management
- Manual therapy treatment including joint mobilization and manipulation for stiff joints, acupuncture or dry needling techniques to release tight muscles, or other soft tissue techniques to release shortened muscles

3.2.3 Medications Management

- Trial of analgesics, anti-inflammatories, antidepressants, antispasmodics and other co-analgesics, and adjuvant medications

3.2.4 Psychological Counselling and Techniques

- Psychological counselling to address potential fear, distress, anger, excessive preoccupation, distortion of reality, anxiety, and phobia
- Visualization
- Hypnotherapy
- Meditation
- Biofeedback

3.2.5 Miscellaneous

- Acupuncture
- Therapeutic Touch or Shiatsu
- Reiki
- Massage Therapy
- Craniosacral Therapy
- Myofascial Release

3.2.6 Community Resources

Community organizations may provide the following resources:

- Information on non-allopathic therapies as part of treatment information programs or libraries
- Referrals to practicing homeopaths and naturopaths
- Culturally relevant strategies or therapies for dealing with pain and illness

- Massage therapies, including Reiki and traditional deep muscle massage (often provided at no charge at some Community-Based HIV Organizations)
- Stretching, yoga, Tai Chi, and fitness classes
- Individual counselling, peer counselling, and support groups tailored to specific cultural groups
- In Ontario, people living with HIV with a confirmed diagnosis of arthritis can make a self-referral to the Arthritis Society Arthritis Rehabilitation and Education Program (<https://arthritis.ca/support-education/support-in-your-community/arthritis-rehabilitation-and-education-program>). Treatment is funded through the provincial government.
- In the rest of Canada, the Arthritis Society provides a variety of services <http://www.arthritis.ca>

3_3 Weakness and Coordination

Many of the common causes of weakness and coordination impairments are shown in [Table 3.3](#). Neurological weakness from either peripheral or central lesions should be distinguished from weakness due to generalized deconditioning or fatigue because the evaluation, management, and prognosis are quite different. Weakness due to underlying peripheral or central neurological disease is often more localized, is associated with abnormalities on neurological examination, and tends to be more common in moderate to advanced HIV disease. Generalized weakness associated with deconditioning (as a result of a prolonged illness or immobility) is also common in advanced HIV disease.

Neurological etiologies will present with typical distributions of strength and reflex changes (e.g. proximal weakness with myopathies; hemiparesis, hyperreflexia, and hypertonia with cerebral or brain stem lesions; and distal weakness with peripheral neuropathy). Sometimes mild coordination problems are due to weakness, but cerebellar disease should also be considered. A variety of diagnostic testing and neuroimaging may be necessary to initiate proper medical treatment before or during rehabilitation intervention.


 **Red Flag:** New neurological findings should result in an immediate medical referral.

Table 3.3 Clinical Aspects of Weakness and Coordination Impairments

| Category | Causes and Considerations |
|---|--|
| Focal lesions of brain | <ul style="list-style-type: none"> • Cerebral toxoplasmosis, fungal or bacterial abscess, PML • HIV-related stroke in cerebrum or brainstem • CNS malignancy (primary lymphoma, metastatic) • Long-term alcohol misuse |
| Spinal cord lesion | <ul style="list-style-type: none"> • HIV vacuolar myelopathy • Tumour of the spinal cord (e.g. lymphoma) • Abscess (bacterial, fungal, TB) • Progressive polyradiculomyelopathy from CMV |
| Inflammatory demyelinating polyneuropathy (acute and Chronic types) | <ul style="list-style-type: none"> • Probably immune-mediated (acute inflammatory demyelinating polyneuropathy clinically resembles Guillain-Barré Syndrome) |
| Myopathy | <ul style="list-style-type: none"> • HIV-related |

Legend: CMV: cytomegalovirus CNS: central nervous system PML: progressive multifocal leukoencephalopathy TB: tuberculosis

3.3.1 Rehabilitation Interventions

3.3.1.1 General Guidelines

- Exercises and functional activities relevant to each person's goals
- Neuro-rehabilitation strategies for central nervous system impairments (e.g. proprioceptive neuromuscular facilitation (PNF) and Bobath techniques)
- Oral exercises to improve dysphagia and decrease risk for aspiration pneumonia
- Oromotor exercises to improve articulation and slurred speech

3.3.1.2 Enhancing Mobility

- Practice ambulation on stairs, uneven surfaces, and outdoor surfaces which resemble community circumstances
- Ensure correct prescription and sizing of mobility aids (including wheelchairs and scooters if appropriate)
- Wear appropriate footwear and orthoses
- Use general strengthening exercises that address large muscle groups (e.g. quadriceps, gluteal muscles)

- Assess both standing and sitting balance
- Use a mirror for visual feedback during gait retraining

3.3.1.3 Problems with Activities of Daily Living

3.3.1.3.1 General Guidelines

- Ensure adequate trunk support and positioning to maximize upper extremity coordination and movement
- Have client dress the weak or uncoordinated side first

3.3.1.3.2 Adaptive Equipment to Enhance Independence

- Grab bars on the tub or by the toilet
- Bath seats and tub transfer benches with a backrest, if balance is poor
- Raised toilet seats to ease transfers on and off toilet
- Floor-to-ceiling pole at bedside to assist with transfers in and out of bed
- Urinal or commode at bedside during the night
- More than one phone at home (cordless preferred)
- Widened or weighted utensil handles to combat loss of coordination

3.3.1.3.3 Decrease the Risk of Falls

- Conduct an environmental assessment of layout and potential safety concerns in the home
- Consider removing throw rugs that may pose a tripping hazard
- Assess clients for cognitive factors, including poor insight and impulsivity, and motor factors which may increase fall risk
- Evaluate medications for their impact on blood pressure, dizziness, coordination, etc.
- Adequately widen paths for walking with assistive devices such as canes and walkers
- Use safety call systems
- Remove extension cords and clutter from home or room
- Ensure adequate lighting including night lights and a clear path to the bathroom from the bed
- Avoid soft and low-height couches or chairs that make rising difficult with weak legs
- Ensure belongings are within easy reach (e.g. reorganize kitchen and office for greatest accessibility to commonly used items)
- Use a reacher to pick things up off the floor
- Use bath mats, non-slip decals or mats in the shower or tub

3.3.1.4 Community Resources

Community organizations may provide the following resources:

- Stretching, yoga, and other fitness classes

- Individualized fitness or weight training programs by qualified instructors
- Individual professional or peer counselling
- Loan of mobility and adaptive equipment (e.g. canes, walkers, wheelchairs, bath seats)

3_4 Fatigue

Fatigue is one of the most common complaints in persons at all stages of HIV infection and is often multifactorial (Pense et al. 2008). There is a myriad of possible medical etiologies for fatigue, as outlined in Table 3.4. Sometimes a specific cause of fatigue is not identified. Important medical considerations include fatigue as a manifestation of systemic infection and as a side effect of medications. In many cases, fatigue will be the primary impairment leading to disability, even in individuals with focal neurological weakness (Ferrando et al. 1998).

The emotional stress of chronic disease and lack of social supports can result in fluctuating levels of anxiety and depression leading to complaints of fatigue, poor motivation, apathy, and anguish. One study's finding on the qualitative effects of fatigue of people living with HIV demonstrates that although most experience chronic fatigue, it is rarely acknowledged or recognized by family, friends, co-workers and even healthcare professionals (Jenkin et al. 2006). Depression should be considered as both an etiology and a sequela of fatigue (Marcellin et al. 2007). When the related conditions of depression, fatigue, and physical disability are present, the root cause of each is difficult to determine.

The situation tends to become even more complicated in clients with multiple disease diagnoses, such as those who are co-infected with HIV and Hepatitis C (HCV). These individuals have demonstrated higher levels of fatigue and depression and lower quality of life. However, this experience appears to be primarily related to socio-economic issues rather than HCV infection (Braitstein et al. 2005).

Fatigue may exacerbate depression related to change of function, fear of losing control, or a perception of the "beginning of the end." A combined pharmacological and psychotherapeutic approach may diminish actual or perceived physical limitation due to fatigue, as well as enhance ongoing rehabilitation interventions.

Note: Fatigue may sometimes result from overly aggressive rehabilitation interventions.

Table 3.4 Clinical Aspects of Fatigue

| Category | Causes and Considerations |
|--------------------------|---|
| Nutritional deficiencies | <ul style="list-style-type: none"> • Deficiency of vitamins, trace elements, protein, lipids, calories (food energy) |

| | |
|----------------------------|---|
| Infections | <ul style="list-style-type: none"> • HIV • Secondary infection (e.g. MAC, cryptosporidiosis, microsporidiosis) • Virtually any chronic infection |
| Malabsorption | <ul style="list-style-type: none"> • HIV enteropathy chronic diarrhea due to other etiologies (e.g. MAC, cryptosporidiosis, microsporidiosis) |
| Anemia | <ul style="list-style-type: none"> • HIV • Chronic disease • Opportunistic infections (e.g. parvovirus, MAC) • Vitamin deficiency (e.g. B12, folate) • Medication-induced (e.g. sulfa antibiotics) |
| Medication-induced fatigue | <ul style="list-style-type: none"> • Pain medication • Anticonvulsant drugs • Substance use |
| Psychological | <ul style="list-style-type: none"> • Depression • Anxiety • Fatigue associated with chronic pain |
| Metabolic | <ul style="list-style-type: none"> • Electrolyte imbalance • Thyroid dysfunction • Adrenal insufficiency |

Legend: MAC: Mycobacterium avium complex

3.4.1 Rehabilitation Interventions

- Selection of priorities
- Time management
- Pacing
- Good posture and body mechanics
- Efficiency
- Organization
- Timing of therapies and activities during "high energy" times of the day
- Planning of outings and errands to reduce transportation time or physical demands
- Setting of priorities by individuals (in the knowledge that energy limitations may preclude "doing everything today")
- Recruitment of assistance or delegation of energy-demanding activities of daily living (e.g. homemaking, errands, shared meal preparation)
- Knowing one's limits

3.4.1.1 Energy Management

Energy conservation is an approach to avoid fatigue through increased awareness of the easiest ways of carrying out necessary activities such as self-care, work, rest, and leisure.

3.4.1.2 Environmental Assessment

- Assessment of the home and workplace, including:
 - Ergonomic assessment
 - Need for and feasibility of worksite modifications
 - Task analysis
 - Need for job or equipment adaptations at work and home
- Change in job structure or home schedule
- Reduction in number of work hours
- Organization of work and storage areas
- Provision of assistive devices

3.4.1.3 Exercise

Aerobic exercise (however, the energy demands of this type of exercise need to be weighed against the other competing life activity priorities requiring energy)

3.4.1.4 Nutrition

- Focus on easy, quick meals with high nutrient density and that address unique needs of individual
- Use friends or family to assist with grocery shopping and other errands
- Refer individuals to community food bank programs
- Focus on efficient preparation techniques
- Use meals-on-wheels programs, delivery services
- Prepare extra portions for freezing for future meals

3.4.2 Medications

- Trials of medication to increase energy (e.g. Ritalin, vitamin B12, testosterone injections, anabolic steroids such as Deca-Durabolin)
- Antidepressants to try to elevate mood, increase activity and enhance energy level, if depression is present

3.4.3 Psychosocial

- Management of stress, depression, anxiety, and sleep disturbances through psychological, educational, and supportive counselling
- Full consideration by the individual of the psychological, emotional, social, physical, and financial aspects of working or returning to work (see [Chapter 6_7](#))

3.4.4 Community Resources

Community organizations may provide the following resources:

- Individual professional or peer counselling
- Support groups
- Nutritional assessments by registered nutritionists and dietitians
- Complementary health programs or funding to subsidize the purchase of vitamins, minerals, herbal remedies, and other complementary therapies
- Health promotion and fitness programs
- Home care
- Loan of mobility and adaptive equipment (e.g. canes, walkers, wheelchairs)

3_5 Weight Management

Involuntary weight loss associated with HIV is a function of an imbalance between food energy intake and total energy expenditure (resting energy expenditure, diet-induced thermogenesis, and expenditure from physical activity). Multiple etiological factors exist (as outlined in [Table 3.5](#)) and a multitude of interventions are required. Both the magnitude and the rate of weight loss are important. The amount of fat lost is proportional to the amount of fat a person has to start with. However, when weight is gained following a significant loss, the composition of the weight gain may be more fat than lean mass.

The introduction of antiretroviral therapy may alter the balance, but this remains to be established. Some experts believe that involuntary weight gain around the waist is a common side effect of certain antiretroviral therapies and should also be taken into account as this can increase the risk of cardiovascular disease (Kressy et al. 2009).

In early HIV disease, transient weight loss is commonly related to anxiety and depression. As HIV progresses, weight loss is associated with abnormalities of multiple organ systems. Infectious processes can affect both the gastrointestinal tract and endocrine system resulting in weight loss. Some medications used to treat specific conditions can result in weight loss secondary to anorexia or nausea (e.g. Septra/Bactrim, chemotherapy). Primary prevention in the area of weight loss and nutrition should be a component of treatment for existing physical limitations.

People living with HIV or AIDS are at risk for nutritional-related health problems and should receive nutritional intervention when changes in body weight or composition occur.



Red Flag: Significant, unexplained weight loss should result in an immediate medical referral.

Table 3.5 Clinical Aspects of Weight Loss

| Category | Causes and Considerations |
|--|---|
| Anorexia | <ul style="list-style-type: none"> • Esophagitis (e.g. CMV, HSV, candida) • Psychological, emotional, or psychiatric problems • Abnormal taste, pain, or dysphagia (e.g. oral and esophageal candidiasis, HPV, KS, OHL, CMV, HSV, aphthous ulcers, drug effect, idiopathic) • Tumour necrosis factor, cytokine dysregulation • Medication-related • Chronic infection |
| Malabsorption with or without diarrhea | <ul style="list-style-type: none"> • HIV enteropathy • Secondary infections (e.g. MAC, cryptosporidium, microsporidiosis) • Medication-related |
| Obstruction | <ul style="list-style-type: none"> • Tumour (e.g. KS, lymphoma) |
| Endocrine dysfunction | <ul style="list-style-type: none"> • Adrenal insufficiency • Hypogonadism • Hypothyroidism |
| Hypermetabolic state or fever | <ul style="list-style-type: none"> • HIV • Tumour |
| Psychological | <ul style="list-style-type: none"> • Depression |

Legend: CMV: cytomegalovirus; HPV: human papillomavirus; HSV: herpes simplex virus; KS: Kaposi's sarcoma; MAC: Mycobacterium avium complex; OHL: oral hairy leukoplakia; PCP: Pneumocystis carinii pneumonia

3.5.1 Rehabilitation Interventions

3.5.1.1 Nutritional

3.5.1.1.1 General Guidelines

Maintenance of a graphic log of both weight and body composition measurements (e.g. skin fold, mid-arm muscle area, bioelectrical impedance analysis) to provide an early warning of wasting and new medical complications.

3.5.1.1.2 Anorexia and Early Satiety

- Small, frequent, nutrient-dense meals
- Multivitamin or mineral supplements
- Enteral or parenteral nutrition
- Positive social environment during mealtimes

3.5.1.2 Alterations in Taste (Dysgeusia)

- Spices and seasonings to mask the offending flavours and foods
- Mouth hygiene maintenance
- Zinc supplements

3.5.1.3 Pain and Inflammation in the Mouth (Mucositis) / Pain on Swallowing (Odynophagia)

- Consume foods at or below room temperatures
- Determine individual tolerance to acidic, rough, or seasoned foods
- Use artificial saliva or candies to help alleviate dry mouth
- "Mask" oral medications in soft or mashed foods to improve swallowing

3.5.1.4 Difficulty Swallowing (Dysphagia)

- Swallowing studies to establish nutritionally adequate diet based on texture and consistency
- Trial feeding, as directed by a speech-language pathologist

3.5.1.5 Dyspnea while Eating

- Choose nutrient-dense meals and use supplemental oxygen as needed
- Ensure that nasal cannula is available at mealtimes

3.5.1.6 Malabsorption and Diarrhea

- Choose low-fat and low-lactose foods
- Be aware of altered insoluble and soluble fibre
- Ensure adequate replacement of vitamins, minerals, electrolytes, and fluid losses (note: suggested dietary modifications are specific to cause and must be individualized)

3.5.1.7 Nausea and Vomiting

- Avoid known triggers of nausea and vomiting
- Avoid sweet, fried, or fatty foods; choose bland or salty foods
- Avoid strong-smelling foods
- Avoid caffeine, alcohol, and gas-producing foods
- Consume liquid and dry portion of the meal separately (allow a one-hour interval)
- Wait until after a meal to take medications associated with nausea
- Eat dry toast, cereals, and crackers
- Take antiemetic medications (e.g. compazine)

3.5.1.8 Abdominal Cramping and Bloating

- Assess lactase status
- Consume nutrient-dense, low-fat, small, frequent meals

- Avoid very hot or very cold foods and beverages

3.5.1.9 Dehydration

- Replace losses (normal fluid replacement is 1,800 - 2,000 mL per day)
- Encourage nutrient-dense fluids (e.g. Ensure, Boost)
- Maintain electrolyte balance (e.g. sports drinks such as Gatorade)

3.5.1.10 Constipation

- Gradually increase amount of soluble or insoluble dietary fibre
- Increase fluids
- Add bulking agents
- Review drug side-effects

3.5.2 Physical

- Strengthening exercises and weight-bearing activities to promote bone-density maintenance
- Short-term, high-intensity progressive resistance training to help retain or increase muscle mass
- Coordination of exercise with nutrition intervention to ensure appropriate energy balance
- Consider stool softeners and motility agents

3.5.3 Medications

- Appetite stimulants (e.g. dronabinol, megestrol acetate)
- Anabolic agents (e.g. oxandrolone, testosterone, growth hormone)
- Cytokine modulators (e.g. pentoxifylline, thalidomide)
- Antiemetic agents
- Antimotility, luminal-acting, hormonal agents
- Motility agents (to facilitate gastrointestinal emptying; e.g. prokinetic agents)

3.5.4 Miscellaneous

- Counselling on body image or eating disorders
- Education on maintenance of skin integrity
- Assistance in obtaining safe, nutritionally adequate food
- Assistance in stabilizing economic and housing situation
- Assistance in stabilizing substance use

3.5.5 Community Resources

Community organizations may provide the following resources:

- Nutritional assessments

- Complementary health programs or funding to subsidize the purchase of vitamins, minerals, herbal remedies, and other complementary therapies
- Food banks and high-calorie dietary supplements (e.g. Boost, Ensure) which may be available to people living with HIV who are on social assistance or who have limited incomes, at reduced prices or at no charge
- The Canadian AIDS Treatment and Information Exchange (CATIE) also produces updated resources for people living with HIV on topics of nutrition that are available online, free of charge <http://www.catie.ca>

3_6 Cognitive Impairments

Cognitive decline is one of the most feared complications of HIV infection. HIV-Associated Neurocognitive Disorders (HAND) occurs in an estimated 30-50% of individuals with HIV (Heaton et al. 2010). The most recent research classification for HAND was determined by an NIH working group in 2007, which was convened in Frascati, Italy, and is therefore commonly referred to as the Frascati Criteria (Antori et al. 2007). The Frascati Criteria allows for three diagnostic categories: Asymptomatic Neuropsychological Impairment (ANI), Mild Neurocognitive Disorder (MND) and HIV-Associated Dementia (HAD). For each of these HAND diagnoses, an individual must demonstrate at least mild neuropsychological impairment in at least two cognitive domains that are attributable, at least in part, to HIV infection. HAND is often under-recognized and under-treated, especially since current screening tools are inadequate for identifying milder forms of HAND (Zipursky et al. 2013). The Mind Exchange Working Group recently developed evidence and consensus-based answers to key clinical questions for the management of HAND (Mind Exchange Working Group 2013). The current consensus among thought leaders is that "what is good for the heart is good for the brain" (Rourke 2014). It is important to note that according to the Frascati Criteria, the essential feature of HAND is a cognitive disturbance; this revision eliminated the possibility of HIV neurocognitive disorders being diagnosed by neuromotor and non-cognitive psychiatric changes such as changes in personality or mood (Gandhi et al. 2010). Many of the common causes of cognitive impairments are shown in [Table 3.6](#).

Early cognitive symptoms include decreases in reaction time, attention, short-term memory, and general psychomotor slowing. Behavioural manifestations include apathy, social withdrawal, and impaired judgment. Motor problems include lower extremity weakness and spasticity, tremor, and balance dysfunction. Notably, as people living with HIV live longer and age with HIV, age-related cognitive issues also emerge. Aging can lead to diminished levels of cognition, memory, fine motor control, usable field of vision and brain

mass. This can manifest as trouble remembering names, misplacing items and forgetting details of conversations (Hoogendam et al. 2014, Harada et al. 2013).

To guide rehabilitation interventions or vocational re-integration, trained personnel can use standardized psychometric tests with proven reliability and validity to establish the diagnosis and to assess relative cognitive strengths and weaknesses. Neuropsychological testing can help determine the relative contributions of organic and psychological etiologies to cognitive dysfunction.

Competence — the ability to make sound decisions and manage one's affairs — is another significant aspect of personal health assessment. All individuals with cognitive impairments should pursue a power of attorney for personal care and finances. In some places, a living will is a recognized legal document that outlines advanced directives for care. Because a change in one's medical status can affect competence, cognitive abilities should be tested following any such change.

Communication deficits in HIV infection have several etiologies. Infection, stroke or tumour of the language cortex in the dominant cerebral hemisphere can lead to aphasia. If cranial nerves and other parts of the brain are also affected, facial weakness, dysarthria and cognitive-communication deficits may also be evident. Severe infections of the mouth and esophagus can lead to difficulty in articulation and swallowing due to pain. Finally, cognitive-communication deficits, such as inappropriate social behaviour, difficulties with information processing and verbal memory may occur in the presence of HIV-Associated Dementia.


 **Red Flag:** Any changes in cognition should result in an immediate medical referral.

Table 3.6 Clinical Aspects of Cognitive Impairments

| Category | Causes and Considerations |
|---|---|
| HIV-Associated Neurocognitive Disorder | <ul style="list-style-type: none"> • HIV |
| Cognitive impairment due to other metabolic or neurological diagnoses | <ul style="list-style-type: none"> • Hypoxia • Cryptococcal meningitis, syphilis, neurovascular disease • Focal cerebral disease • Vitamin deficiency (e.g. B12, B6) • Electrolyte abnormalities • Traumatic brain injuries • Pre-existing developmental delay |

| | |
|-----------------------------|--|
| Psychological disorders | <ul style="list-style-type: none"> • Depression • Anxiety • Delirium • Premorbid psychiatric disorders • Post-traumatic stress disorder |
| Substance-related disorders | <ul style="list-style-type: none"> • Prescription medications (narcotics) • Over-the-counter medications • Street drugs or alcohol: premorbid or current |

3.6.1 Rehabilitation Interventions

There is increasing evidence that whatever is good for the cardiovascular system is likely good for the brain and therefore lifestyle management can target:

- Smoking cessation
- Reduced alcohol intake
- Increased exercise

It is important to increase exercise, as adults who are more physically active perform better cognitively (Vance et al. 2005). Physical activity has the benefit of mitigating several health conditions (e.g. diabetes, heart disease) that are common in HIV (Brown et al. 2005) and which are known to harm the brain (Lewis and Hoeger 2005). Regular exercise stimulates the production of nerve growth factors that are critical for the survival and maintenance of sympathetic and sensory neurons that aid neurocognitive functions. Regular exercise should be an enjoyable activity while maintaining realistic and gratifying exercise goals.

Additionally, there are restorative strategies that promote recovery of damaged neural circuits and restore function in impaired cognitive processes. Research has shown that the brain can grow and modify, even in later years, due to plasticity (Doidge 2007). One double-blinded, multicentre, prospective randomized controlled trial of 524 adults between the ages of 65 and 94 who were randomized to receive Plasticity-based Adaptive Cognitive Training demonstrated a 131% improvement in the speed at which the brain processes information, improved memory by ten years as well as improvement across a variety of standardized memory tests (Smith et al. 2009). As many as 75% of participants reported positive changes. Some examples included:

- 54% increase in brain processing speed
- Better word recall, short-term memory
- Improved hearing
- Improved handwriting
- Improved self-confidence

The brain fitness program by Posit Science (<http://www.positscience.com/>) has identified four primary areas to focus upon while working on brain fitness. These include working on tasks that are:

- Increasingly difficult
- Mentally rewarding
- Unexpected or unusual
- Requiring focused attention

Some Exercises for Brain Fitness include:

- Learning to play music
- Learning a language
- Solving jigsaw puzzles, >500 pieces
- Playing ball or juggling
- Crocheting or knitting
- Using one's "other" hand
- Dancing – waltz versus tango lessons
- Playing bridge, solving crossword puzzles – 'up the ante'

3.6.1.1 Managing Complex and Simultaneous Tasks

- Avoid assuming unfamiliar and novel responsibilities
- Reduce sequential reasoning difficulties by segmenting tasks. Break down complex tasks into several smaller, more manageable steps (may still require verbal or physical cueing by therapist or caregiver)
- Reduce visual and auditory distractions in environment to enhance performance
- Minimize distractions by confining activities to a single task at a time and avoid tasks in which the speed of performance is important
- Ensure clear transition period between activities to provide appropriate cueing to the commencement of a new task
- Use calendars and agenda books to assist in planning appointments
- Create structure in daily routines to prompt rote skills, especially with activities of daily living
- Practice restorative learning (which is not readily generalizable), practice should be goal-directed and useful in activities of daily living

3.6.1.2 Maximize Safety

- Evaluate risks of wandering, and install appropriate environmental controls or supervision to ensure safety
- Ensure that the client wears identification in case they wander or become lost and disoriented
- Evaluate the environment
- Address tripping hazards
- Install railings to help with balance
- Install good lighting

- Wear good footwear
- Unplug stove or remove knobs or fuses to prevent the individual from cooking when alone, if there are concerns about cooking
- Lock up hazardous appliances, poisonous cleaners and medications
- Decrease the hot water temperature to 48.9°C (120°F) or less to reduce the risk of accidental scalding

3.6.1.3 General Cognitive Deficits

3.6.1.3.1 Cognitive Stimulation

- Provide familiar and meaningful activities within the person's abilities
- Practice inductive and deductive reasoning skills (e.g. use of analogies, drawing conclusions, inferencing), using materials such as magazines, articles, videos, television and radio programs, and other relevant items
- Present real-life situations: ask the person to identify the problems, solutions, and consequences of solutions; evaluate the pros and cons, and identify how the person feels in the situation
- Use functional activities to develop practice in categorization, sequencing, prioritizing, and outlining (e.g. following a recipe)
- Train caregivers and communication partners to speak simply and strategically
- Ask the person to explain stories, jokes, and situations (using materials of interest)
- Encourage and stimulate any form of oral expression
- Establish a purposeful response to speech (e.g. "yes" and "no") if cognition is severely limited
- Use cues to enhance comprehension (e.g. short questions, simple directions)

3.6.1.3.2 Behavioural

- Be aware of triggers (antecedents) for behavioural outbursts
- Minimize environmental overstimulation when a person begins to become agitated (e.g. dim light, turn off television and radio)
- Maintain calm when the client becomes confused or agitated and refrain from confronting an agitated client while redirecting or distracting them from inappropriate behaviour
- Structure the environment and routines to support the individual's ability to engage successfully in day-to-day routines (a plethora of unstructured time can lead to increased behaviour problems)

- Engage in relaxation training. Relaxation training improves name and face recall, short-term memory and incidental learning, reduces anxiety and depression and strengthens immune function. It also increases management of behaviour and caregivers' self-efficacy
- Utilize cognitive restructuring methods to modify self-defeating beliefs due to cognitive impairments
- Develop behavioural contracts if cognitive status allows

3.6.1.3.3 Motor

- Use mobility device such as a cane (supervision may be necessary to direct use of the device)
- Use verbal and physical cues to initiate rote movements and activities
- Provide assistance to the bathroom to decrease episodes of incontinence, if reaction time is slowed or person is unable to attend to bathroom needs

3.6.1.3.4 Memory

- A successful memory intervention is tailored to the patient and relevant to improving quality of life
- Post signs to reduce purposeless wandering, loss of energy, and frustration with disorientation
- Use dosette boxes labelled with time of day or meal, if person has difficulty with self-administration of medications
- Provide a verbal cue or a watch with an alarm to help the person remember when medications are due
- Use a variety of cues to build sustained, simultaneous, shifting, and selective attention
- Maintain a routine to which the individual is accustomed and can perform with the least amount of support and assistance from others (when orientation is impaired, times and dates are easily confused)
- Use functional tasks (e.g. letters, lists, diaries) — this also improves connected narrative writing
- Provide memory books with categories
- Develop internal facilitatory strategies (e.g. cues, drawings, repetitions)
- Use cueing hierarchy, delayed repetitions and naming strategies to improve word-finding
- Use photos, written words, and gestures to compensate for anomia
- Use recording devices to dictate thoughts, memories and questions as memory cues
- Use reorganization heuristics, which use an intact skill to overcome a deficient function (e.g. use of visual imagery to compensate for verbal memory deficit)

3.6.1.3.5 Physical Environment

- Ensure that frequently used items are consistently put back in the same place (this will facilitate more independent functioning in addition to providing a cue in itself)
- Develop lists of important items to check when leaving the residence (stove, lights, locks, etc.)
- Keep a telephone log with important contact information proximal to the telephone (to facilitate social interaction)

3.6.1.3.6 Other

- Increase exposure to positive mediators including high socioeconomic status, physical activity, as well as social and mental stimulation to improve sleep hygiene (Vance and Burrage 2006)
- Negative mediators should be avoided when possible. Negative mediators include: poor sleep hygiene, substance misuse, depression, concurrent conditions, and medications (especially polypharmacy) (Vance and Burrage 2006)
- Malnutrition is associated with cognitive dysfunction (Fillit et al. 2002). Therefore intervening at the nutritional level may improve cognitive support (Correa Leite et al. 2001)
- Nutritional education to improve diets to include the B Vitamins, Antioxidants and Omega-3 Fatty Acids which can help improve the speed of processing, recall and recognition and verbal ability. Antioxidants also have implications for prevention of progressive cognitive impairments
- Treatment and prevention of concurrent conditions (e.g. substance misuse, depression, hypertension) can augment cognition
- A pilot study has demonstrated that speed of processing training using a computer improved cognitive and everyday functioning in adults living with HIV (Vance et al. 2012). A subsequent analysis of this study data found that those with a higher HIV viral load, poorer medication adherence, a higher number of years since diagnosis and lower scores in executive functioning testing were correlated with better training gains (Kaur et al. 2014)
- Social stimulation should include meaningful and sustained contact with other individuals that encourages emotional support which provides an avenue for cognitive stimulation in the form of engaging in activities through such social contact (Vance and Burrage 2006)
- Early prevention and treatments should occur before or during mild cognitive impairment, not after significant neural damage has resulted in dementia (Vance and Burrage 2006)
- Enlist the support of family members and significant others at the earliest stages of cognitive decline

- Help individuals and their caregivers and/or support network to be more aware of the above strategies, thereby encouraging their use
- Preparation of an advance directive for the client with early manifestations of dementia including plans for assisted living or other in-home custodial care
- Differentiate between hearing loss and receptive language problems, and refer to audiological services for hearing evaluation and devices as required
- Identify the specific impact of information processing strategy application disorders on real-world task performance. Research suggests that this strategy provides occupational therapists with information necessary to more specifically tailor therapy to the individual performance and participation needs of people with HIV-1-associated dementia (Ranka 2010)

3.6.2 Community Resources

Community organizations may provide the following resources:

- Buddy programs
- Hospital and home visitation programs
- Community day care programs
- Equipment loan programs
- Caregiver support groups
- Respite and home care programs
- Community mental health programs
- Legal and advocacy services
- Wandering client registries (through local police departments)

3_7 Cardiac and Respiratory Impairments

There are many causes of heart and lung problems in HIV infection, including bacterial, fungal, viral, and parasitic pneumonia (see [Table 3.7](#)). Although decreasing in prevalence, pulmonary Kaposi's sarcoma can cause severe respiratory impairment. Lymphoma and other primary lung tumours can also cause a significant decline in respiratory status. Pulmonary emboli are seen with surprising frequency in people living with HIV.


 **Red Flag:** Chest pain and new or acute shortness of breath are medical emergencies that require immediate medical evaluation

Table 3.7 Clinical Aspects of Cardiac and Respiratory Impairments

| Category | Causes and Considerations |
|---------------------------|---|
| Endocarditis | <ul style="list-style-type: none"> • Bacteria • Fungi |
| Cardiomyopathy | <ul style="list-style-type: none"> • Viral pathogens |
| Pericarditis | <ul style="list-style-type: none"> • Infections (e.g. TB) |
| Pre-existing lung disease | <ul style="list-style-type: none"> • Restrictive lung disease • Post-pneumonia fibrosis • Chronic obstructive lung disease (e.g. cigarette smoking, recurrent bronchitis or pneumonia) • Bronchiectasis • Reactive airways disease |
| Acute lung disease | <ul style="list-style-type: none"> • Infections (e.g. PCP) • Pulmonary emboli |
| Psychological | <ul style="list-style-type: none"> • Anxiety • Panic disorder |
| Tumours | <ul style="list-style-type: none"> • Kaposi's sarcoma |

Legend: PCP: Pneumocystis carinii pneumonia; TB: tuberculosis

3.7.1 Rehabilitation Interventions

For cardiac conditions, traditional cardiac rehabilitation programs can be used. The interventions listed below are for pulmonary conditions.

3.7.1.1 Mobilize Secretions and Improve Lung Ventilation

3.7.1.1.1 Traditional Manual Physiotherapy Techniques

- Manual or mechanical percussion and vibration
- Lateral costal facilitation
- Intercostal muscle massage
- Rib springing
- Nasopharyngeal or oropharyngeal suctioning

3.7.1.1.2 Strategies a Client can Perform Independently

- Postural drainage
- Autogenic drainage
- Incentive spirometry
- Cough expectorants (e.g. Guaifenesin)
- Pneumococcal and regular influenza vaccines

- Positive expiratory pressure (PEP) mask
- Deep (diaphragmatic) breathing and coughing exercises
- Aerobic exercise
- Energy conservation techniques, including use of adaptive equipment (e.g. walker, reacher)

3.7.1.2 Aspiration

When intervening for aspiration prevention, it is especially important to consider quality of life and concomitant conditions that may impact on overall oral intake (e.g. oral lesions, gastrointestinal (GI) conditions, effects of medications, depression).

- Consult a speech-language pathologist for a comprehensive swallowing assessment
- Based on the assessment results, ensure client is prescribed the appropriate diet textures and is following the recommended feeding guidelines
- Also consider specific exercises and manoeuvres, and postural and other compensatory strategies. A coordinated team approach involving rehabilitation providers, medical and nursing staff, and a nutritionist is essential for successful outcomes

3.7.1.3 Shortness of Breath and Associated Anxiety

- Use pursed lip breathing
- Focus on exhalation, prolong three times as long as inhalation
- S.O.S. for shortness of breath (<https://www.stjoes.ca/patients-visitors/patient-education/patient-education:-p-t/ways-to-control-your-breathing---resp-rehab-pdf>)
- Sit with upper extremities supported on table or knees
- Relax or "drop" shoulders and arms
- Massage the trapezius and sub-occipital muscles
- Employ relaxation techniques (e.g. visualization and imagery, progressive muscle relaxation, use of tapes, music)

3.7.1.4 Exercise

Exercise guidelines are directly related to the type and severity of the lung condition. Therefore, it is important to consult with the individual's physician.

- Develop activities of low intensity and long duration

3.7.1.5 Oxygen Requirements

- Consult a respiratory therapist
- Check oxygen saturation at rest and on activity
- If home oxygen is required, ensure appropriate carrier is provided (e.g. liquid oxygen canister with shoulder strap)
- Assess need for mobility aid with seat and basket for oxygen

3.7.2 Community Resources

Community organizations may provide the following resources:

- Exercise and nutrition programs
- Buddy programs
- Equipment loan programs
- Home care rehabilitation services

It may also be helpful to attend programs sponsored by the local heart and stroke organization and the local lung organization.

3_8 Sensory Loss

3.8.1 Visual Loss

The advent of antiretroviral therapies and improved prophylaxis treatment have greatly reduced ocular manifestations in people living with HIV, although vision can still be affected by herpes zoster ophthalmicus and Molluscum contagiosum, certain malignancies, including squamous cell carcinoma and Kaposi's sarcoma, as well as retinal vasculopathy, opportunistic infections, unusual malignancies and neuro-ophthalmologic abnormalities. Infection of the retina with cytomegalovirus (CMV) remains by far the most common cause of visual loss in people living with HIV. CMV retinitis almost always occurs late in the disease course, once the CD4 count has dropped below 100. Signs and symptoms of CMV retinitis commonly include loss of visual field, floaters, and cloud-like white patches in the visual field (Banker et al. 2009). Photophobia or light sensitivity is less common. When entire visual fields are lost (e.g. homonymous hemianopsia), lesions of the central nervous system are more likely to occur (see [Table 3.8](#)). Complaints of diplopia are most likely associated with problems with the cranial nerves controlling eye movements. It is important to remember that other, non-HIV-related disease processes (e.g. diabetes mellitus) can also result in visual loss. It should be noted that although there is currently a decrease in many of these ocular manifestations, they do persist for some people living with HIV.

In addition, a new kind of vision loss, associated with the use of newer antiretroviral therapies and known as immune recovery uveitis, has emerged (Banker et al. 2009). More research should be given to ocular manifestations resultant from antiretroviral therapy (Tan et al. 2009) as it has also been shown, in genetically predisposed clients, to trigger the onset of Leber hereditary optic neuropathy (Shaikh et al. 2001).



Red Flag: Any abrupt change in vision should result in an immediate referral to an ophthalmologist with expertise in HIV.

Table 3.8 Clinical Aspects of Visual Loss

| Category | Causes and Considerations |
|----------------------------------|--|
| Retinitis, choroiditis | <ul style="list-style-type: none"> • CMV • Toxoplasmosis, Cryptococcus, Pneumocystis carinii • Acute retinal necrosis due to HSV, VZV |
| Retinal detachment | <ul style="list-style-type: none"> • Primary • Secondary (CMV) |
| Primary retinal vascular disease | <ul style="list-style-type: none"> • Immune complex disease • Microaneurysms • Ischemic maculopathy • Diabetic retinopathy |
| Malignancy | <ul style="list-style-type: none"> • Kaposi's sarcoma • Burkitt's lymphoma of the orbit • Metastatic malignant melanoma |
| Cranial nerve abnormalities | <ul style="list-style-type: none"> • Many potential causes including most causes listed above • Central (e.g. PML) • Peripheral (e.g. mononeuropathy) |
| Cerebral lesions | <ul style="list-style-type: none"> • Occipital lobe disease |
| Drug-induced | <ul style="list-style-type: none"> • High-dose rifabutin |
| Pre-existing disease | <ul style="list-style-type: none"> • Cataracts, glaucoma • Refractive abnormalities |

Legend: CMV: cytomegalovirus; HSV: herpes simplex virus; PML: progressive multifocal leukoencephalopathy; VZV: varicella-zoster virus

3.8.1.1 Referrals

Referrals to the Canadian National Institute for the Blind (CNIB) should be made whenever any visual problem is diagnosed.

3.8.1.2 Rehabilitation Interventions

3.8.1.2.1 Mobility

- Ensure that the environment is free of obstacles
- Ensure that lighting is good
- Close cupboards and doors
- Keep paths clear for safety during ambulation
- Orient the person to the environment and inform the person of any changes to the environment, even if they appear insignificant to the sighted person

- Use a support cane to assist with depth perception for stairs, curbs, detection of obstacles, and changes in level (if person is unsteady)

3.8.1.2.2 Activities of Daily Living

3.8.1.2.2.1 Enhancing Vision

- Refer for oculo-visual assessment
- Use magnifiers
- Compensate for peripheral vision
- Wear an eye patch, if double vision is a problem
- Install proper lighting, including nightlights
- Use larger print/font size
- Use black print on a light background to add contrast
- Use large push-button telephones

3.8.1.2.2.2 Finances

- Order and fold money in wallet by denomination
- Know exact amount of money being carried
- Ask sales clerk to identify bills when giving change
- Pay with bill closest to amount
- Use direct debit and phone systems for regular expenses (reduces need for signature guides and templates for signatures)

3.8.1.2.2.3 Environment

- Keep personal items tidy, organized, and in a consistent location to reduce the need for assistance and labelling
- Encourage caregivers to return things to the same place
- Program names and phone numbers into phone systems
- Make use of phone company service providing listings through operator assistance
- Organize clothing by colour or texture
- Use safety pins or tags to distinguish between similar items
- Organize food in cupboards and refrigerator by type and date of expiration ("first in, first out")
- Use nightlights

3.8.1.2.2.4 Meal Preparation

- Organize workspace and materials
- Adequately label dials and controls on appliances
- Conduct a safety assessment
- Use preparation tips (refer to occupational therapist and the Canadian National Institute for the Blind (CNIB) for assistance)
- Use assistive devices (e.g. knife or slicer guide, liquid level)

3.8.1.2.2.5 Shopping

- Organize lists according to store layout

- Use magnifiers or penlights for reading labels
- Ask store clerks for assistance
- Use a volunteer to do shopping
- Have items delivered

3.8.1.2.2.6 Medications

- Organize by time of day
- Identify containers by shape and size
- Identify containers by using elastic bands, magnetic tape, coloured tape, or marked contrasts in labels
- Contact the pharmacy to explore possibility of alternative packaging (e.g. bubble packs)

3.8.1.2.2.7 Other

- Talking books (available through libraries)
- Voiceprint (available through cable companies)
- Technological aids (e.g. computer software) that enhance vision or permit the use of voice commands

3.8.1.3 Psychosocial

- Counselling and psychotherapy specifically to help cope with feelings that may result from vision loss. These may include confusion, distress, anxiety, depression, rage, and "why me" thoughts (many people have a specific fear of going blind or dying blind)

3.8.1.4 Community Resources

The following resources are available through the Canadian National Institute for the Blind (CNIB):

- Assessment and counselling
- Keyboard skills
- Orientation and mobility instruction
- Visual aids
- Adaptive and technical aids
- Money management instruction
- Library services

3.8.2 Hearing Loss

The etiology of auditory system disorders in people living with HIV falls into three broad categories: HIV or AIDS as the primary cause, opportunistic infections and ototoxicity from drugs used to treat HIV (Kallail et al. 2008). A Canadian study of otosyphilis found that all clients reported tinnitus and almost 90% had some level of subjective hearing loss. Successful treatment with intravenous penicillin G, and in some cases steroids, demonstrates that hearing loss in people living with HIV is potentially reversible (Mishra et al. 2008). An earlier study in the United States demonstrated that otologic manifestations were more prevalent than anticipated, including aural fullness/dizziness, hearing loss,

tinnitus, otalgia, and otorrhea. Otitis media was common and overall, this study found ear disease to affect approximately 30% of people living with HIV.

More research is needed in this area (Chandrasekhar et al. 2000).

3.8.2.1 Referrals

The Canadian Hearing Society has sites across the country that can assist with hearing loss and referral to this organization should be made as soon as an individual is diagnosed (<http://www.chs.ca/>).

Swanepoel and Louw (2010) have published a comprehensive review on HIV/AIDS-related communication, hearing and swallowing disorders.

3_9 Mental Health

3.9.1 Prevalence of Mental Illness with HIV

There is an over-representation of individuals with HIV suffering from mental illness (Meade and Sikkema 2005, Vlassova et al. 2009, Cournos et al. 2001, Lyon 2001, McKinnon et al. 2002, Otto-Salaj and Stevenson 2001). It can be difficult to determine exactly how many people living with HIV experience mental illness because research studies use varying definitions, categories and classifications ranging from those developed using strict criteria to relying on physician reports (Meade and Sikkema 2005, Hartzell et al. 2008). Between 19 and 43% of HIV positive clients are believed to suffer from major depression (Vlassova et al. 2009) and between 3 and 23% of adults suffering from a severe mental illness are HIV positive (Meade and Sikkema 2005).

Mood disorders include bipolar disorder, dementia and depression (Vlassova et al. 2009). These can be accompanied by emotional and cognitive disruption resulting in ramifications in the home and work fronts, and at times, hospitalization may be required (Meade and Sikkema 2005).

Mood disorders are frequently interconnected with substance use disorders [Section 3_10](#), ranging from alcoholism to intravenous drug use (IDU) (Meade and Sikkema 2005, Vlassova et al. 2009, Hartzell et al. 2008). Substance misuse disorders and mood disorders are estimated to co-exist anywhere between the ranges of 25% to 65% of all diagnoses of HIV (Regier et al. 1990).

3.9.2 Mood Disorders as a Primary Complaint

One systematic review suggests that adults with severe mental illness are more likely than demographically similar adults without severe mental illness to engage in certain behaviours that place them at high risk for acquiring HIV including multiple sexual partners, working in the sex trade,

injection drug use, history of childhood sexual abuse and engaging in unprotected intercourse (Meade and Sikkema 2005). Generally, in the context of HIV, mood disorders are categorized in terms of before and after HIV infection. A mood disorder prior to HIV infection is very common and increases one's risk of initial infection. Secondly, mood disorders can emerge following infection.

This can present as a temporary disorder, such as mild depression as a consequence of knowledge of infection or as a result of late-stage infection affecting the nervous system (Colibazzi et al. 2006, Vlassova et al. 2009). Any of these mood disorders can affect the therapeutic management of HIV, and in particular, adherence to antiretroviral therapies (Colibazzi et al. 2006; Vlassova et al. 2009). These disorders can also overlap, thereby presenting additional challenges for diagnosis and treatment. Furthermore, some mood disorder symptoms often mimic HIV symptoms, including fatigue and lethargy. Mood disorders are treatable, and when co-treated with combination antiretroviral therapy (cART), the outcome can be positive (Hartzell et al. 2008).

Notably, persons living with both HIV and a mental illness, as opposed to persons living with only HIV or a mental illness cost the healthcare system significantly more than what a client with one of these diagnoses costs (Rothbard et al. 2009).

3.9.3 HIV Can Cause Mood Disorders

An initial diagnosis of HIV can initiate a time of "grief-like psychological disruptions" which in turn may result in higher stress levels, use of illicit substances and an overall greater propensity to engage in high-risk behaviour (Vlassova et al. 2009). Many people living with HIV, while not necessarily suffering from a major clinical depression, may experience what is understood by experts as demoralization; everyday stresses are more stressful and produce more anxiety than they might have prior to a diagnosis of HIV (Vlassova et al. 2009, Treisman et al. 1998). However, not everyone agrees with this; there are some studies that have found that everyday anxiety levels are lower in the HIV population than in the general population (Pence et al. 2006, Drew et al. 1997). In any case, depression is the most common mood disorder diagnosed in people living with HIV (Hartzell et al. 2008, Treisman et al. 1998). A previous history of major depression and progression of HIV disease are the strongest predictors of an onset of major depression (Atkinson et al. 2008).

3.9.4 Impact of HIV Medications on Mood Disorders

Older HIV drugs, such as Zidovudine, Abacavir and Efavirenz have been known to bring on manic episodes, but this has significantly decreased as a problem since the introduction

of combination antiretroviral therapy (cART) (Vlassova et al. 2009). Evidence suggests that antiretroviral therapy decreases the prevalence of mood disorders, and in particular, depression (Low-Beer et al. 2000, Judd et al. 2000, Chan et al. 2003).

3.9.5 Mood Disorders as a Risk Factor for Acquiring HIV

The characteristics and situation of those with mood disorders who are deemed to be at high-risk for acquiring HIV are complex and multi-faceted. One systematic review demonstrates that those who do fall into this category share one or a combination of the following traits: psychiatric illness, cognitive behavioural factors, history of childhood abuse and history of substance use (Meade and Sikkema 2005).

The overall consensus is that individuals with mood disorders are more likely to fall into the high-risk HIV category (Berg et al. 2007, Chander et al. 2006, Kalichman et al. 1997, Kelly et al. 1993).

3.9.6 Living with Mood Disorders in the Context of Living with HIV

Although not completely understood, the relationship between HIV progression and mood disorders is symbiotic. For instance, not only have depressive symptoms been shown to have negative effects on the immune system of HIV positive individuals (Alciati et al. 2001), but also depression severity seems to increase in tandem with HIV progression (Vlassova et al. 2009). Diagnosis of a mood disorder in an HIV positive person can be difficult as many symptoms, such as fatigue, lethargy and loss of appetite, overlap between the two conditions, making it difficult to determine if the cause is a mood disorder such as depression, a result of HIV or a combination of the two.


3.9.7 Role of Rehabilitation

Recognition of mood disorders and other mental health conditions by practitioners is crucial as this can affect adherence to antiretroviral medication, can affect one's likelihood to attend appointments, and is often compounded by substance use disorders. A mental health specialist, such as a social worker, psychiatrist or psychologist should be included in the care team. Occupational therapists are also mental health providers who with demonstrated competence (often provided by regulatory colleges) provide psychotherapy along with nurses, psychologists, social workers, and physicians.

For many specific mental illnesses, the same medications for those with or without HIV can be used without unique adverse effects on the HIV population. Other methods that are often used to manage mood disorders include cognitive

behaviour therapy (CBT) (Himelhoch et al. 2013, Honagodu et al. 2013, Kennard et al. 2014, Kraaij et al. 2010, Magidson et al. 2014, Sabet et al. 2013, Safren et al. 2012, Seedat 2012, Spies et al. 2013), group interventions (Heckman et al. 2013, Heckman et al. 2011, Honagodu et al. 2013, Sabet et al. 2013, Sacks et al. 2010), self-care interventions (including writing, computer-based programs and content geared to stress and coping ((Eller et al. 2013, Heckman et al. 2013, Kraaij et al. 2010, Magidson et al. 2014, Sabet et al. 2013, Seedat 2012) and telephone-administered therapies (Heckman et al. 2013, Himelhoch et al. 2013). Other approaches include massage (Poland et al. 2013), mindfulness meditation, art, yoga therapy and narrative therapies. Special considerations should be made such that interventions are culturally appropriate and flexible. This can include tailoring support over the telephone for those living in rural or remote regions of the country or encouraging individuals to take comfort in their spirituality or a complementary therapy.

New models of care have also been designed and evaluated to best serve those living with HIV and concurrent mental illnesses (Hackler et al. 2013, Magidson et al. 2014, Painter et al. 2015, Sacks et al. 2010, Sacks et al. 2011, Tominari et al. 2013, Vance et al. 2010c).

 **Red Flag:** If an individual's cognitive ability is compromised to a certain point, a living will should be enacted, or a recognized power of attorney should be engaged to assist with the individual's financial and personal care.

3_10 Substance Misuse

3.10.1 Introduction

Substance misuse is defined as overindulgence in and dependence on a drug or other chemical leading to effects that are detrimental to the individual's physical and mental health, social well-being (social support) and spiritual well-being or the welfare of others.

Among people living with HIV, substance use can have a profound impact on the individual's health as well as those around them. Substance use patterns can affect the quality and efficacy of treatments used by the individual living with HIV. For example, there is evidence suggesting that there is no 'safe' level of alcohol consumption for those undergoing antiretroviral treatment for HIV (Bryant 2006). Therefore it is important for a rehabilitation provider to be aware of an individual's substance use as that information will influence the treatment strategies recommended for the client.

Substance use has been found to be associated with increased risk of infection with HIV and related illnesses. For example, alcohol consumption that has been linked to unprotected sex and contaminated needle sharing from

intravenous drug use. All of these factors put others at risk of HIV infection (Bryant 2006, Centres for Disease Control 2009).

Having a thorough understanding of an individual's substance use history and awareness of current substance use patterns will allow for rehabilitation providers to create the optimal treatment plan for each client.

Interventions do not work the same across types of substances. However, some interventions that may be effective for different populations include:

- Contingency management (Reback et al. 2014, Rajasingham et al. 2012, Petry et al. 2010)
- Cognitive behavioural therapies (Safren et al. 2012, Reback et al. 2014)
- Motivational interviewing with or without telephone follow-up (HealthCall) (Wolfe et al. 2013, Hasin et al. 2013, Hasin et al. 2014, Aharonovich et al. 2012)
- Therapeutic workplace interventions (Holtyn et al. 2014, Aklin et al. 2014)
- Innovative models of care including safe injection sites and peer-led community needle exchange (Sacks et al. 2012, Sacks et al. 2011, Sacks et al. 2010, Scott et al. 2013, Mayer et al. 2013, Hayashi et al. 2010, Andresen et al. 2010)
- Self-management interventions (Carrico et al. 2015)
- Yoga and meditation (Agarwal et al. 2015)

The history of care for persons with substance use issues is laden with judgment, discrimination, criminalization, and stereotyping. All professionals need to identify and examine personal values, attitudes, and beliefs and behaviours about substance use. This may involve analyzing a part of one's personal background, including childhood experiences, which can affect the likelihood or ability of a healthcare professional to be therapeutic and non-judgmental.

3.10.2 Harm Reduction Versus Abstinence

There is an ongoing debate concerning the care of people who use drugs and whether harm reduction or abstinence is the best approach to handling the needs of these individuals.

While abstinence requires the complete cessation of substance use (Peterson et al. 2006), harm reduction advocates for the improvement of the health and safety of the person that is using substances by aiming to reduce the harms associated with it (Lenton and Single 1998).

Those in favour of the harm reduction model argue that abstinence is not a realistic goal for some people who use drugs and therefore should not be used as a barrier to providing services. Those opposed to the harm reduction model argue that this approach encourages further

substance use and impedes the potential treatment and recovery of those individuals. Community organizations working in HIV generally favour the harm reduction model.

3.10.2.1 The Harm Reduction Model

The main characteristics of harm reduction are (Riley et al. 1999):

- **Pragmatism:** Harm reduction accepts that some use of mind-altering substances is inevitable and that some level of substance use is normal in society.
- **Humanistic Values:** The substance user's decision to use drugs is accepted as fact. No moralistic judgment is made either to condemn or to support use of drugs, regardless of level of use or mode of intake. The dignity and rights of the person who uses drugs are respected.
- **Focus on Harms:** The fact or extent of a person's substance use is of secondary importance to the harms resulting from use.
- **Balancing Costs and Benefits:** The pragmatic process of identifying, measuring and assessing the relative importance, their associated harms, and costs/benefits of intervention to focus resources on priority issues.
- **Priority of Immediate Goals:** Most harm reduction programs have a hierarchy of goals, with the immediate focus on addressing the most pressing needs.

Harm reduction programs and policies may include the following (Canadian AIDS Society 2009).

- Needle exchange and distribution
- Access to detoxification centres or programs
- Ongoing counselling support
- Methadone maintenance programs and maintenance programs for drugs other than opiates
- Education and outreach programs to people who use drugs and society at large
- Tolerance zones, such as safe injecting sites and/or safe dealing areas
- Initiatives to address systemic issues such as a re-evaluation of Canada's drug laws and policies
- The right of people who use drugs to receive adequate HIV treatments and inclusion in clinical trials and research for HIV medications and treatments
- Acceptance that substance use is a fact and that abstinence is not necessarily the sole desired outcome
- Acknowledgment of those who use drugs as capable members of our community
- Abstinence-based treatment options should be available to those who want them

3.10.3 The Practitioner-Client Relationship

Information about an individual's substance use is critical in providing optimal care. This underscores the importance of history taking and assessment. Developing a trusting practitioner-client relationship is integral to building a productive therapeutic atmosphere. General components for history taking and assessment for HIV clients are described in [Section 2.3.4.1](#). Additional considerations specific to substance misuse are described below:

3.10.3.1 History-Taking and Assessment

In most healthcare settings, history and assessment information is gathered by a number of people, including physicians, nurses and rehabilitation providers. A thorough client history and assessment should include the following components:

3.10.3.1.1 Medical History

Some of this information may be relevant to the individual's use of substances. For example, testing HIV positive may have resulted in increased drug or alcohol use, or in a relapse if the person was previously abstinent. Many symptoms of HIV resemble those from drug use (e.g. night sweats, weight loss).

3.10.3.1.2 Cognitive Assessment

The cognitive assessment will help clarify the client's ability to participate in the ongoing planning of care. This assessment will also determine the needed levels of care and appropriate referrals (Moyers 1992). Both HIV and substance use can cause cognitive impairment.

3.10.3.1.3 Substance Use History

A detailed substance use history is important for the formulation of an effective treatment plan. Without a substance use history, the rehabilitation provider may be unknowingly struggling with complications arising from a client's undisclosed substance use. It is also important to note that many drug users use more than one substance.

A thorough substance use history should include the following (AIDS Institute 1995, Shernoff 1991):

3.10.3.1.3.1 Substances Used

- Tobacco
- Alcohol
- Marijuana
- Opiates, including heroin, prescription medication
- Stimulants, including cocaine, amphetamines, prescription medication
- Sedative-hypnotics, including benzodiazepines, barbiturates

- Other (hallucinogens, solvents, Phencyclidine [PCP], analgesics)

3.10.3.1.3.2 Routes of Administration

- Injection (intravenous, subcutaneous, intramuscular)
- Inhaled (smoked, snorted, sniffed)
- Use of shared needles
- Use of needle-exchange programs

3.10.3.1.3.3 Pattern of Use

- Age started
- Amount, frequency, cost
- Most recent use
- Relapse history (conditions favouring use, abstinence, and relapse)
- Benefits of use (e.g. What does the client gain from using?)
- Consequences of use: physical, psychological, functional, interpersonal (support network), employment, financial, housing, spiritual

3.10.3.1.3.4 Drug Treatment History

- Detoxification (dates, facts of admission and discharge, follow-up)
- Out-client drug treatment (dates, course of treatment, results following discharge from therapy)
- Twelve-step programs (Narcotics Anonymous, Alcoholics Anonymous past and current participation)
- Residential drug treatment facility (dates, facility, course of treatment, results following discharge from facility)
- Methadone maintenance (dates, program, dosage, course of treatment, and tolerance to regimen)
- Spiritual interventions and/or Pastoral care

Individuals presenting with current substance use may have a very chaotic lifestyle. This will affect whether the client can participate fully in the planned care. A complete history will help to sort out the concerns presented. However, the rehabilitation provider should be aware that complex interactive processes are involved which may prevent clear knowledge about the causes of client difficulties (Moyers 1992).

3.10.3.1.4 Sexual History

A sexual history will permit discussion of the individual's sexual identity, orientation, and risk(s). Assessing the potential for transmission of HIV and other sexually transmitted diseases requires knowledge of unsafe sexual practices. When taking a sexual history from a sex trade worker, caregivers need to be aware that the sexual practices these workers adopt with their clients may differ

from those they use with their partners. Sexual Dysfunction may be an issue. Please see [Section 4_12 Sexual Health and Dysfunction](#) for more information.

3.10.3.1.5 Information About Support Networks

Caregivers may perceive chaos in the lives of clients who use substances. However, relationships in the substance-using community can be meaningful, can enhance quality of life, and can prolong survival. Many substance users who decide to stop using will be required to leave their existing relationships and begin building a new support system. This can be a very difficult process for people who often have been abandoned by family and friends outside the drug culture.

3.10.4 Behaviour Change

Changing substance use behaviour is frequently a long and complex process that can be better understood by referring to the Stages of Change Theory, first outlined by Prochaska et al. (1992).

3.10.4.1 Stages of Change Theory

People who are attempting to modify drug-using behaviour, whether the ultimate goal is harm reduction or abstinence, move through a series of stages (Prochaska et al. 1992). The process is as follows:

Stage I — Precontemplation

- This stage is characterized by no intention of changing behaviour
- People may be unaware of (or deny) a problem at this time
- Substance use continues
- Intervention should be focused on safer substance use

Stage II — Contemplation

- People in this stage can recognize that the use of substance(s) is causing problems but are not taking any action to modify behaviour. This stage is characterized by an internal debate about the pros and cons of continued substance use.
- During this time intervention should continue to focus on safer substance use

Stage III — Preparation

- In this stage, people are preparing to take action to alter behaviour in the near future
- Substance use continues
- Intervention should continue to focus on safer substance use

Stage IV — Action

- At this point in time, people with substance use will take the necessary action to modify behaviour
- As substance use is altered, people will have to make a commitment of time and energy, with relapse being an ever-present possibility

Stage V — Maintenance

- People will now work to prevent relapse and to maintain personal goals

Most people who attempt to modify substance use behaviour will not be successful on the first try. It is important to note that change is not a linear process and that each person's path will be unique (Prochaska et al. 1992). Because relapse is always a possibility, it needs to be normalized and integrated into the work that rehabilitation providers do with clients.

The rehabilitation provider can assist clients by providing referrals to treatment specialists, programs, and self-help groups that are knowledgeable about the issues faced by a person living with HIV. Rehabilitation providers should try to identify the services that are familiar with the range of issues related to living with HIV and substance misuse. If there are no such services, clients should be made aware of that fact before deciding whether to access the services.

Behaviour change goals are not limited to altering substance use behaviour. Behaviour change is the process used by people to stabilize their lives. As part of this process, people will endeavour to develop interpersonal relationships, secure housing, achieve financial security, and access a social support network.

3.10.5 Detoxification

Controversy also surrounds the issue of whether to continue HIV treatments for someone undergoing detoxification. The process of detoxification is stressful and can, therefore, be immunosuppressive. A thorough discussion of all factors needs to occur among staff, the client and his or her physician before a decision is made about whether to stop HIV treatment during detoxification.

A medical crisis or acute illness (particularly one requiring in-hospital admission) is not the time to address detoxification or cessation of substance use. In fact, substance use may increase during this time as the individual tries to cope with a stressful situation.

Providers can address this issue by prescribing other types of medications (e.g. methadone for heroin use) or by recognizing and accepting that the person will continue to use while in hospital. In addition, effective and adequate pain management is essential if the client is to be expected to adhere to the prescribed medical treatment.

3.10.6 Smoking Cessation

The prevalence of smoking among people living with HIV is markedly higher than among the general population in studies conducted in Canada and the United States (Niaura et al. 2000, Balfour et al. 2010, Tesoriero et al. 2010). Mdodo et al. (2015) used nationally representative cross-sectional surveys from the United States to determine that adults with HIV were nearly twice as likely to smoke (as compared to adults without HIV). Advances in antiretroviral therapies over the last decade have lowered the incidence of HIV-related mortalities. However, the proportion of deaths due to tobacco-associated disease has increased in HIV-positive persons (Marshall et al. 2009). Numerous studies show that HIV-positive smokers have an increased risk of chronic obstructive pulmonary disease (COPD) (Crothers 2007), lung cancer (Chaturvedi et al. 2007, Engels et al. 2006, Kirk et al. 2007), and infections such as bacterial pneumonia (Kohli et al. 2006, Le Moing et al. 2006, Miguez-Burbano et al. 2005). Among those who have a lifelong history of cigarette smoking, HIV-positive smokers are almost half as likely to quit smoking (Gritz et al. 2004). Cessation of smoking can improve symptom burden and the quality of life for people living with HIV.

Screening for nicotine addiction should be performed as part of routine HIV care. Evidence-based smoking cessation interventions include a number of options and there is evidence to support the use of novel and more traditional smoking cessation interventions (Vidrine 2009). Behavioural interventions include individual, group and telephone counselling (for example, quit-lines). Motivational interviewing is an approach utilized with patient's who are undecided about quitting smoking because it increases the number of quit attempts. It involves expressing empathy, developing discrepancy, rolling with resistance, and supporting self-efficacy (Fiore et al. 2008). These principles aim to locate and focus on patients' feelings, ideas, and motivations to increase willingness to stop smoking. The effectiveness of this method remains unclear but has shown to increase the number of attempts to quit smoking. Cognitive behavioural interventions are a form of counselling designed to modify a patient's understanding and habits that lead to smoking by promoting thoughts and skills to cause behavioural change (Niaura 2008).

Numerous medications exist to assist patients to quit smoking, and they have been shown to improve quit rates. These include the use of nicotine replacement therapies, such as patches, gums, lozenges, inhalers, and sprays, and oral medications such as bupropion and varenicline. Limited data are available regarding interactions of pharmacologic interventions with HIV medications. The data that is available has been reviewed by Rahmanian et al. (2011). A 2013 review of systematic reviews identified the efficacy of behavioural support over and above pharmacotherapy, as well as the efficacy of cytosine, mobile phone technology,

low-dose varenicline and health professional training to promote smoking cessation (Hartmann-Boyce et al. 2013). A second systematic review published in 2014 reported that the highest likelihood of smoking cessation was in two randomized studies that used cell phone technology (Moscou-Jackson et al. 2014). The authors also reported that multi-strategy smoking-cessation interventions, delivered over multiple sessions, were effective (Moscou-Jackson et al. 2014). They conclude that the most effective interventions were tailored to the unique individual needs of people living with HIV, including assessment of and intervention for poly-substance misuse and mental health issues, as well as the inclusion of access-promoting elements. In the past few years an increasing amount of research has been published this area (Balfour et al. 2013, Browning et al. 2013, Calvo-Sanchez et al. 2015, Healey et al. 2015, Humfleet et al. 2013, Manuel et al. 2013, Moadel et al. 2012, Shirley et al. 2013, Shuter et al. 2014a, Shuter et al. 2014b, Tami-Maury et al. 2013, Vidrine et al. 2015, Vidrine et al. 2012). Calvo-Sanchez et al. (2015) have published a comprehensive narrative review which includes recommendations for clinicians that address how to: a) identify those individuals who are willing to stop smoking and those most likely to succeed, b) choose the most suitable strategy for an individual patient, and, c) help the patient during the process.

It is more difficult for people living with HIV to quit smoking than the general public due to their greater number of challenges ranging from stigma, social, economic, psychiatric, and medical needs, which may impact their attempts at smoking cessation. As a result, cessation strategies for HIV-infected smokers require tailored, intensive

interventions to address motivational and adherence issues (Benard et al. 2007). Quitting smoking successfully usually requires several attempts. Healthcare providers should monitor the progress of HIV patients who are trying to quit and discuss new strategies for the next attempt.

3.10.7 Coordination of Care

With the knowledge acquired during the assessment and history-taking process, the rehabilitation provider will be able to assess the impact of substance use on the cognitive, motor, and emotional functioning of the client (Moyers 1992).

A coordinated approach to care is needed to address the challenges in the client's life, which may include outstanding legal charges, psychosocial problems, medical diagnosis, and functional or vocational issues. Many different professionals will be involved in the client's life. The goal of coordination is to ensure that everyone involved in the care, including the client, receives and practices consistent and clear communication. To avoid overwhelming the client, providers and the client must coordinate their efforts when prioritizing care goals. Setting too many goals at one time will eventually overburden the client and may result in a return to substance misuse or increased substance use.

The goals of care, as well as the role of each rehabilitation provider, need to be clearly communicated to clients and team members to avoid conveying mixed messages. This will go a long way to addressing the real needs of clients and will prevent the providers from getting caught up in clients' behaviour secondary to substance use (Moyers 1992).

CHAPTER 4

Systemic Impacts

4_1 Introduction

HIV compromises the immune system, leading to widespread systemic impacts. All body systems are affected when the immune system is unable to protect from impending illnesses. The direct effects of the virus, as well as side effects of drug therapies, also have a role in influencing the health of various body systems.

The rehabilitation management of HIV requires an understanding of the multi-systemic nature of HIV disease and its complications. Advances in knowledge about HIV replication and treatment of HIV infection have improved survival for people living with HIV. However, antiretroviral treatment has caused dramatic changes in the natural history, long-term outcome, morbidity and mortality in people living with HIV that affects all systems of the body.

While an exhaustive overview of all the potential impacts of HIV, its treatments and associated concurrent conditions is beyond the scope of this section, a brief overview is provided. This is organized by body systems, listing some of the more common clinical manifestations of HIV. A category for malignancy has also been included for consideration.

4_2 Cardiovascular

Since the introduction of antiretroviral drugs, cardiovascular complications as a result of HIV infection have shifted from illness resulting primarily from immunosuppression (e.g. myocarditis, endocarditis, dilated cardiomyopathy and pericardial effusions, potentially leading to cardiac tamponade) to conditions associated with long-term cardiovascular disease, in particular coronary heart disease, peripheral vascular disease and stroke.

4.2.1 Myocarditis and Endocarditis

There are a number of common pathogens in advanced HIV disease that lead to an infection in the heart muscle (myocarditis) and the heart valves (endocarditis) (Rerkpattanapipat et al. 2000). For example, common pathogens associated with opportunistic infections such as *Toxoplasma gondii*, *Mycobacterium tuberculosis*, *Cryptococcus neoformans* and *Mycobacterium avium-intracellulare* complex have presented in people with both myocarditis and endocarditis (Rerkpattanapipat et al. 2000). HIV and its component proteins have also been found in cardiac tissue specimens in the presence of these diseases, indicating that HIV itself may play a role (Calabrese et al. 1987).

4.2.2 Dilated Cardiomyopathy

Dilated cardiomyopathy is a disease that typically affects the left ventricle of the heart causing it to enlarge and ineffectively perform its function of pumping blood throughout the body. Although the pathogenesis of this disease is unclear, it often occurs late in the course of HIV infection and is associated with a significantly reduced CD4 count (Rerkpattanapipat et al. 2000). In addition to heart failure, dilated cardiomyopathy may also present irregular heartbeats (arrhythmia), blood clots or sudden death.

4.2.3 Pericardial Effusion

The accumulation of an excess of fluid around the heart termed "pericardial effusion", is often related to inflammation (pericarditis) but can also occur in the absence of inflammation. Pericardial effusion is one of the most common forms of cardiovascular involvement in HIV infection and can range in size (Rerkpattanapipat et al. 2000). When fluid continues to build it places pressure on the heart muscle preventing the ventricles from filling properly (cardiac tamponade). The specific cause of pericardial effusion is difficult to diagnose and may not be possible to identify as a number of case reports report on multiple unusual organisms associated with pericardial effusion in people with HIV (Rerkpattanapipat et al. 2000).

4.2.4 Coronary Artery Disease

With the introduction of antiretroviral treatment, there has been an increased incidence of coronary artery disease (CAD) and myocardial infarction (MI) among people living with HIV (Boccarda 2003). The risk of an MI in people living with HIV is reported to be twice that of the general population after matching for age, geography and other risk factors (Bozzette et al. 2003). Moreover, in one retrospective analysis, the annual incidence of MI among people receiving antiretroviral treatments with protease inhibitors was four times as high when compared to people living with HIV prior to the antiretroviral era (Rickerts et al. 2000).

Several factors contribute to the role of CAD development. Conventional risk factors (e.g. elevated cholesterol, hypertension, family history of CAD, smoking and diabetes) are also significant for people infected with HIV and may be more frequent in this population (Boccarda and Cohen 2008). HIV and its treatments predispose people to metabolic complications causing dyslipidemia (abnormal levels of fat

and/or cholesterol in the blood) and insulin resistance that are implicated in increased cardiovascular risk (Boccarda and Cohen 2008).

These effects are correlated with the length of time that a person is known to be HIV positive and on protease inhibitors with a longer duration reflecting an increased risk of MI (Boccarda and Cohen 2008). Additionally, there is increasing evidence that chronic HIV infection itself, low-grade chronic inflammation and immunological degradation can assist in the progression of atherosclerosis and atherothrombosis (Boccarda and Cohen 2008).

4.2.5 Peripheral Vascular Disease

Several studies have reported a high prevalence of peripheral arterial disease among people living with HIV when compared to the general population (Mercie et al. 2005, Periard et al. 2008).

4.2.6 Stroke

Stroke has often been cited as a complication of HIV infection. It is difficult however to assess the relative risk of stroke occurrence as a result of HIV due to the multiple medical conditions that influence this risk. Clinical presentation may be confusing when signs of stroke are superimposed on possible neurological manifestations that may be present in up to 60% of people living with HIV only (Boccarda et al. 2003). In one North American population-based study, advanced HIV was found to be strongly associated with both ischemic stroke and intracerebral haemorrhage in the era before antiretroviral therapy after attempts were made to adjust for concomitant etiologies for stroke (Cole et al. 2004). Further studies evaluating the risk of stroke in people living with HIV who are taking antiretroviral treatments are required.

4_3 Gastrointestinal

Gastrointestinal disease in HIV is common. Due to a number of different factors, people living with HIV often present with diarrhea, weight loss, biliary disorders, abdominal pain, dysphagia and other oral diseases. Infections, parasites and malignancies account for some presentations of gastrointestinal discomfort while drug reactions are also frequently reported. Dysphagia can be treated in a majority of cases and therefore requires a thorough assessment to determine the source of swallowing dysfunction. Many people living with HIV experience colitis and complain of abdominal pain and bloody or mucous diarrhea.

4_4 Malignancy

Malignancies remain a significant burden for people living with HIV. Susceptibility to various forms of cancers has been linked to a number of oncogenic viruses including Epstein-

Barr virus (associated with non-Hodgkin's lymphoma, in particular Burkitt's lymphoma and Hodgkin's lymphoma), Human Herpes Virus-8 (the etiological agent in Kaposi's sarcoma) and Human Papillomavirus (linked to anal-rectal and cervical cancers) (Cohen 2000, Boshoff and Weiss 2002, Nickoloff and Foreman 2002).

4.4.1 Epstein-Barr Virus

Epstein-Barr virus (EBV) infects over 90% of humans and is transmitted through contact with oral secretions (Cohen 2000). The virus persists for the lifetime of the person and is mostly kept in check by the immune system where natural killer cells, CD4 and CD8 cells control its proliferation (Cohen 2000). People with advanced HIV show 10 to 20 times the circulating levels of EBV and are at an elevated risk of developing non-Hodgkin's lymphoma. Virtually all central nervous system lymphomas found in people with HIV contain EBV. In Africa, Burkitt's lymphoma, a type of non-Hodgkin's lymphoma is more common, because of the compounded destruction of T-cells due to HIV and malaria.

4.4.2 Human Herpes Virus-8

In the early days of the HIV epidemic, Kaposi's Sarcoma appeared as a hallmark illness associated with HIV infection. Nearly 40% of gay men diagnosed as having AIDS in 1981 also presented with this form of cancer (Antman and Chang 2000). Kaposi's Sarcoma appears as firm, purple-blue or reddish-brown plaques and nodules that arise on the skin as well as in lymph nodes, viscera and mucosa (Antman and Chang 2000). The human herpes virus-8 has been found in 95% of Kaposi's Sarcoma lesions, providing good evidence that it is the oncogenic factor. However, immunosuppression is important for the expression of this illness. Regardless of their HIV status, men who have sex with men have a greater incidence of Kaposi's Sarcoma than the general male population (Martin et al. 1998). Fortunately, Kaposi's Sarcoma has been shown to regress with the cessation, reduction and modification of immunosuppression and has, therefore, demonstrated declines in prevalence with antiretroviral treatments (Antman and Chang 2000).

4.4.3 Human Papillomavirus

The human papillomavirus (HPV) is sexually transmitted. As a result, many HIV positive men and women are co-infected with both viruses. Infection with HPV can cause warts in or around the genitals and anus. HPV can also cause abnormal growths on the cervix, vulva, penis and inside the anus. In some cases, these abnormal growths can transform and become pre-cancerous and can even form tumours.

Anal cancer is triggered by infection with the sexually transmitted virus HPV. This virus can infect cells lining the anal canal and with time, cause them to develop

abnormally, in some cases becoming pre-cancerous and ultimately forming tumours. Generally, abnormalities caused by HPV are slow growing. However, in the setting of HIV co-infection, where the immune system has been weakened, HPV-related abnormalities can become more common and their growth may be faster.

The incidence of invasive anal cancer in people with HIV in one large-scale cohort study indicated a rate 120 times higher than when compared to the age and gender-matched general population (Bower et al. 2004).

As HIV weakens the immune system, HPV infection tends to persist; therefore, co-infected women can have high rates of abnormal cervical growths and cervical cancer compared to HIV negative women.

4_5 Metabolic and Endocrine

With the advent of antiretroviral therapies, people are living longer with HIV; however, metabolic disturbances are a common adverse effect of older HIV treatments. In particular, side effects associated with the use of protease inhibitors include abnormalities in glucose homeostasis, hyperlipidemia and changes in body composition leading to the redistribution of adipose tissue (Yanovski et al. 1999).

It has been reported that up to 64% of people living with HIV treated with protease inhibitors will develop associated lipodystrophies (Carr et al. 1998). 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 (Yanovski et al. 1999). Adipose is not lost but is 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.

The development of insulin resistance in people treated with protease inhibitors increases the possibility of diabetes and complications associated with the increased burden of this disease as a concurrent condition.

4_6 Musculoskeletal

Several conditions affecting the musculoskeletal system are attributed to HIV infection, its related illness and its treatment. The mechanisms leading to HIV-induced rheumatic illness is unclear but is likely multifactorial and may involve direct assault from the virus, immune responses to the virus, genetic, as well as environmental factors (Louthrenoo 2008).

4.6.1 Arthropathies and Arthralgias

Spondyloarthropathies are among the most common HIV-associated manifestations of the musculoskeletal system (Louthrenoo 2008). Examples of these include reactive arthritis, Reiter's syndrome and psoriatic arthritis and they commonly occur in late stages of HIV infection.

HIV-associated arthritis has been known to occur at any point during the course of HIV infection and is characterized as typically being monoarticular and involving the lower-extremity joints. This arthritis can be self-limiting and lasts on average for 2 months.

Arthralgias may appear at any stage in the course of HIV infection and range in intensity. The etiology of these pain syndromes is unclear and can be difficult to manage in the absence of objective clinical findings. One painful arthralgia syndrome has been described as presenting in the late stages of infection and is associated with severe intermittent pain lasting less than 24 hours (Berman et al. 1988).

4.6.2 Myopathies and Myalgias

Muscle weakness is a common complaint of people living with HIV. This weakness can be associated with elevated levels of Creatine Kinase indicating damage to muscle fibres or necrosis of these tissues as a result of several myopathic conditions in addition to side effects of antiretroviral drugs. Nutritional deficiencies secondary to complications of HIV illness and malabsorptive syndromes can interfere with muscular function and lead to wasting syndromes.

Drug-induced myopathies occur with prolonged treatments. Nucleoside analogues, including the first HIV medication zidovudine, can disrupt skeletal muscle mitochondrial activity creating mitochondrial toxicity and ultimately destroying muscle fibres. As the first generation of antiretroviral drugs has been replaced by safer and more efficacious therapies, the prevalence of drug-induced myopathies has been greatly reduced.

Polymyositis is an inflammatory myopathy that can be triggered by HIV or opportunistic infections as a result of HIV. Polymyositis is a condition whereby the immune system begins to break down muscle fibres. It is characterized by progressive, proximal weakness most prominently in the thighs and is usually associated with minimal pain.

Muscle pain related to HIV is not associated with any particular stage of the disease however at the point of seroconversion, acute symptoms can occur which often return if people who have been on long-standing antiretroviral treatments later stop taking these drug regimens. The pathogenesis of myalgia is unclear. Fibromyalgia has also been described in combination with myalgia and is linked with depression in people living with HIV (Simms et al. 1992).

4.6.3 Osteopenia and Osteoporosis

Complications related to disorders in the bone have increased with the introduction of antiretroviral therapy in people living with HIV. Loss of bone mass (osteopenia) along with the incidence of greater reabsorption of bone (osteoporosis) has become more prevalent as people are beginning to live longer with HIV (Arnsten et al. 2007, Conde et al. 2009). Known features that are risk factors for poor bone health are shared features for people living with HIV.

For example, decreased physical activity, prolonged bed rest associated with chronic illness, severe weight loss, malnutrition and hormonal imbalances create an environment for bone loss and are often challenges faced by people living with HIV.

The mechanisms that are responsible for bone mineral loss in people with HIV are unknown. However, several explanations have been proposed and are under investigation. For instance, abnormalities may be as a result of the direct invasion by HIV into the cells of the bone and bone marrow, from abnormal immune responses affecting bone metabolism, disturbed calcium homeostasis and impaired hormone functions needed to regulate bone mineral density.

Those with HIV are at least as likely to develop osteoporosis as postmenopausal women (Clay et al. 2008). Treatment for these individuals should be the same as are seronegative individuals, including Calcium and Vitamin D supplements, and possibly anti-resorptive and hormone replacement therapies (Mondy and Tebas 2003, Clay et al. 2008) and exercise (Clay et al. 2008). Bone density has also been shown to increase in people living with HIV who have osteoporosis when treated with a bisphosphonate, and specifically alendronate (Clay et al. 2008). Primary care guidelines would also benefit from listing people living with HIV as prime candidates for the screening of osteopenia and osteoporosis (Clay et al. 2008).

4.6.4 Osteonecrosis

A number of case reports suggest an association between HIV infection and osteonecrosis (Rademaker et al. 1997). Also termed avascular necrosis (AVN), osteonecrosis is a process whereby the cellular constituents of bone begin to die, often in the absence of an inciting traumatic event. The cause of this phenomenon is unknown and early attempts to treat or arrest bone death in this condition has proved unsuccessful (Thomas and Doherty 2003). Osteonecrosis is most common in the femoral head leading to subchondral collapse and severe osteoarthritis (Thomas and Doherty 2003). The incidence of osteonecrosis in people infected with HIV increases with both the duration of HIV infection and antiretroviral treatment (Mary-Krause et al. 2006).

4_7 Neurocognitive

Cognitive impairments related to HIV infection are complex and can range in severity. Antiretroviral therapies allow individuals to live longer, but also introduce unique challenges for maintenance of cognitive function in people living with HIV.

Cognitive impairment is proposed to be related to a number of factors including the synergistic effect of neuropathology related to aging and age-related diseases of the brain, cerebrovascular disease that may be accelerated by antiretroviral treatments, metabolic conditions associated with HIV and chronic immune system activation (Valcour et al. 2004).

4.7.1 HIV-Associated Neurocognitive Disorders

HIV-Associated Neurocognitive Disorders (HAND) occurs in an estimated 30-50% of individuals with HIV (Heaton et al. 2010). The most recent research classification for HAND was determined by an NIH working group in 2007, which was convened in Frascati, Italy, and is therefore commonly referred to as the Frascati Criteria (Antori et al. 2007). The Frascati Criteria allows for three diagnostic categories: Asymptomatic Neuropsychological Impairment (ANI), Mild Neurocognitive Disorder (MND) and HIV-Associated Dementia (HAD). For each of these HAND diagnoses, an individual must demonstrate at least mild neuropsychological impairment in at least two cognitive domains that are attributable, at least in part, to HIV infection. HAND is often under-recognized and under-treated, especially since current screening tools are inadequate for identifying milder forms of HAND (Zipursky et al. 2013). The Mind Exchange Working Group has developed evidence and consensus-based answers to key clinical questions for the management of HAND (Mind Exchange Working Group 2013). There is a current consensus among experts that "what is good for the heart is good for the brain" (Rourke 2014). It is important to note that according to the Frascati Criteria, the essential feature of HAND is cognitive disturbance; this revision eliminated the possibility of HIV neurocognitive disorders being diagnosed on the basis of neuromotor and non-cognitive psychiatric changes such as changes in personality or mood (Gandhi et al. 2010).

That said, disorders such as depression and anxiety are also common in people living with HIV. Both conditions are of particular concern as they have been shown to significantly impede adherence to medications or may mask or produce somatic symptoms related to other HIV-associated illnesses (Basu et al. 2005). The rate of major depressive disorders in people living with HIV is particularly high especially in those who also have histories of substance misuse, or for females with a history of trauma (Basu et al. 2005). Symptoms of anxiety, and specifically anxiety around death, are common

among people living with HIV and can be associated with symptoms of post-traumatic stress disorder and panic disorder (Basu et al. 2005).

While the variability in clinical presentation of neurocognitive deficits is vast in people living with HIV, practitioners are required to be mindful of the potential effects of HIV on this system. Early detection of symptoms associated with illnesses of this nature allows for interventions and more positive health outcomes.

4_8 Neurological

The neurological manifestations of HIV infection affect every division of the nervous system, including the autonomic, central and peripheral nervous systems.

4.8.1 Autonomic Nervous System

Much is unknown about the presence of autonomic dysfunction in people living with HIV however early studies have shown that prevalence seems to be high, particularly in people with advanced disease (Ruttimann et al. 1991, Welby et al. 1991). With the introduction of antiretroviral therapy, HIV levels are suppressed, however, an array of adverse events such as dyslipidemia and insulin resistance may be linked to autonomic dysfunction (Lebech et al. 2007). Autonomic dysfunction leads to arrhythmias and abnormalities in blood pressure, factors that can cause orthostatic hypotension and syncope, which may impact people when engaged in rehabilitation programs.

4.8.2 Central Nervous System

Numerous central nervous system (CNS) manifestations of HIV infection occur either as a direct result of HIV, which readily crosses the blood-brain barrier, or in response to the presence of opportunistic infections. Exact mechanisms are elusive given that access to the CNS is a challenge and research is often limited to autopsy.

4.8.3 HIV-Associated Dementia

In the era of improved HIV treatments, HIV-Associated Dementia (HAD), which was among the most severe manifestations affecting people with HIV, is now relatively rare (Heaton et al. 2010).

4.8.4 Toxoplasmosis

Toxoplasmosis is the most common cause of space-occupying lesions within the central nervous system (CNS) for people living with HIV. This condition results from exposure to toxoplasmosis gondii, an intracellular protozoan that is present worldwide. Transmission to humans occurs primarily by ingestion of undercooked pork or lamb meat that contains tissue cysts, or by exposure to oocysts either

through ingestion of contaminated vegetables or direct contact with cat feces (Montoya and Remington 2000). Toxoplasmic encephalitis usually occurs in HIV positive people with CD4 counts < 100 cells/ mm^3 (Luft and Remington 1992). Characteristically, toxoplasmic encephalitis has a subacute onset with focal neurologic abnormalities frequently accompanied by a headache, altered mental status, and fever (Renold et al. 1992). The most common focal neurologic signs are motor weakness and speech disturbances. Clients can also present with seizures, cranial nerve abnormalities, visual field defects, sensory disturbances, cerebellar dysfunction, meningismus, movement disorders, and neuropsychiatric manifestations (Renold et al. 1992). It is important to note that toxoplasmosis is reversible with treatment.

4.8.5 Progressive Multifocal Leukoencephalopathy

Progressive Multifocal Leukoencephalopathy (PML) is caused by the reactivation of a common virus in the central nervous system of immune-compromised individuals. The symptoms of PML are the result of an infection that causes the loss of white matter in multiple areas of the brain. Before the introduction of antiretroviral therapy, the prognosis of PML was dismal; progressive deterioration leads to death on a median of 4 to 6 months after diagnosis in the majority of cases (Berger 2007). With antiretroviral treatments, approximately 70% of people diagnosed with PML will survive beyond this time frame (Berenguer et al. 2003). The most common signs and symptoms reported in HIV-related PML include limb weakness, gait disorder and ataxia, speech disorder, visual impairment, sensory loss and seizures (Berenguer et al. 2003).

4.8.6 Cryptococcosis

Cryptococcosis accounts for the most common life-threatening meningitis in AIDS. Cryptococcus is a fungus that grows readily in soil contaminated with avian droppings, particularly those of pigeons. Early in the epidemic, approximately 5 to 8% of people with advanced HIV developed a cryptococcal infection. Where effective antiretroviral treatment is available, the incidence of cryptococcosis, along with other opportunistic infections, has decreased (Michaels et al. 1999, Murphy et al. 2001). Infection typically presents as a subacute process characterized by a headache, fever, and, less often, altered mental status. Complications of central nervous system (CNS) infection include hydrocephalus, motor or sensory deficits, cerebellar dysfunction, seizures, and dementia. Abnormal cerebrospinal fluid can cause increased intracerebral pressures that can be potentially fatal.

4.8.7 Primary Central Nervous System Lymphoma

Primary Central Nervous System Lymphoma (PCNSL) is defined as a diffuse lymphoma presenting in the brain or spinal cord in the absence of systemic lymphoma and commonly presents as a single, contrast-enhancing lesion in the brain parenchyma (although other presentations can occur). Please see the Malignancy section for more detail.

4.8.8 Vacuolar Myelopathy

Vacuolar Myelopathy is an HIV related manifestation affecting the spinal cord in the late stages of HIV infection. Cavities or vacuoles occur in the spinal cord as a result of demyelination of primarily the dorsolateral white matter tracts in the spinal cord. Although the cause of vacuolar myelopathy is unknown, researchers have proposed a number of possible mechanisms including dysregulation of cytokines and/or direct HIV infection of cells in the central nervous system called oligodendrocytes that lead to damaged myelin (Staudinger and Henry 2000). In either case, vacuolar myelopathy can cause slow, progressive spastic paraparesis, hyperreflexia and extensor plantar responses, sensory ataxia and incontinence.

4.8.9 Peripheral Nervous System

Both motor and sensory tracts in the peripheral nervous system are affected by HIV infection. Peripheral neuropathies and their complications can have serious debilitating functional consequences for people living with HIV and have emerged as the most common neurological complication of HIV infection. Several discrete types of HIV-associated neuropathies exist and may be a result of damage caused by the virus, a consequence of opportunistic pathogens and/or vascular damage that occurs as a result of treatment toxicity.

4.8.10 Distal Symmetrical Polyneuropathy

Distal Symmetrical Polyneuropathy (DSP) is the most common form of neuropathy in HIV infection. People living with HIV may complain of a gradual onset of "painful feet" that can progress in severity affecting the ability to weight bear and ultimately a person's activities of daily living. Typically, pain is described as bilateral, and is usually most severe on the soles of the feet with worsening at night (Keswani et al. 2002). The clinical presentation of DSP includes these described complaints as well as decreased or absent ankle jerks, diminished or absent vibratory perception at the toes or decreased pinprick or temperature in a stocking distribution (Schifitto et al. 2002). DSP is characterized by distal degeneration of long axons, known as "dying back" (Pardo et al. 2001).

4.8.11 Inflammatory Demyelinating Polyneuropathy

Inflammatory Demyelinating Polyneuropathy (IDP) occurs more frequently in people living with HIV when compared to seronegative populations. Acute IDP presents most often at the time of seroconversion however it also can occur in late AIDS and can rapidly progress within four weeks. Chronic IDP can occur at any phase of HIV disease and can progress for greater than two months with episodes that relapse and or remit over time. The history, physical examination, and course resemble the presentation within HIV seronegative populations.

4_9 Pulmonary

Pulmonary manifestations are a major cause of morbidity and mortality in HIV. Upper respiratory tract infections are common and can occur early in infection for most people living with HIV. These infections are caused by the same common pathogens that are found in people not infected with the virus and therefore may be passed off as unrelated to HIV immunosuppression. Respiratory infections can also be present as a result of opportunistic infections in the later phases of HIV infection.

4.9.1 Pneumocystis Carinii Pneumonia

Prior to the introduction of antiretroviral treatment, 75% of people living with HIV would develop Pneumocystis Carinii Pneumonia (PCP) during their lifetime (Morris et al. 2004). With advancements in drug therapies (antiretrovirals and PCP prophylaxis), the rates of PCP have markedly declined. This is largely attributed to improved immune function (Morris et al. 2004).

PCP is the most common AIDS-defining illness in North America and remains one of the most significant illnesses associated with HIV. It is frequently the first serious infection experienced by people living with HIV and is a major cause of mortality (Davis et al. 2008). PCP infection causes inflammation within the parenchyma of the lung causing difficulty in breathing and potentially acute respiratory distress.

The pathogen responsible for PCP infection is an atypical fungus (sharing some characteristics with protozoa) called *Pneumocystis jiroveci*. Airborne transmission from a human host to another human host is proposed to be the main vector for this highly prevalent illness in immunocompromised individuals (CD4 counts <200 cells/mm³), however the route of transmission between humans remains unclear (Nevez et al. 2008, Chave et al. 1991, Rivero et al. 2008).

4.9.2 Tuberculosis

Worldwide, tuberculosis (TB) is the most significant respiratory infection to affect people living with HIV and is the leading cause of death. While TB exists as an independent epidemic, the disease poses an increased risk to people with HIV throughout the course of HIV infection and even after initiation of antiretroviral treatments (Havlir et al. 2008). Inadequate TB diagnostic tools and atypical presentations of TB limit diagnosis of TB in people living with HIV. The management is further complicated by drug interactions as well as multi-drug resistant TB that present an ongoing threat to drive the TB epidemic (Havlir et al. 2008).

Tuberculosis is a result of a bacterial infection that most often manifests in the lungs but can travel throughout the body and can lodge almost anywhere in the body. Lung infections, damaged bones, swollen glands, kidney disease and infections in the brain and spinal cord can all be attributed to TB. Prior to any form of treatment, TB was also called "consumption" because people infected with this disease would simply waste away and become consumed by their illness.

During primary infection, inhaled tuberculosis bacteria multiply in the lung stimulating the immune system to respond by attempting to form fibrous scar tissue around the bacteria, to stop it from spreading. If this immune response is successful, the TB is believed to be contained in an inactive state that is non-contagious. Over time and with immunosuppression, the bacteria may become free of this containment and become active once again during secondary TB.

4.9.3 Cytomegalovirus

The most common complication associated with cytomegalovirus (CMV) infection for people living with HIV is retinitis. However, CMV is also known to cause interstitial pneumonitis particularly in those with extremely low CD4 counts (Wallace and Hannah 1987). CMV pneumonia often presents in combination with PCP infection. However, there have been cases where CMV is the pathogen responsible for respiratory complications (Wallace and Hannah 1987).

4.9.4 Histoplasmosis

Histoplasmosis is a fungal infection of the lung, which affects people living with HIV, particularly those living in endemic areas around the Mississippi River in the United States. Once *Histoplasma* is inhaled, it begins to convert to yeast within the parenchyma of the lung. In the absence of an effective immune response, such as in the case of a person living with HIV, this results in respiratory compromise.

4_10 Renal

Abnormalities of the renal system are not uncommon in people living with HIV. HIV-associated Nephropathy (HIVAN) is the most usual form of renal dysfunction and is the result of a focal segmental glomerulosclerosis with possible cystic tubular lesions (Daugas et al. 2005). One of the possible side effects of antiretroviral treatments is the crystallization of the drugs within all the anatomical structures related to the renal system from the proximal tubules to the bladder (Daugas et al. 2005).

4.10.1 HIV-associated Nephropathy

HIV-associated Nephropathy (HIVAN) is characterized by fluid and electrolyte abnormalities, acid-base imbalances and proteinuria that are known to be a leading cause of end-stage renal disease (Daugas et al. 2005). Acute renal failure can result due to low blood volumes (hypovolemia) and restriction of blood flow (ischemia) from the toxic effects of HIV and its medications within the renal system.

4_11 Hepatic

In the years since the development of effective antiretroviral therapies, liver disease has emerged as a major cause of morbidity and mortality in HIV infected persons (Kumar et al. 2008). Hepatitis B virus (HBV), Hepatitis C virus (HCV) and HIV share common routes of transmission, but the different response of these viruses to exposure is impacted by geographic region (Kumar et al. 2008). In addition, some reports suggest that HCV infection may be transmitted sexually between HIV-infected men who have sex with men (MSM) (Sulkowski 2008a). Coinfection alters the natural history of each of these viruses in a peculiar way. Coinfection with viral hepatitis may complicate the delivery of antiretroviral therapies by increasing the risk of hepatotoxicity and impact the selection of specific agents (e.g. those dually active against HIV and HBV) (Kumar et al. 2008, Sulkowski 2008b).

4_12 Aging

In the early days of the epidemic, an HIV diagnosis meant one's life was in immediate peril. However, the characterization of HIV changed dramatically when highly active antiretroviral therapy became widely available in North America in the mid-1990s. It soon became apparent that the damage HIV is capable of inflicting on the human immune system can effectively be halted by modern combination antiretroviral therapies (cART), and in many cases, prolonged treatment will lead to near-full immune reconstitution (Mocroft et al. 2007). In just two decades we have reached the point when the life expectancy of some people living with HIV who take cART is now approaching that of the

general population, although there is still work to be done to improve survival among communities that experience significant health inequities (Samji et al. 2013).

4.12.1 Context

With tools in hand to prevent HIV-related mortality, worldwide attention is now being paid to diagnosing HIV early, referring individuals to ongoing care, and promoting treatment uptake and adherence (UNAIDS 2014). At the same time, we must build our collective capacity to respond to the changing needs of people living with HIV. Whether a person acquires HIV early or late in their life course, the virus will remain with them for as long as they live, so to *live* with HIV is to *age* with HIV. Individuals diagnosed at birth or in childhood are aging with HIV. So are young adults. So are many seniors. Regardless of their chronological age, many people have lived with HIV, and probably HIV treatment, for decades and will continue to do so for at least a handful more. But because the field of HIV and aging is still so new, we continue to work towards understanding the complex interplay between the aging process; the length of time and/or stage(s) of life lived with HIV; the effects of taking different doses of multiple antiretroviral drugs for variable periods of time; and the broader health, social and environmental conditions in which a person ages.

This chapter will focus on the latter end of the aging continuum, examining the impact of HIV on adults who are 50 years of age or older (50+) and rehabilitation interventions that may be efficacious for this demographic.

In 2017, there is a larger cohort of older adults living with HIV in Canada than ever before (UNAIDS 2013). This group will continue to grow for two reasons. First, long-term survivors diagnosed many years ago in their youth or middle age have survived and grown older with HIV, and continue to do so. Second, a greater proportion of new HIV diagnoses in Canada today are among those age 50+ (PHAC 2015).

Under these conditions, with every passing year, a new group of people living long-term with HIV joins the oldest demographic cohort currently described by Canadian epidemiologists: 50+ years of age.

4.12.2 A Growing Group of Older People Living with HIV

4.12.3 Aging with HIV and Long-term Survivorship

The effects of aging with HIV and those of long-term survivorship are sometimes conflated. Not all people living long-term with HIV are over the age of 50, for example, there are people who are now in their 30s who were diagnosed with HIV at birth in the 1980s. Similarly, not all older people with HIV have been living with the virus for

many years. McGowan et al. (2017) report "in contrast to older age, longer time with diagnosed HIV infection was strongly and independently related to poorer physical and psychological health across all measures studied, suggesting it may be a more important factor than chronological age in determining well-being among people living with HIV."

4.12.4 Mental Health, Quality of Life and Aging with HIV

By virtue of their age, many older people lived through an era when people living with HIV were ostracized by society, neglected by decision-makers and dying quickly (Houston 2012). Such experiences of marginalization and multiple losses have had an indelible impact on the lives of older adults, some of who are living with HIV today. Rosenfeld, Bartlam and Smith (2012) describe this as a cohort effect, arguing that navigating through these trying times impacted gay male Baby Boomers, regardless of their HIV status at the time: "the disproportionately high volume of AIDS deaths among gay men aged 25 to 44 at the epidemic's peak (1987-1996) created a cohort effect, decimating their social networks and shaping their personal and social lives during the epidemic, throughout their life course, and into later years."

Unfortunately, stigma related to HIV persists today, and the negative effects of this stigma across the life course may be magnified for individuals who face other forms of prejudice, for example, racism, sexism, homophobia, transphobia, and ableism. Interestingly, an Ontario study of older persons living with HIV found that older women and heterosexual persons were especially vulnerable to HIV stigma, perhaps due to the fact that, in the Ontario context, they represent the minority of people living with HIV and thus find less peer support and community acceptance (Emlet et al. 2013).

Ageism too can increase vulnerability to HIV for older adults and create barriers to care, treatment and support for older adults living with HIV. For example, the lack of frank discussion about sexual health between clinicians and older adults resulting from faulty assumptions about sexual activity and aging may contribute to: a) an underestimation of personal susceptibility to HIV infection among seniors; and b) little support for people aging with HIV who are experiencing sexual dysfunction. A 2010 study reported that depression among older people living with HIV is largely attributable to stigma and loneliness (Groves et al. 2010).

In addition to stigma, other sources of stress identified by community-dwelling older adults living with HIV include HIV and comorbid illnesses, fear, anger and financial strain (De Grezia & Scrandis 2015). These triggers affect the day-to-day quality of life, and their persistent presence can contribute to the development of mental health issues. It is well known that chronic stress can contribute to the development of depression and anxiety in the absence of effective coping

strategies (Hall-Flavin 2014). In addition to these intrinsic and extrinsic stressors, older adults living with HIV may have some of the same risk factors for depression as other older people including bereavement, sleep disturbances, disability, and a history of depression (Cole & Dendukuri 2003).

Mental health issues are often overlooked among older adults because symptoms are non-descript and may be misinterpreted as normal changes occurring with aging, including low energy, aches and pains, difficulties with concentration, and sleep and appetite changes (CCSMH 2016). Women living with HIV, especially women over the age of 40, those experiencing disability, unemployment, stigma or stress, are more likely than men to report severe depressive symptoms (Aljassem et al. 2016). Undiagnosed and/or undertreated depression can significantly impact the lives of older adults living with HIV. Consequences may include neurocognitive symptoms (e.g. memory, trouble problem-solving, language issues), an elevated risk of heart failure, reduced physical and mental health quality of life, an increased number of disability days, and poorer antiretroviral drug adherence and persistence (Rourke et al. 1999, Sherbourne et al. 2000, Springer et al. 2012, White et al. 2015).

Resilience, defined by the American Psychological Association as "the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress," may be protective against depression and anxiety among older people living with HIV. Emler et al. (2011) report that, as a group, older people living with HIV demonstrate resilience developed through the process of overcoming many obstacles. Despite declines in physical health, aging people, including those living with HIV, have a lower prevalence of depression and anxiety symptoms and are more apt to describe themselves as aging 'successfully' as compared to their younger counterparts (Jeste et al. 2013, McGowan et al. 2017).

4.12.5 Cognitive Health, Quality of Life and Aging with HIV

Both HIV and aging independently contribute to oxidative stress and inflammation, which are known to damage the brain (Cohen, Seider & Navia, 2015, Vance et al. 2014). Comorbid health conditions and antiretroviral drugs may also affect the brain health of people living with HIV.

The CHARTER study on HIV-associated neurocognitive disorders (HAND), published in 2010, concluded that over half of people living with HIV experience some degree of cognitive impairment (Heaton et al. 2010). Although the study found that it was much more common for people living with HIV to experience the milder forms of HAND (asymptomatic neurocognitive impairment and mild neurocognitive disorder) than the most severe form (HIV-associated dementia), the results of this study were anxiety-

provoking for many. However, several more recent studies are indicating that the difference in cognitive performance between people living with HIV and controls may be smaller than previously reported (Maki et al. 2015; McDonnell et al. 2014) because the screening tools used to diagnose HAND may be overly sensitive, and inappropriate, unmatched control groups may have been used in past comparative studies (Gisslen et al. 2011, Tedaldi et al. 2015). Nonetheless, studies like the HIV, Health and Rehabilitation Survey have found high rates of self-reported neurocognitive decline (29%) among older adults (O'Brien et al. 2016b).

There is no agreement as yet about whether or not aging potentiates the risk of HIV-associated neurocognitive disorders among people living with HIV (Kissel et al. 2005, Maki et al. 2015, Rodriguez-Penny et al. 2013, Vance et al. 2016). Tedaldi et al. (2015) have hypothesized that, while chronological age itself may not be related to cognitive dysfunction in this population, many people aging with HIV may have reduced cognitive reserve for various reasons, including low levels of education, poverty, trauma, sleep disorders and substance use that results in poorly controlled HIV.

Building cognitive reserve is thought to be protective against neurocognitive impairment. Though the study design did not allow researchers to determine a cause and effect relationship, Fazeli et al. (2014) found that an active lifestyle was associated with better neurocognitive functioning among people living with HIV, approximately half of whom were over the age of 50. In this study, active lifestyle factors included physical exercise, social activity and current employment.

4.12.6 Social Determinants of Health, Quality of Life and Aging with HIV

A complete discussion of the range of social determinants of health for people aging with HIV is beyond the scope of this section, however, there are two social inequities that bear mention because of the magnitude of their potential impact on the health and quality of life of this population.

The first social determinant is employment and how disengagement from the workforce at points across the life course impacts income security as one ages. People diagnosed with HIV early in the epidemic often left the workforce upon receiving their diagnosis, either because of severe illness or because they expected not to survive (Bedell 2000). Even with the introduction of effective antiretroviral drugs in the mid-1990s, many people living long-term with HIV have not been able to return to work, and people living with HIV who are on treatment still experience episodes of disability that can interfere with job security (EDN n.d.). These realities are reflected in unpublished statistics from The HIV, Health and Rehabilitation Survey (HHRS) which found that only 23% of older adults living with HIV (age

50+) who responded to the survey were working for pay while 41% were relying on disability income supports (O'Brien et al. 2016b). Similarly, an Ontario study found that disability was the reason that sixty percent of older adults living with HIV described themselves as retired, unemployed or otherwise disengaged from the labour force (Brennan et al. 2013).

Retirement income is, in large part, determined by contribution to the Canada Pension Plan, a private pension plan, or personal savings during prime working years. Because they have been less able to save over time, many older adults living with HIV rely on a minimal government pension in later life (THT 2017). Poverty can limit access to suitable housing, nutritious food and uninsured health services, and may contribute to social isolation among people aging with HIV (Shimmin 2015). A recent study involving African and Caribbean women living with HIV showed that housing insecurity was linked to increased depression and decreased social support (Logie et al. 2016).

The second social determinant is social isolation. Many older adults living with HIV have small social networks because they experienced the significant loss of friends and partners during the height of the AIDS epidemic. HIV-stigma, ageism, poverty and mobility issues may also contribute to both social isolation and loneliness in this cohort. John et al. (2016) report that 58% of older adults living with HIV reported loneliness and an even greater proportion (66%) perceived that they had low levels of social support. Among older adults, social disconnectedness and perceived isolation are both linked to poorer physical health, and loneliness is strongly associated with poor mental health (Cornwell & Waite 2009). The English Longitudinal Study of Ageing has also determined that social isolation is linked to impaired cognitive function among older adults (Shankar et al. 2013).

4.12.7 Physical Health, Quality of Life and Aging with HIV

4.12.7.1 System-specific Comorbidities

Comorbidity is common among people living with HIV. An Ontario study by Kendall et al. (2014) found that over one-third of people living with HIV had at least one other physical health condition, and almost 40% lived with a comorbid mental health condition.

One study found that older adults living long-term with HIV had a median of four comorbidities, and took a median of 9 non-antiretroviral medications (Greene et al. 2015).

Across the life course, people living with HIV also tend to experience a higher burden of disease as compared to people not living with HIV. Multimorbidity, defined by Kendall et al. (2014) as having two or more chronic health conditions, was 30% more prevalent among people living with HIV. When the multimorbidity prevalence data were

disaggregated by age and sex, there were no significant HIV-related differences in the prevalence of multimorbidity among older men. However, more older women living with HIV experienced multimorbidity as compared to their HIV-negative peers (Kendall et al. 2014).

A large body of research supports the observation that, as compared with the general population, people living with HIV experience a higher prevalence of comorbid illness. Research has emerged showing an increased prevalence of the following chronic and/or age-related conditions among people living with HIV as compared to those who are uninfected:

- Cardiovascular conditions, including myocardial infarction, stroke, congestive heart disease, and peripheral arterial disease
- Cardiovascular risk factors, including hypertension, lipodystrophy, hypertriglyceridemia
- Cognitive impairment
- Kidney disease
- Pulmonary disease, including asthma and chronic obstructive pulmonary disease
- Diabetes
- Cancers of various types
- Bone disease, including low and declining bone mineral density and osteoporosis

(Brown & Qaqish 2006, Grant et al. 2016, Heaton et al. 2011, Kendall et al. 2014, Onen et al. 2010, Pinzone et al. 2012, Schouten et al. 2014).

A recent review implicates chronic inflammation, which can be caused by low-level viremia even in adults with treated HIV or by aging, in the development of metabolic disorders and atherosclerosis, cardiovascular disease, neurocognitive disorders, low bone mineral density and frailty (Nasi et al. 2016). The effects of HIV on immune system function may also play a role in the development of cancers of viral origin (Kaposi sarcoma, lymphoma, anal cancer, liver cancer).

However, many studies associating HIV with these comorbid conditions have employed diverse participants and cross-sectional designs, so researchers have been unable to conclude with certainty that HIV infection is entirely responsible for the increased frequency of these conditions among HIV-positive people. In some cases, HIV treatments, co-infections, modifiable risk factors like exercise, diet and sleep, and social inequities experienced by people living with HIV likely contribute to the overall burden of disease.

A recent meta-analysis determined that exposure to antiretroviral drugs significantly increases the risk of hypertension among people living with HIV (Nduka et al. 2016). Antiretroviral drugs are also believed to contribute to metabolic disturbances, obesity, neurotoxicity and bone loss

(Nasi et al. 2016). Many of these factors increase the chances that a person living with HIV will develop cardiovascular disease.

Regardless of HIV status, behaviours such as smoking, alcohol use, sedentary lifestyle, poor diet, and high-risk sexual practices are known to contribute to disease development. A meta-analysis found that the prevalence range of metabolic syndromes among people living with HIV was similar to that of the general population globally and concluded that this is because people living with HIV share the same common non-HIV-related cardiovascular risk factors as the population at large (Nguyen et al. 2016). However, there are also behaviours and exposures that may be more prevalent among people living with HIV. For example, there is evidence to show that people living with HIV are more likely to smoke and to test positive for high-risk human papilloma infection and/or chronic hepatitis B and C, which may increase their cancer risk (Mdodo et al. 2015, Park et al. 2016). Low levels of education and high stress are implicated in the elevated risk of cognitive impairment among women living with HIV, as compared to women not living with HIV (Vance et al. 2016).

Another important consideration is that aging itself increases vulnerability to these chronic diseases, regardless of HIV status. Now that people living with HIV survive into older adulthood, the likelihood that they will develop age-related comorbidities is increased. The question remains, however, whether there is an interaction effect between HIV and aging for each of these individual comorbid conditions (Wendelken & Valcour 2012). In other words, do people aging with HIV experience a greater burden of disease, earlier onset of chronic health conditions, accelerated worsening of chronic illness, or greater symptomatology than their senior HIV-negative peers?

HIV and older age appear to have an interactive effect when it comes to the prevalence of certain co-morbidities. Rodriguez-Penney et al. (2013) found that older people living with HIV were significantly more likely to experience diabetes, syndromic neurocognitive impairment and malignancy as compared to an age-matched HIV-negative control group, a group of younger people living with HIV, and a group of younger HIV-negative persons. Althoff and co-investigators (2014) found an HIV by age interaction effect for end-stage renal disease and non-AIDS-defining cancers. Despite the latter finding, however, Althoff's team concluded that people aging with HIV did not present with these chronic conditions at significantly younger ages than people not living with HIV.

Many studies are showing that the length of time a person has been living with HIV may have a significant effect on their risk of developing specific comorbidities and/or multimorbidity than chronological age (Guaraldi et al.

2015b; Hernandez-Romieu et al. 2017). Living long-term with HIV may also impact the amount of disability experienced in the context of multimorbidity.

McGowan et al. (2017) report "in contrast to older age, longer time with diagnosed HIV infection was strongly and independently related to poorer physical and psychological health across all measures studied, suggesting it may be a more important factor than chronological age in determining well-being among people living with HIV."

4.12.7.2 Multi-System Impacts

Acronyms that appear in this section include Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL).

4.12.7.2.1 Frailty

Frailty among people aging with HIV has become a topic of substantial interest to both researchers and clinicians in recent years. An early study, published in 2007, found that the odds of men living with HIV being frail were approximately 3 to 15 times as high as for matched HIV-negative controls (Desquilbet et al. 2007). Length of time living with HIV was found to have a major effect, with men who'd been living with HIV for less than four years being 3.38 times more likely than HIV-negative peers to be frail as opposed to men who'd been living with HIV for 8 to 12 years who were 14.68 times more likely to be frail. The same study also found that people living with HIV are vulnerable to premature frailty, meaning they are more likely to become frail at a younger age than those who are uninfected. The prevalence of frailty among relatively newly diagnosed 55-year-old men living with HIV rivalled that of HIV-negative men who were 65 years of age or older. A more recent study by Greene et al. (2015) described 56.1% of their study participants - people living with HIV who were 50 years of age or older, had undetectable viral loads and were taking antiretroviral drugs - as pre-frail.

Brothers et al. (2014) reviewed the existing literature on frailty among people living with HIV who were taking antiretroviral drugs to determine what factors were associated with this condition. Age, HIV-related measures (e.g. longer time since diagnosis, lower CD4 count, lower CD4 nadir, detectable viral load), comorbid conditions (e.g. hepatitis C, diabetes, kidney disease, depressive symptoms, weakness, falls) and social determinants of health (e.g. low education level, unemployment, low income) were all deemed to be relevant in predicting frailty in this population.

Assessing frailty as part of HIV care could enable clinicians to better identify persons living with HIV who may be more vulnerable to poor health outcomes (Brothers et al. 2014). While there is no consensus on the best way to measure frailty among people living with HIV (Erlandson et al. 2014), several potential tools are outlined below:

1. The Fried Phenotype (Fried et al. 2001)
 - Developed in 2001 to assess frailty among older adults (not HIV-specific)
 - Conceptualizes frailty as a syndrome with a unique phenotype
 - Predicts hospitalization, morbidity and mortality
 - Measurement tools are often substituted or modified so it can be difficult to compare across studies
 - People who exhibit a combination of three or more of the following characteristics: 1) unintentional weight loss; 2) self-reported exhaustion; 3) weakness, as measured by grip strength; 4) slow walking speed; and 5) low physical activity, are deemed frail
 - Has been used to assess frailty among people aging with HIV (Rees et al. 2013)
2. VACS Index (Veterans Aging Cohort Study 2016)
 - Better at predicting mortality and risk of hospitalization than the frailty-related phenotype
 - Measures entered into the index are demographic and biomedical, including age, sex, race, CD4, viral load, hepatitis C status and laboratory measures
 - Conceptualizes frailty as an accumulation of deficits (Rockwood & Bergman 2012)
 - The VACS Index Calculator can be accessed at <https://vacs-apps2.med.yale.edu/calculator>
3. The Frailty Index (Guaraldi et al. 2015a)
 - Includes 37 non-HIV-related variables
 - Validated tool for predicting survival and incident multimorbidity
 - Conceptualizes frailty as an accumulation of deficits (Rockwood & Bergman 2012)
 - As of 2016, the University of Modena (Italy) was recruiting participants for the My Smart Age with HIV: Smartphone Self-assessment of Frailty (MySAwH) study, to evaluate an application for people aging with HIV that collects physiological parameters and patient-related outcomes to inform a self-assessment of the aging transition using the frailty index (<https://clinicaltrials.gov/ct2/show/study/NCT02663856>)

Keeping the immune system in good working order through early treatment with antiretroviral drugs is one suggested strategy for lowering the risk of frailty among people living with HIV (Pathai et al. 2013). Evidence is currently lacking for interventions that could be used to address existing frailty among people aging with HIV (Brothers et al. 2014) although a scoping review protocol has been developed (Puts et al. 2016).

4.12.7.2.2 Falls

Two recently published California studies have described a high prevalence of falls among older adults (age 50+) living with HIV. When asked whether they had fallen in the previous year, 25.8% of participants in the first study and 40% of participants in the second responded that they had (Greene et al. 2015, John et al. 2016).

According to published research, risk factors for falls among middle-aged and older people with HIV include multimorbidity, marijuana use, polypharmacy (especially that involving central nervous system active agents), frailty, functional impairment, depressive symptoms, peripheral neuropathy, self-reported neurocognitive impairment and obesity (Erlandson et al. 2012a, Sharma et al. 2016, Tassiopoulos et al. 2016). However, some of these factors, for example, peripheral neuropathy, are contested by other studies (Sandoval et al. 2014).

It is unclear whether age interacts with HIV to increase the likelihood of falls among older adults living with HIV. The Women's Interagency HIV Study, involving 2000 women living with or vulnerable to HIV, found no significant difference in the occurrence of falls based on HIV status (Sharma et al. 2016). They did determine, however, that the prevalence of falls increases significantly as women age. Another study corroborates the negative effect of aging on falls risk among people living with HIV, noting double the prevalence of falls in the previous 12 months among a group of people 60 years of age or older as compared to those 40 to 49 years old (25.8% vs. 12.7%) (Tassiopoulos et al. 2016).

The best methods to predict falls risk among people aging with HIV have not been determined. The Veterans Aging Cohort Study Index Score was not useful in predicting falls risk in one study (Erlandson et al. 2012a). The Johns Hopkins Falls Risk Assessment Tool (JHFRAT) is a validated tool for assessing falls risk in the general population and may serve as a good starting point in the absence of HIV-specific tool. It can be accessed at http://www.hopkinsmedicine.org/institute_nursing/models_tools/fall_risk.html

4.12.7.2.3 Disability

Since 2012, a handful of research studies have provided insight into the functional status of people aging with HIV. Eight particularly recent and demonstrative studies regarding disability, aging and HIV are summarized below:

4.12.7.2.3.1 The HIV, Health and Rehabilitation Survey (HHRS) (O'Brien et al. 2016b)

- This Canadian survey collected data from 941 people living with HIV, almost half of whom (43%) were age 50+

- Half of the study participants were diagnosed with HIV before the introduction of highly effective antiretroviral therapies (median year of diagnosis = 1995)
- Physical comorbidities were commonly reported (median number =4), and were significantly more prevalent among those in the 50+ age group, with joint pain/arthritis (44%), high cholesterol (42%), muscle pain (39%), and high blood pressure (26%) topping the list. Neurocognitive decline was also reported frequently (29%), especially among older adults. Mental health conditions (48%) and addiction (26%) were also prevalent across age groups
- Physical disability and difficulty with day-to-day activities were reported more frequently by older adults living with HIV as compared to their younger counterparts

4.12.7.2.3.2 *The Women of Colour Initiative (Quinlivan et al. 2015)*

- This American study involved 921 women of colour beginning HIV care. Median age was 43.2 years
- Women over the age of 50 living in cities were 4.5 times as likely to experience activity limitation as compared to city-dwelling women under age 30. There were no age differences for women living in rural areas
- Women reporting activity limitations experienced, on average, 13 physically unhealthy days/month and 14 mentally unhealthy days/month
- Having heart disease was associated with a 6 to 7-fold increase in the likelihood of activity limitation

4.12.7.2.3.3 *Correlates of Prevalent Disability Among HIV-Infected Elderly Patients (Avila-Funes et al. 2016)*

- This Mexican study included 184 people, mostly men, living with HIV who were age 50+ and engaged in HIV care
- Overall prevalence of disability: 17.9% of study participants reported difficulties performing at least one IADL without help, and 26.1% reported difficulties performing at least one ADL without help
- Age, detectable viral load and CD4<200 were determined to be associated with disability prevalence
- Poorly controlled HIV (as demonstrated by a CD4<200 plus a detectable viral load) *significantly* increased the likelihood of disability. As compared to study counterparts, the odds of experiencing disability among this group of people living with HIV was 48.2 times for ADLs and 35.6 times for IADLs
- Mental and cognitive health issues, smoking, alcohol use, body mass index and number of comorbid physical conditions were deemed not to have a significant effect on the likelihood of disability

4.12.7.2.3.4 *University of California SCOPE Cohort (Greene et al. 2015)*

- This American study included 156 participants, mostly white males living long-term with HIV (median time since infection = 21 years), who were 50+ years old, on antiretroviral drugs, and had undetectable viral loads for three years or more
- 6% of study participants had two or more geriatric syndromes, including pre-frailty, difficulty with IADLs or ADLs, cognitive impairment, falls, urinary incontinence, hearing impairment, visual impairment or depressive symptoms
- 5% of the study sample reported difficulty with one or more IADLs, and 29.6% reported being dependent on others for performance of at least one IADL
- 2% of the study sample reported difficulty with one or more ADLs, and 10% reported being dependent on others for performance of at least one ADL
- 2% of the study sample reported urinary incontinence
- With respect to mental health, 46.5% of the study sample reported cognitive impairment, and 39.9% reported mild to moderate depressive symptoms
- Factors associated with the likelihood of having a greater number of geriatric syndromes included non-white race, more comorbidity and lower CD4 nadir

4.12.7.2.3.5 *UCSF 360: Positive Care Center/Ward 86 Clinic and San Francisco General Hospital Study (John et al. 2016)*

- This American study included 359 older (age 50+) patients in HIV care in San Francisco
- 39% of study participants reported requiring assistance with at least one IADL
- With respect to mental health, 55% of the study sample reported depression and 40% reported mild cognitive impairment
- Older age was found to be associated with lower CD4 counts, balance issues, slower gait, lower anxiety, poor general health, and good antiretroviral drug adherence
- High VACS index scores were predictive of both IADL dependence and poor antiretroviral drug adherence

4.12.7.2.3.6 *San Diego Study of Synergistic Effects of HIV Infection and Older Age (Morgan et al. 2012)*

- This American study engaged 179 participants and included an HIV- control group
- Older people living with HIV experienced greater ADL and IADL disability (both self-reported and clinician-assessed) than both younger people living with HIV and older uninfected control participants
- HIV and aging also had an interactive effect on emotional functioning

- Independent effects of age and HIV were found with respect to physical health-related quality of life and general perceptions of health
- Aging was associated with bodily pain
- Among older people living with HIV, factors associated with IADL decline are predominantly mental health-related (lifetime major depressive disorder, cognitive impairment and lower cognitive reserve), with the exception of CD4 nadir

4.12.7.2.3.7 HAILO Study (Erlandson et al. 2016)

- An American study of over 1000 people living with HIV
- Preliminary results suggest that HIV+ adults age 40+ experience greater IADL disability than the general population
- Among people living with HIV, IADL disability is experienced more frequently by people who are: less educated, frail, live with neurocognitive impairment, smoke or engage in low levels of physical activity

4.12.7.2.3.8 ASTRA Study (McGowan et al. 2017)

- A UK study of 3258 adults living with HIV
- The physical symptoms most often deemed to be distressing among study participants in the oldest age group (age 60+) were muscle ache/joint pain (23.8%), pain (18.2%) and lack of energy (18.2%), though almost half of older adults reported no symptom-related distress
- Numbness, tingling and pain in the hands or feet was found to be significantly more prevalent among study participants in the oldest age group, as was functional problems

Research into the prevalence of impaired functional status and disability among people aging with HIV is relatively new, and largely observational. Among those studies that have sought to determine which demographic and health-related factors are associated with disability among people aging with HIV, there is little agreement. There appears to be a consistent link between advancing age and increasing disability, which is consistent with observations in the general population (Statistics Canada 2012). It remains to be seen exactly how HIV and aging may interact to impact the likelihood and severity of functional impairment, activity limitations and participation restrictions, and among what populations.

There are also studies available on specific conditions known to contribute to pain and disability among people living with HIV and to be more common among older people living with HIV, for example, peripheral neuropathy (Evans et al. 2011). Sandoval et al. (2014) report that community-dwelling people living with HIV and distal sensory peripheral neuropathy experience moderate to severe pain, poor sleep and slow walking speed. These functional impairments and activity limitations are likely to interfere with active participation in daily life, which could result in isolation, an

issue of particular concern for older adults living with HIV. Among these individuals, higher CD4 counts and a longer duration living with HIV are linked to better sleep quality, which authors posit may point to the development of coping techniques over time.

A number of tools that are used to measure functional status in the general population have been used with people living with HIV, though many have not been validated for this population. When Erlandson et al. (2012b) used Fried's frailty phenotype, the Short Physical Performance Battery and the 400m walk test to assess functional capacity among 542 people living with HIV and receiving antiretroviral treatment, they found the tools were similarly likely to detect the presence of impaired function, but differed in the way they described impairment severity.

4.12.8 Health-Related Quality of Life, HIV and Aging

In a study by John et al. (2016) 30% of older adults living with HIV reported their quality of life as poor or fair. A systematic review by Degroote et al. (2014) categorizes factors affecting quality of life for people living with HIV into four groups: socio-demographic, clinical, psychological and behavioural. This review concluded that current or lifetime depression, anxiety, and neurocognitive impairment all negatively affected quality of life.

Individual studies have also determined that both physical function scores and mental health symptoms are linked to quality of life measures among people aging with HIV. In one study, having fewer depressive symptoms was significantly associated with higher quality of life among middle-aged and older adults living with HIV in Portugal (Monteiro et al. 2016).

The fact that older adults living with HIV have been found to experience more frequent mental health-related symptoms, including agitation, depression, anxiety, apathy, irritability and night-time behavioural disturbances as compared to older adults without HIV (Milanini et al. 2017) indicates the need for rehabilitation interventions which support the mental health of this population.

In another study, researchers found the following weak to moderate associations among 359 people with well-controlled HIV:

- Faster 400m walk pace was associated with improved physical, role physical, and role emotional function as well as decreased pain, better general health and vitality;
- Faster chair rise pace was associated with improved physical, role physical, social and role emotional function as well as decreased pain, better general health and vitality; and

- Greater levels of physical activity were associated with improved physical, role physical, and social function as well as decreased pain, better general health and vitality, and better mental health (Erlandson et al. 2014).

4.12.9 Rehabilitation Interventions for Older Adults Living with HIV

Few rehabilitation interventions specifically designed to address the needs of older adults living with HIV have been evaluated to date. There is some evidence to support the use and further study of the following interventions in this population:

4.12.9.1 Physical Activity Counselling (Shah et al. 2016)

- The intervention consisted of 6 group sessions and involved individual physical activity goal setting (grounded in self-determination theory)
- Individuals receiving the intervention experienced improved physical performance, gait speed, endurance, strength, physical activity level, depression, quality of life and intrinsic motivation among community-dwelling older adults with HIV who were experiencing mild-moderate functional challenges
- A control group was used in this study

4.12.9.2 Exergaming/Virtual Reality Exercises (Veeravelli et al. 2016)

- Pilot study involving 10 older people living with HIV (age 50+)
- The intervention consisted of 12 sessions of virtual-reality exercise (two weekly sessions for six weeks), each 30 to 60 minutes long
- The exercises required cognitive control as researchers wanted to positively impact depression and frailty
- Preliminary findings show that the intervention improved balance, increased gait speed and stride velocity, and decreased pain. The largest improvements were among those with depression who were labelled as being 'pre-frail' in the study

4.12.9.3 Mindfulness-Based Cognitive Therapy (Gonzalez-Garcia et al. 2014)

- Study participants were 40 people living with HIV long-term (diagnosed before 1996) and taking antiretroviral drugs
- As compared to the control group, participants in the mindfulness-based cognitive therapy group intervention experienced improvements in quality of life, psychological stress and symptoms of depression and anxiety

4.12.9.4 Coping Improvement Group Intervention (Heckman et al. 2011)

- Participants were 295 older adults living with HIV (age 50+) in the USA
- The intervention consisted of a 12-session coping improvement group intervention
- Two control groups were used: one group attended an interpersonal support group and the second were eligible for individual therapy as needed
- Both group interventions (coping and interpersonal support) were effective in reducing depression symptoms among participants immediately after, 4 months after and 8 months after the groups ended. The outcomes did not differ between these groups

4.12.9.5 Community-based One-to-one Occupational Therapy (Misko et al. 2014)

- Article describes three case studies, two of which describe occupational therapy support for men in their 50s living long-term with HIV
- Client goals related to home management, financial management, leisure, falls prevention, transportation, exercise, community engagement
- Positive outcomes included increased self-efficacy, problem-solving, time management, self-advocacy, assertiveness, navigation skills, and improved patient/provider relations
- Potential individual-level barriers to intervention efficacy: lack of follow-through on planned actions, self-isolation, lack of capacity to master new skills or integrate them into daily life, bodily limitations
- Tools used included Model of Human Occupation (MOHO) and Self-identified Goals Assessment (SIGA)

4.12.9.6 Spaced Retrieval and External Memory Aids (Neundorfer et al. 2004)

- A pilot study involving 10 older adults living with HIV (age 50+)
- The intervention involved teaching spaced retrieval method
- Two months after the training, 100% of participants reported having met two self-determined memory-related goals through the use of spaced retrieval

4.12.10 Rehabilitation Interventions for People Living with HIV Across the Life Span

There are also rehabilitation interventions that have been studied and found to have positive effects on people living with HIV, but not necessarily older adults living with HIV. Stevens and Nixon (2016) recently published a scoping review on rehabilitation interventions for adults living with

HIV. Exercise interventions were most common, representing 42% of programming evaluated. The 27 unique interventions identified in this review could theoretically be adapted to meet the needs of older adults living with HIV. Mean participant age in five of the 33 publications included was 45 years or older and an additional 13 studies engaged participants over the age of 50 years.

Below is a summary of the kinds of rehabilitation interventions, which may be able to improve function and quality of life among older adults living with HIV, and some of the evidence available to support their use and/or adaptation for this population.

4.12.10.1 Chronic Disease Self-Management Interventions

4.12.10.1.1 Findings of a Scoping Review on Self-Management Interventions (Bernardin et al. 2013)

- Review identified 35 articles on self-management interventions for people living with HIV
- Topics covered within reviewed interventions included: self-care, interpersonal skills, technical knowledge, cognitive skills, positive attitudes, planning for the future, and role management

4.12.10.1.2 Self-Management Strategies for Adults Aging with HIV (Restall 2016)

- Built on the scoping review described above
- Determined that existing self-management interventions for people living with HIV lacked aging-related topics (e.g. menopause, multimorbidity, grand-parenting) and did not take into account changing self-management needs across the life course
- Observed that different intervention formats had not been tested with older adults

4.12.10.1.3 HealthMap (Dodson et al. 2016)

- This study will evaluate a multi-faceted self-management intervention with the following components: 1) a shared health record to facilitate doctor-patient discussion about cardiovascular disease risk and goal-setting; 2) telephone/online coaching; 3) an online learning program, and 4) an online peer chat group
- The study is open to people living with HIV who are age 30+, have no prior history of cardiovascular disease, and no prior participation in a self-management program. A control group will be used
- No results are available as yet

4.12.10.2 Exercise Interventions

4.12.10.2.1 Systematic Review and Meta-analysis of Aerobic Exercise Interventions (O'Brien et al. 2016a)

- The review included 24 randomized controlled trials comparing outcomes for adults living with HIV who were engaged in aerobic exercise programming with those of a control group (mean age 30 to 49 years)
- Aerobic exercise (constant or interval, or combined with resistance exercise), 20 minutes, 3x/week for 5+ weeks had a clinically important positive effect on VO₂max, upper and lower body strength; lean body mass; leg muscle area; percent body fat; mental health, role emotional and physical functioning domains of health-related quality of life
- Aerobic exercise had little or no effect on HIV-related metrics (CD4 count or viral load); weight; body mass index; fat mass; or waist and hip circumference
- The authors concluded that more research was needed to determine the impact of aerobic exercise on older people living with HIV, and the impact of unsupervised exercise

4.12.10.2.2 Group Exercise and Education Intervention (Brown et al. 2016)

- The intervention was an outpatient rehabilitation program led by a physiotherapist which included group exercise and education components
- Participant goals included: improved body image, participation, mobility, fitness and function
- The intervention succeeded in improving endurance, flexibility, strength, and physical and emotional health-related quality of life
- Average age of participants was 51.5 years old

4.12.10.2.3 Systematic Review of Exercise in HIV (Gomes-Neto et al. 2013a)

- Review included 29 studies; mean age of participants ranged from 18 to 60 years
- Resistance exercise undertaken approximately 3 times/week for 60 minutes over 12 weeks improved body composition, mid-thigh cross-sectional muscle area, bone mineral density, body weight, and strength gain. Recommendation was to focus on large muscle groups
- Aerobic exercise undertaken approximately 3 times/week for 30 to 60 minutes over 12 weeks improved body composition, body weight, body fat, waist-hip ratio and aerobic capacity Recommendation was to choose moderate intensity activity
- Combined resistance/aerobic exercise of varying intensity and duration undertaken 3 times weekly improved body composition, thigh muscle volume, % body fat, waist-hip ratio, muscle strength, aerobic capacity, endurance and quality of life

4.12.10.2.4 Tai Chi or Aerobic Exercise Group Intervention (Galantino et al. 2006)

- 38 study participants living with advanced HIV infection
- Two interventions (Tai Chi twice weekly for 8 weeks, aerobic exercise twice weekly for 8 weeks) and a control group
- Participants in the intervention groups experienced positive changes in functional measures (balance, reach, endurance), confusion and anxiety and quality of life
- Those in the intervention groups also reported increased social participation because of the group delivery format

4.12.10.2.5 Physiotherapeutic Exercise for Peripheral Neuropathy (Tumusiime et al. 2015)

- Study involved 120 people living with HIV who were taking antiretroviral drugs and experiencing peripheral neuropathy
- The intervention involved 12 weeks of physiotherapeutic exercise
- Participants who received the intervention had less neuropathic pain, less severe peripheral neuropathy symptoms, better lower extremity function and a reduction in the area affected at the end of the study, as compared to the control group

4.12.10.3 Compensatory Cognitive Interventions

4.12.10.3.1 Mobile Phone Text Messaging Interventions (Mbuagbaw et al. 2015b)

- This meta-review included 9 systematic reviews, each of which analyzed studies to evaluate health-related text messaging interventions
- Evidence supported the use of text messaging interventions to improve medication adherence among people living with HIV, and to improve attendance at appointments in unspecified populations
- There is little evidence to support the use of text messaging for chronic disease self-management purposes, but the authors suggest lessons can be learned from the success of these interventions in HIV

4.12.10.4 Restorative Cognitive Interventions

4.12.10.4.1 SmartBrain Online Intervention (Becker et al. 2012)

- The intervention included activities targeting memory, attention and executive functioning with the goal of stimulating brain plasticity. Exercise difficulty was automatically adjusted based on performance
- The program could be accessed daily by internet for 10 to 30 minutes over 24 weeks
- Participant's age ranged from 40 to 65 years

- Overall, participants in the intervention group did not experience any significant positive effects as compared to the control group. Those who did the SmartBrain activities more regularly (at least once/week) showed significant improvement in cognitive functioning
- Potential barriers to implementation: Individuals with unreliable internet access and/or greater baseline levels of cognitive impairment tended to be less engaged and accessed the intervention less frequently

4.12.10.4.2 Cogmed Working Memory Program (Chang et al. 2017)

- Average age of participants was over 50 years
- The intervention is designed to impact verbal and visuospatial working memory and can be administered in an adaptive or non-adaptive version. The adaptive version increases task difficulty based on performance
- The study required participants to complete 20 to 25 sessions (each 30 to 40 minutes) over the course of 5 to 8 weeks
- Participants living with HIV who completed the adaptive working memory program experienced a 32% improvement in performance and were able to transfer this gain to untrained working memory tasks at 1 month and 6 months after the training. Participation in the program strengthened cognitive performance among people living with HIV so that it matched or exceeded the baseline performance in the HIV-negative control group

4.12.10.4.3 InSight Speed of Processing Training Program (Vance et al. 2012)

- Study engaged 46 middle-aged and older adults living with HIV
- The intervention included 10 hours of computer-based training
- Participants in the intervention group showed improvements on Useful Field of View Test and the Timed Instrumental Activities of Daily Living Test

4.12.10.5 Rehabilitation Interventions for Older Adults in the General Population

Researchers have also studied the effects of rehabilitation interventions to prevent falls and injury resulting from falls, promote medication adherence, and foster social engagement among older adults in the general population. These interventions have not explicitly been implemented with people aging with HIV. A full analysis and summary of these interventions is beyond the scope of this chapter, but *Evidence Summaries* related to aging and exercise, fall and injury prevention, healthy weight, memory and cognition, mental well-being, mobility and physical functioning, social health and other topics are available through the McMaster Optimal Aging Portal at www.mcmasteroptimalaging.org

Below are synopses of reports with particular relevance:

4.12.10.5.1 Fall Prevention Exercise Programs (El-Khoury et al. 2013)

- Systematic review of 17 studies, which evaluated the impact of exercise programs of various descriptions on injurious falls among people age 60+ years
- The duration of the interventions reviewed ranged from 5.5 weeks to 18 months; frequency and intensity of exercise also varied, but most interventions included multiple types of exercise to address a combination of gait, balance, strength, flexibility, and function
- Exercise-based falls prevention programs were found to reduce the risk of injurious falls by 37%, severe injurious falls by 43% and falls resulting in fractures by 61%
- Similar programming may be appropriate and efficacious for people aging with HIV who are experiencing frailty, cognitive impairment and/or low bone mineral density

4.12.10.5.2 LIFE Study – Exercise Intervention to Prevent Major Mobility Disability (Pahor et al. 2014)

- Study participants were physically limited, sedentary older persons (age 70 to 89)
- The intervention included 24 months of tailored aerobic, resistance and flexibility exercises of moderate intensity conducted twice/week at a centre and 3 to 4 times/week at home
- The study population was not dissimilar to older adults living with HIV in that many experienced periods of disability and had to temporarily suspend participation in the intervention during the study period
- As compared to the control group, intervention participants engaged in significantly more weekly physical activity and experienced reduced major mobility disability and reduced persistent mobility disability

4.12.10.5.3 Interventions to reduce social isolation and loneliness among older people (Gardiner et al. 2016)

- Systematic review included 38 studies
- Evidence to support the use of specific interventions was weak overall, though positive outcomes were reported
- The most successful interventions were adapted to the target population, involved older adults in the program planning process, and utilized activities which encouraged 'doing' as opposed to watching or listening
- Interventions included facilitated groups, psychological therapies, professional supports, pet therapy, volunteer companionship, and skills-building activities

4.12.11 Access to Rehabilitation Services by People Aging with HIV

According to the HIV Health and Rehabilitation Survey (HHRS), people living with HIV in Canada are making limited use of rehabilitation services (O'Brien et al. 2016b). Approximately 17%, 6% and 3% of HHRS respondents accessed physiotherapy, occupational therapy or speech-language pathology, respectfully, in the past year. These low rates of rehabilitation service utilization are in stark contrast to the high prevalence of chronic illness-related symptoms reported by the study population.

People living with HIV may experience access barriers when it comes to rehabilitation. These are outlined in a fact sheet entitled [Increasing Equitable Access to Rehabilitation: Frequently Asked Questions \(FAQ\)](#) and a policy brief entitled [Rehabilitating the Bottom Line](#).

In addition to experiencing some of the same barriers to access as their younger counterparts, older adults living with HIV may be less able to access rehabilitation services because of:

- Chronological age-based eligibility criteria, especially for services reserved for 'seniors'
- HIV stigma among providers of aging-related care who may never have worked with this population before (Cahill & Valadez 2013)
- Low income in retirement which limits their ability to pay out of pocket for uninsured health services
- Marginalization of long-term survivors within the HIV community (Merino 2016)

4.12.12 Responding to the Rehabilitation Needs of People Aging with HIV

In Canada, the first formal gathering of stakeholders with a mutual interest in the topic of HIV and aging was organized by *Realize* (formerly The Canadian Working Group on HIV and Rehabilitation) in 2010. This meeting culminated in the establishment of the *National Coordinating Committee on HIV and Aging* (NCC), which is active to this day. Members of the NCC (older adults living with HIV, researchers, front-line service providers, clinicians, funders) work collectively to raise awareness of the needs, assets and experiences of people aging with HIV in Canada, and to foster changes in policy and practice that will lead to better care, treatment and support for older adults living with HIV.

In 2014, aging with HIV across the life course was formally identified as a priority in the field of HIV and rehabilitation research (O'Brien et al. 2014c) and HIV and aging was entrenched as a pillar of the *Realize* 2014-2017 strategic plan, positioning the organization as a leader in this field.

4.12.13 Annotated Resource List

The International Association of Providers of AIDS Care (IAPAC) has a website called myhivclinic.org which houses guidelines and tools for assessing and managing comorbid conditions often experienced by people living with HIV, including cognitive impairment, cardiovascular concerns, diabetes, dyslipidemia, hypertension, osteoporosis, renal impairment, thromboembolic disease and thyroid disease. The website also has an informative section called Healthy Aging with HIV which addresses frailty syndrome and disability among people aging with HIV, among other topics.

To access eight, 20-minute educational videos, which are relevant to the care and support of older adults living with HIV, see the [HIV and Long-term Care Video Series: Compassionate Care in a Changing Landscape](#) produced by Casey House & The Re kai Centres.

Evidence Summaries related to aging and exercise, fall and injury prevention, healthy weight, memory and cognition, mental well-being, mobility and physical functioning, social health and other topics are available through the McMaster Optimal Aging Portal at www.mcmasteroptimalaging.org.

The Ontario HIV Treatment Network (OHTN) produces *Rapid Responses*, short reviews of the available research evidence on various HIV-related topics. There are several Rapid Responses that may be relevant to rehabilitation professionals who are thinking about implementing rehabilitation interventions for older adults living with HIV. These include:

- [Improving healthcare providers' face-to-face interactions with clients living with or at-risk for HIV](#)
- [Reminder systems for people living with HIV](#)
- [Online counselling and support groups for people living with or affected by HIV/AIDS](#)

CATIE produces *Treatment Updates*, which summarize new research relevant to HIV and hepatitis C. Many recent articles focus on HIV and aging and may have implications for the design and delivery of rehabilitation interventions or research projects (e.g. Factors Linked to Falling in Middle-Aged Women). New and archived Treatment Update issues can be accessed at <http://www.catie.ca/en/treatmentupdate>.

ACRIA, located in New York City, is a leading organization on research and programming relevant to the needs of older adults living with HIV. They have produced many resources on this topic, which are available at www.acria.org/hiv-aging.

The HIV-AGE website (www.hiv-age.org) features science spotlights, journal publications, case studies and clinical recommendations for people aging with HIV. The site also houses the document *Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV* (produced by the American Academy of HIV Medicine, AIDS

Community Research Initiative of America and American Geriatrics Society) and regular updates to this document: <http://hiv-age.org/clinical-recommendations/>.

The Graying of AIDS website (www.grayingofaids.org) houses video vignettes of older adults living with HIV telling their stories.

Tools developed to detect cognitive impairment in the general population are not always useful for screening for HIV-associated neurocognitive disorders. More information can be found here: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3814629/> (Zipursky et al. 2013).

On account of the multimorbidity that often occurs among people aging with HIV, polypharmacy is a reality for many in this population. In response, CTAC and *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) co-produced a fact sheet called [The Impact of Polypharmacy on Older Adults Living with HIV](#).

The Episodic Disability Framework (O'Brien et al. 2008) identifies uncertainty as a dimension of disability experienced by people living with HIV. Planning for the future, sometimes called advance care planning, can help older adults living with HIV cope with uncertainty and ensure they can articulate what they want in terms of future treatment, care and support. The [Speak Up Campaign](#) provides a toolkit for starting the conversation about advance care planning.

The [National Initiative for Care of the Elderly](#) website provides a broad range of tools and resources related to gerontology and geriatric care.

A project team, led by Charles Furlotte (McMaster University), conducted a national scan to identify the existence and features of programs and services in Canada that address the needs of older people living with HIV. Two documents emerged from this project: [HIV & Aging: A 2013 Environmental Scan of Programs and Services in Canada – Community Report](#) and a [Directory of Promising Programs and Services for Older People Living with HIV in Canada](#).

Rehabilitation providers looking for assessment approaches, interventions, and contextual factors worth considering for use with older people living with HIV can find recommendations here: [Evidence-Informed Recommendations for Rehabilitation with Older Adults Living with HIV: A Knowledge Synthesis](#) (O'Brien et al. 2014a).

4_13 Sexual Health and Dysfunction

4.13.1 Introduction

This section is intended to assist care providers to discuss issues of sexual health with their clients, particularly since many health professionals feel ill-prepared to address this topic. Addressing some of these topics will also help to

inform a referral to a sexual health expert. There are many excellent resources for health professionals to use to engage clients to discuss their sexual health. For example, the PLISSIT model has been developed to assess sexual health in older adults (Wallace 2008). The first step is to ask permission (P) to begin a sexual assessment following which open-ended questions are then used to begin to discuss sexual health issues. The health professional then provides limited information (LI) about normal and pathologic changes that may affect sexual health. Based on the client's response to the open-ended question, the health professional can then make specific suggestions as a part of a treatment plan. If the issues are beyond the expertise of the health professional, a referral to a professional with advanced training in sexual health for intensive therapy (IT) may be warranted.

The sexual being is a complex and holistic set of life experiences that include (Tino et al. 2008):

- Sensuality
- Intimacy
- Sexual identity (including gender identity, gender expression and sexual orientation)
- Sexual health and reproduction
- The abuses of sexuality (or sexualization – e.g. rape, sexual harassment)

Sexual dysfunction (SD) can occur due to a single or multiple insult(s) in any of these areas. Unfortunately, very little is known about the breadth and depth of SD in people living with HIV due to a lack of research. From what little is known, SD is common in men, women, transgender and non-binary people living with HIV (Mao et al. 2009, Goldmeier et al. 2005, Wilson et al. 2010). Some estimate that 4 out of every 5 gay men with HIV have a single SD, while as many as 50% have multiple SDs (Mao et al. 2009). In women with HIV, estimates of SD are less frequently reported. However, one study on women living with AIDS demonstrates that of the 71% of participants with a sexual partner, 84% report an SD (Goldmeier et al. 2005).

In men, common documented forms of sexual dysfunction include

- Erectile problems
- Difficulty ejaculating
- Premature ejaculation
- Loss of libido
- Lack of pleasure from sex
- Anxiety over sexual performance
- Pain during sex

In women, common documented forms of sexual dysfunction include

- Decline in sexual interest
- Anxiety over sexual performance
- Difficulty attaining orgasm
- Reduced pleasure
- Pain during sex

It is important to note that not having a sexual partner, that is, engaging in abstinence, may be a symptom of a sexual dysfunction, such as a decline in sexual interest related to medication. However, it may also be a conscious decision explicitly made by individuals, regardless of whether they are living with HIV. In this latter case, abstinence should not be interpreted as sexual dysfunction.

4.13.2 Reasons for Sexual Dysfunction in People Living with HIV

Sexual Dysfunction can result from a number of issues, including but not limited to:

- HIV medications (e.g. protease inhibitors)
- Other prescription drugs (e.g. hypertensive medications and antidepressants)
- Emotional issues (e.g. anxiety, stress, grief and depression)
- Smoking
- 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 (e.g. interfering with nerve function to organs of sexual pleasure)
- Lipodystrophy or lipoatrophy (e.g. resulting in stigma and isolation)
- Other concurrent conditions
- Negative associations with sex and/or certain sexual acts as a result of working in the sex trade and/or rape or sexual harassment
- It is important to note that abstinence may or may not be perceived by the person living with HIV as a dysfunction and is, in fact, a chosen option for some

In addition to these factors, a chronic disability that interferes with sexual function can precede or occur with HIV, and as people living with HIV live longer, sexual dysfunction (SD) increases as it does in the general aging population.

Some authors suggest that sexual dysfunction may also result from the criminalization of HIV non-disclosure in some jurisdictions (Mykhalovskiy et al. 2010). A Canadian study

identified problems associated with the disclosure obligation to include: increased isolation, increased stigma and avoidance of sexual relationships (Mykhalovskiy et al. 2010).

4.13.3 Ascertaining the Specific Type of Sexual Dysfunction

What is the specific sexual dysfunction the client is experiencing and how can care providers help?

Many sexual dysfunctions (SDs) can result from the stigmatization of people living with HIV and could be due to social, political, cultural and religious factors that may be out of the individual's personal control. Healthcare providers may be the only conduits for people with HIV to discuss SD and possible solutions. Healthcare providers can benefit from personal development in the area of sensitive practice in the context SDs. Work from the area of erectile dysfunction suggests that there are four communication strategies that health providers and clients use when addressing sexual dysfunction. These include (Green and Kodish 2009):

- Initiating the topic directly
- Initiating the topic with an introduction
- Initiating the topic when there is a high risk-factor
- Allowing the client to bring up the topic

4.13.3.1 Some Questions to Ask

There are several questions that providers can ask to help create an open dialogue and prepare for the possibility of a referral to a qualified sex therapist. It is important to note that asking an individual whether he or she is in a relationship does not necessarily address whether he or she is sexually active.

- Is the client having difficulty with desire, erection, pain, lack of orgasm, or premature ejaculation?
- How often does this happen?
- Is there a relationship between the stated problem and the client's menstrual cycle?
- Does it occur with masturbation and/or with other sexual partner(s)?
- If the client has a single partner, how is his or her relationship with the partner?
- What's up in the client's life in general...is he or she feeling down, sad, anxious or stressed?
- Does it occur with the use of alcohol or illicit drugs?
- Did the problems begin with recently started medications or with medications that a health practitioner mentioned could cause sexual dysfunction (SD)?

It is important that the person living with HIV does not change his or her medications, take someone else's medications for SD or persist with mental health issues when the assistance of a qualified health professional is required.

There may also be an opportunity to discuss the issues together with the client's trusted sexual partner given the client's consent and safety. Often, peers or counsellors at Community-based HIV Organizations may understand and be empathic with SD issues, and there may be locally available resources including peer or professional support. If the person living with HIV tries some simple and medically safe trials at home and has not been successful or has only had limited success, the assistance of a qualified professional help may be required (e.g. physician, nurse, social worker, psychologist, psychiatrist, sexologist, or rehabilitation professional with training in human sexuality, sexual health and dysfunction).

4.13.4 Addressing Solutions to Sexual Dysfunction

Remember to think holistically; the sexual being is complex and has many aspects and this approach needs to be taken to help our clients.

- Clarify thoughts and ideas about sex both in the context of masturbation and/or with partner(s)
- Identify values and opinions held about sex and sexual contact
- Identify whether there are barriers to acting upon desires and values (e.g. condemning thoughts and feelings about sex and sexual contact)

4.13.4.1 Consider General Health

Encourage the client to:

- Eat well and avoid high-fat, heavy meals before sexual activity
- Discontinue or reduce smoking
- Discontinue or reduce alcohol and/or recreational drug use
- Develop balance to enjoy intimate, sensual, sexual relations with oneself and sexual partner(s)
- Create a relaxing and pleasurable environment for sensual and intimate contact. Masturbation is important to assist one in understanding what turns them on. Often this is the best place to start to understand sexual dysfunction as sexual contact with a partner(s) adds additional components to a complex system. One can use the findings from masturbation to educate lovers about sexual and sensual needs and fulfilment of desire
- It might also be helpful to be creative and engage in fantasy. Encourage use all of the senses: taste, smell, sound, sight and touch are all important in sexual arousal, pleasure and satisfaction. Reinforce the need to play safe, and do not forget the many sex toys that can be used to heighten sexual pleasure. Playing safely can reduce anxiety over transmitting sexually transmitted infections

If problems persist, consultation with other health professionals may be required to determine the presence of other contributing factors. Some examples include:

- A change in medication
- Mental health issues
- Sexual health issues

An added bonus is that this additional assistance might improve the client's overall physical or mental health. Finally, collaboration with other healthcare professionals may identify that the client is a good candidate for a trial of sexual dysfunction-related medications (e.g. Viagra, Cialis, sex or thyroid hormone therapy).

4.13.4.2 A word of caution

Be careful of herbal remedies for sexual dysfunction (SD) as many may be harmful to a client's current medication regimen; specifically, the use of some herbal SD supplements may be harmful to antiretroviral therapies.

4.13.5 Resources

- "Urban Tantra – sacred sex for the twenty-first century", Barbara Carrellas (2007)
- "The Multi-Orgasmic Man: Sexual Secrets Every Man Should Know", Mantak Chia, Douglas Abrams (1996)
- "The Joy of Sex: The Ultimate Revised Edition - The Timeless Guide to Lovemaking", Alex Comfort (2009)
- "Sex for One: The Joy of Selfloving", Betty Dodson (1996)
- "Sex and the Sacred – Gay Identity and Spiritual Growth", Daniel Helminiak (2006)
- "Gay Perspective – Things our Homosexuality tells us about the nature of God and the Unknown", Toby Johnson (2003)
- "The Ultimate Guide to Sex and Disability", Miriam Kaufman, Cory Silverberg and Fran Odette.
- "The Whole Lesbian Sex Book", 2nd edition, Felice Newman (2004)
- "The Joy of Gay Sex" 3rd edition, Charles Silverstein and Felice Picano (2003)
- "Sex Toys 101: A Playfully Uninhibited Guide", Rachel Venning and Claire Cavanah (2003)
- "Sex After 50", Ruth Westheimer (2005)

4_14 Female Reproductive Health

4.14.1 Global Context

Around the world, young girls and women face social and biological factors that increase their risk of HIV infection (Gray and McIntyre 2006). Commonly in the international

context, acquisition of HIV occurs via heterosexual contact; however, in Central and Eastern Europe and North America, injection drug use (IDU) is also a contributing factor to infection among women and young girls (Gray and McIntyre 2006). The number of women around the world with HIV has increased over the past ten years (World Health Organization (WHO) 2009c).

In Canada, research suggests that sex workers and intravenous drug users are among the most neglected in terms of HIV policy and access to care (Shannon et al. 2007). Female HIV infection can result in more severe and frequent cervical disorders (such as human papillomavirus [HPV] infection or cervical intraepithelial neoplasia), Candida vaginitis, and pelvic inflammatory disease (Minkoff et al. 1999; Gary and McIntyre 2006). Although the initiation of combination antiretroviral therapy (cART) during pregnancy can dramatically reduce mother-to-child transmission (MTCT) (Manavi 2006), fertility and pregnancy outcomes can be adversely affected by HIV infection, particularly in populations lacking access to care and/or resources (Gary and McIntyre 2006). The use of cART around the world, and particularly in more developed nations, has reduced vertical transmission to approximately 2% (Manavi 2006).

However, women are more likely than men to have antiretroviral treatment side effects (Gray and McIntyre 2006; Hewitt et al. 2001). One study demonstrates that end-stage HIV progresses faster in women than in men (Hewitt et al. 2001). Moreover, certain antiretroviral regimens may impair contraceptive efficacy (Gray and McIntyre 2006).

The Declaration of Commitment of the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), in 2001, gathered reports from 147 countries about gender equity relating to knowledge of HIV, access to HIV testing and access to antiretroviral treatment. The vast majority of countries participating claim to have women-focused policies ensuring equal access to HIV-related services, however, 14% of reporting countries also had laws and policies in place making HIV programs geared for women difficult, if not illegal, to carry out (Careal et al. 2009). About 80% of countries report having included women as a specific "sector" in their multi-sectoral AIDS strategies or action frameworks, yet just over half of those countries report actually having a budget associated with women-oriented programming (Careal et al. 2009, Gray and McIntyre 2006). As of 2007, women constituted just over half of the 33% of individuals using combination antiretroviral therapy. Although the gender gap in HIV knowledge has narrowed, around the world only 36% of young women have accurate information about HIV prevention (Careal et al. 2009). Thus, in spite of these accomplishments in terms of narrowing the gender gap, it is important to remember that due to a myriad of "bio-socio" variables, the experience of contracting and living with HIV

and AIDS as a woman often differs quite profoundly from that of a man (WHO 2009c, Wolfson et al. 2009, Sprague 2008).

4.14.2 Women, Substance Misuse and Mood Disorders

As with men and HIV, substance misuse often intersects with women and HIV. However, research shows that female drug users are often the most neglected in times of HIV policy as it relates to substance misuse (Gollub 2008, Shannon et al. 2007). This is particularly problematic because female injection drug users in North America, Central and Eastern Europe are part of the growing number of women acquiring HIV (Gray and McIntyre 2006). In America, one study found that 1 in 5 women with HIV engaged in hazardous drinking (Cook et al. 2009). Another study found that while alcoholism does not accelerate disease progression in women with HIV, HIV progression is related to depression (Ghebremichael et al. 2009). Moreover, depression and other mood disorders and psychological issues can affect adherence to antiretroviral therapy (Hewitt et al. 2001).

4.14.3 Violence Against Girls and Women and Intimate Partner Violence

The prevalence of global violence against women and girls within the age range of 15 and 49 years old is estimated to be between 10 to 60%. Violence against girls and women, including sexual, emotional, physical violence and intimate partner violence, is believed to greatly increase the risk of HIV acquisition (WHO 2009c, Decker et al. 2009). An American study shows that early childhood sexual abuse is correlated with a greater likelihood of depression, a greater tendency to participate in exchange sex (where sex is exchanged for drugs, money and/or shelter), a higher number of lifetime and current sexual partners, an increased propensity for unfaithful partners and a lesser ability to mediate safe sex practices (Fuentes 2008). Moreover, non-consensual sex can result in skin lacerations, augmenting the likelihood of transmission (WHO 2009c). The World Health Organization and other experts suggest that living with intimate partner violence (IPV) or even fear of violence during a sexual act greatly diminishes the use of condoms (WHO 2009c, Gielen et al. 2002). A Canadian-American collaborative study demonstrates that women who are HIV positive and live with intimate partner violence are 7.0 times more likely than serostatus negative non-abused women to report depression, 4.9 times more likely to report anxiety, 3.6 times more likely to have considered suicide, and 12.5 times more likely to have attempted suicide (Gielen et al. 2005), revealing a vicious cycle between mental health, substance misuse, violence against women and HIV status. It is important to note that IPV and sexual assault also occurs in men.

4.14.4 Prevention Strategies for Women

Abstinence, exclusivity or asking a sexual partner to wear a condom are three of the more successful ways to reduce HIV transmission amongst women (Ruiz et al. 2009). However, due to the prevalence of forced sex and intimate partner violence around the world, as well as general inconsistency around safer sex practices, these options have obvious limitations. Educational programs, such as those promoting "safer sex negotiation" are cited as a way to facilitate these choices. Education geared towards men and boys challenging stereotypical notions of masculinity, such as homophobia and sex with multiple, often significantly younger, women and girls are also thought to be of benefit (WHO 2009c). Beyond this, there are three ways commonly referred to in the literature whereby women may protect themselves, now or in the near future, according to their own control.

4.14.5 Post-Exposure Prophylaxis

Post-Exposure Prophylaxis (PEP) is recommended only in adverse situations, including occupational exposure or sexual assault. PEP, such as zidovudine, lamivudine and nelfinavir, is only likely to be effective when taken within 72 hours of exposure. Although reasonably successful, PEP is not a guaranteed prophylaxis and is therefore only used in extreme cases (Center for Disease Control (CDC) 2005). Nonetheless, it is a valuable option to be aware of, especially when working with female populations, given the high incidence of sexual violence. A Vancouver organization was among the first in Canada to offer PEP in cases of sexual assault. Over the course of 16 months, 256 women and 5 men reported one or multiple assaults and 71 of these took the initial 5-day starter kit. The study concluded that those who are at "high risk of infection [...] defined as those who suffered a penetration assault by one or more assailants known to be HIV-positive or at high risk of HIV infection (injection drug users or men who have sex with men)" (Weib et al. 2000) were the most likely to agree to initial PEP, as well as most likely to adhere to the program.

Most notably in the context of women, delivering this information at a time as traumatic as immediately following an incidence of sexual assault is often more challenging for service workers than anticipated (Weib et al. 2000). Providing information about PEP as part of a general knowledge around HIV might help diminish this discomfort during such an adverse event.

4.14.6 Female Condom

The female condom is another woman-initiated option. Moreover, it is seen as advantageous in that many men, especially if intoxicated or under the influence of an illicit substance, are unlikely to notice and thus resist (Gollub 2008). Although accepted as an appropriate means of

controlling a woman's exposure to HIV, it is not used as often as it might be, thereby indicating a need for more education around female condoms and greater availability (Gollub 2008, Mantell et al. 2008, Mathews and Harrison 2006, Kalichman et al. 1999).

4.14.7 Microbicides

Microbicides are an emerging method for women to control contraction of HIV (Ruiz et al. 2009, Woodsong and Alleman 2008, Stadler et al. 2008, Mathews and Harrison 2006). Microbicides are products that may reduce HIV risk when applied intravaginally (Ruiz et al. 2009). Although favoured as a woman-initiated prevention method (Olsen et al. 2007) and found to impart a sense of empowerment in women (Stadler et al. 2008), there are indications that cultural factors may limit their use in specific places, indicating a need for simultaneous socio-cultural education (Woodsong and Alleman 2008).

Microbicides should not be confused with spermicides, which are known to augment risk for HIV seroconversion (Aberg et al. 2009). It is important to note that the intrauterine device (IUD) has been met with some controversy for women with HIV, and in particular to women deemed to be at high-risk (Aberg et al. 2009).

4.14.8 Education and Knowledge

Education comprises a key element in the prevention of HIV. A South African study demonstrates that the longer a girl stays in school, the less likely she is to contract HIV (Pettifor et al. 2008). Specific outreach is needed for racialized, low-income women for they are at the highest risk (Arya et al. 2009, Tillerson 2008, El-Bassel et al. 2009, Gardezi et al. 2008). In Canada, this constitutes women of the Afro-Caribbean community (Gardezi et al. 2008), and Indigenous peoples (Health Canada 2010). In spite of only making up 3.3% of the Canadian population, Indigenous peoples make up 5-8% of current infection and 6-12% of new infections (Health Canada 2010). To add to the complexity, it is also important to recall that women who are over 50 and are Caucasian are the least likely to be educated by their general practitioners and family doctors regarding safer sex practices and protection from sexually transmitted infections (STIs), including HIV (Grant and Ragsdale 2008, Yates et al. 1999). In Canada and the United States, this may be partly related to the findings of a study that found that medical school students were undereducated about contraception (Steinauer et al. 2009). This presents an opportunity for healthcare professionals in other fields to broach this important subject for women of all demographics.

4.14.9 Pregnancy, Birth and Breastfeeding

Access to contraceptives is not only important to diminish the spread of HIV, but also to provide women living with HIV with a greater ability to control future pregnancies. For instance, a Malawi study found that although women with HIV were three times more likely than serostatus negative women to not want children, pregnancies for women with and without HIV were the same (Kaida et al. 2009). Control of pregnancies and social/community support is equally as important in the more developed world. One American study showed that the more children a woman has who are under the age of 18 and the greater the degree of child-burden she experiences, the less likely she is to adhere to antiretroviral therapy (Merestein et al. 2009). This suggests that women with children benefit from social and community supports. In addition, it is estimated that 80% of women with HIV are of childbearing age (Craft et al. 2007, Aberg et al. 2009). Women are in the unique position of transmitting HIV vertically, also known as mother-to-child-transmission (MTCT). When antiretroviral therapy is initiated for pregnant women, vertical transmission rates drop dramatically. MTCT in non-breastfeeding women can be reduced to less than 2.5% in women receiving antiretroviral therapy (Chou et al. 2012) and can be even lower (<1%) in women who "achieve undetectable HIV loads while receiving treatment" (Aberg et al. 2009).

All women who are not practising consistent contraception or those expressing interest in a future pregnancy should be involved in an in-depth discussion about future pregnancies. Moreover, all women with HIV, even those who do not fall into the aforementioned categories, should be reminded that should they change their mind and pursue a pregnancy, it is advisable to alert their health-care provider as soon as possible so as to initiate an antiretroviral therapy plan (Burdge et al. 2003).

4.14.10 Mode of Delivery

Obstetrical guidelines state that women with viral loads lower than 40 - 50 RNA copies per mm with an appropriate length of antiretroviral therapy should deliver vaginally and should not be offered an elective cesarean (Boucher et al. 2001). It is recommended that women with high viral loads have cesarean sections prior the advent of ruptured membranes or labour (Boucher et al. 2001, Jamieson et al. 2007). It is also recommended that cesarean should be considered in a prolonged labour, instrumental or traumatic delivery, regardless of viral load or pharmacological therapy (Boucher et al. 2001).

It is also recommended that all women with HIV use formula in-lieu of breast milk to further diminish the likelihood of transmission (Burdge et al. 2003). Another option is to feed one's infant breast milk from a milk bank. The donors of milk to human milk banks are from a "low-risk group" for

HIV and are screened and tested for HIV. The milk is never sent out to clients until it has been through rigorous testing, including HIV testing and bacteriological screening before and after pasteurization. The majority of women donating milk are also feeding their own baby/babies at the same time (Fraser and Cooper 2009). There are currently four Canadian human milk banks located in Vancouver, Calgary, Toronto and Montreal (Ndegwa 2015).

Although formula is a well-developed alternative to breastfeeding, the immunological and nutritional benefits of breast milk far outweigh those gained from formula feeding. Consequently, the World Health Organization recommends exclusive breastfeeding for 6 months for all infants around the globe (Fraser and Cooper 2009). Given the health benefits of breast milk, this idea has been included on the belief that it deserves more research and policy attention. Although it is said that "breast is best", women should be assured that formula feeding is the next best alternative.

4_15 People with Pre-Existing Disabilities and HIV

International estimates suggest that 650 million people worldwide are living with a disability (United Nations, WHO, UNAIDS 2009). There are few data on HIV prevalence among persons with disabilities, however a 2004 global survey found that people with disabilities have HIV infection rates up to three times higher than people without disabilities because of their risk of physical and sexual abuse, isolation, general poverty and general access to services and information (World Bank and Yale University 2004).

International service organizations suggest several reasons why HIV information and services are not reaching people living with pre-existing disabilities and HIV (VSO 2009):

- Billboards do not reach blind people
- Radio spots do not reach deaf people
- Complex and vague messages do not reach persons with learning disabilities
- There is a lack of counsellors who can use sign language
- Health staff is not sensitive to the needs of people with disabilities
- People with disabilities are usually too poor to be able to access HIV services and treatment

Ways to make HIV information and services more accessible include (VSO 2009):

- Make materials available in Braille, audio and video format
- Make materials available in a format for illiterate people, such as cartoons and drama

- Clear and easy messages for people with learning disabilities
- Enhanced physical accessibility at all healthcare centres including placing ramps, access to wheelchair scales, up/down examination beds, etc.
- Training for people with disabilities on sexual negotiation skills and empowerment
- Train healthcare providers on the sexual and reproductive health needs of (young) people with disabilities
- Train healthcare providers in basic sign language

There are now global initiatives with clear recommendations to better meet the needs of those living with disabilities that may be at of risk for or living with HIV (WHO UNAIDS 2009, Heidari and 2009).

CHAPTER 5

Paediatrics

5_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. 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 (Worthington et al. 2005). 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.

5_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. 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" (ICF-CY 2012).

5_3 What are the rehabilitation interventions that address 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.

5.3.1 Mental functions

Many children living with HIV have problems with learning and concentration, especially if they did not start antiretroviral therapies 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. While children in resource-poor settings who are infected with HIV are at great risk for developing HIV encephalopathy, HIV encephalopathy has become rare in resource-rich settings.

The presentation of children with neurologic involvement varies significantly and is influenced by social as well as clinical differences.

Some of the clinical signs that 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

- 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)

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

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.

- Secondary infections
- Poor prenatal care
- Repeated hospitalizations

Potential causes of these impairments and rehabilitation interventions are shown in Table 5.3.1.

Table 5.3.1 Clinical Aspects of Mental Functions

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|---|--|--|
| Developmental delay | Other infections e.g. cytomegalovirus, meningitis HIV encephalopathy | <ul style="list-style-type: none"> • 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) • Consider enrollment in pre-school to provide opportunities for peer modelling, as well as rest for parents |
| Increased or decreased muscle tone | <ul style="list-style-type: none"> • Basal ganglia calcification | <ul style="list-style-type: none"> • Encourage active movement of affected muscles using functional activities through full range of movement |
| Poor or absent expressive language (speech) | <ul style="list-style-type: none"> • Hearing loss from chronic ear infections | <ul style="list-style-type: none"> • 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) |

Table 5.3.1 Continued

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|---|--|---|
| Poor or absent expressive language (speech) | <ul style="list-style-type: none"> Hearing loss from chronic ear infections | <ul style="list-style-type: none"> 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 | <ul style="list-style-type: none"> Fatigue | <ul style="list-style-type: none"> 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 | <ul style="list-style-type: none"> Pre-existing learning problems | <ul style="list-style-type: none"> 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 | <ul style="list-style-type: none"> HIV | <ul style="list-style-type: none"> Allow the child to draw and colour Practice cutting out shapes with scissors Do puzzles with the child Look at books and talk about the colours and shapes in the pictures |
| Depression or behavioural problems e.g. aggression and fighting | <ul style="list-style-type: none"> HIV | <ul style="list-style-type: none"> Provide a safe place for children to talk Refer for psychological assessment and counselling |

5.3.2 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 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-Baker Faces Pain scale (2016). These measures can be adjusted according to age, the degree of illness and other factors, such as cultural background and beliefs.

Potential causes of these impairments and rehabilitation interventions are shown in Table 5.3.2.

Table 5.3.2 Clinical Aspects of Sensory Functions and Pain

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|--------------------------|---|--|
| Pain (acute and chronic) | <ul style="list-style-type: none"> HIV | Non-pharmacological Interventions for pain <ul style="list-style-type: none"> Relaxation techniques Massage therapy Distraction Free play time Music Sleep Rest Balanced diet Warm bath Transcutaneous Electrical Nerve Stimulation (TENS) |

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

5.3.3 Hearing

Otitis media is especially common in the first two years of life. Low socio-economic status, attendance of daycare, the absence of breastfeeding, and winter season are all risk factors for developing otitis media (Dashefsky and Wald 1994).

Table 5.3.3 Clinical Aspects of Hearing Impairments

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|--------------|---------------------|---|
| Hearing loss | Otitis media | <ul style="list-style-type: none"> 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 |

5.3.4 Vision

Children have immature visual systems that make 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 Table 5.3.4.

Table 5.3.4 Clinical Aspects of Visual Impairments

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|---------------------------|---|---|
| Infections | <ul style="list-style-type: none"> Cytomegalovirus | <ul style="list-style-type: none"> 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 textbooks |
| "Cotton wool spot" | <ul style="list-style-type: none"> Microvascular infarct of nerve fibre leading to retinal edema | |
| Blindness/ loss of vision | <ul style="list-style-type: none"> Retinal haemorrhage | |
| Strabismus | <ul style="list-style-type: none"> HIV | |
| Peripheral retinopathy | <ul style="list-style-type: none"> Drug toxicity | |

5.3.5 Sensation

Children can get peripheral neuropathies in the same way as adults living with HIV. 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 first-line paediatric antiretroviral regimes in Africa (Peters et al. 2014).

Children may present with numbness, burning and tingling sensations in their feet. They may have decreased sensation and reduced or abnormal ankle reflexes (Sankyan et al. 2014).

Many children who have been on antiretroviral therapies 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 5.3.5 Clinical Aspects of Sensory Impairments

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|--|---|---|
| Sensation changes, including numbness, burning or tingling | <ul style="list-style-type: none"> HIV | <ul style="list-style-type: none"> 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 program consisting of deep pressure and/or vibration, balance and gait re-education, as well as proprioceptive training, is advised |

5.3.6 Voice and speech functions

Expressive 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.

Potential causes of these impairments and rehabilitation interventions are shown in Table 5.3.6.

Table 5.3.6 Clinical Aspects of Voice and Speech Impairments

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|------------------------|---------------------|---|
| Challenges with speech | HIV encephalopathy | <ul style="list-style-type: none"> • 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 |

5.3.7 Functions of the cardiovascular, hematological and immunological systems

5.3.7.1 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 (Dadlani and Lipshultz 2005).

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.

5.3.7.2 Hematological

- Most children living with HIV have problems with their hematological 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.

5.3.7.3 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 Table 5.3.7.

Table 5.3.7 Clinical Aspects of Cardiovascular, Hematological and Immunological Impairments


| Impairments | Possible Etiologies | Rehabilitation Interventions |
|----------------|---|--|
| Cardiovascular | <ul style="list-style-type: none"> • HIV | <ul style="list-style-type: none"> • 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 |
| Immunological | <ul style="list-style-type: none"> • HIV | <ul style="list-style-type: none"> • Rehabilitation cannot directly improve the immunological status of a patient. However, there are aspects of rehabilitation that must be taken into consideration: <ul style="list-style-type: none"> • o Maintain strict infection control to protect the immunocompromised child from secondary infections • o 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 |

5.3.8 Respiratory Impairments

Respiratory tract problems are among the most frequent complications in children living with HIV (Da Cunha et al. 2013).

A form of pneumonitis in children is lymphoid interstitial pneumonia (LIP), a chronic disease characterized by spontaneous exacerbations, intermittent wheezing, and chronic cough (Zar 2008). The chest x-ray pattern often varies, showing migrating interstitial infiltrates. In some cases, the pattern is difficult to distinguish from tuberculosis.

Pneumocystis jirovecii 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.

5.3.8.1 Respiratory muscle function

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

5.3.8.2 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 Table 5.3.8.

Table 5.3.8 Clinical Aspects of Respiratory Impairments

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|----------------------|---|--|
| Respiratory problems | <ul style="list-style-type: none"> • Bacterial pneumonia | <ul style="list-style-type: none"> • 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 program for children with decreased endurance • Encourage all children to be physically active and to participate in sports |

5.3.9 Functions of the digestive, metabolic and endocrine systems

5.3.9.1 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.

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, HIV-positive mothers and their supporters must carefully consider the risks and benefits of breastfeeding.

5.3.9.2 Malnutrition


- 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 and Speech-Language Pathologists 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 diarrhea 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.

Potential causes of these impairments and rehabilitation interventions are shown in Table 5.3.9.

Table 5.3.9 Clinical Aspects of Feeding Problems and Poor Growth

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|--|---|---|
| Inadequate feeding | <ul style="list-style-type: none"> • Poor oral motor skills | <ul style="list-style-type: none"> • 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 breast milk" 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 | <ul style="list-style-type: none"> • Poor fine motor and visual-motor skills | <ul style="list-style-type: none"> • 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) | <ul style="list-style-type: none"> • Mouth/throat sores or pain | <ul style="list-style-type: none"> • Conduct a comprehensive feeding assessment regarding safety of different textures and consistencies and related aspiration risks • 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 | <ul style="list-style-type: none"> • Malabsorption | <ul style="list-style-type: none"> • Treat infections • Assess gastrointestinal motility and use appropriate medications as required • Use dietary interventions as recommended by a registered dietitian, often low-fat, low lactose foods |
| Poor appetite | <ul style="list-style-type: none"> • Nausea | <ul style="list-style-type: none"> • 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 |

5.3.10 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 (Dreimane and Geffner 2005).

Potential causes of these impairments and rehabilitation interventions are shown in Table 5.3.10.


Table 5.3.10 Clinical Aspects of Endocrine Disorders

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|-------------|---|--|
| Poor growth | <ul style="list-style-type: none"> Secondary infection of endocrine glands | <ul style="list-style-type: none"> Regular growth monitoring and appropriate referral to a doctor |

5.3.11 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)

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

Potential causes of these impairments and rehabilitation interventions are shown in Table 5.3.11.

Table 5.3.11 Clinical Aspects of Movement and Coordination Impairments

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|--|---|--|
| Generalized Hypotonia (low tone) and Delayed Achievement of Motor Milestones | <ul style="list-style-type: none"> Cerebral vascular disease | <ul style="list-style-type: none"> 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 | <ul style="list-style-type: none"> Cerebral vascular disease | <ul style="list-style-type: none"> 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 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 |

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|-------------|--|---|
| Weakness | <ul style="list-style-type: none"> Myopathy | <ul style="list-style-type: none"> 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 program consisting of deep pressure and/or vibration, balance and gait re-education, as well as proprioceptive training, is advised |

Legend: CMV: cytomegalovirus; CNS: central nervous system; HSV: herpes simplex virus

5.3.12 Functions of the skin and related structures

Children with HIV are very prone to skin problems including infections, inflammation and neoplasms of the skin (Blauvelt 2005). All healthcare 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.

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 *Sarcoptes scabiei*. 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 dermatitis.

Potential causes of these impairments and rehabilitation interventions are shown in Table 5.3.12.

Table 5.3.12 Clinical Aspects of Skin Problems

| Impairments | Possible Etiologies | Rehabilitation Interventions |
|---------------|-------------------------|--|
| Skin problems | Neoplasms Infections | <ul style="list-style-type: none"> 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 |

5.4 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 Table 5.4. 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.

Table 5.4 Activity Limitations and Participation Restrictions

| Activity Limitations and Participation Restrictions | Rehabilitation interventions |
|---|---|
| Learning and applying knowledge | <ul style="list-style-type: none"> • Environmental adaptation • Assistive devices • Provision of visual education materials • Additional support for children in their classrooms |
| General tasks and demands | <ul style="list-style-type: none"> • Environmental adaptation • Advice on appropriate games and activities • Exercise prescription – aerobic • Exercise prescription – strength • Return to school and sport strategies |
| Communication | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • Assistive devices • Environmental adaptation • Energy conservation and pacing • Advice for the caregiver on meal preparation and nutrition |

| Activity Limitations and Participation Restrictions | Rehabilitation interventions |
|---|--|
| Interpersonal interactions and relationships | <ul style="list-style-type: none"> • Psychosocial rehabilitation • Family support groups and parenting programs • 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 | <ul style="list-style-type: none"> • School education programs • Extra-mural education and activities for learners • School feeding programs • 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 | <ul style="list-style-type: none"> • Advice on appropriate games and activities • Community activities and programs • Involvement and education of spiritual, political, education and community leaders • Education and advice on human rights |
| Policy advocacy | <ul style="list-style-type: none"> • Advocate for policies and programs 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 | <ul style="list-style-type: none"> • Getting involved in prevention programs at a number of different levels. This can include education to support prevention of mother to child transmission, exercise programs for children and youth to prevent complications associated with HIV. • Promoting good health through wellness programs for young people designed to encourage healthy living and lifestyle choices. |

5.4.1 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 pathologist and work in collaboration with the multidisciplinary team to implement therapy.

5.4.2 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.

5.4.3 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 minimize 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.

5.4.4 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.

5.4.5 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.

5.4.6 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, 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.

5.4.7 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. 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.

5.4.8 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, normalize 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.

5.4.9 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. Dietitians or nutritionists may recommend daily multivitamins. Referral can be made to a dietitian (when available) who may conduct a nutritional assessment, counsel individuals, or assist with food provision through referral to nutrition supports. Any advice on nutrition must include information on adequate hydration level for each individual.

5.4.10 Psychosocial rehabilitation

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 friends, family, cultural, religious and other community organizations, can also provide emotional and practical support.

5.4.11 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.

5.5 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 (Spiegel and Futterman 2009).

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.

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 (Speigel and Futterman 2009). Unfamiliarity and the associated stigma of HIV make adherence to antiretroviral regimens in youth with behaviourally acquired HIV a challenge (Speigel and Futterman 2009).

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 (Speigel and Futterman 2009).

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 healthcare system. In most cases, a paediatric 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. (2010) 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 (Fair et al. 2010). 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 (Fair et al. 2010).

CHAPTER 6

Overview of Interventions

6_1 Preventive Rehabilitation

Recent advances in the broad-scale implementation of interventions for the prevention and treatment of infection with HIV have created a significant turning point in the global HIV pandemic (Folkers et al. 2013). This section discusses the importance of preventive rehabilitation for people living with HIV, and covers the following topics:

- The role of exercise
- Strategies for achieving optimal nutrition
- Considerations for risk reduction and risk management for primary and secondary prevention. In addition, ongoing engagement in life roles and feeling connected to the community are linked to positive health outcomes. There is increasing evidence to demonstrate that socially active people age better than those who are not socially engaged.
- Emerging advances including treatment as prevention and vaccines.

6.1.1 Introduction

The goal of preventive rehabilitation is to prevent impairments, activity limitations and participation restrictions for which people are at risk as a result of being HIV positive (WHO 2001). Preventive rehabilitation is a component of health promotion, which may be described as action by people to meet their own, self-determined, positive health goals, pursued through personal, group, and community development in a context of supportive policies, resources, and environments (Trussler and Marchand 1993). The HIV community has a rich tradition of health promotion activities. Most HIV prevention and support programs in Canada have arisen from self-initiated community groups (Trussler and Marchand 1994). Thus, excellent opportunities exist for partnerships between rehabilitation providers and community-based organizations to address issues of preventive rehabilitation.

Preventive rehabilitation encompasses a number of components, which address the determinants of health including exercise and nutrition. Primary and secondary prevention through harm reduction is also important components of preventative rehabilitation. Primary prevention strategies are typically described as inhibiting disease or injury before it occurs. Secondary prevention involves the early detection of disease or its precursors with the aim of preventing disease progression or early cure.

6.1.2 Exercise

Regular exercise is widely accepted as an integral component of optimal health (Stuart et al. 2009). 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

Evidence to support these findings are described in [Section 6_4](#). While systematic reviews for aerobic and resistive exercise exist, no precise exercise prescription guidelines for people living with HIV have been developed. The best advice for people living with HIV is:

- When starting an exercise program, inform physician and rehabilitation providers
- Start early in disease progression and stay fit
- Ensure an adequate warm-up and cool-down
- Choose activities/types of exercise that are enjoyable
- Do not subscribe to the "no pain, no gain" motto, instead exercise with moderation and increase level of difficulty incrementally
- Use common sense when deciding goals and limits (if questions arise, consult a physician, physical therapist or exercise trainer)

In some communities, there are programs that combine exercise and group counselling.

6.1.3 Nutrition

Current nutritional challenges for people living with HIV include malnutrition, cachexia, micronutrient deficiency, obesity and lipodystrophy (Polo et al. 2007). Optimal health for people living with HIV can only be achieved if nutrition is an integral part of preventive efforts. Preventive nutrition involves identifying those factors which lead to the state of being at nutritional risk and then reducing or eliminating them. The goal of preventive nutrition is to provide the person living with HIV with the knowledge, resources, and capability to achieve and maintain an advantageous nutritional state.

Achieving this state may be conceptualized as a function of dietary intake, nutrient absorption, and metabolism. The Canadian AIDS Treatment and information exchange (CATIE) maintains a current online nutrition resource. The "Practical Guide to Nutrition and HIV" can be accessed through <http://www.catie.ca/en/practical-guides/nutrition>.

A broad range of interacting factors influences nutritional status:

- Human biology
- Clinical condition of the disease and any concurrent conditions at that time point
- Lifestyle
- The social and physical environments in which people live

Disturbances in any of the components can lead to a state of malnutrition. While some controversy exists about what constitutes a healthy diet, particularly in relation to micronutrient supplementation, evidence to help define the concept of a healthy diet for people living with HIV is accumulating rapidly.

Malnutrition and its complications can contribute to a person's susceptibility to opportunistic infections, and reduce the effectiveness of and tolerance to medications and therapies. Furthermore, accompanying fatigue, lean muscle wasting, and general malaise diminishes quality of life and may result in decreased ability to perform daily living activities.

Practicing preventive nutrition is better than playing catch-up. For example, prompt nutritional therapy monitors and detects loss of body weight (an indicator of protein-energy malnutrition and micronutrient deficiencies), and is more effective than interventions initiated after severe wasting has occurred. With severe wasting, more intensive interventions are needed to stabilize and replenish lean muscle mass loss. As well, late-stage interventions are not always successful.

6.1.3.1 Key Strategies for Optimal Nutrition

Five different strategies are described below. It is important to recognize that using one strategy on its own will have a limited effect. Maximum benefit is possible only by combining these strategies. As well, nutritional needs will vary with the stage of HIV disease.

6.1.3.1.1 Achieve and Maintain Nutritional Adequacy

Recommended nutrient intakes were established to identify the mean usual dietary intake of a population plus two standard deviations required to maintain health in an already healthy population (Health and Welfare Canada 1990). Health Canada now provides an online resource for Canada's Food Guide (<http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php>) and has developed Dietary Reference Intakes (<http://www.hc-sc.gc.ca/fn-an/nutrition/>

[reference/dri_using-util_anref-eng.php](http://www.hc-sc.gc.ca/fn-an/nutrition/reference/dri_using-util_anref-eng.php)). For people living with HIV, these recommended intakes and allowances are not likely sufficient to maintain health. It is commonly accepted that people living with HIV should prevent weight loss and lean muscle mass loss by maintaining energy and protein balance, and by taking at least a single daily multivitamin and mineral supplement. Most clinics where people living with HIV receive their medical care should have access to a nutritionist who can recommend current best practices for optimal nutrition.

6.1.3.1.2 Monitor Nutritional Status

A comprehensive nutritional assessment should be done at baseline and again whenever the individual presents with significant new symptoms. A change in body weight is the most basic indicator of nutritional status that can be easily monitored by people living with HIV. However, when used alone, this measurement can be deceptive because lean muscle mass loss and malnutrition can occur even in the absence of body weight loss. These changes can happen as a result of a relative increase in extracellular water and a decrease in intracellular fluid and protein. The time at which referrals are made to a nutritionist or clinical dietitian varies according to regional standards and practice. Some are referred immediately, while in other areas, the standard of practice may be to wait for a little while.

In any event, referrals to a clinical dietitian or nutritionist should be made in the following circumstances:

- The presence of dietary, anthropometric, clinical, or laboratory signs of macronutrient or micronutrient deficiencies or excesses
- The presence of symptoms with nutritional implications: fever, anorexia, weight loss or changes in body composition, loss of muscle strength, excessive fatigue, difficulty in swallowing, dementia, maldigestion/absorption, nausea, vomiting, diarrhea
- The presence of paediatric feeding difficulties, evidence of failure to thrive, or indications of poor growth
- When individuals have difficulty adjusting to complex drug regimens with dietary restrictions, or regimens with drug-nutrient interactions
- When people have questions about nutrition-based complementary therapies or adherence to cultural or religious dietary patterns
- When people have food allergies or intolerances or are avoiding food groups without appropriate dietary compensation
- When people have concurrent conditions requiring nutritional intervention (e.g. pregnancy, diabetes, cardiovascular disease)
- When infant formula regimens are initiated

6.1.3.1.3 Implement Safe Food, Water and Sanitation Practices

People living with HIV should:

- Ensure animal foods are cooked adequately
- Use only pasteurized dairy products and purified water
- Avoid cross-contamination of raw or uncooked foods and cooked foods
- Be aware of risks associated with some fruits and vegetables

It is also important to follow kitchen sanitation and safe food storage practices. People living with HIV should be educated about hidden or unrecognized sources of contamination when eating out.

6.1.3.1.4 Establish a Reliable Supply and Variety of Food

Nutritional status is closely linked to dietary intake. If dietary intake is impaired due to lack of available food or access to food, the most effective strategy is a combined intervention by social workers, HIV service organization workers, and nutritionists.

6.1.3.1.5 Explore Use of Nutrition-Based Complementary Therapies

A large proportion of people living with HIV use complementary therapies, many of which are based on dietary modifications and nutritional supplementation. Although peer-reviewed evidence to support or refute many of the claims for these therapies is lacking, most can be classified into three broad categories:

- Beneficial
- Unknown benefits and risks, but unlikely to cause harm
- Harmful

People living with HIV should be encouraged to discuss the complementary therapies of interest to them with their healthcare providers. Therapies that incorporate healthy nutritional practices should be reinforced. A systematic review of nutritional interventions to reduce morbidity and mortality in people living with HIV was based on eight small trials conducted in high-income countries. The authors found limited evidence that macronutrient supplementation such as a balanced diet or high protein, high carbohydrate, or high-fat diets given orally influenced protein and energy intake, and no evidence that such supplementation translates into reductions in disease progression or HIV related complications (Mahlungulu et al. 2007). Thus, caregivers and people living with HIV should be cautious about therapies:

- Suggesting the exclusion of an entire food group or a large number of foods within a food group without replacement from other sources (e.g. some macrobiotic diets)
- Involving unsafe food and water practices (e.g. consumption of raw or undercooked meat)
- Where the costs interfere with the ability to otherwise maintain an appropriate food budget (e.g. multiple nutritional supplements)

6.1.4 Risk Reduction / Risk Management

6.1.4.1 General Transmission Reduction Education

General HIV-risk prevention is an important component of HIV education, particularly for those who are part of an at-risk population. At-risk populations in Canada are very diverse and include gay, bisexual and other men who have sex with men, people who use injection drugs, anyone working in the sex trade, Indigenous peoples, and prison populations. Women, new Canadians and youths are also being targeted for risk prevention strategies.

In general, the majority of intervention- and education-oriented HIV programs target one specific demographic and tailor the intervention accordingly. For instance, one meta-analysis of interventions aimed at African-American women living with HIV determined that those interventions which had female interventionists, used cultural and gender-specific tools, were aimed specifically at African American females, used role-playing and emphasized proper condom use and strategies to negotiate safer sex are the most efficacious (Crepaz et al. 2009). Because acquisition of HIV can occur to such specific at-risk populations and because the reasons for acquisition can be variable across groups, continued examination of population-specific interventions (and their outcomes) continues to be a priority.

6.1.4.2 Psychosocial Implications for Risk Reduction and Management

People living with HIV who are successful in managing their disease face new challenges which are not only physical but also social and psychological because of potential for stigma and discrimination (Bravo et al. 2010). These challenges present many decisions and dilemmas for people living with HIV that involve complex emotional and psychological issues. Bravo et al. (2010) completed a review to examine the psychosocial decision needs of people living with HIV and identified three key decisions: 1) whether or not to disclose their diagnosis to others; 2) decisions about adherence to treatments and 3) decisions about sexual activity and parenthood. Coates et al. (2013) have identified priorities for behavioural and social research for the prevention of HIV. They suggest that behavioural and biomedical interventions

are not enough to control transmission and that given scientific advances prevention and treatment must be mutually considered.

They suggest that combination prevention and treatment strategies should not only include traditional approaches but also must include relevant strategies for the individuals and communities affected. Researchers are now evaluating the role of social networks as an avenue for low-cost and sustainable HIV prevention interventions that can be adapted and translated into diverse populations (Latkin et al. 2013). Social networks can be utilized as a viable approach to recruitment for HIV testing and counselling, HIV prevention interventions, optimizing HIV medical care, and medication adherence. Social network interventions may be face-to-face or through social media and may often include peer-to-peer facilitators.

6.1.4.3 The Importance of Stable Housing

The importance of safe and stable housing has been highlighted through the development of the North American Housing Summit, which also provides an online forum for broad discussion of the role of housing on HIV disease prevention and management. Through the work of the summit, it has been determined that homelessness not only leads to greater HIV risk but also greater HIV risk behaviours. There is also now significant evidence that the provision of stable housing and housing interventions have an independent, direct impact on HIV care, health status, quality of life and mortality of people living with HIV. Access to the Summit resource, which includes publications and fact sheets, is available online at. In Ontario, the Housing Help Association provides access to services that can help people who do not have a place to live, or who are in a difficult situation and may become homeless:

<https://findhousinghelp.org/>.

6.1.5 Guidelines for Primary and Secondary Prevention

The role for rehabilitation providers in the primary and secondary prevention of HIV and its impacts has become increasingly important. Prevention strategies should be considered an important component of care for all people living with HIV.

The United States Centers for Disease Control and Prevention have developed guidelines for incorporating HIV prevention into the medical care of people living with HIV (2014). These recommendations take into account the contextual issues that shape the lives of people living with HIV and their ability to use HIV prevention and care services and adopt HIV prevention strategies. These recommendations can be found at <http://stacks.cdc.gov/view/cdc/26062>.

The International Antiviral Society – USA Panel - has also published practice guidelines for HIV prevention in clinical care. The key points for practice include the recommendations that clinicians should offer HIV testing to all adults and adolescent patients at least once, and should occasionally evaluate each patient's risk of HIV. Treatment should be offered to those at high risk of HIV or those exposed as soon as possible. Once a patient has tested positive for HIV infection, antiretroviral therapy should be offered, with plans to provide support for adhering to therapy (Gunthard et al. 2016).

6_2 Pharmacologic Interventions

6.2.1 Background

The HIV replication cycle has been the target for HIV drug interventions. HIV drugs have been designed to reduce the viral population in order to preserve and/or restore immunity and prolong life. Advances in the treatment of HIV with effective, more convenient and more tolerable antiretroviral therapy (ART) have dramatically changed the face of HIV infection. These advances have led to a sharp reduction in both opportunistic infections and death rates.

However, even in developed countries with access to medications, late presentation of HIV remains a considerable problem that can cause significant morbidity and mortality (Seddon and Bhagani 2011). Some patients may have a suboptimal response to ART due to poor adherence to therapy that may be caused by drug toxicities that lead to interruptions or discontinuations. Others may have a reduced response due to the emergence of drug-resistant viral strains or the use of interacting drugs that compromise antiretroviral drug concentrations. As there are many diverse populations affected by HIV such as children, pregnant women, those with various co-morbidities such as mental illness, addiction, co-infection with hepatitis B and/or C, and each have their own challenges, several detailed treatment guidelines have been developed internationally to address these specific populations and provide guidance on how best to use ART to maximize success of drug therapy. Advancements in care continue to be made; however, knowledge and sensitivity to the complexities of drug therapy are required as a foundation for providing rehabilitation care, treatment and support for people living with HIV.

6.2.2 Online Open Access Treatment Guidelines

6.2.2.1 Canadian HIV/AIDS Pharmacists Network

The Canadian HIV/AIDS Pharmacists Network has published updated clinical practice guidelines for the role of pharmacists in caring for people living with HIV (Tseng et al. 2012). They provide current guidelines for the pharmacist's role in many aspects of care for people living with HIV,

including selecting and reviewing therapy, tailoring treatment for specific populations, managing drug interactions, medication counselling, monitoring response to therapy and guiding transitions of care. This paper includes links to guidelines for treatment of HIV and related conditions, landmark studies, and comprehensive review articles. This article can be accessed at <http://www.cjhp-online.ca/index.php/cjhp/article/view/1120/1454>.

6.2.2.2 International Antiviral Society – USA Panel and the Department of Health and Human Services

Two major resources commonly used by many HIV practitioners in North America are the guidelines by the International Antiviral Society (IAS) and the Department of Health and Human Services (DHHS). The IAS panel provides recommendations for the treatment of adult HIV infection which includes what drugs to use, monitoring parameters for response and toxicities, and managing antiretroviral failure. The DHHS panel provides a variety of guidelines targeted to adults, adolescents, perinatal and paediatric care. Both groups regularly review the literature and update their guidelines when needed.

The IAS guidelines can be accessed at <https://www.iasusa.org/content/antiretroviral-drugs-treatment-and-prevention-hiv-infection-adults-2016-recommendations> (Gunthard et al. 2016), and the various DHHS guidelines can be accessed at <http://aidsinfo.nih.gov/guidelines>

6.2.2.3 European AIDS Clinical Society

The European AIDS Clinical Society (2017) provides comprehensive clinical practice guidelines that include recommendations for the assessment of people living with HIV at initial and subsequent visits, issues related to starting and maintenance of antiretroviral therapies for people living with HIV, prevention and management of comorbidities, clinical management and treatment of chronic hepatitis B and/or C co-infection, and opportunistic infections. This resource can be accessed at <http://www.eacsociety.org/guidelines/eacs-guidelines/eacs-guidelines.html>

6.2.2.4 World Health Organization Consolidated Guidelines for Treating and Preventing HIV Infection.

The World Health Organization (WHO) 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 guidelines are available at <http://www.who.int/hiv/pub/guidelines/en/>

6.2.2.5 Adherence

Adherence due to competing life choices or drug access is currently the biggest barrier to treatment success. Several systematic reviews have been published to review the

literature from the perspective of special populations (e.g. women, youths), patient characteristics (e.g. aging with comorbidities, the role of employment) and treatment strategies (e.g. single dose versus multiple doses, text reminders). Mbuagbaw et al. (2015) completed a systematic review to determine the effectiveness of interventions designed to improve adherence to antiretroviral therapy from studies included in a Cochrane review that reported a clinical and an adherence outcome, with at least 80% follow-up for six months or more. Ten studies reported improved adherence and clinical outcomes.

These studies used the following interventions: adherence counselling (two studies); a once-daily regimen (compared to twice daily); text messaging; web-based cognitive behavioural intervention; face-to-face multi-session intensive behavioural interventions (two studies); contingency management; modified directly observed therapy; and nurse-delivered home visits combined with telephone calls.

6.2.3 Online Open Access Resources

For individuals who may be struggling with medication issues or decisions, the Canadian AIDS Treatment Information Exchange has developed several resources published online including "A Practical Guide to HIV Drug Treatment" (CATIE 2015) and a new resource "A Practical Guide to HIV Drug Side Effects" (CATIE 2013). These resources are intended to be used with a broader resource called "Managing your Health" which is a comprehensive guide to healthy living for people living with HIV (CATIE 2015). This link will connect to all of CATIE's practical guides and booklets: <http://www.catie.ca/en/practical-guides>

6_3 Evidence-Informed Rehabilitation Interventions for HIV

6.3.1 Introduction

Over the past decade, *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) has conducted ongoing work to identify evidence-informed practice guidelines to guide HIV stakeholders in determining which rehabilitative care and rehabilitative professionals are appropriate in managing a range of impairments associated with HIV and its treatments. A comprehensive review was conducted in 2008 and has been updated regularly since that time. Commonly experienced impairments were identified via the British Columbia (BC) Prevalence Study (Rusch et al. 2004) and Aging Research on Older Adults with HIV (Karpiak et al. 2006).

6.3.2 Objectives

- **Phase 1:** To conduct a comprehensive review of published and grey literature to identify relevant articles pertaining to the existence or development of best practice guidelines (e.g. treatment, management, overall care), that address rehabilitative management of a range of impairments due to any underlying condition

The methodology used included the identification of existing guidelines via a comprehensive literature review. An electronic search of published literature in MEDLINE (from inception to November 2008) and grey literature was conducted to identify existing best practice guidelines (e.g. management guideline, treatment guidelines), pertaining to rehabilitative management of a range of impairments as identified from the BC prevalence study (Rusch et al. 2004) and the Research on Older Adults for HIV Study (Karpiak et al. 2006).

The following impairments were included in the search strategy: "Altered sensation", "Diarrhoea", "Reduced libido", "Weakness", "Poor concentration", "Headache", "Migraine", "Chronic fatigue", "Decreased endurance", "Poor appetite", "Decreased memory", "Nausea", "Gastric reflux", "Swallowing", "Wasting", "Depression and anxiety", "Constipation", "Arthritis", "Stiff joints", "Hepatitis", "Neuropathy", "Dermatologic", "Herpes (Shingles)", "Vision loss", "Diabetes", "Neurological", "Neurocognitive", "Hearing loss", "Pneumonia", "Shortness of breath", "Respiratory", "Hypertension", "Heart condition (Cardiovascular)", "Broken bones", and "Stroke".

The search strategy was developed by an expert panel of rehabilitation professionals and other HIV stakeholders (working group), and a consensus by the working group was reached to exclude "staphylococcal infection" and "sexually transmitted diseases" from the search. A search was conducted for each impairment separately, and the following MESH terms were used to search for Guidelines: "exp. Guideline; or exp. Practice Guideline; or exp. Guideline Adherence; or guideline.mp." OR "Best Practice.mp." Publication search limitations were applied to include only English language publications. For impairments where the search yielded a large number of citations (> 300 articles), a search restriction of "review articles" was applied and these results were populated into a reference manager database for further review.

An experienced reviewer performed a manual search of reference listings from all articles retrieved from MEDLINE, and grey literature search (e.g. public health websites and reports/documents [e.g. National Quality Measures Clearing House]) to learn from groups that have developed practice-based guidelines relevant to the identified impairments.

A variety of best-practice guidelines in use provincially, nationally and internationally were found from the following sources: a) the targeted review of scientific and grey literature above; b) subject matter expert input on other groups developing rehabilitation best practice strategies and c) manual search of identified relevant literature. Inclusion criteria were applied to each publication identified in the search and included the following: a) literature pertaining to existing guidelines for the management of the identified impairments/conditions at rehabilitation healthcare provider level (e.g. rehabilitation therapies, care, and referrals) or b) where possible, literature that identify care maps, algorithms or rationale for which rehabilitation providers are most appropriate to provide care for which HIV impairment. Citations pertaining to the guidelines dealing with the pharmacological management or specialist management of conditions were excluded (see Table 6.3). Each citation was either assigned a "relevant" if it met the inclusion criteria or "irrelevant" if it did not.

Table 6.3 Inclusion Criteria for identification of relevant articles

| Include Articles that pertain to: |
|---|
| Guidelines: |
| Best practice guidelines Management/Treatment guidelines Client care guidelines Referral guidelines |
| Rehabilitation Provider: |
| Occupational therapist Physical therapist (Physiotherapist) Speech-language pathologist Physiatrist Mental health therapist/counsellors Complementary or Alternative therapist |
| HIV Impairments: |
| Identified from BC Prevalence Study (Rusch et al. 2004) and Aging Research on Older Adults with HIV (Karpiak et al. 2006) |

6.3.3 Findings

6.3.3.1 Phase 1 (October 2008-January 2009)

Phase 1 included the search and selection of best practice guidelines for impairments due to any underlying condition. Due to the limited number of rehabilitation specific HIV guidelines, the working group recommended conducting a comprehensive review of best practice guidelines specific to overall impairments regardless of underlying condition. The hope was that this would allow identification of relevant guidelines across disease groups. This literature review yielded a total of 4664 guideline articles relevant to the list of impairments based on the initial title and abstract search. No results were obtained for "reduced libido", "poor

concentration", and "poor appetite". For the following impairments "altered sensation", "decreased endurance", "shortness of breath", and "weakness", it was difficult to focus the scope of the search due to the general nature of these terms.

For some impairments, there were a large number of relevant articles identified even though these were limited to reviews "Heart Condition (cardiovascular)" (n=832), and "neurological impairment" (n=596). Overall, the types of publications identified included general practice guidelines, expert recommendations, expert consensus statements, and reviews on rehabilitative therapeutic interventions and disease management. The reference list was reviewed by the working group for relevance to project objective and potential for broad use in the rehabilitative management of impairments. A reference list of HIV specific guidelines was also identified by the reviewer and provided to the working group. A recommendation was made by the working group to conduct a full-text review and data abstraction on HIV-specific literature.

6.3.3.2 Phase 2 (January 2009-September 2009)

Phase 2 included the selection of best practice guidelines specific to impairments due to HIV and its treatment: Full-text of all HIV specific literature identified during Phase 1 were reviewed, and data abstraction was conducted using a standardized extraction tool. The following data were extracted for each report: "impairment addressed", "first author/publication year", "type of article", "scope/purpose", "stakeholder involvement", "target user", "methods used to develop guidelines (if applicable)", "validation (use of tool)", "summary of guideline/recommendation". In addition to publications identified in Phase 1, full-text publications were obtained from subject matter experts, and through a manual search of relevant citations and updated literature search specific to HIV disease and its treatment (conducted from November 2008 to Week 4 September 2009).

A total of 28 HIV specific publications were identified. However, almost half (13/28) did not address any rehabilitation interventions or discuss the role of rehabilitation providers in managing impairments (13/28). Similar to Phase 1, the types of publications that were identified included general practice guidelines, expert recommendations, expert consensus statements, and reviews on rehabilitative therapeutic interventions and disease management strategies. The scope of the impairments addressed are: "HIV overall", "Wasting", "Dyslipidemia", "Weight loss", "cardiovascular disease", "lipodystrophy", "HIV neurological complications", "HIV encephalopathy (HIVE) and myelopathy (HIVM)", "HIV related neuropsychiatric impairments", "Neurodevelopment and neurologic complications", "AIDS-related cognitive impairments", "Somatic symptoms: insomnia, pain, fatigue, poor appetite, weight changes, and sexual dysfunction",

"Mental health", "Depression", "Cognitive disorders: dementia and delirium", "Opportunistic infections", and "Chronic kidney disease". There were no guidelines that were evaluated using a high-quality guideline appraisal tool, and most were limited in the evidence used to develop the guidelines or recommendations. Most guidelines were developed using a clinical expert panel or relied on expert opinion and/or clinical judgment. Those guidelines that did address randomized controlled trials were evaluated but were limited to exercise recommendations for wasting, weight loss, and lipodystrophy impairments.

This study identified that there are no current clinical practice guidelines of high quality to address rehabilitation interventions for the treatment of impairments associated with HIV and its treatment. However, with the increasing availability of research within the context of HIV and rehabilitation, randomized trials are increasingly being conducted, and for some areas like exercise, cognitive behaviour interventions and massage, systematic reviews have been conducted.

6.3.3.3 Rapid Review of Intervention Literature

A systematic search for intervention literature published since 2010 was conducted on 30 November 2015. The search was conducted by the project information specialist and included articles indexed as of that date. The searches were run using the OvidSP search platform in the following databases: MEDLINE, EMBASE, PsycINFO and Social Work Abstracts and the EBSCOHost search platform in the following database CINAHL. A total of 8645 citations were retrieved which included 987 duplicates. The remaining 7658 unique references were transferred to a compressed EndNote library for review against the inclusion criteria. The search strategy included all age groups but was limited to evidence-based methodology terms and English language articles and publication dates of 2010 to the present. After applying the inclusion criteria used for a scoping review of rehabilitation literature in the context of HIV, which was conducted in 2006 (O'Brien et al. 2010a), 183 rehabilitation intervention articles were identified for full review and inclusion in the 2016 e-module update. A full report of the search approach can be requested from *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation).

6.3.3.4 Additional Scoping Studies

Three scoping studies to explore the role for rehabilitation in the context of HIV have been published since the 2006 scoping review conducted by this team (O'Brien et al. 2010a). These include a review of rehabilitation interventions in adults living with HIV (Stevens & Nixon 2016) and children living with HIV (Stevens et al. 2014). An additional review explores home-based interventions for adults living with HIV (Cobbing et al. 2016).

6.3.3.5 E-Module Updates

Annual e-module updates between 2013 and 2018 were completed using the following methods: a) the update team received automated updates of newly published literature based on the specified search criteria set out by the project librarian (general HIV and rehabilitation search strategy); b) targeted literature searches by topic or area; and c) content review by experts familiar with the literature on the topic.

6_4 Exercise

In developed countries, people living with HIV are living longer and now aging with the health-related consequences of HIV, potential adverse effects of treatment and multi-morbidity (Rusch et al. 2004a, Rusch et al. 2004b, Gaidhane et al. 2008, Palella et al. 2006, Willard et al. 2009, Rodriguez-Penny et al. 2013). These health-related consequences are known as disability and include symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty or worrying about future health HIV (O'Brien et al. 2008a).

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 (Botros et al. 2012). 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 (Garber et al. 2011, WHO n.d.). Systematic reviews suggest that aerobic and resistance exercise is safe and may lead to benefits in cardiopulmonary fitness, strength, weight and body composition, and quality of life (O'Brien et al. 2017, O'Brien et al. 2016, Gomes-Neto et al. 2013, Gomes-Neto et al. 2013).

The data reported here is derived from two updates of systematic reviews of aerobic and resistance exercise (O'Brien et al. 2017, O'Brien et al. 2016).

6.4.1 Aerobic Exercise

Aerobic exercise, otherwise known as cardiovascular (cardio) or endurance training, works the cardiovascular system by raising the heart rate and strengthening the heart. It involves carrying out a physical activity at low-to-moderate intensity for an extended period of time. Aerobic exercise helps improve endurance so individuals carry out an activity for longer without feeling fatigued as quickly. Aerobic exercise may be continuous (exercise at a continuous intensity for a duration of time) or interval (exercise at a varied high and low intensity for a duration of time).

Examples of aerobic exercise include stationary bike, walking, jogging, running, rowing, stair-stepping, stationary cycle ergometer, elliptical trainer, or cross-country and ski machine. Exercise intensity for aerobic exercises in the published research range between 50-100% maximum oxygen consumption (VO₂max) or 45-85% heart rate maximum, three times per week for 5-52 weeks (O'Brien et al. 2016).

6.4.2 Resistance Exercise

Resistance exercise or weight training strengthens muscles by contracting them against some sort of force. Resistance training can increase muscle mass, increase the size of muscles and subsequently increase strength. Types of resistive exercise include concentric and eccentric muscle training (weight lifting, push-ups, chin-ups, biceps curls, triceps dips, latissimus pull-downs, leg presses, leg curls, bench press, using nautilus machines and abdominal crunches), isotonic resistance exercises and weight training for the upper and lower body, often in accordance with the American College of Sports Medicine guidelines (Garber et al. 2011). Exercise intensity for resistive exercise in the research include training of major muscle groups in the upper and lower body for approximately 20-90 minutes ranging from 1-5 sets of 4-30 repetitions each, at 50-90% 1 repetition maximum (1-RM) three times per week for 6-52 weeks (O'Brien et al. 2017, O'Brien et al. 2016).

Exercise should also include warm-up and cool-down periods with stretching components. Stretching is important because it improves joint and muscle flexibility and may help to prevent injury. The intensity of exercise is often gradually progressed and may or may not be supervised.

6.4.3 The FITT Principle

6.4.3.1 Frequency – How often should a person exercise?

Research suggests that to obtain (and maintain) benefits of exercise one should exercise at least 2-3 times per week (O'Brien et al. 2017, O'Brien et al. 2016, Gomes-Neto et al. 2013a, Gomes-Neto et al. 2013b).

6.4.3.2 Intensity – How strenuous should the exercise be?

Aerobic exercise in HIV research is usually prescribed so that the individual is exercising at 50-85% of a person's maximum oxygen consumption (VO₂max) or 55-85% of heart rate maximum. Resistance training is usually prescribed so that an individual is lifting between 50 and 80% of the maximum weight they are able to lift (otherwise known as 1-repetition maximum). The intensity of exercise is often gradually progressed over time.

6.4.3.3 Time – How long should a person exercise?

Research suggests that for aerobic exercise the activity should be carried out for at least 20 minutes per session (O'Brien et al. 2017, O'Brien et al. 2016). For resistance training the exercise time should be a minimum of 20-25 minutes, which includes 1-5 sets of 4-30 repetitions for each session (O'Brien et al. 2017, O'Brien et al. 2016).

6.4.3.4 Type – What type of exercise should a person do?

Research suggests engaging in a combination of aerobic and resistive exercise to maximize benefits for a range of health outcomes. This key is to choose an activity that is enjoyable for each individual to maximize adherence and sustainability of exercise over time.

6.4.4 Research on the Impact of Exercise for Adults Living with HIV

Evidence about the safety and effectiveness of exercise for adults living with HIV is well documented in the literature, including narrative reviews that support the benefits of exercise in the context of HIV (Botros et al. 2012, Scevola et al. 2003, Dudgeon et al. 2004, Cade et al. 2004, Robinson et al. 2007, Hand et al. 2009).

Two systematic reviews combined results from 30 randomized controlled trial studies with over 1100 adults living with HIV to assess the effect of aerobic and progressive resistive exercise on health outcomes for adults living with HIV (O'Brien et al. 2017, O'Brien et al. 2016). Ten of the studies assessed the effect of aerobic exercise, six assessed the effect of progressive resistive exercise, and 14 studies included a combination of aerobic and resistive exercise. Results showed that performing continuous or interval aerobic exercise, or a combination of continuous aerobic and progressive resistive exercise for at least 20 minutes, at least three times per week for at least five weeks appears to be safe and can lead to significant improvements in selected outcomes of cardiopulmonary fitness, body composition, strength, and quality of life for adults living with HIV who are medically stable. Minimal to no changes in CD4 count or viral load were found suggesting exercise has little impact on CD4 count or viral load but also indicated the immunological and virological safety of exercise for adults living with HIV. These findings are limited to those participants in the included studies who continued to exercise and for whom there were adequate follow-up data. See Table 6.4 for an overview of the impact of exercise for adults living with HIV according to the results of the systematic reviews.

6.4.5 Exercise and Lipodystrophy

Before the advent of combination antiretroviral therapy, studies on exercise tended to include participants with AIDS-wasting whereas recent evidence includes participants on combination antiretroviral therapy with lipodystrophy, body fat redistribution, metabolic syndrome, dyslipidemia, or hyperinsulinemia. Hence, weight, body composition and metabolic outcomes are becoming increasingly important to monitor when prescribing exercise for adults living with HIV.

While improvements in weight and body composition are documented, emerging evidence is beginning to suggest an association between exercise and improvements in metabolic outcomes such as cholesterol, triglyceride, glucose levels and insulin sensitivity for adults living with HIV (Gomes-Neto et al. 2013a, Trevisol et al. 2012, Guedes and Goncalves 2007, Healy et al. 2008, Fillipas et al 2010, Lindegaard et al. 2008, Ogalha et al. 2011, Fitch et al. 2012). Recent research has also demonstrated that combined exercise (both aerobic and resistance training) is associated with a higher loss of android fat, or fat that exists around the trunk and neck, in lipodystrophic patients when compared to non-lipodystrophic (Guariglia et al. 2018)

6.4.6 Exercise and Other Co-Interventions

Co-interventions with exercise such as metformin (Driscoll et al. 2004a, Driscoll et al. 2004b), creatine (Sakkas et al. 2009), whey protein (Agin et al. 2001), pioglitazone (anti-diabetic drug) (Yarasheski et al. 2011), and low lipid diets (Terry et al. 2006) have also been studied. Studies that assessed anabolic agents (such as steroids, testosterone or human growth hormone) in combination with exercise found that steroids do not improve strength, weight and body composition any more than exercise alone (Grinspoon et al. 2000, Sattler et al. 1999). Also, studies indicated that creatine and anti-diabetic drugs are not more beneficial to strength and body composition outcomes more than exercise alone (Sakkas et al. 2009, Yarasheski et al. 2011).

However, exercise in combination with nutritional counselling has been associated with improvements in weight and body composition and metabolic outcomes (Ogalha et al. 2011, Agostini et al. 2009). Overall, more research is needed to explore the effect of aerobic exercise in conjunction with other treatment interventions.

6.4.7 Women and Exercise

Benefits of exercise have been increasingly documented with women living with HIV (Agin et al. 2001, Dolan et al. 2006, Mendes et al. 2011, Daniels et al. 2018). Nevertheless, women remain largely under-represented in the exercise literature, representing less than 30% of the total participants in recent systematic reviews (O'Brien et al. 2017, O'Brien et al. 2016).

6.4.8 Exercise and Developing Countries

With combination antiretroviral therapy now increasingly reaching developing countries, there is an increase in the number of studies that assess the impact of aerobic exercise in those countries (Multimura et al. 2008a, Multimura et al. 2008b, Maharaj et al. 2011, Roos et al. 2014). Participants with lipodystrophy randomized to six months of exercise training in Rwanda demonstrated reduced metabolic outcomes, improved cardiorespiratory fitness, improved body composition, and improved quality of life compared to non-exercisers (Multimura et al. 2008a, Multimura et al. 2008b). Participants randomized to a 3-month aerobic exercise program carried out at a rehabilitation centre (once per week) and in the home (three times per week) resulted in significant improvements in quality of life compared with non-exercisers (Maharaj et al. 2011). A 12-month randomized study found that a home-based pedometer-walking program improved physical activity, body composition, and high-density lipoproteins among adults with HIV in South Africa (Roos et al. 2014). Recently, an intervention as brief as 6 weeks was shown to have positive psychological effects, where it led to an increase in self-perceived body image in a group of HIV+ positive women across South Africa (Daniels et al. 2018)

6.4.9 Other Forms of Exercise: Tai Chi and Yoga

An increasing number of studies demonstrated benefits of specific types of exercise such as tai chi (Robins et al. 2006, Galantino et al. 2005). Yoga is another form of exercise that may include a combination of aerobic and resistive training. One study investigated the impact of a yoga intervention 2-3 times per week for 60 minutes each for a total of 20 weeks among people living with HIV and at risk of cardiovascular disease. The yoga intervention included a combination of flexibility, balance, strength, and breathing exercises. Participants in the yoga group demonstrated decreases in their blood pressure compared to the control group. No differences were found between groups for reductions in body weight, fat mass, lipids or improvements in glucose tolerance or overall quality of life (Cade et al. 2010). As well, a recently published systematic review looked at seven studies assessing the positive psychological effects of yoga in individuals living with HIV, finding that yoga led to a significant reduction in both perceived stress and anxiety and improved positive affect (Dunne et al. 2018). Further research may consider the impact of yoga, tai chi, or other forms of exercise that include a combination of strength, aerobic and balance training on the health of adults living with HIV.

6.4.10 Exercise with Older Adults Living with HIV

As an increasing number of individuals age with HIV, emerging evidence demonstrates the effects of exercise among older adults living with HIV. Evidence-informed recommendations were developed on the effect of exercise for older adults living with HIV suggesting a combination of aerobic and resistive exercise three times per week for at least six weeks to improve cardiovascular, metabolic and muscle function (Yahiaoui et al. 2012). A prospective study compared the impact of progressive resistance exercise in adults with HIV over 60 years of age compared to healthy older adults and found improvements in strength greater than those achieved among the healthy control group (Souza et al. 2011). While some studies explored the impact of pharmacological interventions such as calcium, vitamin D, and alendronate (drug used to prevent bone resorption) on bone mineral density for people living with HIV, the impact of exercise on bone mineral density is still unclear (Filipas et al. 2010, Lin and Rieder 2007, Clay et al. 2008). As well, a recent scoping review of sixteen studies examining the cognitive benefits of exercise in older adults living with HIV, eight of which were non-interventional, found that physical activity may preserve or improve cognition in people living with HIV (Quigley et al. 2019).

Evidence-informed recommendations on rehabilitation interventions for older adults living with HIV state that 'a combination of aerobic and resistive exercise may be recommended for older adults living with HIV who are medically stable and living with comorbidities including bone and joint disorders, cancer, cardiovascular disease, stroke, mental health, cognitive impairment, COPD and diabetes. The frequency, intensity, time and type of exercise should be individually tailored to the specific goals and capacity of the individual and the specific comorbidity (O'Brien et al. 2017, O'Brien et al. 2016).

High-quality evidence is needed to explore the optimal parameters of exercise among older adults with HIV and those living with multiple concurrent health conditions such as cardiovascular disease, osteoporosis and osteonecrosis which may have implications for the future effect and safety of exercise for people living with HIV.

6.4.11 Summary

Each exercise program should be tailored to the specific capabilities and personal goals of each individual. Hence, it is important for individuals to seek guidance from their rehabilitation provider such as a physical therapist before starting an exercise program. Factors influencing the uptake of exercise among people living with HIV can be environmental (accessibility of fitness centres including location, cost), and personal (self-reported health status, lack of knowledge about benefits of exercise, older age, fatigue,

and anxiety and fear of social stigma exercising in fitness facilities in the presence of 'healthy' individuals) (Pavone et al. 1998, Petroczi et al. 2010, Ciccioli et al. 2004, Jones et al. 2012). Tips to help increase adherence to exercise may include tracking exercise in a log book including dates, the frequency, intensity, time and type of exercise, and combining exercise with a self-management education program (Millard et al. 2013).

Exercising with a partner or group of people may also help with encouragement and maintain motivation.

Table 6.4 Summary of Findings from the Research Evidence from Two Systematic Reviews on Aerobic and Resistive Exercise

| Health Outcome | Summary of Effect of Exercise Based on Meta-Analysis of Studies |
|-------------------------|---|
| CD4 Count | No significant change in CD4 count between adults living with HIV who exercise compared with non-exercisers. However, some meta-analyses suggest a trend towards an improvement in CD4 count among exercisers. |
| Viral Load | No change in viral load between exercisers compared with non-exercisers. |
| Cardiopulmonary Fitness | Significant improvement in maximum oxygen consumption (VO2max) and exercise time (min) among aerobic exercisers compared with non-exercisers. Greater improvements may be seen by individuals who exercise at heavy intensity compared with those who perform moderate-intensity exercise. |
| Weight | Significant increase in body weight among progressive resistive exercisers compared with non-exercisers. |
| Body Composition | Significant increase in arm and thigh girth among progressive resistive exercisers compared with non-exercisers. Significant increase in leg muscle area among combined progressive resistive and aerobic exercisers compared with non-exercisers. Significant increase (improvement) in lean body mass among combined aerobic and resistance exercisers compared with non-exercisers. Significant decrease (improvement) in body fat percentage among aerobic exercisers compared with non-exercisers. |
| Strength | Significant increase (improvement) in upper and lower body strength among exercisers compared with non-exercisers. Greater improvements in strength were seen with progressive resistive exercise versus aerobic exercise. |

| | |
|-----------------|--|
| Quality of Life | Significant improvement in quality of life scores on six out of eight domains of the SF-36 questionnaire (general health, mental health, role physical, role emotional, physical function, and energy/vitality) among exercisers compared with non-exercisers. |
|-----------------|--|

Sources: O'Brien et al. 2016, O'Brien et al. 2017

6_5 Modalities

This section addresses interventions that are often practiced by regulated healthcare professionals for people living with HIV experiencing various symptoms and side effects of their disease. Many of these interventions are considered self-management strategies, as they require the active participation and choice of people living with HIV. Another common branch of self-management entails treatments that fall under the category of Complementary and Alternative Medicines and Therapies (CAMT). Although there will be some degree of shifting between those services which are regulated, unregulated or in the process of becoming regulated, the examples found within this section most often fall under the scope of therapies prescribed and/or performed by healthcare professionals. Distinguishing between various treatments can quickly become complicated. Although the modalities presented below are evidence-based for some diseases, it is important to note that the treatment has not been fully assessed in people living with HIV. Other treatments, which are not commonly offered by regulated healthcare professionals and are often not evidence-based practices, are located in the CAMT [section 6_8_1](#). In both of these sections (6_5 and 6_8_1), some treatments are outlined that may not be HIV specific due to the lack of evidence within HIV.

6.5.1 Acu-TENS/TENS

The Transcutaneous Electrical Nerve Stimulation (TENS) unit is battery operated and uses electrical stimulus to provide analgesia to a specific area of the body. Individuals can try various combinations of amplitude, pulse width and pulse frequency to best suit their needs. The electrodes are usually placed directly over the painful region but can also be put on acupuncture areas or trigger sites.

TENS can be used to treat low back pain (LBP), myofascial and arthritic pain, sympathetically mediated pain, bladder incontinence, neurogenic pain, visceral pain, and postsurgical pain. There have been mixed reviews as to the success of TENS machines (Nnoaham and Kumbang 2008) and there are very few reports within HIV. It has been shown in at least two studies that perception of TENS frequencies when placed on the cranium becomes increasingly inaccurate with HIV severity (Taylor et al. 1992). In a pilot study of low-voltage noninvasive electroacupuncture by Galantino et al. (1999), it was demonstrated that antiviral drug-induced neuropathy could be improved by placing the

non-invasive skin electrodes on leg acupuncture points 20 minutes a day for 30 days. Participants reported improvements in daily activities and well-being. One limitation of these findings was the small sample size.

6.5.2 Arts-Based Therapy

Arts-based therapy is a process of reflecting on one's experience with illness and/or trauma through creating art. Through consideration of both the end product and the process, art psychotherapists help individuals to gain new insight and perspective of one's self and others. This process may also help individuals develop coping strategies and manage stress. The Canadian AIDS Treatment Information Exchange (CATIE) has developed an innovative body mapping initiative, called "Body Map: Women Navigating the Positive Experience in Canada and Africa", a project which is self-healing and educational (Bret-MacLean 2009). Art psychotherapy has also been shown to reduce depression in Black women living with HIV (Field and Kruger 2008) as well as improve general psychological and physical status in people living with HIV (Rao et al. 2009). Another study used self-exploration and self-regulation to increase self-esteem in African, Caribbean and Black youth living with HIV in Toronto, Canada (Ndung and Moyo 2013). Specific techniques included journaling, the use of expressive arts, value-belief system recognition, and training in goal setting. The self-exploration and self-regulation approaches together with workshop presentations led to increased self-confidence, increased assertiveness, increased self-empowerment, increased trust in own values and beliefs as well as improved self-esteem. Several Cochrane reviews have identified that music therapy may help various symptoms, including nausea, vomiting, pain, mood and overall sense of well-being in medical patients (Dileo 2006, Cepeda et al. 2006, Bradt and Dileo 2009, Maratos et al. 2008).

6.5.3 Botulinum Toxin Therapies

Botulinum toxin type A (Botox) can be used for a number of conditions affecting people living with HIV, including pain, spasticity (Noguera 2004) and facial lipoatrophy (Sadick 2008, Scali et al. 2015). Long-term use of botulinum toxin type A (BTA) via muscular injection has been used to successfully control spasticity in children with progressive subacute encephalopathy due to HIV (Noguera 2004). While there appears to be a therapeutic benefit for spasticity after stroke (Shaw and Rodgers 2009), the impact of Botox injections for occipital pain is limited (Vanelderden et al 2010). Other areas of potential use for these products include neurogenic detrusor (bladder) over-activity and chronic migraine.

6.5.4 Cannabinoids

Whiting et al. (2015) completed a systematic review of the benefits and adverse effects of cannabinoids. There was moderate-quality evidence to support the use of cannabinoids for the treatment of chronic pain and spasticity. There was low-quality evidence suggesting that cannabinoids were associated with improvements in nausea and vomiting due to chemotherapy, weight gain in HIV infection, sleep disorders, and Tourette syndrome. Cannabinoids were associated with an increased risk of short-term adverse events. These results support the findings of an earlier systematic review to explore the medical use of cannabis for reducing morbidity and mortality in patients living with HIV and AIDS (Lutge et al. 2013).

There is anecdotal evidence to suggest that the use of a vaporizer reduces contaminants and may enhance the effectiveness. The Canadian Consortium for the Investigation of Cannabinoids posts current information regarding the use of cannabinoids for medical conditions in Canada (<http://www.ccic.net>).

6.5.5 Topical Capsaicin

Baranidharan et al. (2013) reviewed the evidence for the use of the high-concentration capsaicin patch in the management of neuropathic pain, including HIV-associated distal sensory polyneuropathy. An integrated pooled analysis of two randomized trials demonstrated significant reduction in pain for those receiving the capsaicin patch (versus controls). This article also includes detailed instructions for the delivery of treatment with the capsaicin 8% patch. Zamarandescu et al. (2013) found beneficial long-term effects (at 24 months) of high dose capsaicin patches in patients with treatment resistive HIV-associated peripheral neuropathy.

6.5.6 Cognitive Behavioural and Motivational Strategies

6.5.6.1 Cognitive Behavioural Therapy

Cognitive Behaviour Therapy (CBT) often uses group therapy with a trained leader to help individuals achieve coping strategies to transform automatic thoughts into "active problem-solving strategies" including:

- Identification of stressors
- Brainstorming of possible solutions
- Incorporation of relaxation training (e.g. stress management skills, guided imagery, biofeedback, progressive muscle relaxation)
- Reliance/networking based on social support (Brown and Vanable 2008)

Many care providers and people living with HIV turn to CBT in an attempt to:

- Reduce anxiety and depression
- Increase adherence to HIV treatments
- Address issues of substance misuse
- Address issues of mental health
- Manage stress

CBT has been demonstrated to be extremely effective and substantially long lasting for individuals with a wide range of mental health disorders (Crepaz et al. 2008). Researchers believe that because anger, anxiety and depression are common in people living with HIV, and because these three psychological states can negatively affect various aspects of an individual's life (including quality of life, adherence, use of healthcare services and health outcomes) CBT is a promising intervention as it has been shown to successfully address these issues in people with other disorders (Crepaz et al. 2008).

Other examples of the use of CBT include:

- HIV risk reduction for HIV-negative gay and bisexual men who have high social anxiety (Hart et al. 2014)
- Mindfulness-CBT to improve quality of life, emotional status and immune status in aging HIV patients (Gonzalez-Garcia et al. 2014)
- Cognitive behavioural stress management training to improve mental health, social interaction and family function in adolescents of families with one HIV positive member (Keypour et al. 2011)
- Mindfulness and compassion-based cognitive therapy group to address shame and mood difficulties in HIV outpatients (O'Donovan et al. 2015)
- CBT-based pain management program to improve pain, pain-related functioning, anxiety and acceptance and mental health in HIV positive patients with chronic moderate to severe pain seen at public primary care clinics (Trafton et al. 2012)
- CBT to assist HIV-positive women in dealing with HIV and internalized stigma (Tshabalala and Visser 2011)

A recent systematic review of 16 studies that included 2,520 adults living with HIV examined the effectiveness of a heterogeneous range of psychosocial group interventions for improving the psychological well-being of participants (van der Heijden et al. 2017). The authors concluded that group-based psychosocial interventions based on CBT may have a small effect on measures of depression, and this effect might last for up to 15 months after participation, but advise that the clinical importance of this is unclear (van der Heijden et al. 2017). More high-quality research is needed in this area.

6.5.6.2 Motivational Interviewing

Motivational interviewing (MI) is often used alone or in combination with other interventions such as Cognitive Behavioural Therapy (CBT). MI is not driven by a theory or model; it focuses on building client motivation for change and tasks the client with being responsible for change (Carter 2010). Possible topics in MI include exploring the client's point of view (emotional reactions and obstacles to change), eliciting a client's reason to change, and eliciting the client's strengths and resources (Carter 2010). The differences between CBT and MI include: a) building skills in CBT versus building motivation in MI, b) CBT is educative whereas MI is evocative, and c) solutions are preselected in CBT whereas the client picks the solutions in MI (Carter 2010). MI can be provided as a precursor to CBT or at time-points throughout treatment (Carter 2010). Recent studies have demonstrated MI's effects, where it was found to reduce alcohol use among heavy drinking, reduced methamphetamine use, improved medication adherence and fewer acts of condomless sex among MSM (Kahler et al. 2018, Parsons et al. 2018).

6.5.6.3 Other Interventions

A review of systematic reviews of counselling, case management and health promotion interventions for people living with HIV found research evidence to support: centralizing HIV care in high concentration or high volume settings; cognitive behavioural interventions for reducing symptoms of depression, stress and anxiety; interventions to promote adherence and the use of aerobic and progressive resistance exercises (Wilson et al. 2013).

Chang et al. (2014) completed a systematic review of intervention strategies based on the information-motivation-behavioural skills model for health behaviour change. While this protocol focused on chronic diseases, nine of the 12 studies included people living with HIV. The most frequently used intervention strategies were instructional pamphlets for the information construct, motivational interviewing techniques for the motivation construct, and instruction or role-playing for the behavioural skills construct. Ten studies reported significant behaviour changes at the first post-intervention assessment.

Yang et al. (2015) completed a systematic review and meta-analysis to assess the effectiveness of mindfulness-based stress reduction and mindfulness-based cognitive therapies on people living with HIV. These interventions did produce psychological benefits although improvements in CD4 counts were not robust.

6.5.7 Cryotherapy

Cryotherapy is a liquid nitrogen (Mitsuyasu 2000) or histofreezer (Barbosa 1998) therapy that burns off skin lesions. This practice is sometimes used for people with HIV,

particularly those who develop Kaposi's Sarcoma (KS). Although KS can affect urogenital organs (Heyns and Fisher 2005), it is more often part of a systemic disease affecting the gastrointestinal tract, the lymph nodes, lungs and oral cavity (Dezube 2000).

When KS affects external genitalia, such as in the form of tiny lesions, or in other limited cutaneous infections, cryotherapy can be a successful treatment (Webster 1995). These lesions can also be treated with laser or surgical removal (Heyns and Fischer 2005). Histofreezer cryotherapy can also be used in people with HIV who develop plantar verrucae, a type of foot wart, although it does not appear to be more efficacious than other therapies such as bleomycin sulphate or intralesional injections (Barbosa 1998).

6.5.8 Functional Electrical Stimulation

Functional Electrical Stimulation (FES) can be used for neuropathies such as foot drop (Wilkenfeld 2013). Neuro-orthoses (WalkAIDE, Bioness) have not been formally studied. Commercially available devices (WalkAIDE, Bioness) may be considered for use in persons with spasticity-associated foot drop without severe neuropathy as an alternative to traditional ankle-foot orthoses.

6.5.9 Facet Joint Interventions

The American Society of Interventional Pain Physicians has published a series of systematic reviews on facet joint interventions:

- Lumbar Facet Joint Interventions: Good evidence for the use of conventional radiofrequency neurotomy and fair to good evidence for lumbar facet joint nerve blocks for the treatment of chronic lumbar facet joint pain resulting in short-term and long-term pain relief and functional improvement. There is limited evidence for intra-articular facet joint injections and pulsed radiofrequency thermoneurolysis (Falco et al. 2012).
- Cervical Facet Joint Interventions: The indicated evidence for cervical radiofrequency neurotomy is fair. The indicated evidence for cervical medial branch blocks is fair. The indicated evidence for cervical intra-articular injections with local anesthetic and steroids is limited (Falco et al. 2012). There was very little evidence available for this review.
- Thoracic Facet Joint Interventions: The evidence for therapeutic facet joint interventions is fair for medial branch blocks, whereas it is not available for intra-articular injections, and limited for radiofrequency neurotomy due to lack of literature (Manchikanti et al. 2012).

- Sacroiliac Facet Joint Interventions: The evidence was fair in favour of cooled radiofrequency neurotomy and poor for short-term and long-term relief from intra-articular steroid injections, peri-articular injections with steroids or botulin toxin, pulsed radiofrequency, and conventional radiofrequency neurotomy (Hansen et al. 2012).

6.5.10 Manipulation

Manual manipulation (which includes chiropractic) is a method of care where the spine, pelvis, and other articulating joints are manipulated to restore mobility, ease pain, and stimulate the body's own balancing of function. In addition to manipulation, practitioners may use massage, stretching techniques, and electrotherapy to facilitate the treatment. Practitioners may include chiropractors as well as physical therapists with advanced training in manual therapy. While there is limited evidence within the field of HIV, there are many published systematic reviews that review the effectiveness of chiropractic manipulations interventions for a variety of symptoms and conditions. For example, a systematic review of chiropractic management found manual-type therapies and some physiologic therapeutic modalities had acceptable evidentiary support in the treatment of Myofascial Trigger Points and Myofascial Pain Syndrome (Vernon and Schneider 2009). An evidence review by Brontfort et al. (2010) reports that spinal manipulation/mobilization is effective in adults to treat: acute, subacute, and chronic low back pain; migraine and cervicogenic headache; cervicogenic dizziness; manipulation/mobilization is effective for several extremity joint conditions; and thoracic manipulation/mobilization is effective for acute/subacute neck pain.

6.5.11 Orthoses and Prostheses

Orthoses can play a crucial role in mobility and independence (Rosensweet and Fink 1992). Unfortunately, there is limited evidence for the effectiveness of orthoses and prostheses across all diseases. A review of systematic reviews in rheumatoid arthritis identified two systematic reviews for orthotics and splints (Christie et al. 2007). Overall, the quality of research in this area was of low quality and inconclusive. There was some evidence that extra-depth shoes and moulded insoles (versus the shoes alone) decreased pain during weight-bearing activities such as standing, walking and stair climbing. Tian et al. (2015) have recently published a review of knee-ankle-foot orthoses.

Arthritis patient educators provide anecdotal evidence to the effectiveness of orthotics and splints by demonstrating function and describing pain with and without their splints and orthotics during educational activities for rehabilitation and other care providers (Oswald et al. 2008). The effectiveness of these aids may be attributable to the skill of the individual creating the aid although this has not been formally studied.

6.5.12 Osteopathy

Osteopathy is a manual treatment, which relies on mobilizing and manipulating procedures to relieve complaints. While there is no evidence for osteopathy within HIV, there are small randomized controlled trials (RCTs) of its use in chronic conditions such as irritable bowel syndrome (Hundscheid et al. 2007) and some types of pain (Schwerla et al. 2008, Licciardone et al. 2010) although another systematic review by researchers outside the field demonstrated no evidence for the effectiveness of osteopathy as a treatment of musculoskeletal pain (Posadski and Ernst 2011).

6.5.13 Prolotherapy

Prolotherapy involves injecting a mild irritant solution into the affected area. This area has usually been compromised due to injury or strain. The injection is meant to produce inflammation in the affected connective tissue, which in turn activates the healing process associated with inflammation. One review found that prolotherapy was not effective for low back pain (Chou et al. 2009) although another review described some benefit for low back pain when coupled with adjunctive therapies and for treatment of refractory tendinopathies as well as osteoarthritis (Distel and Best 2011).

6.5.14 Sleep Hygiene Techniques

Insomnia commonly occurs in people living with HIV, and there are several basic sleeping practices, also known as sleep hygiene techniques, which are suggested to facilitate a good night's sleep (Hudson et al. 2008). Continued problems with sleep despite using sleep hygiene techniques may merit a referral to a sleep clinic.

- Maintain regular sleep schedule
- Maintain dark, quiet, comfortable sleeping environment
- Exercise in morning or late afternoon
- Use bed for only sleep and sex
- Establish regular bedtime routine
- Avoid caffeine, colas, nicotine, and alcohol near bedtime
- Avoid large meals near bedtime
- Avoid extended daytime naps
- Limit fluid intake near bedtime

6.5.15 Trigger Point Needling

A systematic review of needling therapies for myofascial trigger point pain found that needling directly into the myofascial trigger point is an effective pain relief treatment, regardless of the injection serum (placebo versus a drug). More research is required to determine placebo effects (Cummings and White 2001). Cummings and Baldry (2007)

provide an extensive overview of regional myofascial pain, including a review of the evidence published since the 2001 review. Overall, the evidence supports the role for trigger point needling although there is more evidence to suggest that botulinum toxin injection does not offer any advantage over saline or local anesthetic.

6.5.16 Water Based Therapies

Honda and Kamioka (2012) conducted a review of interventional studies that included aquatic exercise, underwater exercise, hydrotherapy and pool exercise (swimming was excluded). They concluded that aquatic exercise had significant effects on pain relief and related outcome measurements for locomotor diseases.

6_6 Assistive Devices

6.6.1 Introduction

Many people living with HIV experience difficulties with everyday tasks. There is now a large range of assistive, adaptive and accessibility aids and technologies for children and adults with disabilities and special needs; an increasing number of which are incorporating emerging technologies. What is particularly exciting is the availability of information on these resources online.

Some evidence exists from the areas of stroke, arthritis, and aging to demonstrate the efficacy of aids, adaptations and devices as a component of occupational therapy and speech-language pathology to assist in improving activities of daily living, quality of life, and safety in the populations studied (Steultjens et al. 2004, Steultjens et al. 2005, Rao 2005, Wilson et al. 2009, Brose et al. 2010, Vickery 2005, Allin et al. 2010, Dicianno et al. 2010).

Adaptive and assistive aids and technologies may be formal. For example, modified computer keyboards are available for people who may have difficulty with motor control or range of motion in their upper extremities. Speech inputs, or voice-to-text options, also enable people with physical difficulties to write and communicate. People living with HIV may also find informal aids and devices to be helpful. For example, individuals experiencing memory loss may set a reminder on their smartphone to alert them when medication needs to be taken and facilitate adherence to complex medication regimes. Most computers and software packages also have options to increase text size or enable text-to-speech functions that may assist people with visual or other impairments. These informal aids are often available at no additional cost to people who already own smartphones or computers.

6.6.2 Resources on the Net for Rehabilitation Providers

The University of Wisconsin has compiled a comprehensive list of sites to access information on assistive devices for activities ranging from activities of daily living to recreation to work.

- **ABLEDATA** ABLEDATA is a database of information on assistive technology and rehabilitation equipment available from international sources. ABLEDATA contains information on more than 24,000 assistive technology products, from canes to voice output programs. The database contains detailed descriptions of each product including price and company information. The database also contains information on non-commercial prototypes, customized and one-of-a-kind products, and do-it-yourself designs.
- **AbleLink Technologies** <http://www.ablelinktech.com/>
- **com** <http://www.adaptivemall.com/> A database of adaptive devices from a variety of manufactures for children with special needs. Specializes in positioning products, including mobility, bathing, recreation, et cetera.
- **National Registry of Rehabilitation Technology Suppliers (NRRTS)** <http://www.nrrts.org>. NRRTS has created a listing of experienced rehabilitation technology suppliers available to consumers, rehabilitation professionals and payer sources worldwide.

6_7 Vocational Rehabilitation

6.7.1 Introduction

Vocational rehabilitation is a process that enables persons with functional, psychological, developmental, cognitive and/or emotional impairments or health conditions to overcome barriers to accessing, maintaining or returning to employment or other useful occupations (Vocational Rehabilitation Association UK ()). This chapter discusses emerging issues regarding vocational rehabilitation and return-to-work decisions for people living with HIV. It is intended to provide a window of insight into the many personal, clinical, vocational and income support considerations a person living with HIV might consider regarding employment, whether it is for the first time or a re-entry to a long-held position. HIV is considered an episodic disability with common concurrent conditions (Section 1.1.1.2). Either HIV or a comorbid condition can impact on employment. Issues relating to system level factors and institutional changes and supports can be accessed in the work of Worthington et al. (2012) and the work of *Realize* (formerly the Canadian Working Group on

HIV and Rehabilitation). This chapter covers several issues that are tailored more specifically to the individual living with HIV who is considering employment.

6.7.1.1 HIV and Employment

The University of Calgary, in collaboration with the University of Toronto and *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) completed a project to develop a conceptual framework of labour force participation for people living with HIV in Canada (Worthington et al. 2010). Scoping study methodology, consisting of a literature review, interviews and focus groups, led to a conceptual framework for employment. The HIV and Employment Framework incorporates six key components related to labour force participation for people living with HIV.

These include:

- The meaning of work
- Characteristics of work
- Contextual factors that influence employment
- Barriers and facilitators to employment
- Strategies and supports for entering/returning to/ sustaining employment
- Potential outcomes of labour force participation

The authors conclude that changing workplace and income support policies as well as developing programs to assist people living with HIV in participating in the labour force are some of the key challenges in need of attention. This framework can be used by people living with HIV, employers, insurers, healthcare providers, and policymakers, to develop strategies and interventions to promote labour force participation (Worthington et al. 2010). Factsheets and other materials resulting from this work can be found at <http://gettingtowork.hivandrehab.ca>.

Realize offers training for employers, policy makers, rehabilitation specialists and others to better understand barriers to returning to and sustaining work that people living with HIV face. This work also aims to help all stakeholders to better understand the impacts of HIV on the workplace environment and provides accommodation best practices for people living with HIV and those with other episodic disabilities. *Realize* work also addresses how to reduce fear and uncertainty during the return-to-work process. In addition to HIV targeted programs and projects, *Realize* addresses the challenges faced by those living with a wide range of episodic disabilities who may be considering return-to-work.

This work encompasses episodic illness including HIV, arthritis, diabetes, multiple sclerosis, some forms of mental illness and other chronic conditions. *Realize* has developed a new national network on employment, the Episodic

Disabilities Employment Network (EDEN). EDEN has launched a new interactive website for people living with HIV and those with other episodic disabilities on employment supports. The EDEN website can be found at <http://www.edencanada.ca>.

6.7.2 The Significance of Employment for People Living with HIV

Advances in the clinical treatment of HIV have meant improved health and longevity for many people living with the disease. Labour force participation has been identified as a critical social issue facing people living with HIV in Canada. Participation in the labour force provides income stability, promotes social engagement and self-determination for people living with HIV (Worthington et al. 2012). As a result, returning to or remaining in the workforce, despite HIV-related disabilities, has become more feasible and attainable.

Over the past decade, an increasing amount of research has assessed the workforce participation needs of this population and has evaluated the ability of existing public- and private sector programs to respond to the needs of people living with HIV. Studies suggest that 42% to 62% of people living with HIV in developed countries are unemployed, and many are contemplating a return-to-work (Worthington et al. 2012).

Employment may also play a significant role in sexual risk reduction in vulnerable populations. Cui et al. (2013) conducted a systematic review of microenterprise development for HIV prevention by addressing poverty and gender equality. Seven eligible research studies representing five interventions were identified and included in the review. All of the studies targeted women. The three studies that focused on sex workers showed a significant reduction in sexual risk behaviours when compared to the control group while non-sex worker studies showed limited changes in sexual risk behaviour. This review demonstrates the potential utility of microenterprise development in HIV risk reduction programs for vulnerable populations.

6.7.3 Factors that might Facilitate Employment/Return-to-Work

Several factors relating to physical or psychosocial health may have an impact on a decision whether to undertake vocational rehabilitation and seek employment or other productive daily activities. The process of returning to work may seem overwhelming and daunting, and the psychological, emotional, social, physical, and financial aspects of employment should be considered when contemplating a return-to-work. Several studies have documented the factors motivating people living with HIV to consider employment. These include a belief that work will lead to improved mental, and physical health (Hergenrather et al. 2008), increased access to financial resources (Ferrier

and Lavis 2003), emotional benefits (Brooks and Klosinski 1999) and an opportunity to recreate a new vocational identity (Braveman et al. 2006).

When addressing vocational rehabilitation for people living with HIV, it is important to understand the clinical, psychosocial, economic, and institutional issues that affect the possibility of employment. Employment history, workplace accommodation, human resource policies (including sick leave) (Escovitz and Donegan 2005, Hyduk and Kustowski 2003) and other workplace environmental factors must also be considered, along with legal and human rights issues (e.g., the "reasonable accommodation" provisions in human rights and disability laws).

6.7.4 Barriers to Employment or Return-to-Work

A person's demographic background and social standing are equally as likely to contribute to unemployment as is his or her physical health (Fogarty et al. 2007). Additional challenges are faced by other groups vulnerable to HIV including gay men, racial and ethnic minorities (Joyce et al. 2005), recent immigrants (Burns et al. 2007), people who use injection drugs (Dickson-Gomez et al. 2004) and those with concurrent health conditions (Dray-Spira et al. 2007).

Although returning to work, or maintaining employment has increased in recent years, it is important to be aware of some of the possible barriers people with HIV might face in either of these situations. Unfortunately, numerous barriers to work exist for people living with HIV in Canada, and there is a need for collaborative initiatives between multiple stakeholders to promote increased opportunities for labour force participation. While the therapeutic value of returning to the workforce is an important consideration, work can also entail additional stressors that may have a detrimental impact on the health and quality of life of people living with HIV (Glenn et al. 2003).

There are significant social and systemic factors limiting employment opportunities for people living with HIV. Financial concerns (Paul-Ward et al. 2005b), uncertainty about sustained health (Escovitz and Donegan 2005), limited access to extended drug and health benefits, fears of being discriminated against (Brooks et al. 2004), and the need for retraining after being out of the workforce for long periods of time are all factors which act as barriers to the workforce (re-) entry for people living with HIV (unpublished workshop data).

Individuals who have left work and are receiving benefits may be concerned about the risk of losing these benefits if they return to the workforce. In fact, potential loss of health benefits is the primary disincentive for those contemplating return-to-work (McGinn et al. 2005, Hunt et al. 2003, Escovitz and Donegan 2005).

In some cases, medication side effects and adherence issues might also contribute as barriers to employment (Werth et al. 2008, Hyduk and Kustowski 2003), although adherence issues seem to play a more significant role in the United States than Canada.

Moreover, it should be noted that the numerous roles each individual plays in his or her life will affect their relationship with employment.

For instance, research on women living with AIDS has demonstrated there are also specific gendered barriers, limitations and challenges facing these women, including access to childcare, knowledge of employment opportunities and skill set/level (Barkey et al. 2009, Conde et al. 2009). In addition, there are other groups facing multiple barriers, including recent immigrants. Although there has been limited work in this area, a pilot intervention of a bi-weekly training session aimed at bridging the gap between health and employment for people living with HIV facing multiple barriers demonstrated positive outcomes (Bedell 2008).

There is a need to develop employment-related services such as networking and mentorship opportunities for working and nonworking people living with HIV (Popiel et al. 2010). There is also a general need for HIV specific employment supports as only one currently exists in Toronto. See <http://www.employmentaction.org> for more information.

Below is a list of some of the possible barriers commonly encountered:

- Risk of losing one's job after returning to work
- Risk of losing one's benefits if a workplace changes the individual's hours (e.g., a minimum number of hours must be worked to procure benefits)
- Inability and/or unwillingness of employers to provide appropriate insurance coverage and benefits
- Unwillingness of employers to provide appropriate accommodations
- Potential workplace hazards that may have an impact on health
- Lack of supportive workplace policies
- Few workplace HIV and AIDS education and support programs
- Limited access to ongoing vocational services
- Few community resources, ranging from childcare to transportation

6.7.5 Other Potential Barriers

The following section includes general employment factors to consider and three categories of potential issues that have commonly acted as barriers for people living with HIV contemplating returning to work. It is important to keep in mind that not all of these issues will be encountered by each individual. Although some of these questions are difficult,

considering them in light of the individual's personal circumstance is imperative to determine where he or she will likely encounter the greatest obstacles. It is only through identifying potential issues that these hurdles might be overcome.

6.7.5.1 General Factors to Consider

- The overall workplace culture for supporting people with disabilities
- If the individual living with HIV has a preference for a for-profit or not-for-profit environment
- The reputation of the organization for providing accommodation supports
- The availability of an Employee Assistance Program (EAP)
- If the job is in line with future career goals
- Opportunities for advancement and training
- Earning potential

6.7.5.2 Physical Health Factors

- How the individual's current health compares to his or her health at the time of the decision to leave work (some individuals experience improved health upon terminating employment)
- The extent to which work may be a stressor, with effects such as disruptions in sleeping and eating
- How access to medications and maintenance of therapeutic regimens (including medical appointments and follow-up) will be accommodated
- The extent to which constitutional symptoms (e.g., diarrhea, nausea, fevers) will be manageable
- Whether the individual has sufficient stamina to tolerate the physical demands of the job
- Whether fatigue may compromise the regular daily activities (this factor can be more significant if the job involves considerable transportation time to get to and from work)
- Whether the individual has experienced visual changes and changes in the ability to communicate which could affect his or her performance on the job
- Whether the individual has experienced balance, coordination, or dexterity changes that could have an impact on job safety or his or her ability to do the job
- How the episodic nature of HIV, including unpredictable periods of illness and wellness, impacts the individual

6.7.5.3 Cognitive and Behavioural Health Factors

- The extent to which the individual retains skills such as concentration, memory, planning, problem-solving, dealing with pressure and change, and decision-making and organizational ability
- The extent to which the individual's mood stability, emotions, and reactions are appropriate to the situation

- Whether the individual has appropriate coping skills, life skills, and social skills
- Whether the workplace has supportive networks
- Comfort level with dealing with health fluctuations and changes with a work schedule

6.7.5.4 Psychosocial Health Factors

Psychosocial health factors are equally as important as physical health factors in determining the extent to which an individual is ready and able to return-to-work. Living with HIV can be accompanied by unpredictable episodes of illness and wellness; therefore career goals can change dramatically, not only as a result of an HIV diagnosis but also as a result of health status. A wide variety of psychosocial factors should be considered, including:

- The fear, stress and anxiety related to disclosure (including involuntary) of HIV status in the workplace (Brooks et al. 2004)
- The fact that work requires substantial amounts of energy and time
- The extent to which stress associated with the workplace will have a negative impact on health and quality of life
- The risk of experiencing stigma once back in the workplace (e.g., resulting from having to explain one's absence from work, or from the failure to keep the individual's health status confidential)
- Whether the individual would experience greater self-esteem as a result of going off public assistance and into the workforce
- Whether the individual is prepared to cope with relocation or a change in jobs (in situations where the individual's previous job is no longer available or a viable option)
- Whether caring for children or other dependent family members is a consideration
- Whether the individual is concerned about the potential for failure in the workplace
- Whether returning to the workforce will provide the stability of income needed for maintaining access to medications

6.7.6 Return-to-Work Principles

People living with HIV, practitioners, and representatives from community-based organizations in Canada and the United States have developed principles to help guide program development, advocacy, research, and education on this issue. These principles, listed below, are followed by a more detailed discussion of crucial issues and questions related to labour force participation and vocational rehabilitation.

Key Principles for People Living with HIV

- Returning to work must be addressed within the broader context of health
- People living with HIV must be at the centre of the decision-making process. This means that decisions about whether to return-to-work should be made by the individual and should be free from coercion

Key Principles for Service Providers and Income Support Providers

- Returning to work should be an option available as part of the continuum of care
- Return-to-work programs and services must be flexible and responsive to the individual's needs
- Service providers should not make assumptions about the capacity of vulnerable or affected populations, or the ability of any group to participate in or benefit from, return-to-work services

Key Principles for Private and Public Insurance Companies & Drug Plans

- Private and public payers should not base return-to-work decisions solely on existing surrogate markers (such as CD4 count and viral load) but rather on a review of all aspects of individual health and employment capacity

6.7.7 Creating a Network of Support

People living with HIV who are contemplating returning to work may find the support of a variety of people very helpful. Some of the key people to consult are:

- Peers who can provide the opportunity to connect with others from a similar background who have gone through the return-to-work transition (Hunt et al. 2003)
- Employer support resources such as Employee Assistance Programs (EAP)
- Healthcare providers, particularly those supplying supportive documentation for public or private payers
- Staff and others affiliated with Community-based HIV Organizations (CBHOs)
- Family members and friends
- Vocational counsellors or workers from vocational rehabilitation programs
- Workplace resources such as human resources staff, direct supervisors, occupational health and safety committee members or staff, and union representatives
- Academic or educational institutions may provide additional resources. These resources provide retraining or skills development, which may eventually lead to greater employment opportunities
- In some areas, legal supports for employment issues may be available through community legal clinics

6.7.8 Accommodation Options in the Workplace

There are several accommodation options that people living with HIV might explore with an employer. Some of these options include:

- Modifying the physical workplace (such as changing the layout of equipment for someone with joint problems)
- Modifying tasks (such as changes in job structure or work schedules)
- Gradually taking on the job demands (either by increasing the complexity of the task over time or by moving from part- to full-time hours)
- Considering self-employment or working from home options

Employers in Canada have a duty to accommodate employees with workplace disabilities to the point of undue hardship (see). This duty means that the responsibility rests on the employer to provide assistance to employees to help them function more effectively in their job responsibilities. An employer can represent the owner of an organization, a manager, human resources specialist or another individual designated to fill a role in human resources management.

When a need for accommodation arises, employees should:

- Consider how the physical, cognitive and/or psychosocial limitations will impact on their job duties
- Develop suggestions on how these limitations can be addressed with workplace accommodations
- Arrange a meeting to discuss the accommodation needs
- Discuss the needs for accommodation that currently exist and a plan for how these needs might be addressed through accommodations. This discussion does not need to include disclosure of HIV status but does need to include the nature and extent of the limitations that exist. Examples of limitations may include difficulties with: standing for long periods of time, memorizing and retaining information, or feeling restless or unfocused at work
- Be ready to engage in a negotiation of the accommodation

When a need for accommodation arises, employers should:

- Meet with the employee to review the job duties
- Determine if the limitations impact on core responsibilities of the job. These core duties are tasks that must be done in a specific way and cannot be altered without changing the nature of the job. If these core job duties are impacted, determine if the employee can continue performing the job
- Listen to the accommodation options presented by the employee
- Discuss additional accommodation options as needed

- Determine the best course of action to accommodate the limitation
- Discuss confidentiality and privacy

It is important to note that while employers have a duty to accommodate employee needs to avoid undue hardship; employers can determine a form of accommodation that best meets the needs of both the employee and the organization. An example of this type of accommodation would be if an employee needs one day off a week to attend medical appointments and requests that Fridays be designated for this purpose. If the choice of day does not meet the needs of the employer and the appointments can be scheduled for another day of the week, the employee may be asked to take off a different day of the week for this purpose.

Employees may also be asked to provide documentation from a healthcare professional that outlines:

- What the limitation is
- What the impacts are on the employee's job

Common examples of workplace accommodations include:

- Flexible work hours
- A private place to store and take medications
- More frequent breaks
- A quiet room for breaks
- Remote work options
- A workstation close to a washroom
- Time off to adjust to medication changes

6.7.9 Income Security and Health and Disability Insurance

Because income status closely mirrors health status, people living with HIV should be able to pursue their education and employment goals without sacrificing financial security. In Canada, many people living with HIV rely on a public or private medical insurance benefits to address their health needs. Considering work can change an individual's eligibility status for public or private benefits and thus is a critical factor when considering returning to work. The following is only a partial list of elements for the individual who is considering returning to work, particularly regarding balancing demands of work with income security and insurance.

It is critically important that returning to work not jeopardize the income security or health insurance of people living with HIV. However, the reality is that decisions to re-enter the workforce can have a profound impact on long-term health insurance or disability benefits. It is important for individuals, rehabilitation providers, and other caregivers to be aware of this reality. What follows is a general description of income

security and health and disability insurance issues. For individual cases, complete information on the implications of workforce decisions should be obtained from the relevant government agency or private insurer or benefits counsellor/case manager.

Current income support programs in both the public and private sector present many barriers to effective, flexible workforce participation, particularly for people with episodic disabilities such as HIV (Maticka-Tyndale et al. 2002). In Canada, the current patchwork of federal and provincial or territorial income support programs, with differing rules and definitions governing health insurance, disability, and workforce re-entry, make the issue of vocational rehabilitation a difficult one to navigate (Canadian HIV/AIDS Legal Network 2005, *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation 2008).

Provincial and territorial programs include health insurance that covers most or all of the cost of prescription drugs listed on provincial formularies, including many HIV treatments. The drug coverage attached to social assistance benefits is critical to many people living with HIV who would otherwise be unable to afford their HIV and other medications.

Many people have left work to go on social assistance because they had no drug coverage at work. In some provinces, drug coverage normally ends as soon as a person stops receiving public assistance, a factor which constitutes a potential barrier to returning to work. Some provinces are aiming to provide flexible programming to support return-to-work. However, accessibility to drug coverage and related health insurance must be carefully assessed before making employment participation decisions.

The programs described above are undergoing significant reforms in many jurisdictions. These changes may affect the benefit amount, eligibility requirements, and regulations governing the continued receipt of benefits. As well, harmonization efforts between federal and provincial or territorial levels of government may impact the benefit amount that people living with HIV receive. People living with HIV and their caregivers need to know whether the regulations governing these programs allow an individual to participate in a vocational rehabilitation program and pursue employment without jeopardizing his or her benefits.

A large number of people living with HIV are surviving on short- or long-term disability benefits from private insurers, many of whose policies do not include a vocational rehabilitation component. As well, private insurers often have stringent requirements concerning the amount of paid or unpaid work allowable under these policies. People living with HIV who are receiving benefits from private-sector income support programs, and who are contemplating a return-to-work, should get the answers to the following questions:

- Does the insurance program have a rehabilitation component?
- Does the program permit part-time or episodic work without threatening coverage?
- Are the insurance benefits portable (e.g., can the individual switch employers without jeopardizing benefits)?
- If an individual returns to work after a period of illness but then requires benefits again at a later date, can these be easily accessed?

6.7.10 Vocational Rehabilitation Programming

Many existing vocational rehabilitation services were developed for different disability populations and may not be responsive to the needs of people with recurrent disabilities. Rehabilitation providers should not assume that vocational rehabilitation is an integral component of HIV rehabilitation, despite potential pressure from private or public insurers. It is critically important that the person living with HIV be the one to decide whether to pursue vocational rehabilitation as a therapeutic option. Because HIV-related disability is often episodic, rehabilitation providers should also be aware that traditional vocational rehabilitation programming should be adapted to fit the needs of this population. In fact, several authors have expressed the need for HIV specific services as an alternative to mainstreaming people living with HIV into traditional vocational rehabilitation programs (Bowyer et al. 2006, Timmons and Fesko 2004).

6.7.10.1 Basic Tenets of Vocational Rehabilitation

The approach to the topic of vocational rehabilitation in this chapter is based on the following three basic tenets:

- HIV is an episodic disease with no known cure
- HIV vocational rehabilitation is unlike conventional vocational rehabilitation
- The individual's long-term goals are the primary consideration

6.7.10.2 Effective Vocational Rehabilitation

To be effective, vocational rehabilitation programs must be sensitive to the range of psychosocial and clinical issues faced by people living with HIV, including options for part-time or episodic employment. As well, programs need to address retraining or education for people who have been out of the workforce for a significant amount of time or who have never been consistently employed. Characteristics of successful programs include:

- Services that are individualized (McReynolds 1998) and HIV specific (Vetter and Donnelly 2006)
- Services that allow for a facilitated adjustment to the workforce (Conyers 2004)

- Services that provide support for disclosure (Allen and Carlson 2003)
- Support during all phases of the return-to-work transition
- Opportunities for skill development (Brooks and Klosinski 1999)
- Support for career development and career change (Maguire et al. 2008)
- Services that provide peer support or mentorship (Breuer 1998)
- Services that provide on-site job support (Escovitz and Donegan 2005)
- Services that provide advocacy and legal support (McReynolds 2001)

Currently, few links exist among rehabilitation service providers, community-based HIV Organizations (CBHOs), disability organizations, and vocational rehabilitation providers. Those linkages will need to be established. When assessing whether a particular vocational rehabilitation program is suitable for a person living with HIV who is contemplating returning to work, the following questions should be discussed:

- Can people living with HIV access the program? (Many vocational rehabilitation programs are designed to take on the most severely disabled first and so may not be available to the HIV community).
- Does the program have experience providing services to people living with HIV?
- Does the program provide for the possibility of gradual placement from part to full-time positions or trial work periods?
- Does the program provide job counselling, matching, and placement for people who have a range of work experience and require a range of options in returning to work?
- Does the program provide counselling to address poor self-esteem and confidence, fear, and confidentiality of serostatus?
- Is the program accessible to people dealing with substance use issues? (Employment can be an important component of a harm reduction model for such people).
- Is the program sensitive to specific issues related to discrimination faced by many people living with HIV including homophobia (Adkins 2002), racism, and the stigmatizing nature of HIV (Breuer 1998, Conyers et al. 2005)?

The Employment Action website provides information for job seekers living with HIV. See <http://www.employmentaction.org>. For those living in the Toronto area, Employment Action can be contacted directly for support services.

Wagener et al. (2015) report on the development of multidisciplinary, evidence-based guidelines for HIV and employment. Five key questions for the guidelines were formulated with the following themes: determinants of employment, disclosure and stigma, self-management, interventions and the organization of care. The guideline and its summary for daily practice clarify the most important barriers and facilitators to people with HIV either staying at work or returning to work. Robinson et al. (2015) completed a systematic review of interventions for improving employment outcomes for workers with HIV with literature searches current to December 2014. Only one randomized study examined the impact of vocational training, and no studies addressed psychological interventions. The authors could not assess the effect of vocational training due to a lack of data. It is clear that there is an urgent need for high-quality studies that evaluate interventions to improve employment outcomes.

6.7.10.3 Alternatives to Paid Employment

For some people living with HIV, returning to work, or entering the workplace for the first time may not be a desirable move for several reasons. Individuals are advised to carefully assess the impact of returning to work and to consult widely before deciding whether to re-enter the workforce. People living with HIV may want to consider daily activity options outside the paid workforce, such as voluntary work or education and training. For example, people living with HIV are now considering a wide array of options including contract work, self-employment, caregiving, community involvement and involvement in social enterprise (Blustein et al. 2008). These productive daily activities may provide some of the same therapeutic benefits of the paid workforce without endangering private or public disability benefits (Ferrier and Lavis 2003) and may prove more accommodating to the episodic nature of HIV.

6.7.11 Summary

The issue of employment for an individual with an episodic disability such as HIV is complex and multifaceted. Several factors relating to physical or psychosocial health may have an impact on a decision whether to undertake vocational rehabilitation and seek employment or other productive daily activities. Moreover, system level and institutionalized structures may hinder or facilitate access to employment. Several studies have demonstrated that when people living with HIV have access to comprehensive and individualized supports, they can achieve improved rates of employment and retention (Escovitz and Donegan 2005, Kielhofner et al. 2004, Paul-Ward et al. 2005a). Deciding to remain, re-enter or leave the workforce is one that requires a careful cost-benefit analysis as well as a weighing of the potential physical, emotional, spiritual and mental benefits versus drawbacks of employment. The decision should be one that,

with the help of a support network, a vocational rehabilitation expert and/or family and friends, is ultimately determined by the individual.

6.7.12 Retirement on a Low Income

The demographics of retirement have changed in the last decade and will continue to change in the future. People are staying at work longer or are semi-retiring, while others plan to work beyond the age of 65.

Canada's population is aging. The government has to take certain measures to ensure that the labour market and economy adapt to an aging society and remains strong. The federal government has introduced ways to gradually increase the age of eligibility for Old Age Security from 65 to 67 between the years 2023 and 2029. The Government of Canada introduced voluntary deferral of Old Age Security (OAS) pension giving people the option to defer their OAS pension up to five years past the age of eligibility.

To successfully plan for retirement, it is essential to understand the Canadian retirement income system. There are three main sources of retirement income that Canadians may draw from. They include personal savings and investments, government pension benefits and employer pensions.

John Stapleton has worked for the Ontario Government for 28 years specifically in the areas of social assistance policy and operations. He provides information on issues concerning income security, aging society, and child welfare on his website <http://www.openpolicyontario.com>. He addresses retiring on a low income through multiple resources including his report Planning for Retirement on a Low Income. Stapleton recognizes that it is essential for both financial institutions and the Federal Government to provide Canadians with proper information and advice on retirement. This toolkit is intended for people who give financial advice about retirement to low-income earners including: financial planners and advisers, financial writers, and friends and family of low-income earners.

The Government of Canada, Service Canada website provides information on Retirement Planning including information on the Canadian Pension Plan (CPP) retirement pension, OAS pension, Guaranteed Income Supplement (GIS) Allowance, and International benefits.

6_8 Self-Management Strategies

For people living with HIV who have access to antiretroviral therapies, the meaning of living with HIV has shifted from an acute illness to a chronic disease. Chronic diseases present unique challenges for everyday living (Swendemen et al. 2009a, Lorig et al. 2001). Transitioning from a state of acute illness to one that is chronic requires many active changes by the affected individual.

A structured self-management program can help individuals living with a chronic disease address some of these challenges. A landmark study that provided the Chronic Disease Self-Management Program for two years to more than 800 participants living with a chronic disease revealed improved health status, reduced use of healthcare services and improved rates of self-efficacy over the course of two years. The study concluded that this promotion of health self-management is not only economical but can lead to improved health status in those with various chronic diseases (Lorig et al. 2001). Although chronic disease self-management services are in need of universal improvement, the HIV community faces unique challenges not only because it is under-recognized as a chronic disease but also because it has a unique set of barriers involved with service-use, including stigma (Swendemen et al. 2009a).

Self-management is a strategy used by many people living with HIV and can include self-care routines in addition to structured programs. It is important to recognize that not everyone living with HIV will use these strategies. Some may completely avoid any element of care for as long as they can, even if the services are free. Researchers attribute this to three main themes, including a) an avoidance and disbelief of HIV serostatus, b) conceptions of illness and appropriate healthcare, and c) negative experiences with, and distrust of, the healthcare system (Beer et al. 2009). Other research demonstrates if an individual's perception about his or her health is that "not much can be done" the likelihood of actively engaging in self-care is greatly reduced (Reynolds et al. 2009). How individuals share information about their health may also be impacted by the characteristics and attitudes displayed by the healthcare professional. For example, one qualitative Australian study noted that when interacting with non-Aboriginals healthcare specialists, HIV positive Australian aboriginals tended to say "everything is okay" regardless of whether or not this was, in fact, the case (Newman et al. 2007).

In light of this, one way to work towards structured (or even unstructured) self-management for all people in Canada is to administer the "HIV+ Information for Self-Care Quiz" (Nokes and Nwakeze 2005). This quiz quickly maps out what clients do and do not know about self-care for HIV and, perhaps more importantly in the context of client-centred care, what they want to know. With this information, health-care practitioners can quickly and effectively determine a client's self-care priorities (Nokes and Nwakeze 2005).

Swendeman et al. (2009) classify HIV self-care categories into three main pillars:

I. Physical Health

- A framework for understanding illness and wellness
- Health promoting behaviours
- Treatment adherence

- Self-monitoring of physical status
- Accessing appropriate treatment and services
- Preventing transmission

II. Psychological Functioning

- Self-efficacy and empowerment
- Cognitive skills
- Reducing negative emotional states
- Managing identity shifts

III. Social Relationships

- Collaborative relationships with healthcare providers
- Social support
- Disclosure and stigma management
- Positive social and family relationships

In many respects, self-care and self-management operate at two tiers; the individual level and the community level. These levels will intersect to varying degrees based on each person's involvement in his or her care and the actual structure of the specific self-management program involved. Many interventions regarding self-management are structured over a set period of time, ranging from a single intensive workshop to a 7-week program. Bernardin et al. (2013) report that self-management programs seem to work best when targeted towards a specific group, such as women (Webel and Holzemer 2009), minorities and older adults (Gakumo et al. 2015) or youth. These structured programs can also be oriented to geographic areas, including, rural, remote and urban or any combination therein. Programs have been designed to address the needs of African American women (Tufts et al. 2010), inner-city women (DeMarco and Johnsen 2003), individuals who are seeking balance between home, work and illness (Bedell 2008), and those seeking assistance with depression (Lai 2007), or adherence (Smith et al. 2003). Programs have also been designed to emphasize self-efficacy (Kennedy et al. 2007, Shively et al. 2002). This is discussed further in [Section 6_9](#).

The emphasis on structured self-management is usually in a group setting aimed at providing individuals with adequate information to make informed choices about personal wellness. Peer-led interventions have been used to target HIV prevention and care initiatives since the 1990s, and there have been similar findings in systematic reviews of these programs (Simoni et al. 2011, Maticka-Tyndale & Penwell Barnett 2010). Peers can effectively reach HIV positive individuals not in care and help facilitate their engagement in HIV and related care (Bradford 2007, Cabral et al. 2007, Gwadz et al. 2011, Tobias et al. 2007). Peer interventions have also improved HIV services utilization (Broadhead et al. 2002, Knowlton et al. 2001). As well, peer interventions aimed at marginalized groups with an

increased risk of contracting HIV can help to improve use of preventative measures, like regularly taking oral PrEP medications (Groves et al. 2019).

There has also been an increase in the use of digital technology to deliver interventions (Flickinger et al. 2015, Luque et al. 2013, Robinson et al. 2010, Swendeman et al. 2015, Tufts et al. 2015).

Bernardin et al. (2013) conducted a scoping study to address three questions about self-management interventions for people living with HIV. These questions were: a) what knowledge, skills, and attitudes are taught? b) what outcomes are intended? and c) what are the participation experiences of people living with HIV? Thirty-five articles published between 1996 and December 2012 were included. Interventions taught self-care, interpersonal skills, technical knowledge, cognitive skills, positive attitudes, planning for the future and roles. Medication adherence was one of the most consistent components of self-management interventions. Intended outcomes included well-being and quality of life, health and illness management and use of health services. The authors found that current HIV self-management interventions often do not address important concerns in cognition, psychological coping and well-being, social participation and physical function. The authors conclude that self-management interventions often place on the individual the responsibility to create positive change in their own life. They conclude that current self-management interventions do not appear to address environmental factors, such as social stigma or the accessibility of resources for people living with HIV, which may impact the achievement of desired outcomes.

In this e-module, more information on individual-based management strategies can be found in [Section 6_8_1](#) Complementary and Alternative Medicines and Therapies or [Section 6_5](#) Modalities. Information regarding theory-based patient activation interventions can be found in [Section 6_9](#).

6.8.1 Complementary and Alternative Medicines and Therapies

6.8.1.1 Introduction

This section addresses the use of Complementary and Alternative Medicines and Therapies (CAMT) by people living with HIV and briefly describes some of the more common therapies. These therapies constitute an important element of self-management. Another key element of self-management entails treatments that may be received by a regulated healthcare professional. Although there will inevitably be some degree of shifting between those services which are regulated, unregulated or in the process of becoming regulated, the examples found within this section are either unregulated or in the process of becoming regulated. It is important to note, however, that some of

these services may also be offered by regulated health professionals (such as acupuncture provided by a physical therapist).

Research suggests that the use of CAMT by people living with HIV is commonplace. Many individuals report the use of these therapies along with conventional medical treatments. Utilization rates are higher among younger adult women, persons who are better educated, less impoverished, and those who exhibit higher symptom severity or have longer disease duration (Littlewood and Vanable 2008, Dhalla et al. 2006, Agnoletto et al. 2006, Mikhail et al. 2004). Due to the prevalence of CAMT use among people living with HIV, rehabilitation providers need to be knowledgeable on the wide range of therapies available and routinely ask their clients about their use (Burg et al. 2005). Additionally, providers should encourage open and non-judgmental dialogue with individuals who choose to incorporate these therapies into their care.

6.8.1.2 What are Complementary and Alternative Medicines and Therapies?

Complementary and Alternative Medicines and Therapies (CAMT) is a broad term that covers many different approaches to health and healing. In Canada, CAMT refers to any kind of therapy that lies outside the standard conventional western medical model.

CAMT is also known by many names, such as alternative medicine, complementary therapies, integrative medicine and holistic medicine. Although both streams tend to focus on preventative health, distinguishing between the two is important because, for many, CAMT has somewhat different implications. Complementary therapies are often used alongside, and thus in complement, to conventional medical treatment. Alternative therapies usually refer to therapies that are not used in conjunction with western medicine professionals or conventional pharmaceuticals, but rather used instead of traditional medical care (AIDS Committee of Toronto 2007).

Many CAMT emphasize the importance of linking the various dimensions of an individual, including the mental, physical, emotional, sexual and spiritual. CAMT attempts to heal on various levels, explore root causes and not simply address symptoms. There are many CAMT that may help to improve and maintain an individual's quality of life, repair immune damage or treat symptoms, although conclusive evidence for most of these interventions is still lacking.

There is a broad range of CAMT used by people living with HIV. Some of the more commonly used medicines and therapies have been included in this section. While there has been an attempt to include evidence for each CAMT in the context of HIV, sometimes due to a paucity of research, the evidence does not discuss HIV but may come from other complex chronic diseases.

6.8.1.3 How are Complementary and Alternative Medicines and Therapies Used?

Most people living with HIV who use complementary and alternative medicines and therapies (CAMT) do so to supplement their medical care and treatment. Before the introduction of antiretroviral therapy, CAMT was used as an alternative to manage HIV infection with the intent to build one's immune system and prevent opportunistic infections.

People living with HIV are now using these therapies in combination with conventional drug therapies to alleviate HIV-related symptoms, manage treatment side effects and improve general physical and mental well-being (Littlewood and Vanable 2008). While positive benefits have been reported with CAMT use, there are still challenges associated with combining therapies that are ingested. As such, providers should be aware of possible negative effects, including the reduced effectiveness of antiretroviral therapies and/or drug toxicity (Ladenheim et al. 2008, Jalloh et al. 2017, Brooks et al. 2017). Therefore, promoting open communication with individuals around CAMT use is vital to ensure that safe and effective use of CAMT is incorporated into their treatment plan.

6.8.1.4 Examples of Complementary and Alternative Medicines and Therapies

Below is a list of some of the therapies that people living with HIV may benefit from. For the most part, there is limited evidence for many of these interventions (Ontario HIV Treatment Network 2013). It is also important to note that studies of these interventions may test a single intervention or a combination of interventions. As a result, drawing conclusions on the efficacy of any intervention is always difficult due to complex confounding factors. Also, it should be noted that overlap of classifications of various complementary and alternative medicines and therapies interventions is common and this can complicate research findings.

6.8.1.4.1 Indigenous Healing Traditions

Indigenous peoples of Canada, which includes First Nations, Inuit/Innu and Metis, can have different healing traditions, but often share common ideas, beliefs and images. For many Indigenous Peoples, health is viewed from a holistic perspective, as evidenced in the medicine wheel. The medicine wheel is divided into four categories, comprised of spiritual, physical, mental and emotional elements. The intersection of these four categories symbolizes a holistic view of health wherein all four aspects must be balanced for healing to take place. Indigenous healing traditions include sharing and healing circles, traditional ceremonies, elders, traditional medicine, feasts and gatherings. An elder from one's Indigenous community can help Indigenous people living with HIV find a native healer. A recent cohort study

assessed whether partnering with Indigenous Elders at a primary centre when serving Indigenous patients improved health outcomes, determining that it led to a decrease in depressive symptoms, a reduction in suicide risk and an overall drop in mental health emergency department visits by the Indigenous patients studied (Tu et al. 2019).

There are two practices often used by Indigenous people living with HIV. In smudges, four sacred herbs are burned in a cleansing and purifying ritual. In sweat lodges, heated stones are placed in a pit in a small, enclosed structure, water is poured on the stones, and the emanating steam cleanses and purifies the participants (Peat 1994). This form of medicine addresses the spiritual origins of disease and health and is based on the belief that healing arises out of the individual's relationship to the community. Sacred ceremonies, some of which rely on visions and symbolism, are important parts of Native healing. More information about Indigenous health and traditional knowledge can be found on the National Aboriginal Health Organization website <http://www.naho.ca>.

6.8.1.4.2 Acupuncture

Acupuncture is an ancient Chinese treatment involving the insertion of very thin sterile needles into the body at specific points according to the meridian charts (pathways of energy). Although often practised on its own, acupuncture is more authentically used as part of an overall program of traditional Chinese medicine (see below). Many people use acupuncture to control painful conditions such as headaches, arthritis, lower back pain, and allergies, as well as withdrawal symptoms experienced when stopping drugs or cigarettes. A systematic review and meta-analysis conducted by Dimitrova et al. (2015) reviewed the literature available to May 2013 to examine the effectiveness of acupuncture in the treatment of neuropathic pain. The majority of trials demonstrated a positive effect of acupuncture on pain outcomes. Individual observational studies in HIV show some benefit for some patients (Phillips et al. 2004, Shifflett and Schwartz et al. 2011, Chang and Sommers 2011). Orthopaedic physical therapists in private practice are also capable of administering acupuncture as a part of regular physical therapy treatment (usually at no additional cost).

6.8.1.4.3 Affirmations and Visualization

Also called guided imagery, affirmations and visualization are practised by some people living with HIV or AIDS as they believe that having a positive attitude is an important part of survival and healing (Fitzpatrick et al. 2007). An affirmation statement is a declaration in the present tense of wanting something to happen, for example, "I am strong and healthy". Usually, a group leader guides the process of the visualization with spoken instructions. Audio files or CDs can also be used. An older study comparing guided imagery to progressive muscle relaxation or to a control intervention

found greater effects for those at mid-stage disease and for those who were previous users of guided imagery (Eller 1999). A randomized trial of a 5-week group mantra intervention found the intervention to be helpful in providing a convenient, portable tool for managing a wide range of situations related to living with HIV disease (Kempainen et al. 2012).

6.8.1.4.4 Aromatherapy

Aromatherapy is the therapeutic use of natural oils extracted from flowers, seeds, roots, and fruits. Aromatherapists are trained to choose oil appropriate to the need. For example, certain odours can relax, stimulate, or help alleviate depression. They are often applied as part of a massage therapy session, used in the bath, or taken by inhalation. While there are few high-quality studies of the use of aromatherapy across all diseases, there is some evidence of its effectiveness to help reduce anxiety, depression and other symptoms (Yim et al. 2009, Imanishi et al. 2009, Lua and Zakaria 2012). A case study of aromatherapy and shiatsu provision to 1030 HIV positive clients in an HIV multi-agency service found perceived mental and emotional benefits including relaxation, stress relief, and relief of musculoskeletal aches and pains (Lorenc et al. 2014).

6.8.1.4.5 Ayurvedic Medicine

Ayurvedic medicine is a 5000-year-old holistic medical system that originated from India. Ayurveda, which means the "Science of Life", combines two Sanskrit words: "Ayur" means life and "Veda" means "knowledge or science". Ayurvedic medicine uses a variety of products and techniques to balance the body, mind and spirit to help bring the body to a healthy state. Side effects or interactions with conventional medicines are important to consider and should be used under the direction of a trained practitioner (NCCAM 2008, Fritts et al. 2008).

6.8.1.4.6 Dietary and Other Supplements (Including Vitamins and Minerals)

Fawzi et al. have reviewed the role of vitamins and minerals in HIV transmission and disease progression (2005). The importance of micronutrients in the prevention and treatment of childhood infections is well known, and evidence is emerging that micronutrient interventions may also affect HIV transmission and progression (Friis 2006). However, two systematic reviews examining micronutrient supplementation in children and adults with HIV found no conclusive evidence that micronutrient supplementation effectively reduces or increases morbidity and mortality in HIV positive adults (Irlam et al. 2005, Drain et al. 2007). There was evidence of benefit of vitamin A supplementation in children (Irlam et al. 2005). Another systematic review, specifically focused on iron, reported that the current clinical practice of iron supplementation in HIV positive children is based on weak evidence, comprised of observational studies

and expert opinions (Adetifa and Okomo 2009). An exploratory study found positive effects of fish oil and controlled diet on triglyceride levels in adults with HIV (Capili et al. 2013). A systematic review of dietary interventions for the treatment and prevention of HIV-related lipid disturbances determined that both omega-3 supplementation and dietary intervention reduced triglyceride levels in adults with HIV, with the latter possibly to a smaller extent than omega-3 (Stradling et al. 2012).

6.8.1.4.7 Herbal Medicine

Herbal medicines are defined as preparations derived from plants or parts of plants used for treatment of HIV or its symptoms. They may be extracts from a single herb or a compound of herbs. Indigenous healers, herbalists, traditional Chinese medicine practitioners, naturopaths, homeopaths, aromatherapists and Ayurvedic practitioners sometimes use herbal medicines. Some herbal medications can cause harmful side effects and/or interact with other HIV medications making them less effective or even worsen side effects (Piscitelli et al. 2000). A systematic review found that no compelling evidence exists to support the use of the herbal medicines for treatment of HIV (Liu et al. 2005).

6.8.1.4.8 Homeopathy

Homeopathic medicine is a medical system that is specifically oriented to using nano-pharmacologic and ultra molecular doses of medicines to strengthen a person's immune and defence system rather than directly attacking the microbial agents. There is limited evidence of the beneficial role of homeopathy as an adjunctive and/or alternative therapy in HIV (Ullman 2003). A 2003 study found that 21% of people living with HIV in Europe were practising homeopathy (Colebunders et al. 2003). Rastogi et al. (1999) tentatively suggest a role for homeopathy for people living with HIV based on the statistically significant findings in their study of homeopathy for individuals during the symptomatic period, with outcome measures of baseline immune status. However, these findings should be reviewed with caution as a 2005 study found no evidence for the effectiveness of homeopathy in people living with HIV (Mills et al. 2005). It is important to note that the World Health Organization has recommended against the use of homeopathy for serious conditions including HIV, particularly in under-resourced countries (Mashta 2009).

6.8.1.4.9 Massage and Touch Therapies

There are many types of massage and touch therapies. Some involve light superficial touch while other types of massage go deep into the tissue. Touch therapies relax the body, promote circulation, enhance lymphatic flow, and ease musculoskeletal pain. Treatments are either full-body or area-specific and often involve the use of aromatherapy, unscented oils, creams, or powders. Specific types of massage and touch therapies often used by people living

with HIV) include reflexology, therapeutic touch, Reiki, shiatsu, Trager, Bowen technique, osteopathy and chiropractic (AIDS Committee of Toronto 2007).

A systematic review of massage in HIV suggests that there is some evidence to support the use of massage therapy to improve quality of life for people living with HIV, particularly in combination with other stress-management modalities such as meditation (Hillier et al. 2010). The review also suggests that massage therapy may have a positive effect on immunological function although there were few high-quality studies that studied those outcomes (Hillier et al. 2010). There is much less evidence for other interventions although there is anecdotal evidence of improvements reported by individuals receiving Reiki (Schmehr 2003, Miles 2003).

6.8.1.4.10 Meditation

Meditation is an exercise of the mind wherein which one learns to become an observer of one's thoughts. It is a simple practice, but it takes great discipline. Meditation may create a sense of calm, joy and efficiency in everyday life, regardless of disease or condition, although high-quality research to support these findings is limited. Findings from several small observational and randomized studies of meditation alone, or with other interventions, demonstrated a positive effect on several patient outcomes (Creswell et al. 2009, Williams et al. 2005, Gayner et al. 2010)

Mindfulness-based stress reduction is a program that provides systematic training in mindfulness meditation as a self-regulation approach to reducing stress and medical and psychological symptoms. Several studies have reported positive patient outcomes with this approach, however these benefits did not translate to immunological function (Gayner et al. 2010, Chhatre et al. 2013, Duncan et al. 2012, Sibinga et al. 2011, Hecht et al. 2018).

6.8.1.4.11 Mind-Body Approaches

Mind-Body approaches attempt to elicit what is known as a relaxation response. According to this approach, the relaxation response is a state in which individuals evoke a bodily calm that has the opposite effect of the fight-or-flight response, with concomitant favourable physiologic changes that are shown to be associated with improved immune functioning (Chang et al. 2007). Numerous mind-body approaches can elicit the relaxation response including meditation, repetitive prayer, autogenic training, deep breathing exercises, progressive muscle relaxation, biofeedback, and guided imagery (Chang et al. 2007). These are therapies designed to harness the power of the mind to promote and aid healing. A randomized pilot study of the added benefits of relaxation techniques to acupuncture demonstrated a significant improvement in emotional,

spiritual, physical and mental health quality of life in participants who received both interventions versus acupuncture alone (Chang et al. 2007).

6.8.1.4.12 Naturopathy

Naturopathic medicine is a distinct approach to primary health care that incorporates a range of therapies including botanical medicine, acupuncture, clinical nutrition, lifestyle counselling, homeopathy, and in some jurisdictions, such as in British Columbia, a limited formulary of primary care level drugs. A unifying feature of naturopathic medicine is a set of guiding naturopathic principles:

- First, to do no harm
- To treat the causes of disease
- To heal the whole person through individualized treatment
- To teach the principles of healthy living
- To emphasize prevention
- To support the body's natural healing process

The word naturopathy comes from Greek and Latin and translates as "a nature disease". The emphasis is on the whole individual to promote wellness, prevention, and self-care (Fritts et al. 2008). Naturopaths are commonly used in the course of care for HIV as preventative healthcare over both the short- and long-term (Luby and Rubin 1996, Fritts et al. 2008).

6.8.1.4.13 Reflexology

Reflexology is based on the theory that there are places on the head, hands, and feet that are connected to each gland and organ in the body. Reflexologists stimulate the organs and glands through both gentle and deep pressure massage of these points. Some people living with HIV have reported using reflexology for peripheral neuropathy (Nicholas et al. 2007), although it was used less frequently than other interventions such as massage, acupuncture and meditation. A systematic review of reflexology for several conditions determined that the best evidence available to date does not demonstrate convincingly that reflexology is an effective treatment for any medical condition (Ernst 2009, Ernst et al. 2011).

6.8.1.4.14 Shiatsu

Shiatsu is a Japanese word meaning "finger pressure," although thumbs, palms, and elbows are also used in treatments. The therapy is based on the Chinese theory of medicine that identifies meridian lines that relate to the internal organs. According to the principles of Asian medicine, when energy becomes blocked or sluggish, systemic imbalances and various symptoms can occur. By applying sustained pressure along the meridians, the Shiatsu therapist attempts to stimulate the healing abilities of the

body. Although there is no evidence within HIV, a systematic review demonstrated that there is limited evidence to support the use of Shiatsu, although acupressure (similar to Shiatsu) may be beneficial for pain, nausea and vomiting, and sleep (Robinson et al. 2011). A case study of aromatherapy and shiatsu provision to 1030 HIV positive clients in an HIV multi-agency service found perceived mental and emotional benefits including relaxation, stress relief, and relief of musculoskeletal aches and pains (Lorenco et al. 2014).

6.8.1.4.15 Stress Management Techniques

Mills et al. (2005) and Scott-Sheldon et al. (2008) have reviewed the research for up to 46 separate stress management interventions for adults with HIV, many of which are described in this section and fall under the rubric of complementary and alternative medicines and therapies (CAMT).

Stress management techniques reviewed included cognitive restructuring, problem-solving training, coping skills training, social support training, guided imagery, self-disclosure, progressive muscle relaxation, biofeedback, deep breathing, and mindfulness meditation (Scott-Sheldon et al. 2008). The latter review concluded that overall, based on literature published to 2006; stress-management interventions for adults with HIV significantly improve mental health and quality of life but do not alter immunological or hormonal processes. Reviews by Harding et al. (2011) and Brown and Vanable (2011) confirmed the effectiveness of stress-management interventions to enhance coping strategies among people living with HIV and AIDS.

6.8.1.4.16 Tai Chi

Tai Chi is a Chinese martial art involving a series of slow, rhythmic movements. This relaxing exercise may have positive physical and quality of life impacts when used by adults living with HIV (McCain et al. 2008, Robins et al. 2006, Galantino et al. 2005).

Although not specifically focused on HIV, one study examining the positive health effects of Tai Chi demonstrated potential ameliorations in balance, fear of falling, strength, functional mobility, flexibility, and increased psychological well-being, sleep enhancement for those suffering from disturbed sleep and improved cardiovascular functioning (Kuramoto 2006). One review supported the role of Tai Chi in clinical improvements despite methodological challenges with the research conducted to date (Field 2011).

6.8.1.4.17 Therapeutic Touch

Therapeutic touch is based on the premise that each person has localized energy fields, which extend beyond the body. Practitioners believe that in health, life energy flows freely throughout the body, while in disease these energy fields

get blocked or depleted. Through therapeutic touch techniques, the therapist attempts to "tune into" blocked areas by detecting a change in temperature, which indicates a blocked energy field. The therapist attempts to direct life energy into the person to restore balance within the body (Mills et al. 2005). There are few reports of the use of therapeutic touch, or biofield therapies, in the management of HIV. A review across diseases suggests some benefit for pain control, fatigue, anxiety and overall quality of life (Jain and Mills 2011).

6.8.1.4.18 Traditional Medicine Systems

Traditional Chinese medicine is an integrated system of healing and incorporates an intricate theory and practice involving pulse diagnosis and the balancing of element and organ relationships (Ferris and Flannery 1995). Illness is seen as an imbalance of the body's energy flow. Traditional Chinese medicine practitioners use acupuncture and often prescribe the use of herbs, usually in combination (Patterson and Robichaud 1996). For example, a pilot study of acupuncture and moxibustion (mugwort herb) to reduce diarrhea in persons with HIV found promising improvement in frequency and stool consistency (Anastasi and McMahon 2003).

Allopathic practitioners in India are outnumbered by practitioners of traditional Indian medicine and homeopathy, which is used by up to two-thirds of its population to help meet primary health care needs, particularly in rural areas. Fritts et al. (2008) conducted a systematic review of research literature that covered at least one system of traditional Indian medicine and homeopathy including Ayurveda, Unani medicine, Siddha medicine, homeopathy, yoga and naturopathy. Most studies examined either Ayurvedic or homeopathic treatments. Overall, the studies report positive effects and even "cure" and reversal of HIV infection, but frequent methodological flaws call into question their internal and external validity.

6.8.1.4.19 Yoga

Yoga uses deep breathing, stretching, the holding of postures, meditation and relaxation techniques, and a diet of pure foods to establish a balance between body and mind and give better control of muscle systems, including the digestive system. There is some evidence that people living with HIV may experience improved quality of life, more energy and less fatigue with regular yoga practice (Agarwal et al. 2015, Brazier et al. 2006, Marwar et al. 2015). Yoga has also been shown to improve cardiovascular health by lowering blood pressure in pre-hypertensive HIV positive adults with mild-moderate CVD risk factors (Cade et al. 2010). Sibinga et al. (2008) taught yoga, mindfulness meditation, and body scan as a part of a pilot study to determine the feasibility and acceptability of a mindfulness-based stress reduction program for HIV positive youth. Self-

reported effects of participation suggest the potential for improved psychological well-being and self-efficacy in this population.

6.8.1.5 How to Access and Pay for Complementary and Alternative Medicines and Therapies

Many Community-based HIV Organizations (CBHOs) offer financial assistance to purchase complementary and alternative medicines and therapies (CAMT). Some of these organizations provide information on specific complementary therapies. Most of the therapies listed in this section are not paid for by government coverage plans. However, some private health insurance benefits packages cover some of these therapies.

Many ingestible or topical therapies are available from health food, supplement or drug stores although there is a concern regarding the varying degrees of staff expertise and experience (Mills et al. 2003). Other sources include Chinese herbalists and some practitioners.

Options for people in smaller communities where these products are not readily available include mail-order services or internet ordering from reputable suppliers. Providers should encourage their clients to check with their local CBHO as most now have information about how to access reputable CAMT providers in their area. Some CBHOs offer a limited range of CAMT free to people living with HIV or AIDS. Many also hold workshops on various CAMT, where clients can try out these techniques for free, before spending money on them.

6.8.1.6 Considerations for Healthcare Providers

Increasingly, researchers are attempting to evaluate complementary and alternative medicines and therapies (CAMT) interventions and create an evidence base in this area. Points to discuss with clients regarding the decision to use CAMT include:

- Potential for harm, e.g. interactions of ingestible with drugs, potential for injury
- Cost
- Evidence base within HIV or across diseases and conditions

Most healthcare providers would agree that low cost, low harm interventions for which the client reports a perceived sense of benefit could be supported, even with a lack of published evidence. Clients should be encouraged to discuss any decisions to modify their medical regimen, especially considerations to change their prescribed medications, as a result of commencing CAMT or as a result of successful outcomes from the use of CAMT.

6_9 Theory-Based Patient Activation Interventions

Although patient education improves knowledge and health literacy, people living with HIV also require training and support to effectively self-manage their health, communicate their potential need to access rehabilitation services, and participate in shared decision-making with their healthcare provider. The degree to which people understand they must play an active role in managing their own health and healthcare and the extent to which they feel able to fulfil that role is referred to as patient activation (Hibbard et al. 2005). Specifically, patient activation is the individual's knowledge, skill, and confidence to manage his/her own health and healthcare. After reviewing the evidence, Coulter (2012) identified three primary domains of patient activation interventions: health literacy (reading, understanding and acting on health information), shared decision-making (working together with clinicians to select appropriate treatment as or management options), and quality improvement (providing feedback on healthcare processes and outcomes). By triangulating results from several systematic reviews and other analyses, Coulter identified key characteristics of effective interventions. Personalized patient information reinforced by a professional or lay support, patient decision aids, health coaching, question prompts and self-management education and support led to improved patient skills in these three areas (Coulter 2012). In efforts to quantify the impact of chronic disease management programs, Hibbard et al. (2004) designed the Patient Activation Measure to assess an individual's knowledge, skill, and confidence concerning managing his or her health. When individual care plans were tailored to activation levels, people's knowledge and capability to manage their own health improved.

According to Bandura's social cognitive theory of self-regulation, beliefs in one's own capabilities to organize and execute the courses of action required to handle situations in the future influence how people think, feel motivated and act (Bandura 1995). Interventions that incorporate strategies for increasing self-efficacy beliefs are expected to lead to better self-management behaviour (Michie et al. 2005, Bandura 1977). Self-efficacy theory proposes four mechanisms by which to increase self-efficacy: performance accomplishments (experiences of success performing the behaviour of interest), vicarious experience (observing peers performing the behaviour successfully), verbal persuasion (receiving positive feedback about ability from a respected individual), and emotional arousal (minimal levels of fear and anxiety during performance) (Bandura 1977).

6_10 Models of Care

Innovative models of care are increasingly being designed and evaluated to serve the needs of people living with HIV. Interventions include:

Care provided by non-physician regulated professionals (Basu et al. 2012, Blank et al. 2011, Davis et al. 2010, Dunham et al. 2012, Edmonds et al. 2015, Foisy et al. 2015, Gaston et al. 2015, Hinchliffe et al. 2015, Kenya et al. 2013, Kerr et al. 2013, Kibicho et al. 2014, Kietrys et al. 2014, MacLachlan et al. 2011, Mgbemena et al. 2015, Pullen et al. 2014, Shamburger-Rousseau 2014, Sims and Womack 2015, Wong et al. 2012, Young et al. 2010),

Special approaches to primary and specialty care including shared care and clinic types (Brickley et al. 2011, Chinthapalli et al. 2013, Cope et al. 2015, Feldman et al. 2012, Greer et al. 2015, Mapp et al. 2015, Robinson et al. 2014, Weiss et al. 2015),

Strategies to support linkage or retention and engagement in HIV care (Bhaduri et al. 2013, Brennan et al. 2014, Cain et al. 2014, Gwadz et al. 2014, Mbuagbaw 2014, Ogane et al. 2014, Reed et al. 2013, Roth et al. 2012, Saberi and Johnson 2015, Yehia et al. 2013), and,

Care provider education (Bashook et al. 2010, Beach et al. 2013, Murzin et al. 2015).

6.10.1 Dental Care

Opportunistic infections with fungi such as *Candida albicans* or with viruses of the herpes family such as herpes simplex and herpes zoster may be present in people living with HIV. Susceptibility to periodontal breakdown and bleeding gums is somewhat enhanced by the effects of HIV disease and cavities (Johnson 2010, Sy et al. 2011). Also, people living with HIV have a high prevalence of human papillomavirus (HPV), which puts them at greater risk of HIV-associated malignancies (Beachler et al. 2013). While evidence is limited, more than a third of HIV positive dental clients in five different primary care clinics in Florida reported that they did not discuss their oral health status with their dentists (Pereyra et al. 2009). A complete intervention should include oral health, as more than 90% of people living with HIV will experience some form of oral manifestation of HIV (Pereyra et al. 2009).

An intervention to provide oral healthcare to low-income individuals resulted in improvements in mental health status which were associated with a decrease in oral health problems at the last available visit and no pain or distress in one's teeth or gums at the last available visit (Bachman et al. 2012). Healthcare providers working with this population should regularly check dental status.

6_11 Palliative Care

6.11.1 Introduction

Throughout this document, the emphasis has largely been on the shift of HIV from its previous notoriety as an imminent death sentence to a chronic disease characterized by episodic disability. In this newer context, the role of rehabilitation has been pivotal, and with the help of resources such as this e-module, rehabilitation can assist more people living with HIV to lead meaningful lives for many years beyond their initial diagnosis.

Studies have shown that AIDS-related deaths have decreased significantly, and life expectancy has dramatically increased. The most commonly referred to study shows that over the course of eight years (1996 to 2004), death rates for people living with HIV decreased from "7.0 deaths/100 person-years of observation in 1996 to 1.3 deaths/100 person-years in 2004. Cardiovascular, hepatic, and pulmonary disease and non-AIDS malignancies were the primary causes of death by 2004" (Palella et al. 2006). These changes are attributed to antiretroviral therapies and increased understanding of the optimal timing of interventions. Regardless of the cause of death, palliative care of people living with HIV is an important part of care for those living at the end of their life. Knowledge of the important elements of palliative care will make the end stages of life more understandable, manageable and comfortable for the individual and for those around him/her.

The World Health Organization defines the components of palliative care in great detail, believing it to be a fundamental right for all in need and compares the end stages of AIDS with the end stages of cancer (Sepulveda et al. 2002). Individuals with AIDS are likely to be candidates for palliative care, although as noted above, the number of adults who die from causes related to HIV/AIDS have become greatly reduced. Palliative care has a holistic focus, which incorporates the skills of an interdisciplinary team at the point when an individual's disease has progressed to the state of being untreatable. It is important to understand that although the disease itself may be no longer treatable, some of the symptoms associated with the disease are. The focus shifts so that management of symptoms is the goal of care and all efforts are towards making the individual's end stages of life as comfortable as possible. As with all aspects of care, the person (and family and friends) remain the key participants in care direction and decisions. Current concepts of palliative care in HIV include the following components (Sepulveda et al. 2002). Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of care

- Offers a support system to help individuals live as actively as possible until death
- Offers a support system to help the family cope during the individual's illness and in their own bereavement
- Uses a team approach to address the needs of individuals and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

6.11.2 What is the Role of Rehabilitation in the Context of Palliative Care?

Rehabilitation has a role in the context of palliative care for AIDS (McClure 1993), although current research states it could still be expanded upon (Kaboru et al. 2008). A systematic review found that cognitive behavioural therapy, peer/counselling group therapy, massage therapy, and exercise therapy were the most commonly used rehabilitation therapies as part of an effective palliative care approach (Uwimana and Louw 2007). Although the concepts of rehabilitation and palliative care may initially appear to embody contradictory philosophies, these two models of care share many key elements, including commitment to quality of life and an emphasis on helping individuals maintain comfort and autonomy for as long as possible. Rehabilitation for the terminally ill must emphasize balance between "optimal function and comfort" (Santiago-Palma and Payne 2001). The ultimate focus, especially as death nears, should be on comfort and facilitation of the desires of the individual through an interdisciplinary approach that recognizes the physical, social and spiritual aspects of the individual. Unfortunately, current research suggests that people living with HIV continue to be concerned that their end of life decisions will not be addressed (Mosak and Wandrey 2013). Rehabilitation for those individuals living at the end of life is most helpful when the therapeutic approaches are designed to maintain current abilities, strengths and functions for as long as possible, and then shifting to (or adding) adaptive strategies to address progressively lessening abilities. For example, a speech-language pathologist may address diet textures, and/or recommend feeding techniques and postural modifications to facilitate safer, or less painful swallowing by decreasing choking episodes and aspiration related breathing difficulties.

6.11.3 Rehabilitation Interventions for Palliative/End-of-Life Care

6.11.3.1 Physical Modalities for Pain Management

The following physical modalities (and their caveats) have been recommended by Santiago-Palma and Payne (2001). Since then, additional research has demonstrated the effectiveness of rehabilitation interventions for maintaining function even at the end of life (Oldervoll 2011, Bartolo et al. 2012, Kumar and Jim 2010). All can all be done at the bedside.

- Massage
- Heat (hot packs, moist heat, heat lamps) although there is some caution not to apply heat on areas that are insensitive, atrophic or acutely inflamed
- Cold (ice packs, ice compression wraps, ice massage). Cold packs that are soft and pliable are particularly helpful for the palliative care population although ice should not be applied to areas that are atrophic, ischemic limbs or on those with Reynaud's Disease or Syndrome
- Peripheral neuropathy will decrease the person's sensation in their hands and feet, so use caution when applying temperature-specific (hot or cold) treatments
- Bedside exercise, including passive, active and assisted motion can help to reduce stiffness, improve circulation, and ameliorate disposition. 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
- Canes, walkers, shoehorns, rails in the washroom and bedpans are examples of tools that can be helpful. It is important to identify what tools and devices may be useful as early as possible so that a discussion can happen at a time when the client is an active participant in decision-making. It is important to teach about health promotion (i.e. using a rail in the washroom to prevent falls) as those living at the end of life need to know how to support their own health and safety, and stay independent, for as long as possible.

Health providers need to know any medications being used (both prescribed medications and otherwise "acquired") so that the effects of these interventions can be considered when planning and delivering care.

6.11.3.2 Role for Speech-Language Pathology

Speech-language pathologists (SLPs) can assist with swallowing, breathing and communication techniques, including difficulties with speech clarity, voice, language, social behaviour and thinking skills (Santiago-Palma and Payne 2001). End of life care for quality of life feeding or for safer, more comfortable swallowing can also be provided.

Early interventions, (in other words, as soon as it becomes apparent that there may be problems in these areas) are essential.

6.11.3.3 Addressing the Emotional and Spiritual

Many of the complementary therapies and modalities listed in previous sections of this e-module are relevant to people living with HIV at the palliative care level, albeit with it modifications as appropriate. Music movement therapy (Frego 1995) and group art therapy have been found to be effective in addressing the "why me" question that often arises as an individual approaches the end of their life (Mayo 1996). Cognitive Behavioural Therapy (Uwimana and Louw 2007) and meditation (Williams et al. 2005) are also commonly used. Life review or life narrative enablement practices are also techniques used in end-of-life care (Chochinov and Chan 2005). It is essential that people reaching the end of life have opportunities for self-expression. Offering a number of choices will allow the person to choose what works best for them, and to try different things.

6.11.4 Programs

There are several examples of palliative/end-of-life programs across Canada, with a number specifically geared towards people living with HIV.

6.11.4.1 Casey House Palliative/End-of-Life Care

Casey House, in Toronto, prioritizes access to their palliative care program to people living with HIV. For those wishing to spend their final days at home, support is provided through Community Care Access Centres (provincially funded care at no cost to participants) and the Home Hospice Program. The Casey House palliative care program focuses on pain control and symptom management. More information can be found at

6.11.4.2 AIDS Bereavement and Resiliency Program of Ontario

The AIDS Bereavement and Resiliency Program of Ontario (ABRPO) consists of an 8- to 10-week intervention for volunteer or professional caregivers, partners, family and friends of people living with HIV (

An initial needs assessment determined that the multiple loss experienced in the first decades of HIV by people living with HIV and their social and support groups requires a standardized response grounded in a clear theoretical framework to address loss felt by individuals, family and friends and within Community-based HIV Organizations (CBHOs).

The ABRPO mandate provides structured support in order to:

- Assist in assessment and enhancement of individual and agency coping strategies related to loss and transition.
- Develop and deliver agency interventions, educational presentations, workshops, retreats and research initiatives incorporating evidence-based knowledge and bereavement expertise.
- Provide innovative training to organizations, staff and people living with HIV to increase communication skills, peer support and community resiliency strategies.
- Provide timely responses to the changing nature of loss within diverse AIDS-impacted communities.

6.11.4.3 Canadian Hospice Palliative Care Association

The Canadian Hospice Palliative Care Association (CHPCA) maintains an interactive database of hospice programs available in communities across Canada. The database can be searched by province, condition and other keywords. The CHPCA is active in education for health professionals and volunteers, public awareness and research in palliative care. Written and video resources are also available for order at <http://www.chpca.net>.

CHAPTER 7

Current Issues in HIV Rehabilitation in Canada

7_1 Access to Care

Rehabilitation can provide needed services to people living with HIV throughout their lives. How HIV is understood and conceptualized affects the roles rehabilitation providers can provide to people living with HIV.

7.1.1 Demand for Rehabilitation Services

When thinking about HIV from the perspective of an episodic disability, the roles for rehabilitation expand significantly. Deber and Landry (2010) note that the intermittent periods of acute illness in relation to a chronic disease such as HIV can often be prevented and/or minimized with the involvement of a rehabilitative team. This is promising news. However, people living with HIV will face challenges in the coming years as experts forecast that demand for rehabilitation services will increase over the next decade. Landry et al. (2008) attribute this increased demand to several factors, including:

- Aging populations
- Workforce pressures
- Rise in chronic and complex multi-system disorders
- Advances in technology
- Changes in health service delivery models

People living with HIV are affected by all of these factors.

7.1.2 Rehabilitation as Prevention

What is the role of rehabilitation in the context of HIV as an episodic illness? Often, there is a misconception that rehabilitation is used exclusively to restore an individual's physical or psychological ability to a pre-illness/pre-disabled state. There are situations when this is the case, such as for someone recovering from a total knee replacement. However, in the situation of a chronic disease characterized by episodic disability, rehabilitation can apply to many more situations. Rehabilitation services can be used as a form of prevention or 'pre-rehabilitation' (Deber and Landry 2010). Prehabilitation is a preventive, proactive approach to managing one's health, ranging from maintaining physical capability and mobility to learning stress management and pacing skills. Many of the skills listed in the upcoming section can be used at any time while living with HIV, as a means to diminish, delay or even completely prevent certain limiting effects. More information on this form of rehabilitation can be found in Section 6_1 Preventive Rehabilitation.

7.1.3 Rehabilitation as Palliative Care

Rehabilitation can also be used in the context of palliative care for people living with HIV and family members who are dealing with the upcoming loss of life (Deber and Landry 2010). This element of rehabilitation places less emphasis on restoring one's mobility and more on ensuring optimal comfort and independence for those who have reached a state of untreatable illness. More information on this form of rehabilitation can be found in Section 6_10 Palliative Care.

7.1.4 Changes in Health Service Delivery Models

In recent years, the distribution of funding has shifted across the healthcare system, and this has also affected the rehabilitation community (Deber and Landry 2010). There are three tiers of healthcare funding: public, quasi-public and private. Publicly funded services include hospitals and Local Health Integration Networks (LHINs). These services can be funded by global budgets, Schedule 5 funding (for Ontario Physical therapists only), the LHINs budget and the Veteran Affairs Canada budget. Motor Vehicle Accident Insurance and the Workplace Safety and Insurance Board are both partially funded by public sources. Private funding can come from an individual, an employer's funding or private insurance (Deber and Landry 2010).

Moreover, various factors contribute to the way in which a healthcare system is run, all of which have the potential to act as a barrier to access to care (Deber and Landry 2010). These factors include philosophical differences, territorial and power challenges, communication and coordination of information, the organization of services, human resource issues, regional and funding issues, varying user fees and eligibility criteria, urban versus rural differences, coordination of care services between varying providers, multiple versus single entry assessment and case management. Discrepancies within and across institutions and regions related to policies, coordination, funding and more, can often make access to care a challenge.

A framework for organizing healthcare delivery systems for persons with ongoing care needs and their families recommends nine key elements for facilitating access to care as broadly as possible (Hollander and Price 2008). These include:

- A clear statement of philosophy enshrined in policy
- A single or highly coordinated administrative structure
- A single funding envelope
- Integrated electronic information systems

- Rewards and incentives for evidence-based management
- A single- or coordinated-entry system
- Standardized system-level assessment and care authorization
- A single system-level client classification system
- Ongoing system level case management

This best practice framework is a good resource for rehabilitation providers and health planners seeking to maximize access for clients living with complex chronic diseases (Hollander and Price 2008). A single funding envelope is critical to maximizing the efficiency, effectiveness and quality of care provided. A single entry point provides for a consistent screening mechanism that ensures that only those with appropriate needs are provided services.

7_2 Navigation and Advocacy

7.2.1 Background

The Canadian healthcare system can be daunting and confusing for many, including people living with HIV. Clients may have some difficulty entering or manoeuvring through the complex Canadian health system. Assisting clients to navigate through the system is a component of optimal care. For some of these clients, there may be other barriers and hurdles to receiving appropriate rehabilitation services and care. There may be issues around financial coverage, transportation, family care (child/parent/partner), medications/physical supports, social supports, health literacy, fear of stigma, discrimination, etc. This is where healthcare providers (and/or Community-based HIV Organizations) may need to assist with advocacy. There is some preliminary work that healthcare providers can do to set up a safe environment so that the necessary rapport and communication can take place to address the delivery of rehabilitation services including navigation and advocacy (Lawton 2007, NCALL 2007, CATIE 2009).

7.2.2 Sensitive Practice within Client-Centred Care

The term "patient- or client-centred care" has often been used within healthcare and social service circles. This section briefly outlines some of the key concepts in the philosophy of client-centred care. An important component of client-centred care includes a practice of collaboration, not only between the rehabilitation provider and the client but also between the client and the entire healthcare team, including administrative staff and program support workers.

7.2.2.1 Client- or Patient-Centred Care

Client- or patient-centred care attempts to provide healthcare services that are needed by a client, when and how the client desires. This is a balancing act requiring collaboration between the whole healthcare team (including administrative staff). This comes primarily from a partnership between the healthcare provider and the client. Ensuring the design of a practice so that the client feels comfortable and able to participate in the process is a good first step. It is also important to be open to the possibility of needing to transform certain elements of one's practice. This can include asking relevant and appropriate questions followed by active listening and respect for the client as an equal. Some refer to this as sensitive (or responsive) practice. Rehabilitation providers who do not see many people living with HIV as a part of their practice often describe a sense of discomfort because they do not want to offend the individual, particularly individuals who may have been marginalized by the healthcare system in the past (unpublished data).

Some of the factors of sensitive and responsive practice include the following:

- Have a safe, friendly and welcoming environment that is seen by the client upon entering the facility
- Be professional yet caring to encourage a sense of safety and to delineate and maintain appropriate boundaries
- Appreciate the social, cultural and environmental background and context of all clients
- Become comfortable and competent in handling differences
- Understand each client as an individual with "unique values, beliefs, needs and history". This respect also means suspending judgments of the person and their lifestyle or behaviours that may have caused or contributed to the presenting concerns or a medical condition
- Appreciate how harm reduction as an intervention can be an effective approach for both prevention and treatment (Section 3.10.2)
- Have a basic understanding of the determinants of health and marginalization and how social exclusion affects health outcomes
- Indicate how confidentiality is handled both within the practice and for any referrals
- Provide timely services (both appointment booking and the waiting time in the office) and anticipate who else the client may need to see during the course of a healthcare interaction

- Conversely, there are challenges for the most vulnerable clients that may impact on their ability to arrive at appointments on time. Consider flexibility around meeting times and ensure the client has the adequate resources to get to the appointment (e.g., subsidized bus fare)
- Take the time to listen to the client so they genuinely feel heard, understood and valued
- Recognize the fine-line between learning from a client and self-education (prior to or after a client interaction), as some have told their stories many times and feel they must educate the professional in order to receive better care
- Recognize how stigma can affect access, disclosure, motivation and treatment participation
- View prevention, care, rehabilitation and treatment as one seamless continuum
- Provide timely and relevant information for the client to make informed decisions
- See the client as having the necessary assets to achieve optimal health
- Jointly set achievable outcome goals designed for the individual
- Make referrals to other sensitive and responsive places of practice

7.2.2.2 Tips on Client Engagement

Client engagement can be improved with the following strategies:

- Clarify your role and scope of practice as a healthcare provider
- Clarify the purpose of the visit from both your perspective and that of the client
- Limit technical jargon or knowledge that is difficult to understand
- Obtain verbal consent from the client to proceed with visit
- Create a safe, private environment for the meeting
- Maintain eye contact when talking with the client
- Use active listening, body language which reflects openness, and calming facial expressions
- When speaking, modulate tone, rate of speech, volume

Engagement can also be fostered through communication. The following can facilitate engaged communication:

- Use open-ended questions to engage the client in discussing their "story" while keeping in mind that a) they have likely already told their story to other healthcare providers many times, and b) may assume you know more than you do about their issues.

- Pay attention to verbal and non-verbal cues during communication
- Support the client in expressing their feelings, and validate their feelings and concerns by providing realistic reassurance and hope
- Respect the client's boundaries and do not push them into disclosure
- Create an environment and opportunity for clients to discuss sensitive issues
- Address and be attentive to issues of culture/diversity

7.2.3 Navigation

Having a patient- or client-centred and responsive practice can facilitate a meaningful relationship with one's client and improve navigation within the healthcare system. Quite often, the expertise of another healthcare or social service professional or perhaps a community-based organization is required. This is when navigation becomes an important skill. As a healthcare professional, knowledge of this skill can assist people living with HIV to find their way through the care system and to receive the appropriate service desired.

Assisting a client to navigate the healthcare system can include making referrals to other sensitive and responsive places of practice whenever possible, spending adequate amounts of time with the client discussing the reason for referral and explaining what can be expected (a consultation visit, test, procedure, etc.). This may require explaining a few terms or procedures in plain language or providing the information in a simple brochure. Remember what may seem routine and easy to the healthcare professional may be a novel and scary experience for a client who is new to the healthcare system. Some basic health literacy will go a long way in making the next appointment a helpful experience.

Discuss any barriers and/or anxieties that the client might have. Some examples include:

- Receiving and remembering the appointment time and place
- Dealing with a referral that gets lost in the system
- Finding and getting to the place of the appointment; including transportation, location and signage
- Making phone contact with the new referral if there are any changes in plans
- Preparing or collecting any additional information which the new healthcare professional might request
- Filling out any required forms before and during the new appointment

Ensuring the client understands his or her rights in this new situation. This includes:

- Confidentiality
- Informed consent

- Having a family member, friend or advocate accompany them
- Having answers to questions written down
- Assistance communicating effectively with a healthcare team to mitigate any issues around basic literacy, translation or interpretation; or sensitive or stressful issues like palliative care
- Care/responsibility of any family members during the appointment time
- Any costs that might not be covered by provincial medical care (or community services, or private plans, etc.)

7.2.4 Advocacy

Given the complexity of the healthcare system, it is not surprising that there will be clients who will have difficulty navigating the system alone, even with all the information and suggestions he or she is given. This presents the opportunity for the healthcare professional to advocate on the client's behalf or to refer the client to an appropriate advocacy group.

The ideal situation is for the healthcare professional to work with the client to become his or her own self-advocate. This is a learning and capacity building strategy. As this process can take a fair amount of time, it is imperative for all healthcare providers to reflect on the amount and time and energy they can commit to this process. On the one hand, healthcare professionals should not jeopardize the rehabilitation service already provided for the client due to feeling overwhelmed with bureaucratic concerns. On the other hand, not helping may mean that the larger system can jeopardize the good rehabilitation work already provided for a client.

Advocacy on behalf of the client may be needed when healthcare professionals are recommending a referral and/or a course of action for a client, as access may be needed to:

- Additional financial and other support through income assistance
- Assistance with child care and/or support
- Medications, appliances, and other items not otherwise covered
- Assistance with health procedures and services
- Transportation services
- Translation and/or interpretative services
- Housing supports
- Financial planning and trusteeship

Some of the skills that an individual might need to be his or her own self-advocate include:

- Being able to identify and focus on the specific areas where action or change is needed.

- Finding people to work with the client such as peers who have the same issue and/or finding allies and supporters. This might include:
 - Support workers
 - Peer networks
 - Community advocates
 - Organizations with a support/advocacy role
- Making a personal action plan that is realistic and doable
- Being able to express oneself clearly and calmly, either verbally or in writing
- Looking up or seeking needed information
- Developing good questions to ask
- Listening to what is being said and not being said
- Dealing with one's anger or frustration in a non-confrontational way
- Taking notes during or after a meeting; or asking for the answer, direction or decision to be written down in plain language
- Reflecting upon what has happened and learning for the next time

As a rehabilitation provider who is recommending a referral and/ or course of action that has some potential hurdles or barriers, it is important to discuss whether the person living with HIV has the necessary skills and resources to be his or her own self-advocate.

Keeping the needs of the individual at the forefront is the most important aspect of client-centred care. Collaborative teamwork that includes the person living with HIV as an equal part of the team is the easiest way to facilitate such practice.

7.2.5 Looking Ahead

AIDS Service Organizations and other Community-based HIV Organizations have been using outreach for many years to increase engagement and retention for HIV care for the underserved and disadvantaged people living with HIV, with aspects of care coordination becoming part of the model (Bradford 2007a). The standard practice of care for antiretroviral therapy adherence and support and retention for patients who consistently miss appointments have been itemized (Amico 2011). While patient navigators have been available throughout North America for conditions such as cancer, HIV care may also benefit from a systematic navigation approach as well as through a coordinated approach to the various structural, financial and personal barriers at an individual client level, while improving the available mediators such as appropriate care, providers and adherence (Bradford 2007). As improvements in HIV

medication continue and treatment options expand, there will be increased opportunities for HIV rehabilitation to serve a greater and more diverse base of people living with HIV.

The ongoing advancements in HIV treatment and care provide opportunities for the rehabilitation profession to examine, modify and/or integrate its own approaches to treatment and care. Areas of service innovation and future research include:

- Having an outreach strategy to engage harder to reach and serve populations
- Modifying practices of care for rehabilitation adherence, support and/or retention of these diverse populations
- Participating in a more coordinated navigation system for people living with HIV
- Working more closely with HIV care providers and/or community-based organizations

7_3 Identifying Key Research Priorities in HIV and Rehabilitation

HIV is increasingly experienced as a lifelong, episodic disease, characterized by unpredictable cycles of wellness and illness (O'Brien et al. 2008a, 2009). There is a need to develop the field of research, clinical practice, and policy for HIV rehabilitation, to address the range of impairments, activity limitations, and participation restrictions associated with the disease and its treatments. Realize (formerly known as the Canadian Working Group on HIV and Rehabilitation) conducted a scoping study to identify key research priorities related to HIV and rehabilitation that will advance policy and practice for people living with HIV in Canada (O'Brien et al. 2010a).

The Framework of Research Priorities in HIV and Rehabilitation was developed to highlight important topics in HIV and rehabilitation research (O'Brien et al. 2010a). In this framework, research priorities fall into three overlapping themes:

- Living with HIV across the lifespan (e.g. aging with HIV, concurrent health conditions, changing outlook over time)
- Disability (e.g. impairments, activity limitations and participation restrictions)
- Rehabilitation (e.g. access to services, effect of rehabilitation interventions, and impact of education of healthcare providers on HIV and rehabilitation)

These research priorities may be explored through environmental contextual lenses (e.g. urban versus rural, developing versus developed countries, stigma, legal, policy and social justice issues, determinants of health) and/or personal contextual lenses (e.g. sex and gender-based analyses, ethnocultural backgrounds), a social inclusion/

exclusion lens, using different methodological approaches (e.g. using a mixed methods study design, considering cross-disease versus HIV-specific approaches, incorporating longitudinal study designs (to explore disability over time), increasing the number of treatment effectiveness studies (to explore the impact of interventions), and pursuing outcome measure development).

Additional consultation identified six top research priorities that include:

- Disability and episodic disability
- Concurrent health conditions living with HIV (e.g. mental health, bone and joint disorders, cardiovascular disease)
- HIV and the brain (e.g. mild to moderate memory and concentration problems, minor cognitive motor disorder)
- Labour force and income support issues
- Access to and evaluation of rehabilitation
- Development and evaluation of outcome measurement tools

Although there is increasing evidence in this field, there is a need for future research in the area of HIV and rehabilitation (O'Brien et al. 2010a). The six key priorities for HIV and rehabilitation propose a future plan for HIV and rehabilitation research that may increase our knowledge to collectively enhance future practice, programming and policy for people living with HIV in Canada.

7.3.1 National Consensus Statement on Women, Trans People and Girls and HIV Research in Canada

The needs of women, trans people and girls in Canada as they relate to HIV and related issues are extremely complex and diverse and span across legal, cultural, social, political, economic and other spheres. The National Consensus Statement on Women, Trans People and Girls and HIV Research in Canada (Gahagan et al. 2013) was developed to raise key research issues and needs as they relate to women's, trans people's and girls' experiences of HIV in Canada. The consensus statement can be accessed at <https://cdn.dal.ca/content/dam/dalhousie/pdf/Diff/gahps/NationalConsensusStatementEnglishV11.pdf>

7_4 Occupational Exposure / Universal Precautions

7.4.1 General Information

HIV can be transmitted through unprotected sexual intercourse, exposure to blood, blood components or bloody body fluids, perinatal transmission from mother to child, and through breast milk. The risk of occupationally acquired HIV infection through exposure to intact skin or mucous membranes is too low for an accurate estimate.

The greatest risk of occupationally acquired HIV infection is from exposure to blood or bloody body fluids through a hollow bore needle that has been in an artery or vein of a source client who has a high viral load.

7.4.2 Body Fluids Potentially 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

7.4.3 Body Fluids Not Infectious for HIV

- Stool
- Urine
- Tears
- Saliva

It is important to note that if these non-infectious body fluids contain blood, they may be infectious. If someone is potentially exposed to HIV, the person should contact his or her occupational health department, or the emergency department within one or two hours to assess the need for antiretroviral prophylaxis.

7.4.4 Reducing Occupational Exposure to Infections

The following steps are recommended for preventing occupational exposure to any infection:

- Wash hands well
- Use warm running water
- Use moderate amount of soap
- Vigorously rub hands together, including between fingers, under rings and watches, around nails and wrists
- Rinse well
- Dry hands with a paper towel
- Turn the tap off using the paper towel to grip faucet handle

- Wear protective apparel when anticipating contact with blood or bodily fluids
- Use needles and other sharps safely, and dispose of them safely in biological waste
- Use appropriate respiratory precautions

7.4.5 Guidelines for Management of Occupational Exposure

The United States Public Health Service has released updated clinical practice guidelines for the management of occupational exposures to HIV and recommendations for post-exposure prophylaxis (Sucher et al. 2014).

7_5 Privacy, Disclosure and the Law

The Canadian HIV/AIDS Legal Network (www.aidslaw.ca) promotes the human rights of people living with and vulnerable to HIV, in Canada and internationally, through research, legal and policy analysis, education, and community mobilization. The Legal Network is Canada's leading advocacy organization working on the legal and human rights issues raised by HIV. The Legal Network regularly publishes updates on the importance of privacy of health information for people living with HIV, which includes a discussion of current rights and responsibilities. A series of eight brochures outlining the importance of privacy of health information can be found at this link: <http://www.hivlegalnetwork.ca/site/kyr/?lang=en>

7.5.1 The Criminalization of HIV

The Canadian HIV/AIDS Legal Network highlight the importance of continued collaboration between HIV researchers and human rights activists to help inform policy around HIV and criminalization. The criminalization of HIV non-disclosure strips people living with HIV of their right to privacy and puts them at risk of life in prison, affecting their level of social participation and utilization of services due to HIV- associated stigma reinforced by the law. The criminalization of HIV also drives people unaware of their status away from HIV testing, counselling and support, and partner notification. Symington et al. (2014 in CUHRRC 2014) conducted a cross-sectional electronic survey with 204 people living with HIV to assist in creating legal information tools about privacy rights and HIV disclosure obligations in the context of employment, education, childcare and healthcare. From the survey responses, the Canadian HIV/AIDS Legal Network created and distributed legal resources along with hosting community educational sessions across Canada. As the legal needs of people living with HIV vary, increased access to legal information empowers people living with HIV with the practical tools they need to protect themselves (Symington et al. 2014 in CUHRRC 2014).

7_6 Resources

7.6.1 National Rehabilitation Associations

7.6.1.1 Canada

Canadian Association of Physical Medicine and Rehabilitation

Tel.: 613 730-6245

Fax: 613 730-1116

E-Mail: capmr@rcpsc.edu

Internet: <http://www.capmr.ca>

Canadian Association of Nurses in AIDS Care

E-mail: info@canac.org

Internet: <http://www.canac.org>

Canadian Association of Occupational Therapists

Tel.: 613 523-2268

Fax: 613 523-2552

Internet: <http://www.caot.ca>

Canadian Association of Speech-Language Pathologists and Audiologists

Tel: 1-800-259-8519

E-Mail: caslpa@caslpa.ca

Internet: <http://www.caslpa.ca>

Canadian Association of Social Workers

Tel.: 613 729-6668

Fax: 613 729-9608

E-Mail: casw@casw-acts.ca

Internet: <http://www.casw-acts.ca>

Canadian Hearing Society

Tel: 1-877-347-3427

TTY: 1-877-216-7310

Internet: <http://www.chs.ca>

Canadian Home Care Association

Tel.: 613 569-1585

Fax: 613 569-1604

E-Mail: chca@cdnhomecare.ca

Internet: <http://www.cdnhomecare.ca>

Canadian National Institute for the Blind

Tel.: 416 486-2500

Fax: 416 480-7500

E-Mail: info@cnib.ca

Internet: <http://www.cnib.ca>

Canadian Psychiatric Association

Tel.: 613 234-2815

Fax: 613 234-9857

E-Mail: cpa@cpa-apc.org

Internet: <http://www.cpa-apc.org>

Canadian Psychological Association

Tel.: 613 237-2144

Fax: 613 237-1674

E-Mail: cpa@cpa.ca

Internet: <http://www.cpa.ca>

Canadian Physiotherapy Association

Tel.: 416 932-1888

Fax: 416 932-9708

E-Mail: information@physiotherapy.ca

Internet: <http://www.physiotherapy.ca>

College of Massage Therapists of Ontario

Tel.: 416 489-2626

Fax: 416 489-2625

E-Mail: cmtto@cmtto.com

Internet: <http://www.cmtto.com>

Canadian Chiropractic Association

Tel.: 416 585-7902

Fax: 416 585-2970

Internet: www.chiropractic.ca

The Canadian Association of Naturopathic Doctors

Tel.: 416 496-8633, Toll Free 1 800 551 4381

Fax: 416 496-8634

Internet: <http://www.cand.ca>

Homeopathic Medical Council of Canada

Tel.: 416 788-4622

Internet: www.homeopathy.edu

Acupuncture Foundation of Canada

Fax: 416 752-4398

E-Mail: afciweb@afcinstitute.com

Internet: <https://www.acupuncturecanada.org/>

College of Family Physicians of Canada

Tel.: 905 629-0900

Fax: 905 629-0893

E-Mail: info@cfpc.ca

Internet: <http://www.cfpc.ca>

Dietitians of Canada

Tel.: 416 596-0857

Fax: 416 596-0603

E-Mail: centralinfo@dietitians.ca

Internet: <http://www.dietitians.ca>

Canadian Paediatric Society

Tel.: 613 526-9397

Fax: 613 526-3332

E-Mail: webmaster@cps.ca

Internet: <http://www.cps.ca>

7.6.1.2 United States

American Academy of Physical Medicine and Rehabilitation
Tel.: 312 464-9700
Fax: 312 464-0227
E-Mail: info@aapmr.org
Internet: <http://www.aapmr.org>

American Congress of Rehabilitation Medicine
Tel.: 317 915 2250
Fax: 317 915 2245
Internet: <http://www.acrm.org>

Academy of Nutrition and Dietetics
Tel.: 1 800 877-1600
E-Mail: cdr@eatright.org
Internet: <http://www.eatright.org>

The Rehabilitation Accreditation Commission (CARF)
Tel.: 520 325-1044
Fax: 520 318-1129
E-Mail: med@carf.org
Internet: <http://www.carf.org>

7.6.2 National Organizations

7.6.2.1 Canada

Canadian AIDS Society
Tel.: 613 230-3580, 1 800 884 1058
Fax: 613 563-4998
E-Mail: casinfo@cdnaids.ca
Internet: <http://www.cdnaids.ca>

Canadian Haemophilia Society
Tel.: 514 848-0503
Fax: 514 848-9661
E-Mail: chs@hemophilia.ca
Internet: <http://www.hemophilia.ca>

Canadian Aboriginal AIDS Network
Tel.: 604 266-7616
Fax: 604 266-7612
E-Mail: kenc@caan.ca
Internet: <http://www.caan.ca>

The Legal Network
Tel.: 416 595-1666
Fax: 416 595-0094
E-Mail: info@aidslaw.ca
Internet: <http://www.aidslaw.ca>

Community AIDS Treatment Information Exchange
Tel.: 416 203-7122 / 800 263-1638
Fax: 416 203-8284
E-Mail: info@catie.ca
Internet: <http://www.catie.ca>

7.6.3 Other Organizations

7.6.3.1 Canada

Centre for Addiction and Mental Health
Tel.: 416 535-8501/800 463-6273
Fax: 416 595-5017
Internet: <http://www.camh.net>

Hospital for Sick Children
Tel.: 416 813-1500
Internet: <http://www.sickkids.ca>

St. Michael's Hospital, Toronto
Positive Care Clinic
Tel.: 416 864-5245
Fax: 416 864-5310
Internet: <http://www.stmichaelshospital.com/programs/hiv>

7.6.3.2 United States

National Prevention Information Network (NPIN)
Centers for Disease Control
Tel.: 800 458-5231/ 404 679-3860
Fax: 888 282-7681
E-Mail: info@cdcnpin.org
Internet: <http://www.cdcnpin.org>

AIDS Info
US Department of Health and Human Services
Tel: 800 448-0440
Fax: 301 315-2816
E-Mail: ContactUs@aidsinfonih.gov
Internet: <http://www.aidsinfo.nih.gov>

7.6.3.3 Online HIV Information Resources

CATIE
www.catie.ca/

BC Coalition of People with Disabilities
<http://disabilityalliancebc.org/publications/>

CHAPTER 8

Case Studies

Acronyms

| | |
|--------|---|
| ADL | Activities of Daily Living |
| BAD | Bipolar Affective Disorder |
| BMD | Bone Mineral Density |
| CAD | Coronary Artery Disease |
| cART | Combination Antiretroviral Therapy |
| CBHO | Community-based HIV Organization |
| COPD | Chronic Obstructive Pulmonary Disease |
| CP | Cerebral Palsy |
| CVA | Cerebrovascular Accident |
| CXR | Chest X-Ray |
| DAT | Diet as Tolerated |
| EDEN | Episodic Disabilities Employment Network |
| ER | Emergency Room |
| HAND | HIV-Associated Neurocognitive Disorder |
| HA-MND | HIV-Associated Mild Neurocognitive Disorder |
| HIV + | HIV Positive |
| FITT | Frequency, Intensity, Time, Type |
| IADL | Instrumental Activities of Daily Living |
| ICF | International Classification of Functioning |
| ICU | Intensive Care Unit |
| IPPA | Inspection, Palpation, Percussion, Auscultation |
| MI | Myocardial Infarction |
| MoCA | Montreal Cognitive Assessment |
| MSM | Man who has Sex with Men |
| OT | Occupational Therapist or Therapy |
| POA | Power of Attorney |
| PCP | Pneumocystis pneumonia |
| PRN | As required |
| PT | Physical Therapist or Therapy |
| ROM | Range of Motion |
| SDM | Substitute Decision Maker |

| | |
|-----------------|---|
| SLP | Speech-Language Pathologist or Therapy |
| SMART principle | Specific, Measurable, Achievable, Relevant and Time-Bound |
| VAS | Visual Analogue Scale |
| WBAT | Weight Bearing as Tolerated |
| WSM | Woman who has Sex with Men |

Organization of the cases using the SOAP format:

The SOAP note (an acronym for subjective, objective, assessment, and plan) is a method of documentation employed by healthcare providers to write out notes in a patient's chart, along with other common formats, such as the admission note.

Subjective Component: Is the patient's chief complaint. This is a very brief statement of the patient (quoted) as to the purpose of the office visit or hospitalization.

Objective Component: Includes information that the healthcare provider observes or measures from the patient's current presentation.

Assessment: A medical diagnosis for the purpose of the medical visit on the given date of the note written is a quick summary of the patient with main symptoms/diagnosis including a differential diagnosis and a list of other possible diagnoses.

Plan: The plan is what the healthcare provider will do to treat the patient's concerns – such as ordering further labs, referrals given, procedures performed and education provided. The plan will also include goals of therapy and patient-specific disease-state monitoring parameters.

Source: https://en.wikipedia.org/wiki/SOAP_note

A note on stereotyping:

We have given our cases a variety of gender, cultural and social identities for illustration purposes only. The reader should not use these examples to profile how HIV might present itself in one's own region or community. Consult your local HIV prevalence reports or local Community-based HIV Organization to get a more specific overview.

Acute Care, Cardiorespiratory and Neurological

Case #1 – Sonia

Part 1:

Presenting Problem / Background

Sonia is a 35-year-old Indigenous woman who presents to the emergency room (ER) at a downtown urban hospital with fever and chills.

Subjective

Gradually over the last twelve days, Sonia noticed decreased energy levels and for the last four days she has had a persistent cough, fever and shortness of breath. She went to the local hospital ER because she was burning up and sweating. During the assessment, the doctor discovers that Sonia has a family history of heart disease and epilepsy, and takes antiepileptic medications to control grand mal seizures. She does not have a family physician. She has been seen previously at walk-in clinics and outreach services and therefore her health records are not all in one place.

Sonia works as a community support worker helping people get supportive housing. She lives alone off reserve, and her family members live quite far away in a community accessible by plane only. She has become too weak to care for herself and is finding it increasingly difficult to get to work each day for the past two weeks. She reports the use of marijuana and occasional injection drugs, mainly heroin, over the last year. She has Drug Benefits and Aboriginal Affairs coverage. She states to staff at the ER "I've been feeling terrible lately and I want to know what's going on with my health, I want to be active again."

Objective

On physical examination Sonia has a fever of 39 degrees C, appears underweight for her size and there is evidence of recent multiple upper extremity injection access sites. She presents with lymphadenopathy. Her chest X-ray (CXR) shows diffuse, bilateral interstitial infiltrates. She is admitted to hospital. The multidisciplinary team receives a referral – "Assess and treat, plan for discharge"

Vital Signs: Respiratory Rate 28, Blood Pressure 105/70, Heart Rate 127 beats per minute, oxygen saturation 94% on 3 litres of oxygen via nasal prongs.

Cardiorespiratory: On auscultation: Decreased breath sounds throughout but particularly to lower lobes bilaterally suggesting decreased air entry. Cough is voluntary, weak, dry and non-productive, and elicits pain. No cardiac murmur.

Musculoskeletal: Complains of pain in the costal margins bilaterally and intercostal muscles are tender on palpation of lower ribs bilaterally.

Mobility & Function: Poor mobility – requires moderate assistance of 1 for all transfers and for ambulation short distances (approximately 5 to 10 metres) to the bathroom.

Activities of daily living (ADL): Assistance of 1 for self-care (dressing and toileting).

Cognition: Oriented to person and place. She is inconsistent with her orientation to month and year. Appears confused and agitated at times.

Initial laboratory results were consistent with sepsis, and follow-up blood work confirmed Sonia was HIV positive (new diagnosis): CD4 count: 50 cells/mm³ viral load; 500,000 copies/ml blood.

Guiding Questions

1. *Given Sonia's CXR and physical examination findings, what might you think is her diagnosis?*

Notes: Bilateral interstitial infiltrates and dry cough could indicate pneumocystis pneumonia (PCP). This is an HIV-Associated condition. Given the new diagnosis of HIV, Sonia's CD4 count is quite low resulting in her immunocompromised status making her susceptible to opportunistic infections such as PCP. [Chapter 4_9: Systemic Impacts - Pulmonary](#)

2. *Why do you think Sonia received an HIV test? What are considerations for HIV testing?*

Notes: Her history of injection drug use as well as some of her symptoms may suggest she is at risk of HIV infection. When testing, it is important that the "3 C's" are considered – counselling, consent, and confidentiality. It is important to ensure that Sonia was provided with all the necessary information about testing and consented to the process. It is not explicitly stated in the case whether Sonia was provided with these components surrounding testing. [Chapter 1.1.2 – Pathogenesis of HIV Infection](#)

3. *What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Sonia is experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced and classify using the International Classification of Functioning (ICF) Framework [Chapter 3 – Symptoms and Impairments](#); [Chapter 3_7 - Cardiac and Respiratory Impairments](#)

Some examples include:

- Impairments: decreased oxygen saturation, shortness of breath, decreased ventilation to lungs throughout, pain, decreased cognition (lacks orientation to time, confusion and agitation), decreased weight, weakness. Sonia may also experience increased anxiety, uncertainty and stress surrounding the news of her new HIV diagnosis in conjunction with her current medical issues (PCP and sepsis) and potential impairments due to drug withdrawal.
 - Activity limitations: decreased mobility, difficulty with ADLs for self-care including dressing and toileting, decreased activity tolerance.
 - Participation restrictions: inability to work, decreased financial status, potential risk for losing housing if lack of income support, potential for cultural dislocation from her Indigenous community.
4. *What personal and environmental factors might influence Sonia's disability and ability for discharge?*

Notes: She has a history of drug use, which may further exacerbate her health challenges. She appears to have a lack of social support (she lives alone and her family is in a different province). She is concerned about disclosing her HIV status to anyone in her social circle, as this group is somewhat dysfunctional. These challenges raise issues for discharge and her ability to function independently on discharge. Given she is not currently working she may have issues surrounding income support and maintaining independent financial status. She has some support via her drug benefits and Aboriginal Affairs coverage. She may also experience cultural dislocation and potential stigma surrounding her diagnosis from the Indigenous community and in relation to her gender. [Chapter 1_2 - Interacting with Communities Affected by HIV](#)

5. *What additional factors should be considered?*

- Nutrition: are there any issues regarding weight loss, nutritional habits or other needs (e.g. food security)? Suggest referral to a dietitian. If appropriate and if necessary, discuss options for community food banks, suppers, food boxes and community cooking programs (which also provide social support).
- Review sleep and rest /stress management. If required, follow up with a pamphlet, discussion or referral for good sleep hygiene.

- Determine if the client has a reliable mode of communication to ensure contact with health professionals. Alternatives may include landline, cell phone, leaving messages with a friend or relative who is in regular contact with her.
 - Potential additional health challenges due to withdrawal.
6. *What are some of the short-term and long-term rehabilitation goals for Sonia?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Use the SMART principle (Specific, Measurable, Achievable, Relevant and Time-Bound).

Many of the goals related to her cardiorespiratory status will be short-term:

- To increase ventilation to lung fields throughout in one day as measured by increased breath sounds bilaterally.
- To decrease pain on cough in 1 day as measured by decreased report of pain on visual analogue scale (VAS).
- To ambulate 25 metres with minimal assistance or walker in 1 day.
- To become independent with ADLs (dressing, toileting, bathing) in 1 week.

Long-term rehabilitation goals might revolve around discharge from hospital and include:

1. To ambulate 100 metres independently on discharge from hospital in 1 week.
2. To negotiate stairs independently on discharge from hospital in 1 week.
3. To understand the implications of her new HIV diagnosis (including options for treatment and support services) in 3 months.
4. To return to work as a social services worker as Sonia's health permits after discharge.
5. To assess Sonia prior to discharge from hospital to determine her eligibility and requirements for home care. If eligible and with sufficient need, home care services should be arranged to start on date of discharge. [Chapter 2- Rehabilitation Best Practices](#)
6. *What rehabilitation treatment strategies might be used to address Sonia's impairments, activity limitations and participation restrictions?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. It is important that the strategies used to address her challenges take into account the ICF. By setting goals that address her impairments, this can lead to improvements in her activity limitations and participation restrictions. Consider using the process of shared decision-making to prioritize treatment choices/strategies, and provide rationale. Some treatment interventions to address her short-term goals might include

diaphragmatic breathing exercises, splinted cough, functional ambulation with gait aid if needed, strengthening exercises (isometric and concentric), graded ADL practice (e.g. daily reduction of assistance required when bathing and dressing). Consider what elements of rehabilitation may be potentially self-managed by Sonia and what others might require rehabilitation support. She will also potentially need assistance with instrumental ADLs (IADLs) such as shopping initially after discharge. She may also benefit from stair rails, bathing equipment and education about energy conservation techniques.

Record keeping (e.g. tracking of exercise, medications, and other self-management techniques) may help Sonia maintain her goals. If Sonia seems overwhelmed, suggest that she set one goal for the day to provide a purpose for getting up. Additional strategies may include keeping a daily reflection record, especially to identify items for discussion at the next healthcare appointment. All clients should also be encouraged to engage in some type of cognitive activity (e.g. reading, word games, or games on their cell phone).

Some of the interventions to address her long-term goals might include: referrals to social worker and/or HIV physician to address new HIV diagnosis, referral to a vocational rehabilitation specialist to assist with return to work, referral to an addictions counsellor to address substance use and safe injection practices, links to appropriate services to address potential mental health and social support required surrounding her new diagnosis, and links to community-based organizations that may be specific to women and Indigenous communities if available.

[Chapter 6 - Overview of Interventions](#); specifically [Chapter 6_3 - Evidence-Informed Rehabilitation Interventions for HIV](#); and [Chapter 6_8-Self Management](#)

8. *What types of educational, health promotion, prevention, care, treatment and support materials or information might the team provide for Sonia?*

Notes: After Sonia recovers from her PCP pneumonia she will require education surrounding her new HIV diagnosis and referrals to HIV medical care. She will be likely linked to the Infectious Disease specialist at the hospital. She may require psychosocial support to help her deal with the news of her new HIV diagnosis and to navigate the system and choices surrounding treatment options, accessing services, safe injection practices, and health promotional strategies. Any post-test counselling should also include legal issues such as disclosure and prevention of further HIV transmission. Other community links may include Community-based HIV Organizations (CBHO) that are geared towards Indigenous people and women living with HIV. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>). Many people benefit from peer support

programs. Examples of the range of peer support content include discussing a new diagnosis, sharing anxieties, support for exercise and other topics. If referral is to a non-HIV peer support program, the program should be screened for policies around discrimination and there should be a discussion as to whether disclosure of HIV status is needed. [Chapter 6_8-Self Management](#); [Chapter 6_9-Theory-Based Patient Activation Interventions](#); [Chapter 1_2 - Interacting with Communities Affected by HIV](#)

9. *What other health or social services might Sonia also benefit from having access to? Why?*

Notes: Identify other services and providers that might help to address Sonia's impairments, activity limitations and participation restrictions and the news of her new HIV diagnosis. Consider how you would go about referring to the other service providers and services. Consider the potential barriers that Sonia might encounter in attempting to access these services. How might you advocate with Sonia to enable her to better access the needed services?

Sonia will need to liaise with an Infectious Disease specialist surrounding her new HIV diagnosis (modes of transmission, available treatment options, etc.) for education and with a social worker for considerations of the available supports that she may wish to access, such as:

- An addictions counsellor may help her address her substance use and educate on safe injection practices to reduce risk for HIV transmission.
- A social worker can assist Sonia to link with further sources for mental and social support. And potential links to income support if not working, and help to ensure that she is able to sustain her housing while not currently working.
- A vocational rehabilitation specialist or occupational therapist (OT) to assist with returning to work if/when Sonia is ready.
- Link with a CBHO to learn about support services in Sonia's area and specifically any resources specific to Indigenous people and women.
- Link with a community-based epilepsy consumer organization to help her to continue to manage the epilepsy that she has been living with for a number of years, in light of her recent HIV diagnosis.

10. *What issues might Sonia need you to help her advocate for?*

Notes: Sonia will probably need assistance to connect with the necessary services needed in order to help her deal with her new diagnosis; including a primary care physician familiar with HIV. She will need assistance to access rehabilitation at an outpatient facility (healthcare centre or outpatient hospital clinic) if needed. Eventually, she will need assistance to access vocational rehabilitation if/when Sonia would like to return to work. The challenge will be linking to

all the above health providers and community organizations in a way that is driven by Sonia and not overwhelming in light of the multitude of medical and social issues that she is dealing with, preferably services specifically geared towards Indigenous women to address any potential forms of cultural dislocation or stigma. [Chapter 7-Current Issues in HIV Rehabilitation in Canada](#), specifically [Chapter 7_2-Navigation and Advocacy](#)

Part 2: Four months later...

Presenting Problem / Background

Sonia was discharged from hospital after her first admission and linked with an HIV primary care physician and started a combination of antiretroviral therapy (cART). During that time, she got behind in paying her rent, lost her apartment and moved into a women's shelter. She is greatly troubled by her HIV diagnosis and was unable to follow up with recommended health professionals because her cell phone account was cancelled due to non-payment.

Four months later, Sonia presented to the ER by ambulance from a detox centre with uncontrolled seizures. The ER doctors administered her anti-seizure medication. Sonia recovered well enough to be sent back to the women's shelter. Within 12 hours, she presented to the same ER again with seizures.

Subjective

Sonia has been largely non-adherent with her HIV and antiepileptic medications and doctor's appointments due to her addictions, compounded by her housing situation and lack of a phone. She has a pay-as-you-go cell phone but can't afford to add minutes to it. She states that she is overwhelmed by all her health issues and needs help getting back on her feet.

Objective

CT imaging revealed positive findings. A serum cryptococcal antigen test confirmed that Sonia has cryptococcal meningoencephalitis (now her second AIDS-defining illness).

She has advanced HIV disease with a viral load of >500,000 copies RNA/ml and a CD4 of 1 cell/mm³. She also shows elements of wasting (86-94 pounds).

Sonia was admitted to hospital and ordered high doses of antifungals (Amphotericin B followed by Fluconazole).

She quickly became unresponsive with very high blood pressure. When she woke, she suffered from severe dysphagia, dysarthria, cognitive deficits (biting off PICC line x2), slurred speech, unsteady gait (numerous falls) and

decreased sensation to right hand and forearm (she drops things frequently as she is right handed). She is inconsistent with her orientation to person, place and time.

According to the Speech-Language Pathology (SLP) report, Sonia was noted to chew her food for a "significantly long period of time". The final comments were to "downgrade diet to DAT (diet as tolerated) with thin fluids". The use of straws was recommended with Sonia, and she was monitored for throat clearing. OT and PT assessments were requested.

Guiding Questions

1. *What is cryptococcal meningoencephalitis?*

Notes: AIDS-defining illness, neurological condition.

[Chapter 4_8 - Neurological](#)

2. *What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Sonia is experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced and classify using the ICF Framework. [Chapter 3 – Symptoms and Impairments](#)

Some examples include:

- Impairments: any problem with body structure or function (e.g. dysphagia, dysarthria, decreased cognition, slurred speech, decreased balance, decreased sensation to right hand and forearm, decreased strength potentially in right hand and arm).
 - Activity limitations: decreased mobility, decreased ability to swallow, reduced ability to grip, falls.
 - Participation restrictions: diminished financial status, drug benefits, homeless, not working.
3. *What personal and environmental factors might influence Sonia's disability and ability for discharge?*

Notes: Her ongoing history of drug use which may further exacerbate her health challenges; potential lack of social support, drug benefits and Aboriginal Affairs coverage, her diminished financial status, her homelessness, potential stigma experienced from her Indigenous community.

[Chapter 1_2 - Interacting with Communities Affected by HIV](#)

4. *What additional factors should be considered?*

- Determine if the client has a reliable mode of communication to ensure contact with health professionals. Alternatives may include landline, cell phone, leaving messages with a friend or relative who is in regular contact.
- Determine adherence with medications (HIV and other). Adherence may be improved with blister packs or a record-keeping technique (e.g. phone alarm).

5. *What are some of the rehabilitation goals for Sonia?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Use the SMART principle.

1. To be able to be oriented to person, place and time in 3 days.
2. To be able to ambulate independently with gait aid 100 metres in 1 week.
3. To be able to carry out ADL tasks (dressing, bathing, toileting) independently in 1 week.
4. To be able to swallow pill medications safely without need for crushing pills in 1 week.
5. To be able to swallow soft-textured foods and thin fluids safely with supervision in 1 week.
6. To be able to speak intelligibly with assistance from a communication partner in 3 days.
7. *What rehabilitation treatment strategies might be used to address Sonia's impairments, activity limitations and participation restrictions?*

Notes: Consider patient values and preferences when discussing treatment strategies. Consider the process of shared decision-making when prioritizing treatment strategies. It is important that the strategies used to address her challenges take into account the ICF. By setting goals that address her impairments, this can lead to improvements in her activity limitations and participation restrictions. Some treatment interventions might include stretching exercises, strengthening exercises, functional ambulation, balance retraining, practice with functional ADL tasks such as bathing, dressing, eating, cognitive retraining, diet texture modifications, feeding training, articulation exercises. [Chapter 6 - Overview of Interventions](#); specifically [Chapter 6_3 - Evidence-Informed Rehabilitation Interventions for HIV](#)

Record keeping (e.g. tracking of exercise, medications, and other self-management techniques) may help the client to maintain her goals. If Sonia seems overwhelmed, suggest that she set one goal for the day to provide a purpose for getting up. Additional strategies may include keeping a daily reflection record, especially to identify items for discussion at the next healthcare appointment. All clients should also be encouraged to engage in some type of cognitive activity (e.g. reading, word games, or games on their cell phone).

7. *What types of educational health promotion, prevention, care, treatment and support materials or information might the team provide for Sonia?*

Notes: After Sonia recovers from her cryptococcal meningoencephalitis she will require much support to help her with housing and getting back onto HIV and antiepileptic medications. She will likely be linked to the Infectious Disease specialist at the hospital again and other community-based supports to help her deal with her homelessness (which will have an impact on her ability to store and adhere to her HIV and antiepileptic medications).

Other community links may include CBHO, particularly if there is a local organization geared towards Indigenous peoples and women living with HIV. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>). [Chapter 6_8-Self Management](#); [Chapter 6_9-Theory-Based Patient Activation Interventions](#); [Chapter 1_2 - Interacting with Communities Affected by HIV](#)

8. What other health or social services might Sonia also benefit from having access to? Why?

Notes: Identify other services and providers that might help to address Sonia's impairments, activity limitations and participation restrictions and the needs of her new HIV diagnosis. Consider how you would go about referring to the other service providers and services. Consider the potential barriers that Sonia might encounter in attempting to access these services. How might you advocate with Sonia to enable her to better access the needed services?

Sonia would benefit from a referral to:

- An Infectious Disease specialist to address her new HIV diagnosis (modes of transmission, available treatment options, etc.) and would benefit from a referral to social work for education and considerations of the available supports that she may wish to access.
- An addictions counsellor may help her address her substance use and provide education on safe injection practices.
- A social worker that can assist Sonia to link with further sources for mental and social support, and potential links to income support. A social worker can also help to explore housing options given her new state of homelessness, either a shelter (if needed in the short-term) or a form of supportive housing.
- A dietitian to assist with nutritional requirements and referral to an SLP to continue with speech and swallowing re-assessment and treatment.
- PT and OT to continue with improving grip, mobility, balance, strength, cognition, and functional ADLs.
- A vocational rehabilitation specialist to assist with returning to work if/when Sonia is ready.
- Link with CBHOs to learn about support services in Sonia's area and specifically any resources specific to Indigenous people and women. Accessing a CBHO with a good peer support or support coordinator and/or peer buddy program can help her navigate the system of rehabilitation.
- Link with community-based epilepsy consumer organization to help her to continue to manage the epilepsy that she has been living with for a number of years, in light of her recent HIV diagnosis.

- Chapter 1_3 - Introduction to Rehabilitation for Clients, Families and Other Care Providers; Chapter 7-Current Issues in HIV Rehabilitation in Canada, specifically Chapter 7_2-Navigation and Advocacy; and Chapter 3_10 - Substance Use
9. *What issues might Sonia need you to help her advocate for?*

Notes: Sonia may require continued advocacy support to address housing issues, income support, addictions issues and hopefully return to work (consider part-time return to work or alternative duties).[Chapter 7-Current Issues in HIV Rehabilitation in Canada](#), specifically [Chapter 7_2-Navigation and Advocacy](#)

- Initiate cART and ensure follow up with a local family physician who is HIV-trained or with an infectious diseases specialist for regular blood work, medication assessment, and support.
- Addictions counselling, consider follow up with a local psychologist to manage not only addictions but also the new diagnosis of HIV.
- Education about HIV and risks of transmission.
- Ensure patient has been assessed for concomitant blood-borne illnesses such as Hepatitis B and Hepatitis C.

Medical Management – Infectious Disease Specialist Recommendations for Sonia Part 1

Assessment: Sonia more than likely has PCP, but could also have non-PCP pneumonia, fungal infection, tuberculosis (TB), and endocarditis with septic emboli to the lungs. She is a very high-risk individual for adverse health outcomes.

Plan:

Management of Acute Illness:

- Acute resuscitation/supportive care: IV fluids, broad-spectrum antibiotics with coverage for PCP. Sputum culture with direct fluorescent antibody (DFA), blood cultures, and echocardiogram would be warranted.
- Airborne isolation and sputum for Acid-Fast Bacillus (AFB) given high risk for TB as well. If negative patient should have a follow up TB skin test once acute illness is resolved.
- Monitor and treat for substance withdrawal.
- Consult infectious diseases team or local HIV specialist (if available) for assistance with linking up with local resources.
- Consult PT, OT and social work as patient seems significantly deconditioned and may require increased supports or rehabilitation prior to discharge home.

Long-term Management:

Musculoskeletal – Knee Pain

Case #2 – Geoff

Presenting Problem / Background

Geoff is a 42-year-old Asian male who works for a large hotel chain as a service manager. Geoff presents to an ambulatory outpatient clinic with right knee pain.

Subjective

Past Medical History

Geoff has been living with HIV for 12 years and contracted HIV before meeting his current male partner who is HIV negative. He is adherent to his cART regimen and reports his T cells are 700 with an undetectable viral load. Geoff has had few problems related to his HIV and is conscious about taking care of himself through balancing exercise, diet and sleep. He tries to reduce unnecessary stress and seeks out support from friends when needed. He tracks his daily regime of healthy self-managed care as well as his regular lab results using a spreadsheet and health monitoring application on his cellphone.

Current Medical History

Recently, Geoff noticed a deep "boring" pain in his right knee that has been progressively getting worse, particularly at night. He attributes the pain to a twisting injury that he sustained on the job four weeks ago. He recalls stepping down from a supply truck and twisting his knee and ankle. The ankle was swollen and sore for a few days but then subsided. However, the knee pain has persisted and is most apparent with stair climbing, prolonged standing and at night when Geoff tries to sleep. His knee is stiff after it has been immobile for a period of time.

He has been using Tylenol for pain control.

Geoff is frustrated at having to continually use the hotel elevator to access his office from the main lobby because the stairs are quicker and more convenient. He is also irritable and is finding his concentration is affected at work because he has not been getting much sleep. Although he is generally pleasant to everyone, he is aware that as of late, he has been short tempered with a few of his closest work colleagues. The other day they went out after work and decided not to invite him. He lives with his partner Mike in a house. Mike has been very supportive in the past but finding it emotionally difficult during Geoff's

increasingly common temper spells. They have a small circle of very close friends. Geoff mentions several times that he wants his life back the way it was before.

Objective

On manual testing, Geoff's ligaments are intact however there is considerable pain with McMurray's testing (test whereby the knee is placed in rotation to determine whether there is a tear of the meniscus, cartilage of the knee). Geoff reports his right knee pain is 4/10 at rest or while trying to sleep and 8/10 when climbing stairs on the Visual Analogue Scale (VAS). Geoff denies any locking, snapping or "catching" in his knee. He is very frustrated by the deep ache that it causes. An x-ray and subsequent MRI of his right knee are ordered. An area of concern is identified.

Guiding Questions

1. *Describe additional components you might include in your assessment with Geoff.*

Notes: Describe components of your subjective interview and objective assessment.

Subjective Interview: What is Geoff's home environment like (does it have stairs)? What does his exercise regime entail - number of times per week, what exercises does he perform, does it include lower extremity work that will be impacted by his injury? What other self-management strategies is he using? Overall, how helpful are these techniques? What sleep hygiene and stress management strategies is he using with the onset of pain? ; Does he have any other concurrent health conditions that he might be living with? What social supports are available to Geoff to assist with instrumental activities of daily living (IADLs) if needed? What support does he receive from his partner?

Objective Assessment: strength assessment, cognitive assessment (in relation to decreased concentration; despite fact that seems to be attributed to pain and frustration).

[Chapter 4_6 - Musculoskeletal](#)

2. *Given Geoff's physical examination and MRI findings, what might you think is his diagnosis?*

Notes: Differential diagnosis may include Avascular Necrosis, a bone disorder in which the bone deteriorates due to interruption in the blood supply. [Chapter 4_6 - Musculoskeletal](#); [Chapter 3.2.2 - Musculoskeletal and Joint Pain](#)

3. *What are some of the (a) impairments (b) activity limitations and (c) participation restrictions that Geoff is experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced and classify using the ICF framework. [Chapter 3 – Symptoms and Impairments](#), specifically [Chapter 3.2.2 - Musculoskeletal and Joint Pain](#)

Some examples include:

- Impairments: pain in right knee, night pain, swelling of the ankle, ankle pain, decreased range of motion (ROM) of right knee, decreased concentration.
- Activity limitations: decreased ability to negotiate stairs, decreased ability to sleep due to pain, decreased standing tolerance, and decreased mobility.
- Participation restrictions: impact of personal relationships at work, potential impact on his exercise routine and risk for decline in health, potential impact on his personal relationship with his partner.

There is also the potential for a further decrease in Geoff's health status if the knee pain is impacting his sleep and exercise routine. This may ultimately affect aspects of his life that he does to maintain his health.

4. *What personal and environmental factors might influence Geoff's recovery?*

Notes: Personal factors include Geoff's young age, active lifestyle, self-management strategies, and overall, his positive attitude towards his illness.

Environmental factors include the fact that he likes to use the stairs at work and that he has good support from his partner and friends. Determine whether his home environment has stairs as well. [Chapter 1_2 - Interacting with Communities Affected by HIV](#); [Chapter 1_3 - Introduction to Rehabilitation for Clients, Families and Other Care Providers](#)

5. *What are some of the short-term and long-term rehabilitation goals for Geoff?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Use the SMART principle.

Short-term goals:

- To decrease pain in right knee as measured by decrease in VAS scale at rest and during stairs to 1/10 by 2 weeks.
- To be able to negotiate stairs pain-free in 2 weeks.
- To increase ROM of right knee to full range in 2 weeks.

Long-term rehabilitation goals might revolve around getting back to his exercise and workplace routine:

- To return to a full exercise routine in 6 weeks.
- To return to stair negotiation at his workplace in 6 weeks.

6. *What rehabilitation treatment strategies might be used to address Geoff's impairments, activity limitations and participation restrictions?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. Consider using the process of shared decision-making to prioritize treatment choices/strategies, and provide rationale. It is important that the strategies used to address his challenges take into account the ICF. By setting goals that address his impairments, this can lead to improvements in his activity limitations and participation restrictions. Some treatment interventions might include active and passive ROM exercises, gentle stretching and strengthening, adaptive equipment if needed to facilitate pain-free ambulation. Strategize ways Geoff can modify his exercise regime so that he is still able to maintain his exercise routine while reducing the weight bearing and pain in his right knee (e.g. upper extremity work, perhaps stationary bike, walking poles, swimming, or water running). [Chapter 6 - Overview of Interventions](#); specifically [Chapter 6_3 - Evidence-Informed Rehabilitation Interventions for HIV](#)

Geoff already practices regular record keeping (e.g. tracking of exercise, medications, and other self-management techniques) which helps many clients to maintain their goals. If Geoff seems overwhelmed, suggest that he set one goal for the day. Additional strategies may include keeping a daily reflection record, especially to identify items for discussion at the next healthcare appointment. All clients should also be encouraged to engage in some type of cognitive activity (e.g. reading, word games, or games on their cell phone).

7. *What types of educational health promotion, prevention, care, treatment and support materials or information might the team provide for Geoff?*

Notes: After some of the immediate symptoms associated with Geoff's knee have resolved, he will require education regarding potential prevention of future exacerbation, and how he might modify his exercise regime to prevent exacerbation. Geoff may also benefit from mindfulness techniques to help him to control his pain. [Chapter 6_8-Self Management](#); [Chapter 6_9-Theory-Based Patient Activation Interventions](#); [Chapter 1_2 - Interacting with Communities Affected by HIV](#)

8. *What other health or social services might Geoff also benefit from having access to? Why?*

Notes: Identify other services and providers that might help to address Geoff's impairments, activity limitations and participation restrictions surrounding his avascular necrosis of the right knee. Consider how you would go about

referring to the other service providers and services.
Consider the potential barriers that Geoff might encounter in attempting to access these services.

9. *What issues might Geoff need you to help him advocate for?*

Notes: Geoff may need help to access rehabilitation at an outpatient facility (healthcare centre or outpatient hospital clinic). Depending on the types of benefits that Geoff has from his workplace – either private insurance or benefits through work – he may or may not have access to PT services, and the access that he has might be limited to a certain number of visits. You may want to help him to arrange the PT sessions so that they align well with his current work hours. [Chapter 7-Current Issues in HIV Rehabilitation in Canada](#), specifically [Chapter 7_2-Navigation and Advocacy](#); and [Chapter 6_7 Vocational Rehabilitation](#)

Aging, Cognition, Community, Stroke

Case #3 – Louis

Part 1:

Presenting Problem / Background

Louis is a 63-year-old Caucasian male living with HIV who presents with failure to thrive in the community. He has been referred for a home care rehabilitation assessment.

Subjective

Past Medical History

Louis is an unmarried, shy gay man who came out 5 years ago. He was diagnosed with HIV infection approximately 2 years ago. Currently, his viral load is slightly above detectable and he has a CD4 count of 450. Louis is currently considering his HIV specialist's recommendation to start cART. You are the first healthcare provider to visit him at home. Louis has a history of cardiovascular disease and bipolar affective disorder (BAD).

Social History

Louis lives alone in a one-bedroom apartment in the downtown area. He is a retired classical musician and moved this past year to be closer to his extended family. He was giving private piano lessons to augment his income, until stopping a few months ago due to his deteriorating health.

Louis has not contacted any local resources since his HIV diagnosis and he has very few friends his age. He has no HIV positive peers and therefore he has had no discussion with anyone other than his HIV specialist about the short and long-term implications of his HIV diagnosis.

Louis tells you that he has increasing difficulty getting out to run errands, some of which require taking the bus. He tells you he has a companion, Paul, who is 40 years old, who assists him with grocery shopping and to run a few errands. Upon developing a rapport with Louis, he reports that he had to sell his prized cello in order to pay for Paul's services. His companion claims to be having financial problems and sends money to support his family abroad. At the present time, Louis states that his finances are not in order and he is concerned as Paul uses Louis' debit card to make grocery purchases.

Objective

During your home visit, you notice that his home is cluttered, disorganized and has not been recently cleaned. During your assessment, you note that Louis has difficulty with ambulation and uses the furniture around his home to provide support for walking.

He has decreased strength of his lower extremities bilaterally (quads = 3/5 and hamstrings = 3/5). He has decreased strength of his upper extremities bilaterally (biceps = 3/5 and triceps = 3/5). He scored 16/30 on the Montreal Cognitive Assessment (MoCA), with main deficit areas being executive/visuospatial and attention. He has difficulty navigating his utensils while eating lunch.

Based on this assessment you suspect that Louis may have some degree of HIV-Associated Neurocognitive Disorder (HAND), particularly the less severe form known as HIV-Associated Mild Neurocognitive Disorder (HA-MND). You refer to the community OT who undertakes functional neurocognitive testing and assessments of Louis' function including assessing his physical, sensory and cognitive impairments and abilities. These assessments include both formal tests using pen and paper tasks, and a functional task of preparing a light snack and a drink. The pen and paper assessment indicates areas of impairment and provides a repeatable, scored outcome measure, whilst the functional assessment indicates activity limitations. Together they describe a picture of overall functioning and enable the therapist to extrapolate how performance may be affected across a variety of everyday activities. From the assessment, the OT reports that Louis is grossly oriented, and his stored knowledge (remote recall) is also grossly unimpaired. His ability to attend to most tasks is grossly intact although during the kitchen task he had difficulty attending to more than one task at a time (divided attention). Constructional ability on the formal task and fine motor control on the functional task were both impaired, suggesting that there is an impairment of cognitive-motor function, while he has generally intact verbal fluency. Some impairment to recent recall was noticed on formal testing but was less apparent in the functional task. The most significant impairments, however, are to judgment, planning and organization, which are poor for both the functional and formal assessments. Louis' ability to self-evaluate his performance is also impaired which affects the level of insight into the difficulties he is having. The functions of judgment, planning, organization, self-evaluation and insight together are called executive function. The OT reports that individuals with impairments in these areas are at increased risk of financial abuse from other people or may manage their own finances poorly, often have poorer health self-management.

This is because they often have poor insight into the need for medication or other self-management strategies, and are at risk of self-neglect including not maintaining a hygienic home environment, not monitoring safety and not monitoring sell-by dates of foods.

The OT also completes an assessment of the home environment and finds many trip hazards from cluttered furniture and recommends that these are moved or removed.

Guiding Questions

1. *What is HAND? Specifically, what is HIV-Associated Mild Neurocognitive Disorder?*

Notes: HIV-Associated Mild Neurocognitive Disorder (HA-MND) is defined as an acquired impairment in at least two domains that produce at least mild interference in day-to-day activities, including self-reported changes in functional ability or observations by individuals who know the person well. HA-MND is considered a concurrent health condition and may be associated with aging and HIV. Individuals with HA-MND often present with features of sub-cortical dementia such as difficulty with cognitive-motor function. Executive function is often also affected whereas language and remote recall are often preserved in early stage disease. [Chapter 3_9 - Mental Health](#) [Chapter 3_6 - Cognitive Impairments](#)

2. *What are some of the (a) impairments (b) activity limitations and (c) participation restrictions that Louis is experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced and classify using the ICF Framework. [Chapter 3 – Symptoms and Impairments](#), specifically [Chapter 3_9 - Mental Health](#); [Chapter 3_3 - Weakness and Coordination](#); [Chapter 3_4 - Fatigue](#); [Chapter 3_6 - Cognitive Impairments](#)

Some examples include:

- Impairments: decreased strength in upper and lower extremities, impaired high-level cognitive functions (insight, judgment, problem-solving, cognitive flexibility), impaired psychomotor control, impaired divided attention, impaired short-term memory, query loneliness or isolation.
- Activity limitations: decreased mobility indoors and outdoors, decreased balance, decreased ability to carry out ADL, difficulty solving problems and making decisions, decreased ability to carry out IADL such as household chores, grocery shopping, and managing finances.
- Participation restrictions: financial problems, relationship with Paul is potentially problematic – query risk of financial abuse, inability to give piano lessons, query relationship with extended family.

3. *What personal and environmental factors might influence Louis' recovery?*

Notes: Personal factors include: aging, his concurrent health condition of BAD (are cognitive issues related to BAD or HIV?). Environmental factors include the level of social support – query companion relationship, extended family, and access to income supports. Also, consider risk of falls due to cluttered environment, risk of infections due to poor hygiene in environment, query other community care supports such as personal care. [Chapter 1_2 - Interacting with Communities Affected by HIV](#); [Chapter 1_3 - Introduction to Rehabilitation for Clients, Families and Other Care Providers](#)

4. *What additional factors should be considered?*

- Nutrition: are there any issues regarding weight loss, nutritional habits or other needs (e.g. food security)? Suggest referral to a dietitian. If appropriate and if necessary, discuss options for community food banks, suppers, food boxes and community cooking programs (which also provide social support).
- Review sleep and stress management. If required, follow up with a pamphlet, discussion or referral for good sleep hygiene.

5. *What are some of the short-term and long-term rehabilitation goals for Louis?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Consider patient values and preferences when developing goals with Louis. Use the SMART principle.

Short-term goals:

- To be able to independently prepare a simple snack and hot drink with no significant safety problems within 2 weeks.
- To be able to safely ambulate within his apartment with a cane in 2 weeks.
- To increase strength to upper and lower extremities to 5/5 in 2 weeks.
- To be managing all medication doses using a Dosette Box and alarm system within 2 weeks.

Long-term rehabilitation goals:

- To be able to carry out independent basic ADLs in 6 weeks.
- To be able to ambulate outdoors with a rollator walker in 6 weeks.
- To be able to identify and engage in one enjoyed activity or social activity outside the home in 6 weeks.
- To be able to form a realistic weekly budget with assistance from a social caregiver in 6 weeks.

6. *What rehabilitation treatment strategies might be used to address Louis' impairments, activity limitations and participation restrictions?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. Consider using the process of shared decision-making to prioritize treatment choices/strategies, and provide rationale. It is important that the strategies used to address his challenges take into account the ICF. By setting goals that address his impairments, this can lead to improvements in his activity limitations and participation restrictions. Some treatment interventions might include: ambulation training – he might be a candidate for a cane indoors and rollator for longer outdoor distances (to increase his independence to get out to run errands); strengthening exercises, stretching exercises, cognitive training exercises. Referral for personal care services through the community access centre. [Chapter 6 - Overview of Interventions](#); specifically [Chapter 6_3 - Evidence-Informed Rehabilitation Interventions for HIV](#)

Record keeping (e.g. tracking of exercise, medications, and other self-management techniques) may help Louis to maintain his goals. If Louis seems overwhelmed, suggest that he set one goal for the day to provide a purpose for getting up. Additional strategies may include keeping a daily reflection record, especially to identify items for discussion at the next healthcare appointment. Louis should also be encouraged to engage in some type of cognitive activity (e.g. reading, word games, or games on their cell phone).

7. *What kind of educational health promotion, prevention, care, treatment and support materials or information might the team provide for Louis?*

Notes: Suggest visit to HIV care physician and family doctor to discuss HIV status and potential need to start medications. Consider HIV medication in light of potential HAND as there is increasing evidence to support the benefits of cART in reducing the symptoms of HAND. Provide information on where Louis might be able to access additional community services such as a personal care attendant to assist with ADL and IADL, food banks or community meal programs and CBHO. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>). Louis may also benefit from referral to a peer support program. Examples of peer support content include discussing diagnosis, sharing anxieties, support for exercise and other topics (i.e. coping as a single mother). If referral is to a non-HIV peer support program, the program should be screened for policies around discrimination and there should be a discussion as to whether disclosure of HIV status is needed. [Chapter 6_8-Self Management](#); [Chapter 6_9-Theory-Based Patient Activation Interventions](#); [Chapter 1_2 - Interacting with Communities Affected by HIV](#)

8. *What other health or social services might Louis also benefit from having access to? Why?*

Notes: Identify other services and providers that might help to address Louis' impairments, activity limitations and participation restrictions. Consider how you would go about referring to the other service providers and services. Consider the potential barriers that Louis might encounter in attempting to access these services. How might you advocate with Louis to enable him to better access the needed services?

Contact with his psychiatrist, therapist or family doctor to reassess his concurrent BAD diagnosis should be considered as a part of the differential diagnosis. Many of the symptoms Louis is experiencing can also be present in depression and therefore a reassessment gives an opportunity for psychiatric reassessment to monitor the stability of his BAD.

Louis would benefit from ongoing PT, and a referral to OT to specifically to target neurocognitive rehabilitation. He would also greatly benefit from a referral to social work to address the finances and relationship with his companion and perhaps pursue linkage with extended family. The local CBHO can provide information and potentially access to food bank services and additional personal care services if available. He would also benefit from a visit to his HIV physician or family physician to address the deterioration in health and its relation to his HIV and BAD.

9. *What issues might Louis need you to help him advocate for?*

Notes: Louis may require advocacy to address his relationship with Paul, which appears problematic, especially since there is concern that Louis may be taken advantage of with his deteriorating cognitive status. Louis has had to rely on Paul's assistance to date, but perhaps with additional health and social services, he will be less dependent. [Chapter 7-Current Issues in HIV Rehabilitation in Canada](#), specifically [Chapter 7_2-Navigation and Advocacy](#)

Part 2 - 3 weeks later...

Presenting Problem / Background

Louis was receiving weekly PT and OT interventions through his Community Care Access Centre. He had recently started cART after his recent visit to his HIV specialist physician. He presented to the ER at the local hospital with slurred speech and left-sided weakness. He was diagnosed with a right cerebrovascular accident (CVA) or stroke, and admitted to hospital and referred to rehabilitation. He indicates life is getting worse for him and he needs help to get his life back together again.

Objective

On physical examination, Louis presents alert and awake.

Speech and Swallowing: His speech is slurred. Swallowing assessment indicates he has difficulty swallowing.

Cardiorespiratory: Decreased breath sounds and fine crackles bilaterally in lower lobes.

Strength: Left sided weakness, greater in the leg than arm and leg (quadriceps strength: 2/5 and biceps 3/5). Left truncal weakness resulting in poor postural control.

Mobility: Able to roll to the right and left in bed with minimal assistance.

Lying to sitting requires moderate assist. Requires minimal assist for sitting; 10 minutes sitting tolerance.

Sit to stand requires maximum assist X 1.

Standing tolerance of 10 seconds.

Ambulation: 2 steps with 2 high-wheeled walker and maximal assist X 2.

ADL: Assist of 1 for all self-care (dressing, toileting, bathing).

Cognition: Oriented to person and place but not time.

Louis articulates to you with his slurred speech that he would like to "get better so that he can get back home".

Guiding Questions

1. *What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Louis is experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced and classify using the ICF Framework. [Chapter 3 – Symptoms and Impairments](#), specifically [Chapter 3_9 - Mental Health](#); [Chapter 3_3-Weakness and Coordination](#); [Chapter 3_4 - Fatigue](#); [Chapter 3_6 - Cognitive Impairments](#); [Chapter 3_7 - Cardiac and Respiratory Impairments](#); and [Chapter 4_8 - Neurological](#)

Some examples include:

- Impairments: decreased cognition (orientation to time), decreased speech, decreased ability to swallow, decreased strength in left upper and lower extremity, decreased postural control, decreased ventilation to lower lung fields bilaterally. The possibility of HAND is now compounded with potential cognitive impairment from Louis' stroke.

- Activity limitations: decreased mobility (rolling and transfers and ambulation), decreased ADLs (dressing, toileting, bathing, eating), and decreased sitting and standing tolerance.
- Participation restrictions: query status of financial problems, relationship with his companion Paul is potentially problematic, inability to give piano lessons impacts his ability to generate income and for social interaction, relationship with extended family.

2. *What are some of the short-term and long-term rehabilitation goals for Louis?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Consider patient values and preferences when discussing and developing goals. Use the SMART principle.

Short-term goals:

- To increase postural control in sitting by 2 weeks.
- To increase ventilation to lung fields bilaterally in 2 days.
- To increase strength of left upper and lower extremity in 2 weeks.
- To be able to carry out independent bed mobility in 2 weeks.
- To improve transfer ability with lying to sitting with minimal assist, independent sitting X 5 minutes, and sitting to standing with minimal assist, and standing X 5 minutes with minimal assist in 3 weeks.
- To be able to swallow an oral diet safely in 1 week.
- To be able to communicate functionally with alphabet board supplementation in 2 weeks.
- To be oriented X 3 (person; place; time) in 2 weeks.

Long-term rehabilitation goals are goals that might be carried out in rehabilitation hospital.

- To be able to carry out ADLs independently in 6 weeks.
 - To be able to ambulate independently with a rollator walker in 6 weeks.
 - To be able to swallow a regular diet with thin fluids in 6 weeks.
 - To be discharged from rehabilitation to home in 6 weeks.
3. *What rehabilitation treatment strategies might be used to address Louis' impairments, activity limitations and participation restrictions?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. Consider using the process of shared decision-making to prioritize treatment choices/strategies, and provide rationale. It is important that the strategies used to address his challenges take into account the ICF. By setting goals that

address his impairments, this can lead to improvements in his activity limitations and participation restrictions. Some treatment interventions might include transfer training, postural control exercises, bridging exercises, isometric strength training, functional task practice (ADLs), gait training, speech training, swallowing training, augmentative/alternative communication tools, etc. [Chapter 6 - Overview of Interventions](#); specifically [Chapter 6_3 - Evidence-Informed Rehabilitation Interventions for HIV](#); [Chapter 6.1.3-Nutrition](#)

4. *What other health or social services might Louis also benefit from having access to? Why?*

Notes: Identify other services and providers that might help to address Louis' impairments, activity limitations and participation restrictions. Consider how you would go about referring to the other service providers and services. Consider the potential barriers that Louis might encounter in attempting to access these services. How might you advocate with Louis to enable him to better access the needed services?

- Referrals to PT, OT and SLP. Further cognitive-communication assessment and treatment by SLP may be beneficial for cognitive-communication changes from stroke and HAND.
- Referral to social work to follow up with home situation.
- Depending on Louis' goals, explore referral to rehabilitation hospital in stroke rehabilitation to return to independent living.
- Follow up with Infectious Disease physician regarding his HIV status and his recent cART regimen.
- Reassess neurocognitive status.
- Referral to a CBHO to assist with social support. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>).
- General healthy living advice offered to stroke survivors: exercise, diet, smoking cessation, etc.
- [Chapter 1_3 - Introduction to Rehabilitation for Clients, Families and Other Care Providers](#); [Chapter 7-HIV and Rehabilitation in Context](#), specifically [Chapter 7_2-Navigation and Advocacy](#); and [Chapter 6_8-Self Management](#)

5. *What issues might Louis need you to help him advocate for?*

Louis may need you to advocate strategies to further explore family relationships and his relationship with his companion Paul. Explore what Louis' goals are and whether there is potential to have a family meeting with Louis to discuss options for rehabilitation if he is unable to return home

directly from acute care. [Chapter 7-Current Issues in HIV Rehabilitation in Canada](#), specifically [Chapter 7_2-Navigation and Advocacy](#)

6. *What added complexity does Louis' concurrent health conditions (stroke, BAD) have as he ages with HIV on his overall health?*

Notes:

- There is an increased risk of stroke in advanced HIV, however, the general risk factors for stroke are also important, e.g. age (older), gender (male), weight (obesity), smoking status, family history. Louis requires both good standard stroke care as well as ongoing HIV care and will need input from both HIV and stroke services.
- If Louis has issues with medication adherence due to either stroke or HIV related cognitive changes and needs medication for his BAD, then he would be at increased risk of a relapse (mania, depression). There are also associations with stroke and depression and HIV and depression and having a BAD history may increase this risk.
- Equally if Louis' BAD is well controlled it may not have any interaction with his stroke or HIV diagnosis. Good collaborative care between physical health and mental health services will maximize management of each concurrent health condition. [Chapter 3 – Symptoms and Impairments](#), specifically [Chapter 3_9 - Mental Health](#); [Chapter 3_3 - Weakness and Coordination](#); [Chapter 3_4 - Fatigue](#); [Chapter 3_6 - Cognitive Impairments](#); [Chapter 3_7 - Cardiac and Respiratory Impairments](#); and [Chapter 4_8 - Neurological](#)

Medical Management – Infectious Disease Specialist Recommendations

Assessment: Louis is a 63-year-old male living with HIV and is representative of a very high-risk sector of the HIV population (newly infected adults dealing with the effects of aging). His situation is deeply concerning as the tests show he is not only functionally challenged but he is also cognitively impaired and socially at risk of financial or physical abuse, with minimal support to deal with this issue should it occur. Louis has HAND but he also was not on cART initially. If his cART regimen allows drugs to pass through the blood-brain barrier, there is increasing evidence to suggest that his HAND may improve.

Plan:

- Ensure that Louis has a family physician or HIV specialist that he can visit at regular intervals. Discuss with local geriatrics unit/memory clinic whether they would consider seeing him for his cognitive dysfunction despite his young age.

- Initiate work-up to rule out reversible causes of his cognitive decline, should have at minimum: Blood work for electrolytes/extended electrolytes, TSH, B12, folate, syphilis serology and a CT head to rule out hydrocephalus, cerebrovascular disease or space-occupying lesions.
- Perform formal capacity assessment and assist Louis in identifying an appropriate Power of Attorney (POA)/Substitute Decision Maker (SDM) immediately.
- Submit referral to a community access program to assess for whether he would qualify for assistance programs.
- Discuss with Louis the possibility of retirement homes and eventual long-term care, and provide information about local options.

Complex Case – Musculoskeletal, Episodic, Cardiorespiratory

Case #4 – Stella

Part 1:

Presenting Problem / Background

Stella is a 58-year-old female living with HIV. Stella and her daughter immigrated to Canada from an HIV endemic country ten years ago. Stella underwent a right total knee arthroplasty one week ago due to longstanding and worsening osteonecrosis in the knee. She was discharged home on postoperative day 5 with a referral to home care rehabilitation.

Subjective

Stella was diagnosed with HIV 25 years ago. She was discharged to home 3 days ago from the hospital with a two-wheeled walker. She is ambulating independently with the walker, weight bearing as tolerated (WBAT). She rates her pain at 4/10 except when she forces her knee into extension and then pain increases to 7/10 as measured by the Pain VAS.

Past Medical History

For pain management, Stella is taking Tylenol 3 PRN (about 2 tablets/day). She continues to suffer from bilateral peripheral sensory neuropathy in her feet that began when she initially started antiretroviral therapy 15 years ago but never resolved, even after switching her medications. A bone mineral density (BMD) scan was recently ordered by her physician, which showed accelerated bone mineral loss in several areas, likely related to antiretroviral use. She reports some challenges with her adherence to her cART, and as a result, she was admitted to hospital 2 years ago with PCP. Stella is a previous smoker and also suffers from longstanding chronic obstructive pulmonary disease (COPD) (emphysema), experiencing exacerbations approximately six times per year that require hospitalization.

Social History

Stella lives with her 20-year-old daughter who is also HIV positive; she is healthy and attending college. They live in a two-story home in a large city. Stella volunteers at the Lung Association two days per week and hasn't engaged in paid work since 15 years ago when she worked as a postal worker. She is currently on a provincial Disability Support Program and has a drug card enabling her to

access her antiretroviral medications. Stella does not have other family members in Canada, and most of her social circle does not know of her HIV status.

Stella's friend Mona has been staying with her to assist with meal preparation and any other chores that need to be done. Stella would like to get back on her "own two feet" to take over some of the burdens her friend and daughter have taken on in caring for her. She also would like to return to her volunteer work at the Lung Association, as she states this is her way of "feeling productive in life".

Objective

Assessment findings include: ROM (flexion/extension = 95°/5°) and strength (quadriceps = 4+/5 and hamstrings =4+/5). She has poor eccentric control of her quadriceps, as seen in mini squats. Stella "bums" up and down the stairs to access her bedroom and the shower, which is located on the second floor. She experiences shortness of breath when "bumming" up and down the stairs.

Guiding Questions

1. *Describe additional components of your assessment with Stella.*

Notes: Describe components of the subjective interview and components of the objective assessment. These include cardiorespiratory, musculoskeletal, and neurological components of assessment, functional mobility, etc. Also include IPPA (inspection, palpation, percussion, auscultation), strength assessment, ROM, sensory assessment, functional mobility for ambulation and stairs, sensory assessment (lower limbs secondary to neuropathy), cognitive assessment (if applicable), etc. [Chapter 2- Rehabilitation Best Practices](#); [Chapter 3_2 - Pain](#)

2. *What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Stella is experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced by Stella and classify using the ICF Framework. [Chapter 3 – Symptoms and Impairments](#), [Chapter 3_3 - Weakness and Coordination](#); [Chapter 3_4 - Fatigue](#); [Chapter 3_2 - Pain](#)

Some examples include:

- Impairments: decreased strength in lower extremities, decreased ROM of right knee, pain in right knee, pain bilaterally in feet due to peripheral neuropathy, potential decreased balance (due to peripheral neuropathy and surgery), paresthesia, fatigue, diarrhea, headaches, nausea (from antiretroviral medications), shortness of breath.
- Activity limitations: decreased mobility (difficulty walking), difficulty negotiating stairs, difficulty dressing, meal preparation, difficulty ambulating long distances prior to surgery secondary to peripheral neuropathy.
- Participation restrictions: concerns about caring for her daughter who is also HIV positive, difficulty volunteering at the Lung Association, not currently engaged in paid work, financial challenges – provincial drug support program.

3. *What additional factors should be considered?*

- Nutrition: are there any issues regarding weight loss, nutritional habits or other needs (e.g. food security)? Suggest referral to a dietitian. If appropriate and if necessary, discuss options for community food banks, suppers, food boxes and community cooking programs (which also provide social support).
- Review sleep and rest /stress management. If required, follow up with a pamphlet, discussion or referral for good sleep hygiene.
- Concurrent Health Conditions: Peripheral neuropathy and COPD, which add further complexity to, the disability experienced by Stella. These conditions will impact the type of intervention strategies to address Stella's health challenges.

4. *What are some of the short-term and long-term rehabilitation goals for Stella?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Use the SMART principle.

Short-term goals:

- To decrease pain in right knee in 2 weeks.
- To be able to ambulate independently with a cane in 3 weeks.
- To be able to negotiate stairs independently with a cane in 3 weeks.
- To increase ROM in right knee to 0 to 90 degrees flexion in 2 weeks.
- To increase strength in right knee to 4+/5 in 2 weeks.
- To independently carry out transfers in 2 weeks.
- To be able to prevent shortness of breath on stairs.

Long-term goals include:

- To be able to independently ambulate outdoors longer distances in 6 weeks with a cane.

- To be able to independently carry out household chores (laundry, cooking) in 4 weeks.
- Consider concurrent health conditions of COPD (periodic exacerbations of emphysema) and peripheral neuropathy.

5. *What types of evidence exists related to the success of joint arthroplasty for people living with HIV/AIDS?*

Notes: Consider all types of evidence (clinical experience, basic pathobiology, anatomy, physiology, patient values and preferences along with research evidence). There is evidence on the success of joint arthroplasty among people living with HIV. However, one should investigate this literature and be able to discuss the potential complications of joint arthroplasty for people in this population.

6. *What rehabilitation treatment strategies might be used to address Stella's impairments, activity limitations and participation restrictions?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. Consider using the process of shared decision-making to prioritize treatment choices/strategies, and provide rationale. It is important that the strategies used to address Stella's challenges take into account the ICF. By setting goals that address her impairments, this can lead to improvements in her activity limitations and participation restrictions. Some treatment strategies include: stretching, strengthening exercises, functional ambulation, stair training, education to prevent shortness of breath with activity, balance training (taking into account her decreased sensation from neuropathy), education on proper footwear, outdoor ambulation, gait training with cane and progression to no gait aid. [Chapter 6 - Overview of Interventions](#); specifically [Chapter 6_3 - Evidence-Informed Rehabilitation Interventions for HIV](#); [Chapter 5.5.1 - Rehabilitation Interventions](#)

Record keeping (e.g. tracking of exercise, medications, and other self-management techniques) may help Stella to maintain her goals. Additional strategies may include keeping a daily reflection record, especially to identify items for discussion at the next healthcare appointment. All clients should also be encouraged to engage in some type of cognitive activity (e.g. reading, word games, or games on her cell phone). Mindfulness strategies (for example, mindful meditation) may help Stella to manage her symptoms, stress and uncertainty.

7. *What kind of educational health promotion, prevention, care, treatment and support materials or information might you provide for Stella?*

Notes: Stella would benefit from reviewing the *Managing Your Health* resource published by CATIE (<http://www.catie.ca/en/practical-guides/managing-your-health>). Stella would also benefit from information on total

knee arthroplasty, self-management strategies for preventing an exacerbation of COPD, education surrounding proper footwear and strategies to address peripheral neuropathy. Since Stella is considering a return to paid work and/or volunteer work she can be referred to the Episodic Disabilities Employment Network (EDEN), a website where people in Canada living with episodic disabilities, including HIV, can connect with each other and discuss employment questions. (<http://www.edencanada.ca/>). [Chapter 6_8-Self Management](#); [Chapter 6_9-Theory-Based Patient Activation Interventions](#); [Chapter 1_2 - Interacting with Communities Affected by HIV](#)

8. *How would you monitor this plan of intervention?*

Notes: Establish what the treatment priorities are at this time and consider how often you should assess, re-assess and treat Stella. Identify the types of outcome measures you should use in your assessment and re-assessment and provide a rationale for their use – consider their purpose for using the measure (descriptive, predictive or evaluative) and consider the measurement properties of the instrument (reliability, validity, feasibility, sensibility, responsiveness (if evaluative)). [Chapter 2- Rehabilitation Best Practices](#), specifically [Chapter 2_2 - Outcomes and Measurement in Rehabilitation Practice](#)

9. *What other health or social services might Stella also benefit from having access to? Why?*

Notes: Identify other services and providers that might help to address Stella's impairments, activity limitations and participation restrictions. Discuss how you would go about referring to the other service providers and services. Discuss the potential barriers that Stella might encounter in attempting to access these services. Discuss how you might advocate with Stella to enable her to better access the needed services.

- Refer Stella to a social worker and assess how Stella's friend and daughter are coping while having to care for Stella.
- If available, referral to an ethnic-specific CBHO. The Theresa Group is a supportive CBHO for families infected or affected by HIV that provides access to meal programs, supportive counselling for parents and kids. Note: the Theresa Group is Ontario, based so you will need to search for similar types of supports in other provinces or locally (<http://www.teresagroup.ca/>). CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>).
- Referral to OT and PT (if not already involved).

- Since Stella is considering a return to paid work and/or volunteer work a referral can be made to local vocational services where available. Both the EDEN and the HIV411 websites have links to employment and financial services (<http://hiv411.ca>).
- [Chapter 1_3 - Introduction to Rehabilitation for Clients, Families and Other Care Providers](#); [Chapter 7-HIV and Rehabilitation in Context](#), specifically [Chapter 7_2-Navigation and Advocacy](#); and [Chapter 6_8-Self Management](#)

10. *What issues might Stella need you to help her advocate for?*

Notes: Stella may need help to access rehabilitation at an outpatient facility (healthcare centre, outpatient hospital clinic). She may also need assistance to access vocational rehabilitation services for support to return to volunteer work, to determine if she can ever return to paid work, and to potentially plan for the transition into retirement. [Chapter 7-Current Issues in HIV Rehabilitation in Canada](#), specifically [Chapter 7_2-Navigation and Advocacy](#)

Part 2: 6 weeks post-op...

Presenting Problem / Background

The rehabilitation professional (OT or PT) has seen Stella in her home once every 2 weeks to monitor the treatment program and re-assess her progress. At 6 weeks post knee replacement, the rehabilitation professional returns to see Stella for re-assessment and re-evaluation of goals.

Subjective

Stella is recovering well from her total knee arthroplasty and is now ambulating independently without an aid. She is able to negotiate stairs but continues to get short of breath climbing one flight of stairs. She considers herself fairly healthy, except for the longstanding fatigue she often experiences, which makes it difficult for her to carry out her day-to-day household activities (especially on days when she volunteers). Stella's friend is no longer staying with her but continues to drop in weekly to help out with any groceries or cleaning as needed.

Despite her knee feeling better, Stella reports experiencing many fluctuating "good days" living with HIV, but occasionally has some "bad days" when she wakes up feeling unable to even get out of bed. On these days, she finds it difficult to get around her house, feeling very weak and exhausted, and unable to make it to the store to shop for groceries. During these times, she is unable to attend her daughter's college basketball games due to fatigue. On these days she barely manages to make a meal for herself and her daughter. She is reluctant to ask for help from her daughter around the house because she "doesn't want to interfere in her life". Her daughter is currently healthy but

Stella worries about what might happen to her in the future if her HIV status deteriorates. At times she finds herself feeling down, isolating herself from others, and worrying about the uncertainty of her future.

On the "good days", Stella cleans her house entirely from top to bottom, without any rest breaks. She reports that this helps her feel "productive" and "alive" by cleaning and ensuring that her daughter lives in a safe and clean house. However, at the end of these "cleaning binges", Stella finds herself completely exhausted, requiring 1 to 2 days to recover in bed.

Stella has experienced some changes in her body composition (lipodystrophy) due to the previous use of older antiretroviral medications - she gained weight in her trunk area, developed a buffalo hump at the back of her neck and has apparent wasting below her cheekbones (Grade 3 on the Carruthers Facial Lipoatrophy Severity Scale). She tells you that she is embarrassed by her appearance and is fearful that others will know that she is HIV positive. She has become more and more reluctant to get out and interact with others, fearing stigma and discrimination she may experience from others due to her HIV status.

Stella is considering returning to work, as she is finding it more and more difficult to provide for her family solely on provincial income support funding. However, she is unsure whether she can handle full-time work, and is unsure where to begin her pursuits given she's been out of the workforce for 15 years. She is concerned about the gap in her resume, her age, and is hesitant to disclose her HIV status to potential employers for fear that she may be discriminated against.

Guiding Questions

1. *What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Stella is currently experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced by Stella and classify using the ICF Framework. Keep in mind how her disability is fluctuating and episodic in nature – characterized by unpredictable periods of wellness and illness (good days and bad days). [Chapter 3 – Symptoms and Impairments](#), [Chapter 3_3 - Weakness and Coordination](#); [Chapter 3_4 - Fatigue](#); [Chapter 3_2 - Pain](#); [Chapter 6.7.4 - Barriers to Employment or Return to Work](#)

Some examples might include:

- Impairments: fatigue, shortness of breath, weakness, diarrhea, nausea, emotions – fear, isolation, worrying about the future – anxiety, body composition changes related to lipodystrophy.
- Activity Limitations: difficulty carrying out day-to-day activities, meal preparation, decreased mobility.

- Participation Restrictions: difficulty/barriers in returning to paid work, financial challenges, potential stigma and discrimination, decreased community or social interaction with others.

Notes: Consider the ups and downs that come with living with HIV and the uncertainty that Stella may be experiencing. An added difficulty is the fear of returning to work – what happens if she returns to work, gives up her provincial funding support and gets sick again and has to leave work again? Is there the potential of having difficulty getting back on income support if needed? She is also concerned about the time gap on her resume – how does she explain being out of the workforce for so long, especially if she is reluctant to disclose her HIV status to potential employers? On "good days" Stella appears to "overdo it" when cleaning the house, which then causes her to need a couple of days to recover. The unpredictability of living with HIV can affect many life decisions such as returning to work, buying a house, or starting a new relationship. [Chapter 1_1 - Introduction, specifically Episodic Disability](#)

2. *What added complexity does Stella's concurrent health conditions have as she ages with HIV on her overall health?*

Notes: Consider concurrent health conditions such as osteonecrosis, COPD (and potential for future exacerbations), PCP pneumonia a few years ago, peripheral neuropathy, potential for other concurrent health conditions such as cancer (e.g. lung), cardiovascular disease, and health challenges related to menopause. With aging, what are the implications for her returning to the workforce – might she consider retirement in the future? What are the implications for income support?

[Chapter 3_2 - Pain](#); [Chapter 6.7.4 - Barriers to Employment or Return to Work](#)

3. *What additional factors should be considered?*

- Review sleep and rest /stress management. If required, follow up with a pamphlet, discussion or referral for good sleep hygiene.
- Determine compliance with medications (HIV and other). Adherence may be improved with blister packs or a record-keeping technique (e.g. phone alarm).
- Concurrent health conditions of peripheral neuropathy and COPD; the potential for further concurrent health conditions as Stella ages with HIV (e.g. lung cancer, cardiovascular disease, osteoporosis, osteoarthritis).

4. *What are some of the rehabilitation goals for Stella?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Use the SMART principle.

1. To be able to manage fatigue by structuring her schedule using principals of pacing and prioritization within the next 2 weeks.
2. To attend a group exercise program a minimum of 2 times per week.
3. To better understand the episodic nature of her concurrent diseases and the strategies that can be used to live with day-to-day variations in health.
4. To link to an HIV support organization to receive support in dealing with body composition changes.
5. *What are some of the potential treatment strategies that might be used to address Stella's impairments, activity limitations and participation restrictions?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. Consider using the process of shared decision-making to prioritize treatment choices/strategies, and provide rationale. It is important that the strategies used to address Stella's challenges take into account the IC. By setting goals that address her impairments, this can lead to improvements in her activity limitations and participation restrictions. Consider living strategies that Stella might use to prevent an episode of disability or reduce the severity of an episode. Stella may be a good candidate for an exercise program of combined aerobic and progressive exercise –look to systematic review evidence demonstrating the safety and beneficial effects of exercise for adults living with HIV – be sure to consider the FITT (Frequency, Intensity, Time, Type) principle, progression of intensity of exercise, potential access to community gym centres, level of supervision required, and factors that will support sustainability and adherence to an exercise program.

Also, consider principles of prioritization on days when feeling fatigued; education on being "balanced" with her activity (for example, reducing cleaning binges, etc.) [Chapter 6 - Overview of Interventions](#); specifically [Chapter 6_3 - Evidence-Informed Rehabilitation Interventions for HIV](#); [Chapter 6_4-Exercise](#)

Record keeping (e.g. tracking of exercise, medications, and other self-management techniques) may help Stella to maintain her goals. Since Stella tends to do too much on 'good days', suggest that she set only one goal for the day. Additional strategies may include keeping a daily reflection record, especially to identify items for discussion at the next healthcare appointment. All clients should also be encouraged to engage in some type of cognitive activity (e.g. reading, word games, or games on their cell phone). Mindfulness strategies (for example, mindful meditation) may help Stella to manage her symptoms, stress and uncertainty.

6. *What kind of educational health promotion, prevention, care, treatment and support materials or information might you provide for Stella?*

Notes: Stella would benefit from reviewing the *Managing Your Health* resource published by CATIE (<http://www.catie.ca/en/practical-guides/managing-your-health>). Since Stella is considering a return to paid work and/or volunteer work she can be referred to the Episodic Disabilities Employment Network, a website where people in Canada living with episodic disabilities, including HIV, can connect with each other and discuss employment questions. (<http://www.edencanada.ca/>). [Chapter 6_7 Vocational Rehabilitation](#).

7. *What other health or social services might Stella also benefit from having access to? Why?*

Notes: Identify other services and providers that might help to address Stella's impairments, activity limitations and participation restrictions. Consider how you would go about referring to the other service providers and services. Consider the potential barriers that Stella might encounter attempting to access these services.

- Referral to a CBHO may also be beneficial. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>).
 - Referral to local vocational services where available. Both the EDEN and the HIV411 websites have links to employment and financial services (<http://hiv411.ca>).
 - Stella may benefit from a referral for home assessment by an OT (if not already received).
 - The episodic nature of HIV is a particular factor to consider in this case when approaching intervention strategies and self-management.
 - Consider the ethics for disclosure of HIV status when referring to other disciplines or services.
 - [Chapter 1_3 - Introduction to Rehabilitation for Clients, Families and Other Care Providers](#); [Chapter 7-HIV and Rehabilitation in Context](#), specifically [Chapter 7_2-Navigation and Advocacy](#); [Chapter 6_7 Vocational Rehabilitation](#) and [Chapter 6_8-Self Management](#)
8. *What issues might Stella need you to help her advocate for?*

Notes: Stella may need your assistance to access rehabilitation at an outpatient facility (healthcare centre, outpatient hospital clinic). She may also need support to explore her ability to return to work or to begin thinking about a future transition into retirement. [Chapter 7-Current Issues in HIV Rehabilitation in Canada](#), specifically [Chapter 7_2-Navigation and Advocacy](#)

9. *You plan to discharge Stella from your caseload. Discuss what your discharge plans might be.*

Notes: Consider her recent arthroplasty, bilateral peripheral neuropathy, COPD and risk for future pneumonia, as well as the episodic and unpredictable nature of HIV. Are there any long-term rehabilitation programs that Stella could contact if she has an episode of disability after her discharge? [Chapter 2- Rehabilitation Best Practices](#)

Medical Management – Infectious Disease

Specialist Recommendations

Assessment: Stella is living with HIV but also living with a number of other complicating medical comorbidities that are contributing to her difficulty managing. She requires a full assessment of each of these issues in order to truly optimize her function at home.

Plan:

- Optimization of COPD: Ensure patient is on appropriate puffers, has recent pulmonary function tests, and link up with a COPD outreach program and/or pulmonary rehabilitation. Given her smoking history and HIV status, she should also be evaluated for cardiac dyspnea with a thorough history and echocardiogram.
- Given her decreased BMD ensure supplementation with vitamin D, calcium and bisphosphonate therapy.
- Peripheral neuropathy: Patient should do daily foot checks and see a podiatrist to be fitted with appropriate footwear to avoid development of neuropathic ulcers.
- If Stella's condition persists, refer to a community psychologist to discuss worries and issues. Stella may then benefit from cognitive behavioural therapy or initiation of medication.
- Explore local options to obtain increased funding for Stella and her family if return to full-time work is not a likely possibility.

Diabetes, Neuropathy, Substance Use

Case #5 – John

Presenting Problem / Background

John, a 46-year-old Caucasian male who is living with HIV, is admitted to the acute care hospital after a community health nurse found him in his apartment unconscious from a drug overdose. John uses street drugs as well as prescription drugs.

One day later, with the immediate crisis over, John is medically stable, fully conscious and is insisting on being discharged from the hospital. His behaviour in hospital has been difficult to manage. He removes all his lines and tubes, presents with sudden outbursts, offensive language and refuses to eat that is sometimes expressed with a thrown meal tray. The treating physician feels that John still requires another day or two of monitoring and has some concerns about his uncontrolled viral load ($>100,000$ copies/ml blood) and low CD4 count (89 cells/mm^3) which John does not appear to be concerned with. There is also a question of his ability to care for himself given his extensive medical history and repeat admissions. While John's personality is usually confrontational, he appears to be particularly agitated on this admission.

Subjective

Past Medical History

John's medical history includes a six-year known history of HIV. He has a history of diabetes and as a result, had a left below knee amputation four years ago. He usually wears a prosthesis. Two years ago he was admitted to the intensive care unit (ICU) for sepsis from a wound infection on the site of his left below knee amputation. He has also been seen at the hospital for two drug-related admissions in the past 18 months. John is currently being followed by a community health nurse for dressing changes of a similar wound that has not healed. As a result, he has not been able to use his prosthesis and lately has been using a wheelchair for outdoor ambulation and crutches in his apartment.

John has peripheral neuropathy secondary to his diabetes leaving him with a mild decrease in sensation in both lower extremities (right foot and left at amputation site) and hands. At times he finds that he stumbles while walking with his prosthesis and has difficulty with some manual dexterity tasks, and now has difficulty navigating the wheelchair.

While HIV medications have been offered to him in the past, to-date he has declined to take them, as he is afraid that his roommates will learn of his HIV status. He lives with friends in a small 3rd-floor apartment (with elevator access) and is very eager to go back as soon as possible. His friends have their own health challenges, and they live together to pool their disability allowances. He has been on long-term disability for 5 years and wants to eventually get back to work, but is concerned about his ability to keep up with the demands of work in light of his addiction to prescription medications and fluctuating energy levels. He previously worked as a respiratory therapist in a community hospital. His energy levels fluctuate, and some days he needs to sleep in the afternoon for 2 to 3 hours. When his energy is low he finds it difficult to exert himself; he is not sure that he can maintain a full day of work.

The rehabilitation team has been asked to see him to provide recommendations on how to optimize his care.

Objective

Upon entering his hospital room, John is found lying on the ground covered in cereal and the remaining food items from his breakfast tray. He is fully conscious, alert and oriented but appears emaciated. He reports having climbed down onto the floor because the bed was too soft. John demonstrates he is fully capable of transferring back up onto the bed and then into a chair but does so impulsively and recklessly, without regard for the use of safety features such as the brakes on his wheelchair or consideration of the positioning of the chair.

Guiding Questions

1. *What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that John is currently experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced by John and classify according to the ICF Framework. Keep in mind how his disability may include fluctuations that are episodic in nature and characterized by periods of wellness and illness (good days and bad days). [Chapter 3 – Symptoms and Impairments](#), specifically [Chapter 3_9 - Mental Health](#); [Chapter 3_3 - Weakness and Coordination](#); [Chapter 3_4 - Fatigue](#); [Chapter 3_6 - Cognitive Impairments](#); [Chapter 3_7 - Cardiac and Respiratory Impairments](#); [Chapter 4_8 - Neurological](#)

Some examples might include:

- Impairments: fatigue, weakness, agitation, decreased sensation, decreased balance, decreased dexterity; impaired insight and judgment skin integrity.
 - Activity Limitations: difficulty carrying out day-to-day activities, decreased mobility (wheelchair and use of prosthesis).
 - Participation Restrictions: difficulty/barriers in returning to work, financial challenges, risks to maintaining personal safety, nature of social support from friends/roommates, fear of stigma with HIV disclosure.
2. *What added complexity does the episodic nature of John's disability have on his overall health?*

Notes: Consider the ups and downs that come with living with HIV and the uncertainty that comes with it. What happens if John is unable to use his prosthesis, what if he has another wound infection? What if his diabetes remains uncontrolled and results in another amputation? [Chapter 1_1 - Introduction, specifically Episodic Disability](#)

3. *What added complexity does John's concurrent health conditions have on his overall health?*

Notes: HIV, diabetes, substance use, previous amputation. Neuropathy related to diabetes. He is at risk of developing further complications due to HIV and diabetes. [Chapter 4-Systemic Impacts](#)

4. *What additional factors should be considered?*
- Nutrition: As John is a diabetic, nutrition support is crucial. Are there any issues regarding weight loss, nutritional habits or other needs (e.g. food security)? Suggest referral to a dietitian. If appropriate and if necessary, discuss options for community food banks, suppers, food boxes and community cooking support programs (which also provide social support).
 - Review sleep and rest /stress management. If required, follow up with a pamphlet, discussion or referral for good sleep hygiene.
 - Determine if John has a reliable mode of communication to ensure contact with health professionals. Alternatives may include landline, cell phone, leaving messages with someone who is in regular contact and knows of his HIV status.
5. *What are some of the short-term and long-term rehabilitation goals for John?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Use the SMART principle.

Short-term goals include:

- To improve motivation to become independent with ADLs (dressing, toileting, bathing) in 2 weeks.

- To be able to consistently perform safe and independent transfers to prevent further injury in 2 weeks.
- To be able to mobilize safely in the wheelchair 200 metres in 2 weeks.
- To be able to ambulate with his prosthesis 100 metres in 2 weeks.
- To be assessed for cognitive impairment which may be exacerbating his agitation.

Long-term rehabilitation goals might include:

1. To link with community-based supports to reduce his isolation regarding his HIV diagnosis.
2. To link with supports that can help John in decision-making (e.g. whether to start HIV medication and to take steps to manage his substance use).
3. *What are some of the potential treatment strategies that might be used to address John's impairments, activity limitations and participation restrictions?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. It is important that the strategies used to address John's challenges take into account the ICF. By setting goals that address his impairments, this can lead to improvements in his activity limitations and participation restrictions. Consider using the process of shared decision-making to prioritize treatment choices/strategies, and provide rationale. Priorities include addressing his agitation, safe transfer and mobility training with a wheelchair, wound care, upper extremity strengthening exercises, lower extremity strengthening – quadriceps and hamstrings, ADL training and seating assessment. John may also require neurocognitive interventions if he demonstrates cognitive impairments during the cognitive assessment. [Chapter 6 - Overview of Interventions; specifically Chapter 6_3 - Evidence-Informed Rehabilitation Interventions for HIV](#)

Recordkeeping (e.g. tracking of exercise, medications, and other self-management techniques) may help John to maintain his goals. If John seems overwhelmed, suggest that he set one goal for the day to provide a purpose for getting up. Additional strategies may include keeping a daily reflection record, especially to identify items for discussion at the next healthcare appointment, teaming up with a friend or buddy to share an activity and be reminders for each other. All clients should also be encouraged to engage in some type of cognitive activity (e.g. reading, word games, or games on his cell phone). Mindfulness strategies (for example, mindful meditation) may help John to manage his symptoms, stress and uncertainty.

7. *What kind of educational health promotion, prevention, care, treatment and support materials or information might you provide for John?*

Notes: John would benefit from reviewing the *Managing Your Health* resource published by CATIE (<http://www.catie.ca/en/practical-guides/managing-your-health>). CATIE also provides a variety of educational materials regarding common concurrent conditions such as diabetes. Education regarding wound care is also warranted. However, in his present state, he may benefit from a peer support volunteer to help him go through relevant sections and discuss the options. The local CBHO may have trained peer support volunteers available if John is willing to participate.

If John really intends to return to work, he can be referred to the Episodic Disabilities Employment Network, which hosts a website where people in Canada living with episodic disabilities, including HIV, connect with each other and discuss employment questions (<http://www.edencanada.ca/>). Referral can also be made to local vocational services where available. Both the EDEN and the HIV411 websites have links to employment and financial services (<http://hiv411.ca>). [Chapter 6_8-Self Management](#); [Chapter 6_9-Theory-Based Patient Activation Interventions](#); [Chapter 1_2 - Interacting with Communities Affected by HIV](#)

8. *What other health or social services might John also benefit from having access to? Why?*

Notes:

- CBHO provide a wide range of services to those living with HIV in Canada. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>).
- Many people benefit from peer support programs. If referral is to a non-HIV peer support program, the program should be screened for policies around discrimination, and there should be a discussion as to whether disclosure of HIV status is needed.
- John will benefit from a referral for addictions counselling.
- Referral to OT or PT for seating assessment.
- Eventual link to an Employment Action Program at his local CBHO or other community organization to help facilitate his re-entry into the workforce.
- EDEN website for tools and information to understand living with an episodic disability (<http://www.edencanada.ca/>)
- Diabetes support organizations.
- [Chapter 1_3 - Introduction to Rehabilitation for Clients, Families and Other Care Providers](#); [Chapter 7-HIV and Rehabilitation in Context](#), specifically [Chapter 7_2-Navigation and Advocacy](#); [Chapter 6_7Vocational Rehabilitation](#) and [Chapter 6_8-Self Management](#)

9. *What issues might John need you to help him advocate for?*

Notes: John may need your help to acquire mobility devices (and a new prosthesis if needed). He may also need your help with income support. If John decides to investigate his work choices once he has stabilized he may need your help to access vocational rehabilitation services. [Chapter 7-Current Issues in HIV Rehabilitation in Canada](#), specifically [Chapter 7_2-Navigation and Advocacy](#)

Medical Management – Infectious Disease Specialist Recommendations

Assessment: John is living with untreated HIV and diabetes, which resulted in an amputation. Wound management continues to be a challenge along with behavioural issues.

Plan:

- Counsel to initiate combination antiretroviral therapy as well as Septra and azithromycin prophylaxis.
- CT head to rule out focal frontotemporal pathology as patient is behaving in a significantly erratic and disinhibited fashion.
- Referral to addictions counselling/detoxification centre.
- Referral to community psychologist.
- Optimize his glycemic control – this is likely contributing to his poor wound healing and neuropathy.
- Assess for other complications related to diabetes (e.g. ophthalmology).
- Discuss the pros and cons of if and when to begin HIV treatment.

Transition from Paediatric to Adult Care

Case #6 – Natasha

Presenting Problem / Background

Natasha is a 17-year-old Caucasian female living with cerebral palsy (CP) and HIV who presents to her paediatric rehabilitation facility to commence planning for transition to adult health and social care services.

Subjective

Natasha has dysarthria and uses a Zygo Lightwriter (handheld voice output computer) to augment her verbal communication. She ambulates with a walker indoors, and for outdoor mobility, she uses a scooter. Recently she has been having increasing difficulty with ambulation, especially with transferring on and off of her scooter. She has lost approximately 60 pounds over the last month and now weighs 120 pounds with a height of 5 feet 11 inches. She stays in bed for most of the day because of dizziness and nausea. Natasha has a history of falls within the home.

She has recently started cART and finds the side effects make her feel weak and nauseous. Despite this, she has been taking cART as prescribed.

Social History

Natasha currently lives with her mother in a two-bedroom apartment. Both have the support from her 24-year-old unmarried stepsister and other relatives that come in occasionally to help out with meal preparation. Natasha contracted HIV during a trip abroad to visit family when improperly sterilized instruments were used during a medical procedure. Natasha and her mother are the only family members aware of her HIV status. She states that if any of her relatives are curious about her condition, she states that she has cancer. Natasha expresses that she does not want to be stigmatized or discriminated against, especially considering her family's religious background. She is currently attending local high school and also does not want the kids in her class to learn about her HIV status. She also wishes to participate in as many school activities as possible. She hopes that upon graduation she can pursue further education and employment prospects. Natasha attends the rehabilitation centre with her stepsister and mother; you note from the chart they have joint POA for Natasha's care.

The care transition is complicated by several factors: a) how a physical disability such as CP is supported, b) how HIV care is provided in her community, c) the availability of community supports, and, d) the availability of services (e.g. transportation, vocational training, financial assistance).

Objective

An objective assessment was not completed.

Guiding Questions

1. *What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Natasha is currently experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced by Natasha and classify according to the ICF Framework. [Chapter 5-Paediatrics](#)

Some examples might include:

- Impairments: dysarthria, weight loss, dizziness, nausea, weakness.
 - Activity Limitations: decreased mobility (transfers, and walking), decreased meal preparation.
 - Participation Restrictions: decreased interaction with community (staying in bed), stigma and fear of disclosing HIV status to others outside her mother, POA (stepsister does not know HIV status), transition into adulthood – will she eventually live independently without her mother?
2. *What added complexity does Natasha's concurrent health conditions have on her overall health?*

Notes: Natasha has CP in addition to HIV so there is a strong potential for episodes of ongoing illness. [Chapter 5-Paediatrics](#)

3. *What environmental factors and personal factors might influence Natasha's ability to transition to adult care?*

Notes: Environmental factors include fear of stigma - only her mother knows her HIV status despite both stepsister and mother having POA. There are supports from other family members around meal preparation. Personal factors include the fact that she is getting older and needs to prepare to transition to adult care. [Chapter 5-Paediatrics](#)

4. *What additional factors should be considered?*

- Nutrition: Natasha has experienced unplanned rapid weight loss, so nutritional habits or other needs (e.g. food security) should be reviewed. Suggest referral to a dietitian. If appropriate and if necessary, discuss options for community food banks, suppers, food boxes and community cooking support programs (which also provide social support).
- Review sleep and rest /stress management. If required, follow up with a pamphlet, discussion or referral for good sleep hygiene.
- Determine if Natasha has a reliable mode of communication to ensure personal and confidential contact with health professionals. Alternatives may include landline, cell phone or leaving messages with mother only.

5. *What are some of the short-term and long-term rehabilitation goals for Natasha?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Use the SMART principle.

Short-term goals:

- To increase postural control in sitting in 4 weeks.
- To improve transfers in 4 weeks.
- To increase tolerance for ambulation in 4 weeks.
- To actively participate in meal preparation and other ADL in 4 weeks.
- To determine if local services exist to help her to transition to adult care (e.g. case manager or peer navigator).

Long-term goals:

- To develop a support network, and in particular, access to a teen or young adult support group.
 - To be able to participate in the community and increase her independence.
6. *What are some of the strategies that might be used to address these impairments, activity limitations and participation restrictions and help with the transition into adult care?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. Consider using the process of shared decision-making to prioritize treatment choices/strategies, and provide rationale. [Chapter 5-Paediatrics](#)

Strategies:

It is important that the strategies used to address her challenges take into account the ICF. By setting goals that address her impairments, this can lead to improvements in her activity limitations and participation restrictions. From a PT perspective, if her weakness is addressed, this can

improve her ability to transfer thus increasing her ability to participate in her community and increase her independence. Linking her with a "teen/young adult group" will help her feel more supported with her HIV status, especially since her mother is the only one aware of her HIV status. The Theresa Group is a supportive CBHO for families infected or affected by HIV that provides access to meal programs, supportive counselling for parents and kids (<http://www.teresagroup.ca/>). (The Theresa Group is Ontario based, however, CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology (<http://hiv411.ca>). Many people, including youth living with HIV, benefit from peer support programs. Examples of the range of peer support content include discussing diagnosis, sharing anxieties, support for exercise and other topics (i.e. coping as a single mom). If referral is to a non-HIV peer support program, the program should be screened for policies around discrimination, and there should be a discussion as to whether disclosure of HIV status is needed.

Linking with public transit for those with a disability could allow Natasha to participate more in her community and promote her independence. Having a social worker, case manager or peer navigator accompany her to the adult clinic for orientation will help with the transition and make the experience less intimidating.

Recordkeeping (e.g. tracking of exercise, medications, and other self-management techniques) may help Natasha to maintain her goals. Additional strategies may include keeping a daily reflection record, especially to identify items for discussion at the next healthcare appointment. All clients should also be encouraged to engage in some type of cognitive activity (e.g. reading, word games, or games on their cell phone). Mindfulness strategies (for example, mindful meditation) help many people living with HIV and concurrent disorders to manage their symptoms, stress and uncertainty.

7. *What kind of educational health promotion, prevention, care, treatment and support materials or information might you provide for Natasha?*

Notes: Education about adult care, what services are available to assist with IADL, stigma, disclosure issue, link with support group for young adults, drug benefit programs and other assistive programs through various community agencies. [Chapter 5-Paediatrics](#)

8. *What other health or social services might Natasha also benefit from having access to? Why?*

Notes:

- PT, SLP, OT, Dietitian [Chapter 5-Paediatrics](#)

- Follow up with augmentative/alternative communication clinic for up-to-date SLP and OT high-tech communication tools.
 - Apple iPads and tablet PCs are now adapted for use in augmentative/alternative communication and are relatively affordable.
 - Link to CBHO if she is interested (there may be barriers due to fear of stigma and unwanted disclosure by association to a CBHO).
 - Any links to service organizations for CP?
9. *What issues might Natasha need you to help her advocate for?*

Notes: Natasha may need help in linking with needed services in adult care and access to adult rehabilitation services. It will be important for her current team to liaise with whoever will be taking on Natasha's care to ensure a smooth transition. It will be important to check that the partners in this transition of care have sufficient HIV education and resources; appropriate contacts should be suggested if available. [Chapter 5-Paediatrics](#)

Supplemental Case Studies without Leading Questions

Need more practice? Julie Phillips, HIV Advanced Practice Nurse at Sunnybrook Health Sciences Centre, Toronto, Canada, developed these supplemental cases. We are hoping to develop a comprehensive rehabilitation focus and guiding questions and notes for each of these new cases. We can use your help! If you are interested to participate in the development of these cases, answer these questions and send your recommendations to us. Your content will be used to help further develop these cases, and you will be cited as a contributor on the final published version. Please forward your comments or content to *Realize* (formerly the Canadian Working Group on HIV and Rehabilitation) at <http://realizecanada.org> or info@realizecanada.org.

1. *What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that this patient is currently experiencing?*

Notes: Consider the physical, cognitive, social, emotional and psychological challenges faced by the patient and classify according to the ICF.

2. *What added complexity does the patient's concurrent health conditions have on his/her overall health?*
3. *What personal and environmental factors might influence the patient's recovery?*
4. *What additional factors should be considered?*
5. *What are some of the short-term and long-term rehabilitation goals for this patient?*

Notes: Consider patient values and preferences, and principles of shared decision-making, when discussing and developing goals. Use the SMART principle.

6. *What are some of the strategies that might be used to address the impairments, activity limitations and participation restrictions experienced by this patient?*

Notes: Consider patient values and preferences as well as key medical issues when discussing treatment strategies. Consider using the process of shared decision-making to prioritize treatment choices /strategies, and provide rationale.

7. *What kind of educational health promotion, prevention, care, treatment and support materials or information might you provide for this patient?*
8. *What other health or social services might this patient also benefit from having access to? Why?*
9. *What issues might this patient need you to help him or her advocate for?*

Case 1 - Reynaldo

Reynaldo is a 48-year-old gentleman who was on vacation in the Philippines in August 2013 when he developed headaches, visual changes and fever. He was admitted to hospital in the Philippines and diagnosed as HIV positive (HIV+) with cryptococcal meningoencephalitis. Reynaldo remained in hospital in the Philippines for 28 days and returned to Toronto and was admitted for treatment. Between October 2013 and September 2014, he required 8 admissions to hospital – spending more time in hospital versus out of hospital for a number of sequelae from HIV or treatment complications including fever, renal failure, *C. difficile* colitis.

Past Medical History: Type 2 Diabetes mellitus; gout

Social History: Prior to August 2013, Reynaldo worked two jobs as a machine operator. He was economically independent and owned his own condominium. His ethnicity is Filipino; he came to Canada in 1993. He is one of 5 children; he has 2 older sisters, 1 younger sister and brother. His sexual orientation is MSM.

After August 2013, Reynaldo sold his condominium, as he was unable to live on his own due to his ongoing health issues. He is now on long-term disability and is unable to return to work at this time. Reynaldo currently lives with his 2 sisters. His family members prepare his meals, provide transportation and accompany him to all his appointments.

Current Medical History:

- HIV+
- Disseminated Mycobacterium kansasii
- Polyarthritis
- Gout
- Hypertension
- Type 2 diabetes mellitus
- Stage 3 Chronic Kidney diseases
- Perinephric hematoma secondary to lithotripsy
- Depression

Medications:

| | |
|--|--|
| abacavir 600 mg OD ethambutol 800 mg OD ramipril 2.5 mg OD 3TC 300 mg OD isoniazid 300 mg OD rifabutin 150 mg OD darunavir 800 mg OD prednisone 15 mg OD pantoprazole 40 mg OD | ritonavir 100 mg OD fluconazole 200 mg OD hydroxyzine 50 mg po OD amlodipine 5 mg po OD mirtazapine 30 mg qhs febuxostat 80 mg OD insulin aspart 9 u s/c ac meals insulin glargine 27 u s/c |
|--|--|

Issues:

- Re-creating independence from family.
- Cannot go back to previous work – query return to school or retraining.
- Transitioning from the sick role.

Case 2 - Christopher

Christopher is a 55-year-old gentleman who was diagnosed as HIV positive in 1997. He has been on antiretroviral therapy since time of diagnosis. CD4 counts $>400/\text{mm}^3$ and viral load results have been below the level of detection. Earlier this year he was admitted to hospital with fever and abdominal pain. He was diagnosed with sepsis secondary to sigmoid perforation requiring total colectomy and several weeks in the ICU. He was discharged to a rehabilitation facility but was readmitted after 3 days with bleeding from his stoma. Investigations revealed cirrhosis of the liver and emphysema.

Past Medical History:

- HIV+ – 1997
- Pulmonary tuberculosis – 1997
- Kaposi sarcoma – 1997
- Recurrent anal abscess

Social History: Single. Currently lives alone and his housing is connected to his job as a building manager. Estranged from his brother (until this hospitalization). Parents are deceased. Friends described as his family but they do not live in Ontario. Ethnicity – Caucasian/English. Sexual Orientation – MSM. Christopher reports 4-5 drinks/night and 30 years of smoking one pack to a pack and a half of cigarettes/day.

Current Medical History:

- HIV+
- Cirrhosis of the liver
- Emphysema
- Total colectomy

Medications:

Atripla 1 tablet OD
spironolactone 25 mg OD
furosemide 40 mg OD
ipratropium bromide 20 mcg/puff ii puffs q6h
Gaviscon oral suspension OD – bid
pantoprazole 40 mg OD
Proferrin 1 tablet OD

Issues:

- Decreased mobility and strength.
- Previous to hospitalization he was independent with ADL but is now dependent.
- Unable to return to work at this time as building superintendent and therefore housing issues.
- New diagnosis of cirrhosis – recommended changes in lifestyle especially alcohol intake.
- New diagnosis of emphysema – dealing with smoking cessation.
- Mood changes secondary to body image – total colectomy.

Case 3 - Bill

Bill is a 59-year-old gentleman diagnosed as HIV positive in 2000. He experienced a myocardial infarction (MI) earlier this year but received no intervention other than Plavix and beta-blocker as the clot was over 48 hours. Bradyarrhythmia was asymptomatic and in normal sinus rhythm. Bill will require routine follow-up and if he becomes symptomatic then surgical intervention will be required. Bill's driver's licence was suspended because of the MI and he is to be reassessed.

Past Medical History:

- HIV+ – 2000
- Burkitt's Lymphoma – 2004
- Stage 3 Chronic Kidney Disease – secondary to chemotherapy
- Superior mesenteric vein thrombosis – 2002
- Anal fistula
- Obstructive sleep apnea
- Peripheral neuropathy secondary to chemotherapy
- Major depression in 2010 secondary to employment, financial and social stressors

Social History: Bill lives alone and has frequent job changes. His family lives in Montreal. He has no identifiable friendships/social network. Ethnicity – Caucasian/English. Sexual Orientation – MSM. Bill experiences ongoing financial stresses.

Current Medical History:

- HIV+
- Obstructive sleep apnea
- Peripheral neuropathy
- Restless leg syndrome
- Stage 3 Chronic Kidney Disease
- MI
- Obesity – BMI 37

Medications:

Kivexa 1 tablet OD
 Kaletra 2 tablets bid
 Pantoprazole 40 mg OD
 Plavix 75 mg OD
 Crestor 10 mg OD
 metoprolol 12.5 mg bid
 NTG spray PRN

Issues:

- Obesity – weight loss as treatment for coronary artery disease (CAD).
- Sedentary lifestyle – worsening of CAD.
- Current employment in jeopardy because of CAD.
- Increased risk for mood alterations because of MI and lifestyle changes required.
- Minimal social support.

Case 4 - Gail

Gail is a 54-year-old woman diagnosed HIV positive in 2013 after her husband tested HIV positive. She was diagnosed with non-Hodgkin's lymphoma in December 2012. Initial absolute CD4 count 10/mm³ and viral load viral load 295,000 copies/mL. One year later, her absolute CD4 count is 294/mm³ and viral load below the level of detection. Her non-Hodgkin's lymphoma is in remission. She does not feel physically able to return to work and has ongoing financial stress.

Past Medical History:

- HIV+
- Hypothyroidism
- Osteoarthritis
- Anxiety

Social History: Gail has been married for 30 years. Her husband was diagnosed as HIV positive 2012. Her parents are deceased and she has 2 sisters. Gail worked as a

collection officer until she went on long-term disability with the diagnosis of non-Hodgkin's lymphoma. Ethnicity – Caucasian/English. Sexual Orientation - WSM

Current Medical History:

- HIV+ 2013
- Hypothyroidism
- Osteoarthritis
- Anxiety
- Stage 2 Chronic kidney disease secondary to long-term use of meloxicam
- Abnormal Pap tests
- Shingles

Medications:

Truvada 1 tablet OD
 raltegravir 400 mg bid
 Meloxicam 15 mg OD
 lorazepam 1.5 qhs
 Elavil 150 mg qhs
 Synthroid .125 mg OD
 Cycloprine 10 mg OD
 Oxycocet PRN

Issues:

- Impaired ability to carry out ADL secondary to pain associated with osteoarthritis.
- Decreased energy levels.
- Persistent anxiety regarding finances and long-term disability.
- Social isolation – only she and her husband.

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