E-MODULE FOR EVIDENCE-INFORMED HIV REHABILITATION (E-MODULE)

2011
E-Module for Evidence-Informed HIV Rehabilitation (e-module)

Acknowledgements

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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 CWGHR or any sponsoring organizations.

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The content of this resource module has been updated from the 1998 publication:

A comprehensive guide for the care of persons with HIV disease. Issued also in French under title: Un guide complet de soins aux personnes atteintes d’une infection à VIH.

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CWGHR is a national multi-sector, multi-disciplinary, charitable organization of stakeholders involved in rehabilitation in the context of HIV. CWGHR 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 for 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 for 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 the Canadian Working Group on HIV and Rehabilitation (CWGHR) 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, CWGHR 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 CWGHR. 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 physiatry), nursing, occupational therapy, psychology, physical therapy, speech-language pathology, social work, pediatrics, midwifery, and policy. Through the leadership of CWGHR, 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.

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 seven chapters. Chapter 1 includes an introduction including 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 physiatry), 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 pediatrics. 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 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 specific 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.

How to Cite:

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CWGHR’s resources are intended to be shared with as broad a range of stakeholders as appropriate and the use of these materials is encouraged.

For further information on use of resources go to
http://hivandrehab.ca/EN/resources/documents/Form.doc

Keeping the E-Module Current

With the continually changing field and newly emerging evidence on HIV and rehabilitation, the electronic format of this e-module will facilitate timely updates to continually incorporate best current evidence.

For further information, to provide feedback, or to suggest updates for this e-module, please contact the Canadian Working Group on HIV and Rehabilitation (CWGHR) at www.hivandrehab.ca or info@hivandrehab.ca.

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ACRONYMS

Acronyms will occur 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.

ABPO: AIDS Bereavement Project of Ontario
ACT: Acceptance and Commitment Therapy
ABPO: AIDS Bereavement Project of Ontario
AFO: Ankle Foot Orthoses
AIDS: Acquired Immunodeficiency Syndrome
ASOs: AIDS Service Organizations
AVN: Avascular Necrosis
AZT: zidovudine
Botox: Botulinum toxin type A
BTA: Botulinum toxin type A
cART: Combination Anti-retroviral therapy
CAD: Coronary Artery Disease
CAMT: Complementary and Alternative Medicines and Therapies
CAS: Canadian AIDS Society
CATIE: Canadian AIDS Treatment and Information Exchange
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
ddC: zalcitabine
ddi: didanosine
d4T: stavudine
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
HSV: Herpes Simplex Virus
HRQL: Health Related Quality of Life
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
PHA: Person Living with HIV or AIDS
PHAs: People Living with HIV or AIDS
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.

CANADIAN WORKING GROUP ON HIV AND REHABILITATION – 2011 3
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- Capsaicin Patch
- Cognitive Behaviour Therapy
- Cryotherapy
- Dental Care
- Functional Electrical Stimulation
- Localized Injections and Radiofrequency Neurotomy

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- Arts Based Therapy
- Botox
- Canabanoids
- Capsaicin Patch
- Cognitive Behaviour Therapy
- Cryotherapy
- Dental Care
- Functional Electrical Stimulation
- Localized Injections and Radiofrequency Neurotomy

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1.1.1.1 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 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 (PHAs) 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 PHAs.

The Canadian Working Group on HIV and Rehabilitation (CWGHR) 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 PHAs in this new context (www.hivandrehab.ca). Guided by the ICF framework, CWGHR 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:

CWGHR 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. However, there are a number of 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, chiropractors, CAMTs), 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 International Classification of Functioning, Disability and Health (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 PHAs, including their role in enhancing their labour force and overall social participation.

1.1.1.2 A New Concept - Episodic Disability

Along with advocacy efforts geared specifically at HIV, the Canadian Working Group on HIV and Rehabilitation (CWGHR) 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 which 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 refer to experiences of disableness that are unpredictable and intermittent in nature.

Recognition of the unpredictable nature of living with HIV has proven to be a crucial milestone in the Canadian context for advancing policy advocacy. CWGHR has coordinated ongoing efforts in this area. This includes 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 multisectoral summit on episodic disabilities in 2006 (http://www.hivandrehab.ca/EN/resources/episodic_disabilities.php).

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. 2008a, O’Brien et al. 2009). Participants perceived disability as multi-dimensional and episodic in nature, 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 in order 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. 2008a).

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. The Episodic Disability Framework describes disability experienced by adults living with HIV, as multi-dimensional and episodic in nature (O’Brien et al. 2008a and 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:

A. 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.

B. 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 health care services and personnel, and programme 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).

C. 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. 2008a, 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 their 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. More information can be found on the CWGHR website (www.hivandrehab.ca). 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 health care needs, by the very nature of their disease process, tend to fluctuate.

As PHAs who have access to antiretroviral therapy live longer, the long-term impacts of HIV and its treatments, in combination with aging itself, may include 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). The common feature of these other conditions are that they can all be episodic both in nature and impact. As such, PHAs may experience several episodic conditions concurrently, all with different fluctuations in their
functioning and health. Thus, the corresponding need for rehabilitation is expanding in order 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 or AIDS (PHAs) 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 and AIDS (PHAs) 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 be the focus of the care which may be provided by a wide range of professional and non-professional care providers. Evidence-based treatment options are discussed in Section 6. The approach of rehabilitation providers to client-centred care is compatible with the needs of PHAs. 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 (www.hivandrehab.ca).

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/AIDS and to build capacity for rehabilitation professionals to better address the health-related challenges of PHAs.

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 includes those without a condom or barrier device either through engaging in vaginal, anal or oral intercourse and cannot include 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), heroine 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 (http://www.sida-aidsmoncton.com/hiv.php).

1.1.2.1.3 Mother-to-Child Transmission
Mother-to-child transmission, also referred to as vertical transmission or peri-natal 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 breast feeding. 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 breastmilk (World Health Organization 2006). Transmission can be significantly reduced with the use of antiretroviral therapies.

1.1.2.1.4 Occupational Exposure
In health care settings, occupational exposure occurs when the HIV virus enters into a health care worker’s blood stream. 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. Current estimates of transmission by occupational needlestick exposure has been estimated to be 1 in 300 (Aberg et al. 2009).

When working with people living with HIV or AIDS, use standard precautions should be used regardless of serostatus. 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 contractility which 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 with respect to HIV transmission is “if it dries; it dies”. However, it is very important to remember that there are other blood borne pathogens which last longer outside the body, such as Hepatitis C.

1.1.2.1.5 Blood and Blood Products
Current estimates 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 and thus blood and blood products pose predominantly a theoretical risk. Screening includes both blood testing and interviews of donors to identify those who may pose a risk of transmission.

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. This 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 to occur 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 restoration of immune function.

1.1.2.2.1 Viral Load
Viral load is a surrogate marker which 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 millimetre cubed (cells/mm³) or cells/ul. A healthy, normal CD4 count level is between 500 to 1500 cells/mm³. 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 less than 200 cells/mm3.

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) are 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 "integrate", 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 target 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 naive 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 factors and can be variable depending on stressors, illness, time at which was measured and other factors. 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. 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/mm3 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). A low or undetectable viral load indicates that the virus is less active and therefore is less likely to cause cell damage or to be transmitted since there are fewer viruses in circulation. It is important to note however that it is still possible to transmit the virus.

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 their HIV status. There becomes 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. Throughout this module individuals living with HIV and/or AIDS will refer to people living with HIV or AIDS (PHAs).

1.1.3 Epidemiology

In a 2008-2009 report, the World Health Organization estimated that there were 33.4 million cumulative worldwide cases of HIV and that 2.7 million people were infected in 2008 alone (WHO 2009a).

1.1.3.1 HIV in Canada

An estimated 65,000 adults and children are living with HIV in Canada (Public Health Agency of Canada (PHAC) 2009a, 2009b). Of these, approximately 30% do not know they are infected. 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 in the last 10 years have been relatively consistent. Recently, however there has been a slight increase in the number of new infections with approximately between 2300 to 4500 new cases per year reported in 2005 (PHAC 2009a, 2009b).

The introduction of combination antiretroviral therapy (cART) in the mid-1990s has dramatically reduced the morbidity and mortality associated with HIV among clients who have access to treatment (Mocroft et al. 2003). Life expectancy with HIV in well-resourced countries is now estimated to be up to two-thirds that of the general population (Antiretroviral Therapy Cohort Collaboration 2008, Lohse et al. 2007).

1.1.3.2 Canadian Impact

The Public Health Agency of Canada identified certain populations are particularly vulnerable to HIV in Canada (PHAC 2009a, 2009b). 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 accounts 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. These terminology will be used throughout the rest of this manual, with certain caveats as addressed under each classification (PHAC 2009a, 2009b).

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 becomes 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 2009a, 2009b). 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 and share drug use equipment are at high risk for HIV transmission and represent almost 20% of the infected population in Canada (PHAC 2009a). 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).

1.1.3.2.3 Aboriginal Peoples

Aboriginal peoples represented approximately 9% of new HIV infections in Canada in 2005 (Boulos et al. 2006) and comprised 24.4% of reported AIDS cases in 2006 (PHAC 2007a). People who identify as Aboriginal (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 Aboriginal population to HIV infection and limit the ability of communities to give high priority to HIV prevention initiatives. Not only do many Aboriginal peoples face disproportionately high and frequent levels of poverty, drug abuse, 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 Aboriginal communities, constituting the majority of all HIV infections for Aboriginals for whom exposure category information exists (Miller et al. 2006). Even though the proportion of cases attributed to heterosexual exposure is similar to non-Aboriginal communities in Canada, Aboriginal peoples have a higher proportion of HIV infection from injection drug use and a lesser proportion than the rest of the Canadian population from gay, bisexual and other men who have sex with men (MSM).

HIV has an impact on Aboriginal women that significantly differs from its impact on the non-Aboriginal female community (Duncan et al. 2010). In contrast to HIV and AIDS cases in the non-Aboriginal population, where women make up a little less than 20% of the total HIV positive population in Canada, Aboriginal females represent nearly half of all positive HIV test reports among Aboriginal peoples. Most Aboriginal women infected with HIV attribute their infection to IDU, while approximately one third relate it to heterosexual exposure.

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

Current evidence predicts that the HIV epidemic in Aboriginal communities is not slowing down. The HIV situation in Aboriginal communities is complicated by challenges commonly encountered in vulnerable populations, including substance abuse, 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 Aboriginal peoples, this legacy can contribute to a continued distrust of institutions, including health care organizations. Consequently, intervention strategies must take into account the unique needs of Aboriginal peoples and their communities. This can include involving members of the Aboriginal communities in developing policy and strategies, as well as incorporating a holistic view of health that neither under-mines the emotional and spiritual elements of many Aboriginal belief systems nor excludes Aboriginal 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/national-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.

Aboriginal peoples are overrepresented in the Canadian prison system, comprising 2.7% of the national population while constituting 18.5% of the federal prison population (Office of the Correctional Investigator (OCI) 2010). Notably, female Aboriginal Peoples are even more overrepresented in the Canadian Prison System than are their male counterparts (OCI 2010). Moreover, Aboriginal youth are more likely to be imprisoned than non-Aboriginal Canadian youth. Aboriginal youth are also more likely to be incarcerated for longer periods of time, beginning at an earlier age (OCI 2010). This clearly 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 10 to 24 years of age still represent a relatively small percentage of the total incidence of people infected with HIV in Canada (Public Health Agency of Canada (PHAC) 2007b). However, the potential for HIV transmission is high among this group based on reported risk behaviours, including sexual behaviour, substance abuse, and perceptions amongst youth. Youth considered to be at high risk for infection includes 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 bi-sexual youth are more vulnerable than their heterosexual peers; and Aboriginal youth are at greater risk than non-Aboriginal populations.

1.1.3.2.6 Women

The number of women living with HIV and AIDS in Canada continues to grow, particularly in Aboriginal populations. By the end of 2005, women accounted for approximately 20% of people living with HIV in Canada (Boulos et al. 2006). While HIV affects both women and men, a number of socio-economic factors fuel the epidemic and place women at increased susceptibility to infection in addition to physiologic differences. Issues such as poverty, marginalization, gender power inequalities, and violence, increase the vulnerability of women to HIV infection (Gatali and Archibald 2003). 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 pre-natal screening policies and measures to provide treatment to reduce the risk of transmission. Pre-natal 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 0.5% in 2007.

Correspondingly, the proportion of HIV positive mothers receiving antiretroviral therapy increased steadily, reaching almost 90% in 2007 (Public Health Agency of Canada 2008).

1.1.3.2.7 People from HIV-Endemic Countries

In 2007, people arriving from countries where HIV is endemic accounted for almost 15% of the total number of positive HIV tests reported to the Public Health Agency of Canada (PHAC 2008). The number of positive HIV tests attributed to people from endemic countries decreased by 45.5% between 2006 and 2007. This decline was especially pronounced among women. A variety of factors may explain the decrease in the number of positive HIV tests that cite origin from an HIV-endemic country as the main risk associated with HIV infection, including changes in data reporting practices, in immigration and/or settlement patterns, testing behaviours and/or access to culturally appropriate HIV prevention and treatment services (PHAC 2008).

1.2 Interacting with Communities

This section explores the social dimensions of HIV disease from the perspective of people living with HIV or AIDS (PHAs). 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 chapter was written by a PHA panel 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, Aboriginal 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 government support programs; some of which face service cuts, while others are discriminatory. For instance, some assistance programs specifically disqualify people whose disability arises from drug or alcohol use.

Despite set-backs, a climate of renewed hope has developed among those for whom drug treatments have been successful. Some people living with HIV or AIDS (PHAs) are making long-term plans again, considering returning to work, and even viewing the uncertainty surrounding treatment with optimism. Today, care providers will encounter a broader spectrum of attitudes towards HIV.

In the affected communities in Canada, few people have escaped chronic emotional trauma and loss. Almost everyone has been touched by HIV either through his or her own infection, the illness of friends or family members, or the death of partners in the prime of their lives. Some PHAs become remarkable survivors, coping with illness, and actively participating in their own care. They grow personally from the experience. Many make extraordinary contributions to their communities. Others do not, and are physically and psychologically devastated; of these, some can move forward with supportive intervention.
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 and AIDS (PHAs). In many ways, AIDS service organizations (ASOs) 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 from 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 “PHAs helping PHAs”. 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 PHAs, 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 changing constantly. 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 PHAs, 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, bread-winner and care provider, all at once. Notably, in the process of developing 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 or AIDS (PHAs) report that at times, HIV dominates their identity, superceding 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 Aboriginal person,” each being true. Furthermore, identity evolves. People change as life unfolds.

As a health care 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 the a perception of what “that type of person is like” is usually fraught with pitfalls. Often times, 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 can play a key role in helping individuals to attain significant identity milestones. For example, speech-language pathologists play an important role for those undergoing sex reassignment by helping people to speak like the gender they are becoming or have become (Carew et al. 2007, Associated Press 2010).

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 in their 60s and beyond, age is now an increasingly complex issue for people living with HIV (PHAs). Age should be incorporated and recognized as part of a PHA's identity.

1.2.7 Chosen Family

Many people develop close ties with people from their own communities who serve as a “chosen family”. 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.

In addition, 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 health care 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
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 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 and AIDS (PHAs) 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
- 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

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 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, underlying complications, such as severe mental illness, particularly when coupled with homelessness or addiction, make it difficult for some people living with HIV or AIDS (PHAs) to address HIV. This highlights the need for comprehensive care programs that emphasize holistic treatment. In this sense, the relationship between a PHA and a 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.

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.
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 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](http://www3.who.int/icf/icftemplate.cfm).

While many health care providers have been providing rehabilitation treatment and care to PHAs 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 health care professionals who have not traditionally been involved in HIV issues, such as physiatrists, occupational therapists, social workers, speech-language therapists and physiats, as well as specialists in complementary therapies and alternative medicines. To a large degree, the incorporation of complementary and alternative medicines was initiated by PHAs. All care providers have an important role to play in helping people living with HIV and AIDS (PHAs) 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.

Interventions designed to prevent or postpone disease progression play an important role in helping people living with HIV and AIDS (PHAs) 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 PHA 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 through 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 PHAs can be found in Section 7.5 Resources.

Some of the challenges faced by PHAs may be caused by physical changes in the body.

### 1.3.2 Physical Rehabilitation

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### 1.3.2.1 Physical Therapist

A physical therapist (physiotherapist) 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 can help people living with HIV or AIDS (PHAs) to manage daily activities and make adjustments in the home or workplace to allow for any physical 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
- Suggesting ways of organizing activities in order to conserve energy
- Accessing helpful aids or equipment
- Strategizing around complex medication schedules
- Determining how family or other services in the community can provide support

An important companion guide for PHAs is the 4th Edition of Managing Your Health: a guide for people living with HIV (CATIE 2009) 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 ([www.catie.ca](http://www.catie.ca)).
1.3.2.3 Speech-Language Pathologist
A speech-language pathologist (speech therapist) can be involved with (but not limited to):

- Helping with issues affecting communication and swallowing
- Helping to maximize 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 and AIDS (PHAs). Unfortunately, some health care 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 PHAs also find that CAMTs are 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 CAMTs for PHAs (www.catie.ca; note CATIE will be changing their information management system in 2011 and therefore direct links to individual reports have not been included).

1.3.4 Vocational Rehabilitation
As a result of changes in the treatment of HIV, returning to or remaining in the work force, 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 work force participation, particularly for people with episodic disabilities such as HIV. Many community-based AIDS 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 counseling, financial and career planning, and vocational rehabilitation).

In addition, there are very recent initiatives to improve programs to allow flexible work force participation. This area is discussed in detail in Section 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 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, to develop and implement a realistic vocational plan.
1.3.6 Basic Components of a Rehabilitation Program

In rehabilitation, the person living with HIV or AIDS (PHA) 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 PHA, 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 PHA’s decision
- 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
- Discharge planning and coordination of services

Additional information on client-centred care, health system navigation and advocacy is 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 AIDS Service Organizations
- A Client’s own Home
- Hospices
- Work Settings
- Schools
- Wellness Centres
- Community Parks and Recreation Programs (e.g., YMCAs)
- Public Health Services

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

The Canadian AIDS Society (www.cdnaids.ca) can help identify an AIDS Service Organization (ASO) in specific areas. The Canadian AIDS Treatment Information Exchange also maintains an online database of ASO contact information (http://www.aso411.ca). ASOs 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.
1.3.8 How Can People Living with HIV Access Rehabilitation Services?

In many cases, people living with HIV or AIDS (PHAs) 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 the service is provided by a local AIDS service organization (ASO), a referral may not be necessary and the service may be free. Once at the specific rehabilitation service, the PHA 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, as well as a number of other factors including insurance requirements and standards of practice for each rehabilitation service being sought out. Some ASOs have been able to successfully partner with professional schools. In one Toronto ASO, student clinicians and their respective supervisors from the fields of acupuncture, massage therapy and physical therapy provide treatments to ASO 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 generally 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 or AIDS (PHA) and his or her care provider will negotiate with local rehabilitation providers, human resource departments, insurance companies and/or their local AIDS service organization to find out what is covered. Some of the possibilities include:

1.3.9.1 Provincial Health Plan

If rehabilitation services are provided while in hospital they are covered by most provincial health plans. 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 AIDS Service Organizations

Local AIDS service organizations (ASOs) may provide some rehabilitation services for free either on site or through a referral system to a local provider. Some ASOs also offer financial assistance to their clients by providing partial or full reimbursement for some health care services and expenses.

Despite the importance of rehabilitation for people living with HIV or AIDS (PHAs) 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. The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, non-profit, multi-sector and interdisciplinary organization, on HIV and rehabilitation. For additional resources, information and links visit the CWGHR website at www.hivandrehab.ca.
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 include those related to the effectiveness and safety of interventions; the frequency or rates of diseases or conditions; aetiology 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 the strength of 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 (http://library.downstate.edu/EBM2/2100.htm). Some authors suggest that the current evidence hierarchy has limitations and that a broader evidence base is needed to implement patient-centred care (Rycroft-Malone et al. 2004, Upshur 2001). 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.

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 limitation (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, 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 indi-
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 AIDS (PHAs), 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 policy makers 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 particular point in time. This description can then be used to compare the client to other clients or the general population. For example, measuring CD4 count at one point in time or measuring 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 it 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 the measure is free from error (Streiner and Norman 2008). It is important that measures are reliable (or consistent) to compare scores accurately 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 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.

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) in the score for a given measure (Streiner and Norman 2008, Beaton et al. 2002). For example, the MCID for the six minute walk test is 25 metres 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 that the client had 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 or questionnaire cluster at the more negative health state end of scale. For instance, if the scale were administered a second time, there would be no room to detect any possible deterioration in the client, even if that were the case.

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 improvements, even if they had in 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 PHAs, 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) 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.

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” 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 concept. Is the intent to describe; predict; or evaluate change over time? Different outcome measures are developed with 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 exist to choose from. It is important to review the literature and talk to other health professionals about different outcome measure options available to measure the desired concept. Consider feasibility such as the length of the outcome measure (number of items), 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 and AIDS (PHAs)? If evaluating change over time, determine whether this measure has been considered to be responsive. More specifically, is it 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 PHAs 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 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 the rehabilitation provider to compare how a client might be doing in comparison to other people living with HIV or AIDS (PHAs), 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 health care 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.
<table>
<thead>
<tr>
<th>Measure</th>
<th>Construct Measured</th>
<th>Generic versus Specific</th>
<th>Purpose</th>
<th>Administration</th>
<th>Number of Items</th>
<th>Number of Domains</th>
<th>Measurement Properties</th>
</tr>
</thead>
</table>
| Centres for Epidemiological Studies Depression Scale (CES-D) (Radloff 1977) | Depression         | Generic                 | Descriptive        | Self-reported questionnaire | 20 items        | 8 domains         | Reliability: high internal reliability (≥ 0.85) and adequate test-retest reliability on a general adult population.  
Validity: Concurrent construct validity on a general adult population.  
Also demonstrated predictive construct validity and high internal consistency reliability on a population with Hepatitis C. (Clark et al. 2002) |
| Functional Assessment of HIV Infection (Cella et al. 1996)             | Health-related quality of life | HIV-specific            | Descriptive         | Self-reported questionnaire | 47 items        | 5 domains         | Reliability: Internal consistency reliability (>0.73 Cronbach’s alpha for all domains)  
Validity: convergent and discriminant validity among adults living with HIV.  
Responsiveness to change among adults living with HIV. (Peterman et al. 1997) |
| HIV Symptom Index (Justice et al. 2001)                                | Symptom presence and bothersome | HIV-specific            | Descriptive         | Self-reported questionnaire | 20 items        | Not Applicable    | Validity: Good construct validity among people living with HIV on combination anti-retroviral therapy. |
| HIV Fatigue Scale (Barroso and Lynn 2002)                              | Fatigue            | HIV-specific            | Descriptive         | Self-reported questionnaire | 56 items        | 3 domains         | Reliability: High internal consistency reliability. Cronbach’s alpha was >0.90 on all domains) among people living with HIV-related fatigue.  
Cronbach’s alpha for the entire tool was 0.94.  
Test-retest reliability was moderate with a correlation coefficient of 0.43.  
Validity: Good convergent construct validity among people living with HIV-related fatigue. (Pence et al. 2008) |
| 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) | Demonstrated reliability and validity among people living with HIV.  
Reliability: Good internal consistency reliability among people living with HIV (all Cronbach alpha values typically > 0.80) and good test-retest reliability.  
Validity: Demonstrated content validity, criterion validity, construct validity with people living with HIV (McHorney et al. 1993, McHorney et al. 1994) |
<table>
<thead>
<tr>
<th>Measure</th>
<th>Construct Measured</th>
<th>Generic versus Specific</th>
<th>Purpose</th>
<th>Administration</th>
<th>Number of Items</th>
<th>Number of Domains</th>
<th>Measurement Properties</th>
</tr>
</thead>
</table>
| 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) | **Reliability:** Good internal consistency (>0.75 Cronbach's alpha) for all dimensions for people living with HIV.  
**Validity:** Convergent and discriminant construct validity with people living with HIV. (Wu et al. 1997b, Badia et al. 2000) |
| Multidimensional QOL Questionnaire for HIV/AIDS (MQoL-HIV) (Avis 1997) | Health-related quality of life | HIV-specific            | Descriptive       | Self-reported questionnaire | 40 items       | 10 domains            | **Reliability:** Good internal consistency reliability (>0.70 Cronbach's alpha for 8 out of 10 domains) and test-retest reliability (correlation coefficient >0.70 for all domains except cognitive functioning) among people with asymptomatic and symptomatic HIV infection.  
**Validity:** Discriminative construct validity among people with asymptomatic and symptomatic HIV infection.  
**Responsiveness:** Responsive to change in number of symptoms, viral load and CD4 count during a 3 month period for people living with HIV starting or changing an anti-retroviral therapy regimen (Badia et al. 2000) |
| Perceived HIV Self-Management Scale (PHIVSMS) (Wallston et al. 2010)   | Self management self efficacy | HIV-specific            | Descriptive       | Self-reported questionnaire | 8 items       | 1 domain            | **Reliability:** Good internal consistency reliability with Cronbach's alpha 0.78 with adults (primarily men) living with HIV.  
**Validity:** Construct validity demonstrated in adults living with HIV with correlations to criterion measures of HRQL and depression ranging from 0.37-0.66. |
<table>
<thead>
<tr>
<th>Measure</th>
<th>Construct Measured</th>
<th>Generic versus Specific</th>
<th>Purpose</th>
<th>Administration</th>
<th>Number of Items</th>
<th>Number of Domains</th>
<th>Measurement Properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>World Health Organization Quality of Life HIV Instrument (WHOQOL-HIV) (O’Connell et al. 2003, WHOQOL HIV Group 2004).</td>
<td>Health-related quality of life</td>
<td>HIV-specific</td>
<td>Descriptive</td>
<td>Self-reported questionnaire</td>
<td>120 items</td>
<td>6 domains</td>
<td><strong>Reliability</strong>: 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. <strong>Validity</strong>: Good discriminant validity among people living with HIV in diverse cultural settings. (Fang et al. 2002, WHOQOL HIV Group 2004)</td>
</tr>
<tr>
<td>HIV Stress Scale (Pakenham and Rinaldis 2002)</td>
<td>Stress</td>
<td>HIV-specific</td>
<td>Descriptive</td>
<td>Self-reported questionnaire</td>
<td>29 items</td>
<td>3 domains</td>
<td><strong>Validity</strong>: Convergent construct validity among men living with HIV. (Pakenham and Rinaldis 2002)</td>
</tr>
<tr>
<td>HIV Stigma Scale (Berger et al. 2001)</td>
<td>Stigma</td>
<td>HIV-specific</td>
<td>Descriptive</td>
<td>Self-reported questionnaire</td>
<td>16 items</td>
<td>4 domains</td>
<td><strong>Reliability</strong>: Good internal consistency reliability (Cronbach’s alpha ≥ 0.90 for subscales and 0.96 for the summary scale) among people living with HIV. <strong>Validity</strong>: Construct validity in a sample of people living with HIV.</td>
</tr>
<tr>
<td>Medical Outcomes Study Social Support Survey (MOS-SS) (Sherbourne and Stewart 1991)</td>
<td>Social Support</td>
<td>Specific to Chronic Illness</td>
<td>Descriptive</td>
<td>Self-reported questionnaire</td>
<td>19 items</td>
<td>5 domains</td>
<td><strong>Reliability</strong>: High internal consistency reliability (Cronbach’s alpha ≥ 0.90) among people living with HIV. <strong>Validity</strong>: Convergent and discriminant construct validity demonstrated among people living with HIV.</td>
</tr>
<tr>
<td>Brief Coping Scale (Carver et al. 1989)</td>
<td>Coping response</td>
<td>HIV</td>
<td>Descriptive</td>
<td>Self-reported questionnaire</td>
<td>28 items</td>
<td>14 domains</td>
<td><strong>Reliability</strong>: Adequate internal reliability (all α ≥ 0.50) among general population. <strong>Validity</strong>: Construct validity demonstrated among general population (Carver 1997)</td>
</tr>
</tbody>
</table>

* Cronbach’s alpha (α) 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). Nunally suggests that a Cronbach’s alpha of >0.9 is defined as acceptable for individual patients (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). The Canadian Working Group on HIV and Rehabilitation (CWGHR) 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 or AIDS (PHAs), researchers, educators, practitioners, and policy makers with expertise in HIV and rehabilitation, across Canada and internationally (O’Brien et al. 2008c). The purpose of this study was to develop 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. 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 or AIDS 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 or AIDS (PHAs) living in their social context.

Best practices should:
- Incorporate an understanding of the diversity of PHAs
- Understand the social justice issues and challenges PHAs 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

2.1.3.3 Theme Three

Theme Three addresses systems level issues that greatly impact on the rehabilitation care that may be received by persons living with HIV or AIDS (PHAs).

Best practices should:
- Address access to care and include strategies to maximize access to rehabilitation services and assisting PHAs 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
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 up in the client-provider relationship.

2.3.4.1 History-Taking and Assessment

In most health care 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:

2.3.4.1.1 Medical History

The medical history of a person living with HIV or AIDS (PHA) 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. 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 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.

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.
CHAPTER 3
SYMPTOMS AND IMPAIRMENTS

3_1 Introduction

Providing rehabilitation services for people living with HIV or AIDS (PHAs) is not a new concept. Since the beginning of the epidemic, health care professionals and clients have been actively involved in enhancing performance at home and work throughout the entire continuum of HIV disease.

Fortunately, general rehabilitation philosophy and management principles can be readily applied to rehabilitation services for PHAs. This chapter links basic medical and rehabilitation information to symptoms and impairments, which allows rehabilitation providers to provide appropriate care for PHAs. 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 a wide range of rehabilitation interventions is outlined in Section 6.

Table 3.1 Examples of Rehabilitation Intervention Categories

<table>
<thead>
<tr>
<th>General Intervention Category</th>
<th>Examples of HIV-Related Complications</th>
<th>Examples of Possible Rehabilitation Interventions</th>
</tr>
</thead>
</table>
| Prevention of further complications | • prolonged bed rest from medical illness | • positioning and mobility assessment  
• muscular contractures due to hemiparesis from cerebral toxoplasmosis  
• dysphagia from brainstem tumor | |
| Enhancement of affected systems | • right-sided weakness from CNS lymphoma | • neuro-facilitation techniques by therapists  
• dysarthria from PML  
• generalized weakness from HIV-associated weight loss | |
| Enhancement of unaffected systems | • paraplegia due to vacuolar myelopathy | • strengthening of arms for transfers and wheelchair propulsion  
• left-sided weakness following stroke in a left-hander | |
| Use of adaptive equipment | • shoulder weakness due to AZT-induced myopathy | • use of bilateral forearm orthosis for table-top activities  
• ankle weakness due to mononeuropathy simplex | |
• ankle foot orthosis to facilitate ankle dorsiflexion during gait |
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 in high risk populations (Grant et al. 2010).

3.1.4 Uniqueness of Persons Served

HIV disease has hit hardest among certain segments of the population, such as persons in mid-life or younger, gay and bisexual men, people who use injection drugs, the poor, urban minorities, prison inmates and Aboriginal 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 with him or her and his or her 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 or AIDS (PHAs), depression can manifest as sadness, crying, changes in sleep and appetite, depressed mood, apathy, and lack of pleasure. Depression is sometimes confused with early HIV dementia because other conditions - such as impaired concentration and judgment, agitation, psychomotor retardation, diminished motivation, and lethargy - exhibit symptoms similar to those associated with depression. The diagnosis of depression is even more complicated when the individual:

- Is involved in substance use and abuse
- 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 to 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/AIDS services organizations (commonly called ASOs) provide a wide range of health promotion services and programs for people living with HIV or AIDS (PHAs) and their caregivers. Although not usually described as “rehabilitation services,” many are designed to enable PHAs 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 PHAs 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 PHAs and their caregivers to relevant professional and community resources. Community-based ASOs 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 a PHA. 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 sections 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 described in this chapter could 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 shown 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.
Management of pain in HIV infection generally 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 immediate medical referral.

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

Note: The tables and lists of interventions presented in this chapter 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 or AIDS (PHAs). 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 premorbid injury, tend not to be life-threatening. Likewise, rheumatological 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.

Table 3.2 Clinical Aspects of Pain

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
</table>
| Myofascial pain (including headache) syndromes| • inactivity, poor posture, deconditioning  
• exacerbation of pain by anxiety or depression  
• inadequate sleep |
| Joint pain                                    | • 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 painful right knee) |
| Myopathy                                      | • inflammatory (e.g., polymyositis)  
• non-inflammatory  
• toxic (e.g., AZT) |
| Respiratory tract disease                     | • infection (e.g., PCP, TB)  
• tumour (e.g., KS)  
• pneumothorax  
• pulmonary embolus  
• pleural infarction |
| Pain associated with CNS lesions (including headache) | • 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 | • HIV-mediated  
• drug-induced (e.g., ddC, d4T, ddi)  
• vitamin deficiency (e.g., B12) |
| Mononeuropathy simplex and multiplex | • primary effect of HIV  
• secondary immune complex  
• CMV (in late disease) |
| Progressive polyradiculo-myelopathy | • CMV infection of the cauda equina |
| Esophageal and abdominal pain | • infections (e.g., esophagitis)  
• malignancies  
• renal colic  
• hepatitis  
• drug-induced (e.g., narcotics, indinavir)  
• obstructions  
• biliary tract disease  
• pancreatitis  
• colitis  
• enteritis  
• malabsorption |
| Somatization, psychological pain disorder | • psychological factors have a major role in onset, exacerbation, severity, and maintenance of pain |
| Other sources of neuropathic pain | • acute herpes zoster, post-herpetic neuralgia |

**Legend:** **AZT:** zidovudine, **CMV:** cytomegalovirus, **CNS:** central nervous system, **ddc:** zalcitabine, **ddl:** didanosine, **d4T:** stavudine, **KS:** Kaposi’s sarcoma, **PCP:** Pneumocystis carinii pneumonia, **TB:** tuberculosis.
3.2.1 Rehabilitation Interventions

3.2.1.1 Peripheral Neuropathic Pain

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 (AFO) 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, antiseizures, antispasmodics and other co-analgesics, and adjuvant medications
• The International Association for the Study of Pain has recently released a review of interventions for painful HIV-associated sensory neuropathy (Phillips et al. 2010).

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

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)

3.2.3 Medications Management
• Trial of analgesics, anti-inflammatories, antidepressants, antiseizures, antispasmodics and other co-analgesics, and adjuvant medications

• Carefully check the temperature of bath water with unaffected limb
• Use caution when trimming toenails
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
- Reiki
- Massage Therapy
- Craniosacral Therapy
- Myofascial Release
- Shiatsu

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 practising 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 AIDS Service 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 or AIDS (PHAs) with a confirmed diagnosis of arthritis can make a self referral to the Arthritis Society Arthritis Rehabilitation and Education Program (www.arthritis.ca/ontario). Treatment is funded through the provincial government.
- In the rest of Canada, the Arthritis Society provides a variety of services 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 neuro-imaging may be necessary to initiate proper medical treatment before or during rehabilitation intervention.

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

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focal lesions of brain</td>
<td>• cerebral toxoplasmosis, fungal or bacterial abscess, PML</td>
</tr>
<tr>
<td></td>
<td>• HIV-related stroke in cerebrum or brainstem</td>
</tr>
<tr>
<td></td>
<td>• CNS malignancy (primary lymphoma, metastatic)</td>
</tr>
<tr>
<td></td>
<td>• long-term alcohol abuse</td>
</tr>
<tr>
<td>Spinal cord lesion</td>
<td>• HIV vacuolar myelopathy</td>
</tr>
<tr>
<td></td>
<td>• tumour of the spinal cord (e.g., lymphoma)</td>
</tr>
<tr>
<td></td>
<td>• abscess (bacterial, fungal, TB)</td>
</tr>
<tr>
<td></td>
<td>• progressive polyradiculo myelopathy from CMV</td>
</tr>
</tbody>
</table>
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
- Assess clients for cognitive factors, including poor insight and impulsivity, and motor factors which may increase fall risk
- 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
- 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 reacher to pick things up off the floor

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, bathseats)
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 are 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 recent study’s finding on the qualitative effects of fatigue of people living with HIV or AIDS (PHAs) demonstrates that although most experience chronic fatigue, it is rarely acknowledged or recognized by family, friends, co-workers and even health care 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, which has been shown to have even higher levels of fatigue and depression and lower quality of life than those living only with HIV or seronegative individuals (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>
<thead>
<tr>
<th>Table 3.4 Clinical Aspects of Fatigue</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category</strong></td>
</tr>
<tr>
<td>Nutritional deficiencies</td>
</tr>
<tr>
<td>Infections</td>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>Malabsorption</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Anemia</td>
</tr>
<tr>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Medication-induced fatigue</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Psychological</td>
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<tr>
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<tr>
<td></td>
</tr>
<tr>
<td>Metabolic</td>
</tr>
<tr>
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</tr>
</tbody>
</table>

Legend: AZT: zidovudine; MAC: Mycobacterium avium complex
3.4.1 Rehabilitation Interventions

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. Some examples include:

- 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

3.4.1.2 Environmental

- 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 decadurabolin)

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 counseling
  - 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
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.

Table 3.5 Clinical Aspects of Weight Loss

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia</td>
<td>• esophagitis (e.g., CMV, HSV, candida)</td>
</tr>
<tr>
<td></td>
<td>• psychological, emotional, or psychiatric problems</td>
</tr>
<tr>
<td></td>
<td>• abnormal taste, pain, or dysphagia (e.g., oral and esophageal candidiasis, HPV, KS, OHL, CMV, HSV, aphthous ulcers, drug effect, idiopathic)</td>
</tr>
<tr>
<td></td>
<td>• tumour necrosis factor, cytokine dysregulation</td>
</tr>
<tr>
<td></td>
<td>• medication-related (e.g., AZT, ddI, ddC, ritonavir, indinavir, saquinavir)</td>
</tr>
<tr>
<td></td>
<td>• chronic infection</td>
</tr>
<tr>
<td>Malabsorption with or</td>
<td>• HIV enteropathy</td>
</tr>
<tr>
<td>without diarrhea</td>
<td>• secondary infections (e.g., MAC, cryptosporidium, microsporidium)</td>
</tr>
<tr>
<td></td>
<td>• medication-related (e.g., ddI, ritonavir, nelfinavir)</td>
</tr>
<tr>
<td>Obstruction</td>
<td>• tumour (e.g., KS, lymphoma)</td>
</tr>
<tr>
<td>Endocrine dysfunction</td>
<td>• adrenal insufficiency</td>
</tr>
<tr>
<td></td>
<td>• hypogonadism</td>
</tr>
<tr>
<td></td>
<td>• hypothyroidism</td>
</tr>
<tr>
<td>Hypermetabolic state or</td>
<td>• HIV</td>
</tr>
<tr>
<td>fever</td>
<td>• tumour</td>
</tr>
<tr>
<td>Psychological</td>
<td>• depression</td>
</tr>
</tbody>
</table>

Legend: AZT: zidovudine; CMV: cytomegalovirus; ddC: zalcitabine; ddI: didanosine; 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
- Maintain 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

3.5.1.1.3 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

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

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

3.5.1.1.6 Malabsorption and Diarrhea
- Low-fat and low-lactose foods
- Altered insoluble and soluble fibre
- Replacement of vitamins, minerals, electrolytes, and fluid losses (Note: suggested dietary modifications are specific to cause and must be individualized)

3.5.1.1.7 Nausea and Vomiting
- Avoid known triggers to 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)

3.5.1.2 Alleviation of Taste (Dysgeusia)
- Spices and seasonings to mask the offending flavours and foods
- Mouth hygiene maintenance
- Zinc supplements

3.5.1.3 Abdominal Cramping and Bloating
- Assess lactase status
- Consume nutrient-dense, low-fat, small, frequent meals
- Avoid very hot or very cold foods and beverages

3.5.1.8 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)

3.5.1.9 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 or AIDS (PHAs) 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 PHAs on topics of nutrition that are available online, free of charge

www.catie.ca

3.6 Cognitive Impairments

Cognitive decline is one of the most feared complications of HIV infection. However research has highlighted that early recognition and treatment of cognitive dysfunction is likely to lead to a better outcome, with less permanent impacts on the nervous system (Selnes 2005). Many of the common causes of cognitive impairments are shown in Table 3.6. The most severe form — HIV Cognitive-Motor Complex, also known as HIV Dementia or AIDS Dementia Complex — presents with cognitive, behavioural, and motor dysfunction. Research has shown that HIV-related dementia was reduced sharply with the introduction of highly active antiretroviral therapy (McArthur 2004). However, it is still estimated that half of HIV-infected adults and children will present at one time during their disease course with a neurological disorder (Grović-Ferbas and Harris-White 2010). 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 PHAs 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.

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 or tumor of the language cortex in the dominant cerebral hemisphere leads to aphasia. Facial weakness or cranial nerve dysfunction can result in dysarthria. Severe infections of the mouth and esophagus can lead to difficulty in articulation and swallowing due to pain. Finally, cognitive-linguistic deficits can occur in the presence of HIV Cognitive-Motor Complex.

Red Flag Any changes in cognition should result in immediate medical referral
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’

http://www.positscience.com/

### 3.6.1 Rehabilitation Interventions

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 (diabetes, heart disease) which are known to harm the brain (Lewis and Hoeger 2005) and are common in HIV (Brown et al. 2005). Regular exercise stimulates the production of nerve growth factors that are critical for the survival and maintenance of sympathetic and sensory neurons which aid neocognitive 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 differences. Some examples included:

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

### Table 3.6 Clinical Aspects of Cognitive Impairments

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<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Cognitive-Motor Complex (HIV Dementia)</td>
<td>• HIV</td>
</tr>
</tbody>
</table>
| Cognitive impairment due to other metabolic or neurological diagnoses | • hypoxia
• cryptococcal meningitis, syphilis, neurovascular disease
• focal cerebral disease
• vitamin deficiency (e.g., B12, B6)
• electrolyte abnormalities |
| Psychological disorders                            | • depression
• anxiety
• delirium
• premorbid psychiatric disorders
• post-traumatic stress disorder |
| Substance-related disorders                        | • prescription medications (narcotics)
• over-the-counter medications
• street drugs: premorbid or current
• alcohol: premorbid or current |
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 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 railing 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)

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 which improves name and face recall, short-term memory and incidental learning, reduces anxiety, 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
- For low-volumed voices, train to use breath support, phrasing strategies and amplification

3.6.1.3.4 Memory

- A successful memory intervention is one that 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 dosettes 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
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 for 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

- 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).
- The Cognitive Reserve Model of Aging With HIV can be utilized to determine when to intervene and which mediators to use to build cognitive reserve when intervening (Valcour and Sacktor 2004).
- Enlist the support of family members and significant others at the earliest stages of cognitive decline.
- Help individuals and their caregivers and 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. Recent 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).
- Neurocognitive performance and severity of emotional distress were found to be strongly associated with overall quality of life (QOL). QOL depends on a person's ability to engage in the important, basic activities of everyday living. It is important to increase the availability and access to cognitive resources (community programs, functional strategies, rehabilitation professionals) which are important determinants of functional capacity, which in turn influences perceived QOL (Osowiecki et al. 2000).

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 etiologies for heart and, especially, lung problems in HIV infection, including bacterial, fungal, viral, and parasitic pneumonias (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 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 which require immediate medical evaluation.

Table 3.7 Clinical Aspects of Cardiac and Respiratory Impairments

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endocarditis</td>
<td>• bacteria</td>
</tr>
<tr>
<td></td>
<td>• fungi</td>
</tr>
<tr>
<td>Cardiomyopathy</td>
<td>• viral pathogens</td>
</tr>
<tr>
<td></td>
<td>• AZT-induced</td>
</tr>
<tr>
<td>Pericarditis</td>
<td>• infections (e.g., TB)</td>
</tr>
<tr>
<td>Pre-existing lung disease</td>
<td>• restrictive lung disease</td>
</tr>
<tr>
<td></td>
<td>• post-pneumonia fibrosis</td>
</tr>
<tr>
<td></td>
<td>• chronic obstructive lung disease (e.g., cigarette smoking, recurrent bronchitis or pneumonia)</td>
</tr>
<tr>
<td></td>
<td>• bronchiectasis</td>
</tr>
<tr>
<td></td>
<td>• reactive airways disease</td>
</tr>
<tr>
<td>Acute lung disease</td>
<td>• infections (e.g., PCP)</td>
</tr>
<tr>
<td>Psychological</td>
<td>• anxiety</td>
</tr>
<tr>
<td></td>
<td>• panic disorder</td>
</tr>
<tr>
<td>Tumours</td>
<td>• Kaposi’s sarcoma</td>
</tr>
</tbody>
</table>

Legend: AZT: zidovudine; 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
- 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 which 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
- 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 check out 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 or AIDS (PHAs), although a PHA’s vision can 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 are 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 PHAs. In addition, a new kind of vision loss, associated with use of newer antiretroviral therapies and known as immune recovery uveitis, has
Any abrupt change in vision should result in immediate referral to an ophthalmologist with expertise in HIV.

Table 3.8 Clinical Aspects of Visual Loss

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retinitis, choroiditis</td>
<td>• CMV</td>
</tr>
<tr>
<td></td>
<td>• toxoplasmosis, cryptococcus, Pneumocystis carinii</td>
</tr>
<tr>
<td></td>
<td>• acute retinal necrosis due to HSV, VZV</td>
</tr>
<tr>
<td>Retinal detachment</td>
<td>• primary</td>
</tr>
<tr>
<td></td>
<td>• secondary (CMV)</td>
</tr>
<tr>
<td>Primary retinal vascular disease</td>
<td>• immune complex disease</td>
</tr>
<tr>
<td></td>
<td>• microaneurysms</td>
</tr>
<tr>
<td></td>
<td>• ischemic maculopathy</td>
</tr>
<tr>
<td></td>
<td>• diabetic retinopathy</td>
</tr>
<tr>
<td>Malignancy</td>
<td>• Kaposi’s sarcoma</td>
</tr>
<tr>
<td></td>
<td>• Burkitt’s lymphoma of the orbit</td>
</tr>
<tr>
<td></td>
<td>• metastatic malignant melanoma</td>
</tr>
<tr>
<td>Cranial nerve abnormalities</td>
<td>• many potential causes including most causes listed above</td>
</tr>
<tr>
<td></td>
<td>• central (e.g., PML)</td>
</tr>
<tr>
<td></td>
<td>• peripheral (e.g., mononeuropathy)</td>
</tr>
<tr>
<td>Cerebral lesions</td>
<td>• occipital lobe disease</td>
</tr>
<tr>
<td>Drug-induced</td>
<td>• high-dose rifabutin</td>
</tr>
<tr>
<td>Pre-existing disease</td>
<td>• cataracts, glaucoma</td>
</tr>
<tr>
<td></td>
<td>• refractive abnormalities</td>
</tr>
</tbody>
</table>

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 of 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)
• Use a sighted escort (proper techniques can be taught to caregivers, friends, family, and volunteers)

3.8.1.2.2 Activities of Daily Living

3.8.1.2.2.1 Enhancing Vision
• Refer for oculovisual assessment
• Use magnifiers
• Compensate for peripheral vision
• Wear an eyepatch, if double vision is a problem
• Install proper lighting, including night lights
• Use larger print 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 night lights

3.8.1.2.4 Meal Preparation
• Organize work space 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)

3.8.1.2.5 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

3.8.1.2.6 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)

3.8.1.2.7 Other
• Talking books (available through libraries)
• Voice print (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 cope with feelings that may result from vision loss, such as: 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 or AIDS (PHAs) falls into three broad categories: HIV or AIDS as the primary cause, opportunistic infections and otoxicity from drugs used to treat HIV (Kalilai et al. 2008). A recent 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 PHAs 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 PHAs. 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 diagnosed http://www.chs.ca/

Swanepoel and Louw (2010) have recently 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 or AIDS (PHAs) 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 schizophrenia, bipolar disorder, dementia, depression and post traumatic stress disorder (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 abuse disorders and mood disorders are estimated to co-exist anywhere between the range of 25% to 65% of all diagnoses of HIV (Regier et al. 1990).

3.9.2 Mood Disorders as a Primary Complaint

A recent systematic review suggests that adults with severe mental illness are more likely than demographically similar adults without severe mental illness to engage in certain behaviors 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 to 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 difficulty in diagnosing 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 or AIDS (PHAs), 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 which 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 of PHAs (Hartzell et al. 2008, Treisman et al. 1998). Previous history of major depression and progression of HIV disease are the strongest predictors of an onset of a major depression (Atkinson et al. 2008).
Some experts believe that mood disorders can also occur as a result of viral infection of the central nervous and immune systems (Alciati et al. 2007). Moreover, HIV-Associated Dementia (HAD) affects approximately 15% of HIV positive individuals.

Characteristics include (Vlassova et al. 2009):
- Apathy
- Difficulty with maths and reading
- Decreased comprehension and memory capacities,
- Very subtle movement disorders, such as the occasional stumble or a minor tremor

More information about HAD can be found in Section 4.11.5.10.1 HIV-Associated Dementia

3.9.4 Impact of HIV Medications on Mood Disorders

Older HIV drugs, such as Zidovudine, Abacavir and Efavirnz 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. A 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 substance use (Meade and Sikkema 2005). With the possible exception of people living with schizophrenia, who tended to have lower rates of sexual activity (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 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 like depression, a result of HIV or a combination of the two.

3.9.7 Role for Rehabilitation

Recognition of mood disorders 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. For many specific mental illnesses, the same medications for those with or without HIV can be used without unique adverse affects on the HIV population. Other methods that are often used to manage mood disorders include cognitive behaviour therapy (CBT), art psychotherapy, yoga therapy, Acceptance and Commitment Therapy (ACT), mindfulness meditation 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.

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 to assist with the individual’s financial and personal care.

3.10 Substance Abuse

3.10.1 Introduction

Substance abuse is defined as overindulgence in and dependence of 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 or AIDS (PHAs), 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 a PHA. For example, there is evidence that suggests 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 because 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; including alcohol consumption that has been shown to be linked to unprotected
sex and contaminated needle-sharing from intravenous drug use - all of which 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.

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 own personal backgrounds, including childhood experiences, which can affect the likelihood or ability of a health care professional to be therapeutic and non-judgmental.

3.10.2 Harm Reduction Versus Abstinence

There is an ongoing debate concerning the care of substance users 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 substance users and therefore should be 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. The Canadian Harm Reduction Network monitors and comments on regulatory and academic findings in this area. [http://www.canadianharmreduction.com/](http://www.canadianharmreduction.com/)

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 a 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 in order 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 the drug using population 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 the desired outcome
- Acknowledgment of those who use drugs as capable members of our community

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 abuse are described below:

3.10.3.1 History-Taking and Assessment

In most health care 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 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)

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, and anesthetics)

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

(Shernoff 1991)

3.10.3.1.3.4 Drug Treatment History

- Detoxification (dates, facts of admission and discharge, follow-up)
- Outpatient 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).

3.10.3.1.2 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.

3.10.3.1.3 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 which 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 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:
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 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 abuse 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).
4_1 Introduction

With the immune system compromised, HIV has sweeping 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 or AIDS (PHAs). However, antiretroviral treatment has caused dramatic changes in the natural history, long-term outcome, morbidity and mortality in PHAs that affects all systems of the body.

While an exhaustive overview of all potential impacts that HIV, its treatments and associated concurrent conditions is beyond the scope of this chapter, it does provide a brief overview organized by body systems of some of the more common clinical manifestations presented by 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 generally 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 and may not be possible to identify for the number of case reports showing multiple unusual organisms associated with pericardial effusion in people with HIV (Rerkpattanapipat et al. 2000).

4.2.4 Coronary Artery Disease

With the introduction to antiretroviral treatment, there has been an increased incidence of coronary artery disease (CAD) and myocardial infarction (MI) among people living with HIV or AIDS (PHAs) (Boccara 2003). The risk of an MI in PHAs 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 (Boccara and Cohen 2008). HIV and its treatments predispose people to metabolic complications causing dyslipidemia and insulin resistance that are implicated in increased cardiovascular risk (Boccara and Cohen 2008). These
effects are correlated with the duration that a person is known to be HIV positive and on protease inhibitors with a longer duration reflecting increased risk of MI (Boccara 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 (Boccara 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 (Boccara et al. 2003). In one North American population based study, advanced HIV was found to be strongly associated with both ischemic stroke and intracerebral hemorrhage 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 or AIDs who are taking antiretroviral treatments are required.

4.3 Gastrointestinal
Gastrointestinal disease in HIV is common. People living with HIV or AIDS (PHAs) often present with diarrhea, weight loss, biliary disorders, abdominal pain, dysphagia and other oral diseases as a result of a number of different factors. 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 PHAs 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 or AIDs. Susceptibility to various forms of cancers has been linked to a number of oncogenic viruses including Epstein-Barr virus (associated with Non-Hodgkins lymphoma, in particular Burkitts 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 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 (MSM) 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 HIV treatment. 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 or AIDS (PHAs) 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 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 of 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 to present 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 or AIDS (PHAs). 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.

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 breakdown muscle fibres. It is characterized by progressive, proximal weakness most prominently in the thighs and is 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 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 or AIDS (PHAs). Loss of bone mass (osteopenia) along with 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 PHAs.
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 are 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 PHAs with osteoporosis upon taking bisphophonate, and specifically alendronate (Clay et al. 2008). Primary care guidelines would also benefit from listing PHAs as prime candidates for 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 have 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 or AIDS (PHAs).

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 Dementia

HIV-Associated Dementia (HAD), once termed AIDS dementia complex, is the most common cause of cognitive dysfunction in people living with HIV or AIDS (PHAs). Soon after HIV infection, the virus crosses the blood brain barrier and directly invades the central nervous system. Damage to the brain may be as a direct result of the virus itself, however the mechanism by which HIV infection leads to dementia is likely multifactorial and is the subject of intense research.

HAD is characterized by cognitive deficits, behavioural changes and atypical motor involvement (Robinson-Papp et al. 2008). It is the most common cause of dementia in adults less than 40 years of age and presents a highly variable clinical course (McArthur et al. 1999). Signs and symptoms range from subtle cognitive and motor impairments to profound dementia that can lead to severe disability and death. Deficits associated with cognitive functioning include memory encoding, retrieval and working memory, speed of information recall, verbal fluency and abstract or executive reasoning. Behavioural changes may include symptoms of depression, apathy and social withdrawal. Motor functional impairments have been described as slow movement, gait abnormality, limb incoordination, hyperreflexia, hypertonia and weakness (Robinson-Papp et al. 2008). Cognitive, behavioural and motor abnormalities such as these impact extensively on quality of life issues for PHAs.

Other cognitive disorders such as depression and anxiety are also common in PHAs. 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 PHAs is particularly high especially in older individuals, those who also have histories of substance abuse, or for females with history of trauma (Basu et al. 2005). Symptoms of anxiety, and specifically anxiety around death, is common among PHAs 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 PHAs, practitioners are required to be mindful of the potential affects of HIV on this system. Early detection of symptoms associated with illnesses of this nature allow for interventions and greater 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 or AIDS (PHAs) 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 with autonomic
dysfunction (Lebech et al. 2007). Autonomic dysfunction leads to
arrhythmias and abnormalities in blood pressure, factors that can
cause orthostatic hypotension and syncope for people 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 as in response to the presence
of opportunistic infections. Exact mechanisms are allusive given
that access to the CNS is a challenge and research is often
limited to autopsy.

4.8.3 HIV-Associated Dementia
HIV-Associated Dementia (HAD) is among the most common
and severe manifestations affecting people with HIV. This
manifestation is described more in Section 4.12.5.10.1
HIV-Associated Dementia.

4.8.4 Toxoplasmosis
Toxoplasmosis is caused by, and presents as, the most common
cause of space occupying lesions within the central nervous
system (CNS) for people living with HIV or AIDS (PHAs). This
condition results from exposure to toxoplasmosis gondii, an intra-
cellular protozoa 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). Toxo-
plasmic encephalitis usually occurs in HIV positive people with
CD4 counts < 100 cells/mm3 (Luft and Remington 1992). Char-
acteristically, toxoplasmic encephalitis has a subacute onset with
focal neurologic abnormalities frequently accompanied by head-
ache, 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 distur-
bances, 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 (polyomavirus JC) 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 lead 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
within soil contaminated with avian droppings, particularly those
of pigeons. Early in the epidemic, approximately 5 to 8% of
people with advanced HIV developed 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 head-
ache, 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 Malign-
nancy 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 vacular 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, vacular 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 or AIDS (PHAs) 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 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 or AIDS (PHAs) 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 resembles 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 or AIDS (PHAs). 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 or AIDS (PHAs) 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).

Pneumocystis carinii pneumonia (PCP) is among 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 or AIDS (PHAs) 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 jirovecii (formerly known as pneumocystis carinii f. sp. hominis). Airborne transmission from a human host to another human host is proposed to be the main vector for this highly prevalent illness in immuno-compromised individuals (CD4 counts <200 cells/mm3), however the route of transmission between humans remains unclear (Nevez et al. 2008, Chave et al. 1991, Rvero et al. 2008).

4.9.2 Tuberculosis
Worldwide, tuberculosis (TB) is the most significant respiratory infection affecting people living with HIV or AIDS (PHAs) and is the leading cause of death. Tuberculosis exists as an independent epidemic however, TB 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). Diagnosis of TB in PHAs is limited by TB diagnostic tools and atypical presentations of TB. 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 has the ability to 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, in order 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 immuno-suppression, 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 affecting people living with HIV or AIDS (PHAs), 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 PHA, 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 is 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, recent 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).
These authors also identify women 50 years of age and older as a special population (Zunzunegui and Roy 2008) for several reasons:

- Less frequent use of condoms by those who have an HIV positive partner
- Increased risk due to postmenopausal dryness
- Forced sexual relations that could lead to HIV transmission
- Decreased condom use among women who have sporadic sexual encounters (particularly those who are under the influence of drugs or alcohol)

Several authors have also identified differences between younger and older people living with HIV or AIDS (PHAs)

- Most older women and a third of older men choose sexual abstinence than do younger PHAs (Siegal and Scrimshaw 2003)
- Older adults living with HIV are more likely to notify their partners, families, and friends of their HIV status than are younger PHAs (Emlet 2006)

4.12.2 Navigation and Advocacy for Older People Living with HIV or AIDS

Studies have also examined broader social issues related to aging with HIV. Older adults have significant problems navigating HIV specific services. Often, these were designed for the needs of a younger population or are staffed with providers who are not experienced with older clients (Emlet and Farkas 2002). A review by Linsk et al (2003) identified how collaboration at various levels of government is required to bridge the gap in HIV service delivery for older adults. Scrimshaw and Siegal (2003) interviewed HIV positive adults over the age of 50 and found that ageism emerged as a major theme; participants believed that older adults were viewed with less sympathy and support than their younger counterparts. A “double jeopardy” occurs; these individuals must deal with both ageism and HIV status act as elements of discrimination (Emlet 2006).

There is a large body of literature in both the areas of aging and HIV however, the aging world and the HIV world continue to be separate and are only beginning to merge. In order to meet the needs of the new emerging population of older adults living with HIV, further research needs to be conducted. This area if inquiry was a recently highlighted as a research priority of the Canadian Working Group on HIV and Rehabilitation (CWGHR) (O’Brien et al. 2010a). Using a scoping study methodology, O’Brien et al. (2010a) concluded that future development of HIV rehabilitation research and practice should consider the physical, social and psychosocial impact of aging with HIV, concurrent health conditions (or comorbidities), the added complexity and disableness that may arise from these concurrent conditions as they accrue over time, and the effect of rehabilitation interventions in addressing or preventing this disableness.

4.12.3 Normal Aging

Determining what constitutes normal aging is a complex question that is beyond the scope of this manual, in part because definitions of normal aging vary from source to source. The World Health Organization (WHO), in it’s Active Aging Policy Statement, states that “functional capacity (such as ventilatory capacity, muscular strength, and cardiovascular output) increases in childhood and peaks in early adulthood, eventually followed by a decline. The rate of decline, however, is largely determined by factors related to lifestyle – such as smoking, alcohol consumption, levels of physical activity and diet – as well as external and environmental factors” (World Health Organization 2002). Thus, while many authors agree that some aspects of physical and cognitive function are prone to decline with aging, they also recognize that the rate at which this decline occurs is contingent upon the individual’s lifestyle.

4.12.4 Aging with HIV

There are a number of issues that need to be considered when examining the interaction of aging and HIV. First, people living with HIV or AIDS (PHAs) are now living longer. This also means that these individuals are more susceptible to specific chronic conditions associated with older age such as cardiovascular disease, diabetes, arthritis, dementia and some cancers. These diseases may be associated with higher incidence and poorer outcome due to co-infection with HIV, or may simply occur with greater frequency due to older age. Notably, there may be an interaction of medical treatments for these diseases with the treatment for HIV. Concurrent conditions can include coronary artery disease, hypertension, hypercholesterolemia (cardiovascular), hypogonadism, erectile dysfunction, diabetes, peripheral neuropathy, hepatitis C (HCV), esophageal gastric reflux disease, cognitive dysfunction and renal disease (Justice 2010). These conditions are described in greater detail in Section 4.12.6. Not surprisingly, with a greater number of concurrent conditions come more prescribed medications. Fortunately, research has demonstrated that the older the PHA, the greater the likelihood of increased adherence to medicines and medical appointments (Vance et al. 2010a).

A second important consideration in terms of aging and HIV is that older people with HIV are often diagnosed later in the natural course of HIV infection, partially due to the natural deterioration of aspects of the immune system in older age, but also due to misdiagnosis and late diagnosis. Misdiagnosis and late diagnosis are often attributed to the similarity between common HIV related illnesses and some illnesses associated with older age, as well as the perception of older adults not being “at-risk” of HIV (Mitchell and Aspinall 2008, Gebo 2006, Bhavan et al. 2008). This highlights the need for not only the general population, but also for health care professionals, to reconceptualize their views of older adults and sexual activity, and thus the risk behaviours that these individuals may be engaging in.
Emerging therapies have changed the lived experience of PHAs, however the causes of death for younger versus older PHAs remain quite different. While younger PHAs are most likely to die from an HIV related infection or an AIDS defining illness, older people are more likely to die from cardiovascular disease and malignancies, more closely mirroring the diseases seen in the general population (Justice 2010). Thus, the shift from known HIV markers such as CD4 count and AIDS-defining illnesses to a broader chronic disease management model that includes age, hemoglobin, renal function, liver function, chronic hepatitis B and C, diagnoses of alcohol and drug abuse and dependence is necessary (Justice 2010). As drug toxicity from combination antiretroviral therapy (cART) appears to be relatively similar in older and younger people, and as adherence is generally better in older adults, it is a reasonable projection that, over the next decade there will be a considerable increase in the number of older PHAs in settings where treatment is available (Mitchell and Aspinall 2008).

One French study from 2007 suggests that PHAs who are able to achieve good virological control on antiretroviral medication will have similar mortality rates to the rest of the population. Of the 2435 participants receiving antiretroviral treatment over six years, 16% were able to achieve and maintain a CD4 count of over 500 and had mortality rates comparable to the general population. Notably, not all PHAs are able to achieve such virus suppression and it should be emphasized that the same cohort had an overall seven-fold increase in mortality rates in comparison to the general population (Lewden et al. 2007).

Conversely, in settings where treatment remains unavailable, life expectancy continues to decrease. Very little data is available on older PHAs in resource poor settings and settings with limited treatment availability. The United Nations AIDS (UNAIDS) organization, which publishes the seminal annual report on the epidemic and the global response, publishes it’s main data with an upper age of 49 (UNAIDS 2008). Little mention of older people or aging is included in most related resources and older people are not listed as one of the UNAIDS organization sixteen key populations. Recently, the World Health Organization (2009b) also discussed the clear lack of epidemiological, behavioural or clinical research on older adults with HIV in the developing world, despite the fact that evidence exists that there is a second peak of new diagnoses in older adults. There is a lack of primary sexual health promotion, screening and appropriate interventions targeted at older people. Those without access to any type of antiretroviral medication who are older and living with HIV progress more quickly to illness and death than younger people (World Health Organization 2009b).

In spite of a proliferation of published work in the past few years on the topic of HIV and the older adult, many questions remain unanswered. Available data has to be carefully interpreted. In an epidemic that is constantly changing and in its current form is only a decade old, the delay in reporting and publishing can mean that the best available data is already beginning to date. For the purpose of this review, published literature is primarily from the past two to three years with cohort data published since 2002.

4.12.5 Increased Risk of Concurrent Conditions

It is often difficult to separate HIV related symptoms from concurrent conditions related to the normal aging process (Becker et al. 2004). This suggests the need for increased attention to HIV and aging and the importance of rehabilitation for this new emerging population. The consequences for those aging with HIV include the long term impact of living with the virus and the adverse effects of combination antiretroviral therapy (cART), coupled with the natural processes of physical changes (decline and deterioration) associated with aging. Adults aging with HIV can experience the added complexity related to the social determinants of health and the double stigma of ageism and living with HIV. These factors have an additive and synergistic effect on increasing the risk for numerous common concurrent conditions (Henry 2009). Evidence suggests that some concurrent conditions are more likely to be present for aging people living with HIV and AIDS (PHAs) than the general population (Goodroad 2003).

The following sections deal with systemic and disease level issues, and psychosocial and functional issues in the context of aging with HIV.

4.12.5.1 Immune System and Immune Response

Both aging and HIV infection are associated with profound changes in immunity and host defense, with marked similarities and some differences. The thymus, which is responsible for the production of CD4 and CD8 T-cells, deteriorates with both age and HIV infection. T-cells are key cells involved in a healthy immune system, and it is well known that the number of naive T-cells decreases with both age and HIV infection. It has also been well established that T-cells become less responsive both as a result of increasing age and HIV infection. This is seen most markedly in the gut, where mucosal immunity is important in providing defense against gastro-intestinal infections. Some changes in CD8 T-cell response appear to lead to similar risks of the development of varicellar zoster viruses (such as shingles) in older people with or without HIV. Interestingly however, other similar chronic viruses such as cytomegalovirus (CMV), or CMV-end organ disease and mortality, are common with advanced HIV positive older individuals yet are rarely seen in older seronegative people (Mitchell and Aspinall 2008, Effros et al. 2008). Moreover, there is evidence that, compared to younger people living with HIV or AIDS (PHAs), older adults with HIV may not have as strong a CD4 response in their first year and may take up to 2 years of antiretroviral therapy to achieve the same response as younger PHAs (Justice 2010).
4.12.5.2 Response to Antiretroviral Medication in Older People

The data on the efficacy of antiretroviral medication in older people paints a mixed picture. While older people are more likely to adhere to their first antiretroviral regimen (Justice 2010), the speed of recovery of CD4 count and the total restoration of CD4 is poorer than in younger people. Conversely, virological response to antiretroviral medication - how well HIV viral load is suppressed - has been shown in several studies to be better in older adults. Despite this, older people living with HIV and AIDS (PHAs) have been shown to have an increased risk of new opportunistic infections and death compared with younger PHAs. While it is thought that less failure on first regimens may be related to better medication adherence among older adults, the differences in response at a virological control and cellular level are yet to be well explained and the medical community is calling for much more research in this area (Effros et al. 2008).

4.12.5.3 Metabolic and Cardiovascular Changes

There are multi-factorial risks with HIV in terms of a range of metabolic and cardiovascular function and this area is currently a key area of further research. In particular, cardiovascular risks leading to increased rates of myocardial infarction, fat redistribution syndromes such as lipodystrophy and diabetes risks are all being studied.

4.12.5.3.1 Cholesterol and Triglycerides

It is well documented from the era before antiretroviral medication that HIV infection was associated with decreases in total cholesterol, but increases in triglycerides. Specific HIV medications such as ritonavir are associated with high triglyceride levels (Effros et al. 2008).

4.12.5.3.2 Cardiovascular Risk

Many studies have shown an increased rate of cardiovascular disease with extended duration of antiretroviral treatment. While increases in diastolic blood pressure are associated with aging and with HIV infection and treatment, increases in systolic blood pressure is much more significantly associated with HIV infection and HIV treatment than aging (Effros et al. 2008). Several studies have shown a greater amount of atherosclerotic disease in HIV positive individuals compared with age-matched subjects. There are several hypotheses as to why this might occur; with the most widely reported being an association with specific antiretrovirals that lead to increases in cholesterol and triglycerides. However, other studies have suggested that the cellular level HIV replication process is a catalyst for atherosclerotic plaque formation (Lichtenstein 2008).

Despite evidence of either antiretroviral medication or HIV infection potentially increasing the risk of a cardiovascular event such as a myocardial infarction or cardiovascular accident, multiple studies have consistently shown that the cumulative additional risk from these factors is far outweighed by the general risk factors, such as age, hypertension, diabetes mellitus, obesity, dyslipidemia, gender, smoking and family history. Accordingly, the most potent management strategies of cardiovascular risk lie in the modifiable general risk factors. Conventional management, including smoking cessation, healthy diet and exercise, are also the top three recommendations for managing cardiovascular risk in an HIV positive population. In particular, smoking cessation is indicated as a priority for health service wide promotion methods as in the UK and North America there are considerably higher rates of smoking amongst people living with HIV or AIDS (PHAs). For clients with a higher cardiovascular disease risk, there is also value in switching antiretroviral therapies to those that are less implicated in elevating lipid levels (Lichtenstein 2008, Sabin and Worm 2008). A large and ongoing study continues to produce data on antiretrovirals and recent data suggests a relationship between risk of myocardial infarction and current use of didanosine and abacavir and cumulative exposure to select protease inhibitors (Lundgren et al. 2009). It is also important to note that as increasing number of PHAs survive and as they age, their cardiovascular risk from non-HIV sources will continue to increase (Sabin and Worm 2008).

4.12.5.3.3 Lipodystrophy

The syndrome of lipodystrophy was first described in an HIV context in 1998, soon after the introduction of effective antiretroviral therapy. There is mixed data on the risk of lipoatrophy with an aging population. While there is a clear link between HIV treatment and lipoatrophy, this type of fat loss is shown by some studies to have a link with aging but not in others (Effros et al. 2008). In studies of older adults with HIV, some association between older age and decreased leg subcutaneous fat has been shown, but much more research is needed in this area (Greenblatt and Tien 2008).

4.12.5.3.4 Diabetes Mellitus

Cumulative exposure to Nucleoside/Nucleotide Reverse Transcriptase Inhibitors, (NRTIs) (one particular family of antiretroviral medications), is associated with increased incidence of insulin resistance and diabetes. Interestingly however, HIV infection itself is associated with less insulin resistance (Effros et al. 2008, Greenblatt and Tien 2008). Hormonal changes related to menopause in women and decreasing testosterone in men have been linked to increased rates of diabetes in older people. Older age has been associated with diabetes mellitus in HIV positive individuals, but there is mixed data on whether this is due to NRTI use or other factors. Further research is required in this area (Greenblatt and Tien 2008, Butt et al. 2009).

4.12.5.4 Hepatic Function

Incidence of liver disease is higher both with HIV infection and older age. Mortality associated with liver disease is high amongst people living with HIV or AIDS (PHAs). For older PHAs, morbidity and mortality associated with liver disease is four times higher
than younger people living with HIV (Effros et al. 2008). There is limited data on the natural progression of liver disease in older adults living with HIV and there is no gold standard on treatment (Effros et al. 2008).

4.12.5.5 Renal Function
Renal function is also known to deteriorate with age, with HIV infection and with HIV related treatment. Poorer renal function affects drug clearance and increases the risk of drug toxicity. Although survival rates have increased since the advent of anti-retroviral therapy, the incidence of end-stage renal failure has not decreased. Few studies have looked specifically at end-stage renal failure in older people living with HIV or AIDS (PHAs), although some suggest that PHAs are more likely to develop end-stage renal failure than matched HIV negative populations (Deeks and Phillips 2009). While dialysis and transplantation are options for PHAs, there is limited data on transplantation. Much more research is required in this area (Effros et al. 2008, Wyatt 2008).

4.12.5.6 Respiratory Function
Respiratory disease is one of the most common serious complications for people living with HIV or AIDS (PHAs), in particular Pneumocystis Carinii Pneumonia or pneumocystis jiroveci pneumonia. In many countries rates of pulmonary tuberculosis (TB) are also increasing. It is generally believed that older people often have higher rates of pulmonary TB. This is partially attributable to the fact that the older an individual, the more likely he or she is to have been exposed to TB. Moreover, because the immune system weakens with age, latent disease is more likely to be reactivated. Age-related changes in the lung, including loss of elastic recoil, reduced capacity of thoracic musculature and calcification of intercostal cartilage, all reduce respiratory capacity, rendering recovery from respiratory disease more difficult and likelihood of residual lost capacity more likely.

4.12.5.6.1 Chronic Obstructive Pulmonary Disease and Lung Cancer
Chronic Obstructive Pulmonary Disease (COPD) (including emphysema) and lung cancer are two diseases associated with either smoking or the combination of smoking and aging, both of which are more common in HIV populations. This is due to higher smoking rates in HIV positive populations, and higher rates of bacterial pneumonia amongst older people (which can be up to 25 times higher amongst HIV positive populations). This represents an incidence of approximately 15% of an HIV population with an even higher incidence amongst individuals receiving antiretroviral medication (Brown and Qaqish 2006). In another study of 559 men aged 50 and over, a relationship between bone mineral density, HIV status, and increased fracture risk was shown, although HIV status was not independently associated with a statistically significant increased fracture risk (Arnsten et al. 2007). Several studies have shown considerably higher rates of osteoporosis in HIV positive women compared to HIV negative females. One study shows lumbar spine osteoporosis in 42% of the HIV positive cohort and only in 23% of the control population, with prevalence of hip osteoporosis being almost 10% higher for the positive cohort than in the matched controls (Conde et al. 2009). It is thought that the cause of loss of bone mineral density is multi-factorial and includes metabolic changes secondary to antiretroviral therapy and secondary causes such as vitamin D deficiency. Recommendations are now emerging suggesting that older individuals be regularly screened for bone mineral density to instigate appropriate preventative treatment for osteoporosis. There is also some early evidence of positive indication for lifestyle management of osteoporosis risk including physical exercise, a diet rich in calcium and regular exposure to sunlight (Conde et al. 2009).

4.12.5.8.1 Osteoporosis and Osteopenia
One meta-analysis of twenty studies reports a threefold increase of osteoporosis in an HIV population versus the general population. This represents an incidence of approximately 15% of an HIV population with an even higher incidence amongst individuals receiving antiretroviral medication (Brown and Qaqish 2006). In another study of 559 men aged 50 and over, a relationship between bone mineral density, HIV status, and increased fracture risk was shown, although HIV status was not independently associated with a statistically significant increased fracture risk (Arnsten et al. 2007). Several studies have shown considerably higher rates of osteoporosis in HIV positive women compared to HIV negative females. One study shows lumbar spine osteoporosis in 42% of the HIV positive cohort and only in 23% of the control population, with prevalence of hip osteoporosis being almost 10% higher for the positive cohort than in the matched controls (Conde et al. 2009). It is thought that the cause of loss of bone mineral density is multi-factorial and includes metabolic changes secondary to antiretroviral therapy and secondary causes such as vitamin D deficiency. Recommendations are now emerging suggesting that older individuals be regularly screened for bone mineral density to instigate appropriate preventative treatment for osteoporosis. There is also some early evidence of positive indication for lifestyle management of osteoporosis risk including physical exercise, a diet rich in calcium and regular exposure to sunlight (Conde et al. 2009).

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4.12.5.7 Gastrointestinal System
The mucosal lining of the gut is a major part of the immune system and both older people and people living with HIV related immunosuppression have been shown to have higher rates gastrointestinal disease including clostridium difficile, shigella and cryptosporidiosis. Both groups, when compared to a younger, HIV negative population, tend to have more severe symptoms, take longer to recover and have higher rates of mortality.

4.12.5.8 Skeletal System and Bone Health
There are many musculoskeletal manifestations of HIV disease including inflammatory joint disease, infection, malignancies and bone disease.

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4.12.5.8.2 Joint Disease
In a large study of more than 1000 older adults living with HIV in New York in 2006, the second most prevalent concurrent condition listed was arthritis (Karpiak et al. 2006). While there is little published on the interactions between an HIV arthralgia and non-HIV joint disease, joint disease is clearly a major concern for many people living with HIV or AIDS (PHAs).

4.12.5.8.3 Rehabilitation Interventions
- Joint protection
- Splinting
- Body positioning
- Specific exercises
- Ergonomics
4.12.5.9 Visual System

The two primary complications of HIV disease that result in visual disturbances are from a retinitis secondary to viral disease such as cytomegalovirus (Dixon 2007) or varicella zoster virus (Shingles), or visual disturbances secondary to HIV related central nervous system space-occupying lesions. General deterioration of vision secondary to HIV disease is not described in the literature and the interaction between age related loss of acuity is not widely investigated in literature on HIV and aging. More research in this area is needed.

4.12.5.9.1 Rehabilitation Interventions

- Colour coding
- Magnifying eyewear
- Background lighting
- Using the clock as a way to position oneself from items (e.g., the fridge is at your 4 o’clock)
- Community linking to the appropriate resources

In Canada, the Canadian National Institute for the Blind (CNIB) is a good resource for those losing their sight or who have become blind.

4.12.5.10 Central Nervous System – Neurocognitive Functioning

There are a number of mechanisms by which central nervous system impairment may occur in individuals living with HIV. Broadly, these include HIV-associated conditions that can lead to space occupying lesions, meningitis, or encephalitis. Additionally, HIV can have a direct action on the brain in what is sometimes termed HIV encephalopathy (HIVE). The extent of impairment can range from very minor through to severe, and for people with advanced disease, more than one pathology may be present. Differing pathologies may be on differing courses, dependent on availability of and response to treatment, as well as the presence of other concurrent conditions (for example, cerebral toxoplasmosis). For many individuals, recovery can be quite quick, while recovery from progressive multifocal leukoencephalopathy (PML), is contingent upon factors such as CD4 count and the length of time the individual has been on antiretroviral therapy. For instance, those with PML who were previously naïve to antiretroviral therapy (ART) had significantly better outcomes than those already on them and even better for those who did not take ART before or after prognosis of PML (Antinori et al. 2003) Another example of variability within neurocognitive pathologies is that the medium term prognosis for a primary central nervous system (CNS) lymphoma is much poorer. Types of impairment can range the neurological spectrum and might include motor loss, sensory changes, cognitive changes, visual processing deficits, disorders of praxis, behavioural changes. Moreover, there is no typical pattern for laterality. Spinal complications can also occur.

- HIV Related Neurocognitive Disorders can be divided into three main categories:
- HIV-Associated Dementia
- HIV-associated Mild Neurocognitive Disorder

4.12.5.10.1 HIV-Associated Dementia

HIV-Associated Dementia is defined as marked acquired impairment in cognitive functioning in two or more domains, typically producing significant interference with day-to-day functioning.

4.12.5.10.2 HIV-Associated Mild Neurocognitive Disorder

HIV-Associated Mild Neurocognitive Disorder (HAND) is defined as an acquired impairment in at least two domains that produces 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.

4.12.5.10.3 Asymptomatic Neurocognitive Impairment

Asymptomatic Neurocognitive Impairment is defined as acquired impairment in cognitive functioning. This is documented by performance on neuropsychological functioning and does not include impairments interfering with everyday functioning (Foley et al. 2008). This raises some interesting questions about the sensitivity of neuropsychological testing versus the sensitivity of assessment of everyday functioning. Both test situations also rely quite heavily on understanding what is normal for the individual prior to any possible impairment and is also reliant on appropriate adjustments for age related changes (Grant 2008).

4.12.5.10.4 Interventions for Those with Recognized Cognitive Challenges

- Heat food items in microwave rather than stovetop or oven
- Connect client with a food delivery service such as “Meals on Wheels”
- Use visual cues (e.g., a calendar to remind the client of important appointments)
- Incorporate verbal cues (e.g., reminder calls for appointments)
- Use auditory cues (e.g., cell phone alarm or wrist watch that would “beep” to remind them to take their medications)

4.12.5.10.5 Interventions for Anticipated Functional Neurocognitive Impairment

- Change antiretroviral regimen to one with greater central nervous system (CNS) penetration
- Increase reliance on compensatory strategies
- Task re-design and use of appropriate technology in the workplace
- Brain exercises
- Referral to occupational therapy when warranted
It is important for the occupational therapist to conduct a functional assessment both in clinic and at home to determine any significant deficits that could be compensated. Researchers found a high prevalence of HIV-associated cognitive dysfunction among individuals with undetectable viral load for a mean of 48 months (Ruiz et al. 2010). The functional demands on the brain in a cohort of aging people living with HIV or AIDS (PHAs) were found to be equivalent to non-HIV individuals who were 15 to 20 years older (Ruiz et al. 2010). Recently, experts in this area suggest the use of the Montreal Cognitive Assessment which is more sensitive to HIV than the Mini-Mental Status assessment (personal communication, Mark Halman, Casey House, 2008). The interactions between HIV-Associated Mild Neuropsychological Disorder (HAND) and age-related dementias such as vascular-type dementia are not yet well understood, and much more research is required in this area. There is a difference in appearance on scans, thus a neuro-radiology report can help delineate the cause of the dementia. This is key because with good central nervous system (CNS) penetrating antiretroviral treatment, there is definite recovery that can occur with HIV dementia. This is thought to be because the damage from an HIV dementia occurs in the supporting structures, which have some capacity to regenerate. This differs from vascular dementia where neuronal damage and cell death is typical. Unfortunately, most research is on younger people with HIV dementia and it is unclear whether positive responses to treatment and therapy in this demographic are not also due to better underlying physical health, greater neuroplasticity and increased adaptation skills compared with an older person living with HIV or AIDS (PHA). Much more research is required in this area.

4.12.5.10.6 Cortical versus Subcortical Dementia

Schiller et al. (2010) have described the key features to differentiate cortical versus subcortical dementia.

Key features of Cortical dementia (for example, Alzheimer’s) include:
- Memory impairment (recall and recognition) (Aretouli and Brandt 2010).
- Language impairments (Roher et al. 2010).
- Apraxia, agnosia, visual and/or spatial deficits

Key features of Subcortical HIV dementia include:
- Greater impairment in recall memory
- Decreased verbal fluency (York et al. 2001).
- Generalized working memory impairment (Schiller et al. 2009).
- Slowed thinking – decreased psychomotor processing speed (Grant and Heaton 1990).
- Depressed mood (Vance et al. 2010b)
- Apathy
- Decreased attention and/or concentration and learning
- Mild encoding deficits (Schiller et al. 2009).

Rates of HIV dementia declined in the era immediately following the introduction of highly active antiretroviral therapies, but has since begun to increase as antiretroviral medications has lengthened life expectancy.

While most research into HIV-associated neurocognitive impairment has focused at the dementia end of the spectrum, there is increasing interest in management of more subtle cognitive changes such as difficulties with prospective memory causing difficulty with adherance, appointments and work performance, subtle impairment to executive function affecting complex task performance, managing complex health needs or subtle changes in behaviour presenting as disinhibition, increased irritability or decreased motivation.

4.12.5.11 Cancer and Malignancies

There are two main mechanisms by which malignancies are thought to be triggered in an HIV positive population. First there are opportunistic cancers such as Kaposi’s sarcoma which occur in an immunosupressed state. The second grouping of malignancies occur where there is a clear epidemiological link between HIV and the particular type of cancer. These do not necessarily occur in individuals with low CD4 counts, although they are more common in individuals who have been HIV positive for a longer period of time. This suggests some sort of causal link perhaps related to long-term, low level abnormal immune activity. Rates of incidence vary, from modest increases of two or three fold, which may in part be counted for by co-risk factors such as smoking, to other cancers which occur at rates of over 1000 times the general population (Patel et al. 2008).

Paradoxically, the rates of incidence of cancer in an HIV context initially dropped following the advent of antiretrovirals but began to increase as people survived longer and their overall risk of developing a malignancy increases. At the same time, the interaction between HIV treatments and cancer treatment has also evolved and some cancers survival rates in an HIV context are now reaching similar rates as in an HIV negative context. The most common cancers seen in people living with HIV are diffuse large B-cell lymphomas, sometimes presenting as primary central nervous system lymphomas, Multicentric Castleman’s Disease, Burkitt’s lymphoma, Hodgkin’s Disease and Kaposi’s Sarcoma. Increases in small cell lung cancer, ano-rectal and gastro-intestinal cancers, multiple myelomas and hepatocellular cancer are also all described in the literature as having significantly higher rates of incidence. Interestingly, breast and prostate cancers, which are commonly seen in older people, do not have an increase in incidence in an HIV population when compared to the general population (Patel et al. 2008).
4.12.5.12 Sexual Health, Sexual Behaviour and Sexual Well-Being

In most settings, sexual transmission remains by far the most common method of transmission of HIV. The negative stereotype of the “asexual older adult” is changing rapidly. This is characterized by increasing rates of later-life remarriage rates, a growing trend for sexually intimate relationships amongst older people who are not in a cohabiting relationship, and advances in the treatment of sexual dysfunction (SD) with drugs such as Viagra (Mitchell and Aspinall 2008). It should be noted however that other studies demonstrate that individuals who are using erectile dysfunction medications do not report higher rates of risky sexual behaviour (Cook et al. 2010). It is likely that the increased risk of transmission occurs “at each exposure due to increased prevalence of HIV infection among older individuals” (Justice 2010). Data also suggests an increased rate of other sexually transmitted infections amongst older people, and studies point to a paucity of targeted sexual health information campaigns aimed at older people. Condom use is lower in older men and erectile dysfunction may complicate condom use. Postmenopausal women may avoid previously used barrier methods of contraception in the absence of pregnancy risk, and there is also evidence to suggest an increased HIV risk from increased fragility of the vaginal mucosa and decreased lubrication (Conde et al. 2009). Studies have also shown that younger health workers find it more difficult to raise sexual health issues with older clients, and older individuals are often less likely to raise sexual health issues with a health worker (Bhavan et al. 2008). See Section 4.13 for scripts to start the conversation about sexual health with clients. When older adults never had to use safer sex strategies, raising this topic may require a demonstration as he or she has likely had little to no education on safer sex practices beforehand. If the practitioner is uncomfortable with the topic, the practitioner should refer to another colleague that could assist, as it will be important to be thorough in this educational session. It may be the individual’s first safer sex educational experience. Older adults also have less access to HIV testing than their younger counterparts (Ruiz et al. 2010).

Researchers also report a phenomenon whereby there is a distinct group of men within the gay community who have not reported/experienced HIV infection in their 20s, 30s and 40s, but who seroconverted in their 50s or 60s. This is particularly noteworthy as they are not reporting a correspondingly significant difference in the number of reported unprotected sexual contacts. This suggests that other biological factors such as reduced host immunity or behavioural aspects of the type of sexual contact may be implicated (Effros et al. 2008).

4.12.5.13 Menopause and Sex Hormone Changes in Men

4.12.5.13.1 Menopause

The female sex hormones estrogen and progesterone are known to have a broad effect on lymphocyte numbers, proportions and functions, and the overall the efficacy of immune responses to women. While it is suggested that postmenopausal women are more likely to have lower CD4 counts and thus poorer immune health, there is a paucity of data in this area. One physiological risk factor common in older, postmenopausal women is vaginal dryness which may increase HIV transmission (Ruíz et al. 2010). Studies have also shown a link between HIV and symptoms associated with menopause such as depression, forgetfulness, arthralgia, and sweats, which were also associated with lower CD4 counts; however as the symptoms studied are also characteristic of advancing HIV infection, it has been difficult to establish the direction of the cause and effect relationship. More research is required in this area (Greenblatt and Tien 2008, Conde et al. 2009).

A full discussion on women’s reproductive health can be found in Section 4.14.

4.12.5.13.2 Male Sex Hormone Changes

For younger men with androgen deficiencies that treatment with testosterone can lead to improvements in muscle mass and cognitive function. It is also known that androgen levels decrease with age in men. Some studies suggest that hypogonadism is more prevalent in older HIV positive men than in matched negative populations, although results have often been confounded by variables such as opiate use and the interpretation of symptoms such as depression and erectile dysfunction is complex. More research is required in this area (Greenblatt and Tien 2008).

4.12.5.14 Adherence

One of the first United Kingdom based studies to study adherence behaviour in older people, found that despite little difference in educational attainment, employment status, physical and psychological burden, the older group showed significantly better tolerance to medication, were less likely to switch medications and were much more likely to be fully adherent or partially adherent compared with their younger counterparts, who were more likely to be non-adherent. The older group was significantly less likely to report “being burdened by food restrictions, pill burden, taste, nausea, diarrhoea, sleep disturbance, concentration problems, anxiety, depression, skin rashes, liver complaints or a need for simpler regimens”. They were also significantly more optimistic about treatment (Sherr et al. 2009). An American study of 431 HIV positive adults found similar results but also identified a sub-grouping of older people with neurocognitive functioning deficits. Not surprisingly, this group had poorer adherence than those with normal scores on neurocognitive testing (Ettenhofer et al. 2010).

4.12.5.15 Psychosocial Issues

In a detailed study of over 1000 older adults living with HIV in New York in 2006, depression was reported by over 50% of respondents, which is nearly twice as prevalent as any other reported concurrent condition. On a self-rate depression scale, 38% of the population was moderately depressed and a further
26% could be categorized as severely depressed. The authors suggest that mood disorders are frequently under-diagnosed in older people living with HIV or AIDS (PHAs) and highlight the complex interaction between mood, immune status and social networks. They also found comparatively high rates of current or previous substance misuse, including alcohol, cigarettes, illegal and prescription medication. Respondents also typically scored highly on a scale of loneliness and many had limited social networks (Karpiak et al. 2006).

There is evidence in the literature that living with age-related changes and losses, along with the challenges of living with HIV, may exacerbate existing stressors and severely compromise one’s resources for coping (Vance et al. 2010b). This can overwhelm an individual’s coping abilities, possibly resulting in higher rates of depression, suicidal ideation, and suicide than those in the general population. The identified factors for PHAs among the older adult population include stigma and loneliness (Vance et al. 2010b).

The two subcortical areas regulating mood are the basal ganglia and the substantia nigra both of which have been shown to be compromised in aging and HIV (Vance et al. 2010b). HIV compromises the subcortical structures which may cause poor regulation of mood. This is identified in those individuals who tend to ruminate the negative aspects of their lives and older PHAs “may find it more difficult to initiate an alternative thought that may be more positive” (Vance et al. 2010b).

There is also evidence that older PHAs experience executive functioning challenges such as examining problems, developing solutions, judging alternatives, and making decisions (Vance et al. 2010b). This could result in individuals being unable to formulate their own coping strategies by adapting or confronting the stressors and may result in feeling overwhelmed with novel stressors (Vance et al. 2010b). This is compounded with substance use such as alcohol and marijuana.

Another factor to consider is that most older PHAs may live in isolation with minimal supports as they are already retired, are alone most of the time, and have minimal structured social networks (Ruiz et al. 2010).

4.12.5.1 Interventions

- Increase social supports, community resources and linking, day programs
- Cognitive Behavioural Therapy
- Mindful Based Stress Reduction
- Cognitive remediation therapy if appropriate

Hammond and Treisman (2008) have developed a conceptual framework demonstrating the relationship between HIV, aging, mental illness and medical concurrent conditions. Low mood can lead to poorer adherence and less effective health seeking behaviours, as well as leading to increased use of drugs and alcohol. This places the older person at increased risk of developing concurrent conditions that will in term impact mood and adherence. Studies show that around 10% of older people living with HIV have contemplated suicide (Vance et al. 2008).

4.12.6 Stigma

The New York Research on Older Adults with HIV study showed high levels of stigma as measured by the Berger HIV Stigma Scale (Karpiak et al. 2006). People living with HIV or AIDS (PHAs) already experience stigma on the grounds of diagnosis alone. The risk of marginalization is further exacerbated by sexuality, physical, cognitive or sensory disabilities, drug and alcohol use and for this group of PHAs, age. It is easy to see how people become disengaged from family, services and society. Ethnicity and/or immigration status are also important to consider as they intersect with socioeconomic status, resettlement, loss of independence, communication barriers and along with other psychosocial issues (Masi and Dinsman 1994). All of these factors further contribute to the prejudice existent within the rehabilitation profession as a whole in Canada, as evidenced by the finding that almost half of a random sample of rehabilitation professionals were unsure as to whether they would work with HIV positive individuals (Worthington et al. 2009).

4.12.6.1 Disclosure and Stigma Management

For many individuals, HIV disclosure may result in stigma and isolation. For the older adult population living with HIV, not disclosing one’s HIV status can be understood as a protective mechanism termed “stigma management”. One study reveals several disclosure styles used by older people living with HIV or AIDS (PHAs) (Poindexter and Shippy 2010). These include:

- **Partial disclosure of diagnosis**: this occurs when the individual perceives he or she had only partial control of disclosure because someone had already guessed or speculated about their health status.
- **Anticipated disclosure**: this occurs when certain stereotypes are linked together. For instance, when the public links HIV to being gay and when a suspected older adult falls ill, the public presumes the illness is HIV. This may be a disclosure phenomenon experienced by gay men.
- **Unintended disclosure**: this is usually precipitated by physical appearance, such as in a case of lipodystrophy caused by antiretroviral therapy.

Stigma resistance goes beyond stigma management and is the process of widespread or complete voluntary diagnosis disclosure, thereby preventing a label from becoming a stigma. “HIV disclosure, therefore, is a delicate, time-sensitive, necessary decision that can be highly hurtful or highly helpful depending on how it is handled” (Poindexter and Shippy 2010).
4.12.2 Interventions

- Remember the individual's choice and his or her uniqueness, as well as the general principles that are involved with each case. See Section 1.2 for recommendations for interacting with communities affected by HIV, which was written by people living with HIV or AIDS (PHAs).
- Communicate appropriately. This includes non-verbal communication, as clients may not want to disclose if they feel "unsafe" or feel "judged". The practitioner’s role is to create an atmosphere where the client can feel comfortable to freely express themselves.
- Practice empathy. This "has two facets in that it’s the ability to take another's person's point of view and the capacity to be concerned by the emotions of another person" (Squier 1990).
- Exchange information in a manner that respects the integrity of the practitioner-client relationship. Keep in mind that for clients who are using language translators, it may be appropriate in some instances and inappropriate in other instances to speak with full disclosure. This is especially true if a family member, such as a son or daughter, has not been informed of his or her parent's status in spite of the fact of being there to help with the translation. This example may call in question of the security and confidentiality of the practitioner and client interaction and would be a great risk for unintentional disclosure.
- Practice client-centred care. More information on this can be found in Section 7.2 Navigation and Advocacy.

4.12.7 Services and Physical Environments for People Aging with HIV Infection

There are no known specific services or facilities for older people living with HIV or AIDS (PHAs). While some support groups do exist in some third sector organisations, they are far less prevalent than services for other groups such as young people, women, gay men, and intravenous drug users. Many stakeholders would like to see a merge between senior's groups and HIV groups, but this barrier has yet to be overcome.

We can expect a higher proportion of older adults with HIV over the next decade. Health care professionals should be alert to the unique issues facing older PHAs as well as the commonalities to the general aging population. Attention should be directed not only at serving this group as the unique population that it is, but also bringing them together with the general aging population. Attention should be directed not only at serving this group as the unique population that it is, but also bringing them together with the general aging population. Health care professionals should be alert to the unique issues facing older PHAs as well as the commonalities to the general aging population. Attention should be directed not only at serving this group as the unique population that it is, but also bringing them together with the general aging population.

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Practice client-centred care. More information on this can be found in Section 7.2 Navigation and Advocacy.

The Canadian Working Group on HIV and Rehabilitation (CWGHR) recently received funding to develop interdisciplinary rehabilitation guidelines for the care and management of people aging with HIV. Work will begin in late 2010 and the first draft of the guidelines are being planned for early 2012. More information about this project can be found on the CWGHR website (www.hivandrehab.ca).

4.13 Sexual Health and Dysfunction

4.13.1 Introduction

This chapter is intended to assist care providers to discuss issues of sexual health with their clients, particularly since may 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, 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 patient's response to the open-ended question, the health professional can then make specific suggestions (SS) 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 includes:
- Sensuality
- Intimacy
- Sexual identity (including gender identity and sexual orientation)
- Sexual health and reproduction
- The abuses of sexuality (or sexualization – e.g., rape, sexual harassment) (Tino et al. 2008).

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 or AIDS (PHAs) due to a lack of research into many of these areas. From what little is known, SD is common in men, women and transgender (or third gender) PHAs (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 a SD (Goldmeier et al. 2005).
Some authors suggest that sexual dysfunction may also result from the criminalization of HIV nondisclosure in some jurisdictions (Mykhalovskiy et al. 2010). A recent 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 or AIDS (PHAs) and could be due to social, political, cultural and religious factors that may be out the PHA’s personal control. Health care providers may be the only conduit for PHA to discuss SD and possible solutions. Health care providers can benefit from personal development in the area of sensitive practice in the context SDs. Recent 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:

- 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

(Green and Kodish 2009)

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 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)?

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
- 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, but it may also be a conscious decision explicitly made by individuals, regardless of whether they are living with HIV or AIDS.

4.13.2 Reasons for Sexual Dysfunction in People Living with HIV or AIDS

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

- HIV medications such as protease inhibitors
- Other prescription drugs (e.g., hypertensive medications and antidepressants)
- Emotional issues (anxiety/stress/grief and depression)
- Smoking
- Alcohol use
- Recreational drug use
- Hormone dysfunction (testosterone deficiency and thyroid dysfunction in men and women, early menopause in women with HIV)
- Autonomic and/or peripheral neuropathy (interfering with nerve function to organs of sexual pleasure)
- Lipodystrophy or lipoatrophy (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 or AIDS (PHA) 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 PHAs live longer, sexual dysfunction (SD) increases as it does in the general aging population.
It is important that the person living with HIV or AIDS (PHA) not change 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 client’s trusted sexual partner given the client’s consent and safety. Often, other PHAs or counselors at community-based AIDS Service Organizations (ASOs) may understand and be empathic with SD issues and there may be locally available resources including peer or professional support. If the PHA 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 sex
- 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 fulfillment 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.

- Encourage communication with a partner about what is pleasurable and what is not. If open discussion is difficult, couples counseling to discuss sexual dysfunction may be beneficial.

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 of health care professionals may indicate 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

- “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 (Carel et al. 2009). About 80% of countries report having included women as a specific «sector» in their multisectoral AIDS strategies or action frameworks, yet barely more than half of those countries report actually having a budget associated with women-oriented programming (Carel et al. 2009, Gray and McIntyre 2006). As of 2007, women constituted just over half of the 33% of individuals using combination antiretroviral therapy. The gender gap on HIV knowledge has narrowed, however around the world today, only 36% of young women have accurate information pertaining to HIV prevention (Carel et al. 2009). 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 Abuse and Mood Disorders

As with men and HIV, substance abuse 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 abuse (Gollub 2008, Shannon et al. 2007). This is particularly problematic in light of the fact that 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 for depression, a greater tendency to participate in exchange sex, a higher number of lifetime and current sexual partners, a increased propensity for unfaithful partners and a lesser ability to mediate safe sex practices (Fuentes 2008). Moreover, nonconsensual 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 IPV are 7.0 times more likely than serostatue negative nonabused 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 abuse, violence against women and HIV status.

4.14.4 Prevention Strategies for Women

Abstinence, exclusivity or asking a sexual partner to wear a condom are three of the more likely 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 is 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 traumatic a time such 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 and AIDS might help diminish this discomfort during such an adverse event.

4.14.6 Female Condom

The female condom is another option which is woman-initiated. 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, Woodson 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 soci-cultural education (Woodson and Alleman 2008). Although there seems to be an overall acceptance by women of microbicides, they are not yet available on the market (Ruiz et al. 2009). 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 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, TIlerson 2008, El-Bassel et al. 2009, Gardezi et al. 2008). In Canada, this constitutes women of the Afro-Carribean community (Gardezi et al. 2008), and Aboriginal peoples (Health Canada 2010). In spite of only making up 3.3% of the Canadian population, Aboriginal 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 caucasan are the least likely to be educated by their general practitioners and family doctors regarding safe sex 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 recent study which 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 infected women 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. A recent American study shows that the more children a woman has who are under the age of 18 and the greater the degree of childburden 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 has reduced by 2% of all cases of pregnant women taking combination antiretroviral therapy (Manavi 2006) 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 practicing consistent contraception or those expressing interest in a future pregnancy should be involved in an in-depth discussion about bearing children. 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 states 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 breastmilk to further diminish the likelihood of transmission (Burdge et al. 2003). Another option is to feed one's infant breastmilk 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 vigorous testing, including the aforementioned HIV test as well as bacteriological screening before and after pasteurization. Donated milk is collected in sterilized bottles and is immediately refrigerated, then frozen within 24 hours. The majority of women donating milk are also feeding their own baby/babies at the same time (Fraser and Cooper 2009). Any woman with a prescription from a physician or midwife anywhere in Canada is eligible for this service, although it is not free. Women who are unable to breastfeed their babies due to health circumstances, such as women with HIV, are given preferential treatment. At present, there is only one human milk bank in Canada the BC Women's Milkbank http://www.bcwomens.ca/Services/PregnancyBirthNewborns/HospitalCare/Breastfeeding.htm.

There is talk of milk banks opening within the next 3 years in Ontario and Quebec (per comm. Newman Breastfeeding Clinic Oct. 26, 2010). This option is much more viable for those who live within close proximity of the milk bank, as it only costs three to five dollars an ounce. It is the shipping of breast milk which can get quite costly and those interested should contact the BC women's milk bank directly. Although formula is a well developed alternative to breastfeeding, the immunological and nutritional benefits of breastmilk far outweigh those gained from formula feeding. Consequently, the World Health Organization (WHO) 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

Recent 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 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 are able to 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
- Placing ramps at healthcare centres.
- 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 who may be at risk for or living with HIV (WHO UNAIDS 2009, Heidari and Kippax 2009).
5_1 Introduction

With the numerous advances made in research and practice infants, children and adolescents who have access to effective therapies are surviving HIV. Mother-to-child transmission (MTCT) has been significantly reduced, particularly in the developed world, with rates as low as 2% (World Health Organization (WHO) 2009d, Manavi 2006). Moreover, survival rates and health status for infants born to HIV positive women have also dramatically increased. From 1990 to 2002, hospitalization rates and admission to intensive care units (ICUs) have significantly decreased. This was especially notable following 1996 triple therapy guidelines for HIV positive pregnant women (Bertolli et al. 2006). Although perinatally infected individuals now experience increased survival rates and overall health improvements, this has translated the experience of living with HIV into living with a chronic disease, resulting in other issues including “treatment fatigue, crisis of trust due to delayed diagnosis disclosure, parental guilt and overprotection, as well as stigma” (Speigel and Futterman 2009).

The management of HIV infection in infants and children presents significant challenges for rehabilitation providers. An important consideration is the impact of HIV infection on the family. In many cases, diagnosis of HIV infection in the child or infant may be the first indication of HIV infection in the mother and other family members. The skills of each member of the rehabilitation team are required to address the complex psychosocial and physical needs of the child or infant and his or her family. Further considerations for children on antiretroviral therapy for HIV, acquired perinatally or otherwise, include adherence. (Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children (PATMMHC) 2010). Importantly, “differences in the clinical and psychosocial presentations of youth with perinatally versus behavioral acquired HIV infection are important and influence the acceptance of illness, self-efficacy, and antiretroviral treatment adherence” (Speigel and Futterman 2009). It is also important to note that those with perinatally acquired HIV experience the disease in somewhat different manners from those children/adolescents acquiring HIV. Children and adolescents with behaviourally acquired HIV are more likely to mirror the psychosocial, racial and economic demographics, as well as the sexual and substance abuse practices of adults who acquire HIV (Speigel and Futterman 2009). Although many of the rehabilitation interventions described in Section 6 are relevant to children and infants living with HIV, there are some unique considerations for children and infants and these are described in this chapter. Although exercise for children is not reviewed in Section 6, there is now some evidence to demonstrate the effectiveness of exercise for improving general fitness and strength as well as lean body mass in children with HIV (Miller et al. 2010).

5.1.1 Disclosure

Perinatally-infected clients differ from behaviorally acquired HIV as it relates to disclosure in terms of control and timing. For those born with HIV, disclosure is often a gradual process controlled by caregivers/parents. Those who acquire HIV later on in life, such as in childhood or in adolescence, must make 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).

5.1.2 Adherence

Adherence is often difficult to achieve with medication requiring near perfect compliance and always carries challenges for any age group. In pediatric populations, unique considerations affecting adherence can be attributed to volume and frequency of doses, taste and forgetfulness (Chesney 2000). Greater than 90% adherence is critical for optimal outcomes with antiretroviral therapy, however nonadherence for these drugs is reported to lie somewhere between 50 and 70% (Chesney 2000). Although reasons for nonadherence for perinatally infected versus behaviourally infected individuals tend to overlap, they also differ in some important aspects. While perinatally infected individuals have possibly had many years of experience in the hospital setting and with a pharmacological routine, rebellion can contribute to a change in compliance. On the other hand, with an older age of infection, associated stigma and general unfamiliarity make adherence by behaviourally acquired HIV youth a challenge (Speigel and Futterman 2009).

These issues can be addressed by a wide range of health care professionals, including social workers, occupational therapists, pharmacists and physicians.
5.1.2.1 Means to Determine Adherence Levels

**Note:** Asking both the child and the caregiver the following is important:
- Describe medication use in the past 24 hours or week
- Who gives the medication
- What the specific names and dosing of each medication are
- Where the medications are kept
- Where the medications are taken
- The time(s) the medication is taken

Providing space for more open-ended discussion aimed at identifying unique issues for either the child, the caregiver or both is also important. Caregivers can also be asked to provide prescription records to determine timing of refills.

5.1.2.2 Strategies to Facilitate Adherence

- Actively incorporate the caregiver and family in the medication plan
- Creating a daily schedule and ensuring all involved parties are onboard
- Educate the child and caregiver about the medication (For example, highlighting the differences between generic and brand names can help diminish confusion)

5.1.2.3 Strategies to Assist in Persistent Adherence Problems

Directly observed therapy (DOT) in a facility or home observation
- Calendars
- AM/PM pill containers
- Alarms

These are all affordable ways to build reminders into the child/caregiver’s day.

If possible, speak to the child’s specialist or pharmacist and explore the possibility of simplification of medication. Relaxation techniques (particularly for issues around pill swallowing/association of medication with certain adverse side effects) are also recommended. Speech-Language Pathologists can be especially valuable in this context.

A psychosocial assessment to determine the mental health status of the child, caregiver and any other family members, any evidence of substance abuse, or any indication of major changes in the recent past may also be appropriate. This assessment should address school and any issues arising therein as well. Finally, the child and caregiver should be asked about their respective beliefs towards their medications. In extreme cases, child protection services or alternate living arrangements should be considered if adherence challenges appear perpetual.

5.2 Feeding problems and poor growth

There are various issues unique to infants and children as it relates to feeding and growth.

Proper nutrition is one of the easiest ways to facilitate immunocompetence. Although antiretroviral therapy has dramatically reduced the poor growth, such as low weight gain, below average linear growth, weight loss, anorexia, and stunted height associated with childhood HIV positive status, it is nonetheless important to attend to the nutritional needs of infants and children living with HIV. Malnutrition can have a negative effect on immunity and make it more difficult to fight infections. It should be noted however that almost 50% of children and adolescents who acquire HIV are overweight or obese thereby complicating the issue of diet, malnutrition and negative outcomes associated with pediatric HIV. Interventions once primarily focused on preventing malnutrition are now geared to 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.

5.2.1 Breastfeeding

Because of the potential for maternal-to-infant transmission of HIV, breastfeeding is not recommended for infants born to mothers with HIV/AIDS whenever safer alternatives exist. Instead, infants can be fed infant formula fortified with iron. Another option is to procure milk from a human 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 vigorous testing, including the aforementioned HIV test as well as bacteriological screening before and after pasteurization. Donated milk is collected in sterilized bottles and is immediately refrigerated, then frozen within 24 hours. The majority of women donating milk are also feeding their own baby/babies at the same time (Fraser and Cooper 2009). Any woman with a prescription from a physician or midwife anywhere in Canada is eligible for this service, although it is not free. Women who are unable to breastfeed their babies due to health circumstances, such as women with HIV, are given preferential treatment. At present, there is only one human milk bank in Canada the BC Women’s Milkbank [http://www.bcwomens.ca/Services/PregnancyBirthNewborns/Hospital-Care/Breastfeeding.htm](http://www.bcwomens.ca/Services/PregnancyBirthNewborns/Hospital-Care/Breastfeeding.htm)

There is talk of milk banks opening within the next 3 years in Ontario and Quebec (per comm. Newman Breastfeeding Clinic Oct. 26, 2010). This option is much more viable for those who live within close proximity of the milk bank, as it only costs three to five dollars an ounce. It is the shipping which can get quite costly and those interested should contact the BC women’s milk bank directly. Although formula is a well developed alternative to breast-
feeding, the immunological and nutritional benefits of breastmilk far outweigh those gained from formula feeding. Consequently, the World Health Organization (WHO) 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. More information about this can be found at the Human Milk Banking Association of North America (http://www.hmbana.org/) or the BC Women’s Milkbank http://www.bcwomens.ca/Services/PregnancyBirthNewborns/Hospital-Care/Breastfeeding.htm. Although it is said that breast is best, women should be assured that formula feeding is the next best alternative.

5.2.2 Feeding Problems and Poor Growth

Infants and children living with HIV are at high risk for malnutrition, which can have a negative effect on immunity and make it harder to fight infections. Malnutrition causes a lack of weight gain, poor growth, and even weight loss. Interventions are primarily focused on preventing malnutrition. 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.

The many causes of malnutrition include poor appetite, nausea, vomiting, diarrhea, mouth sores, depression, parent-child interaction, environmental/feeding practices (see Table 5.2). When an infant or child has a secondary infection, his or her caloric needs may be higher than normal. Gastroesophageal reflux and delayed gastric emptying are common problems in children with encephalopathy, and contribute to the risk of aspiration and increased incidence of vomiting, nausea, abdominal pain, and anorexia. In extreme cases, supplemental tube feeding, for short-term, and sometimes on a longer term basis, may be necessary.

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 pivotal roles in this context particularly.

Red Flag Any deviation from previously stable growth curves requires prompt 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 and can be related to issues such as:
- Developmental delay (if the child does not have age-appropriate cognitive and motor skills, they will likely not be age appropriate in their eating/feeding either)
- Oral motor skills
- Swallowing problems (including aspiration)
- Poor appetite
- Gastro-intestinal (GI) issues (such as nausea, diarrhea, gastroesophageal reflux, delayed gastric emptying, malabsorption, etc)
- Increased caloric needs
- General health status

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.

Prior to initiating 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 gastrointestinal (GI) discomfort (e.g., reflux or nausea) with oral feeds.
Table 5.2 Clinical Aspects of Feeding Problems and Poor Growth

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
</table>
| Inadequate feeding               | • poor oral motor skills  
• poor coordination of breathing or swallowing  
• tires easily/decreased endurance  
  - consider whether the child is limiting their intake as an adaptive/protective response due to another reason listed below |
| Self-feeding problems            | • unable to self-feed / poor fine motor and visual-motor skills  
• tires easily/ decreased endurance  
• developmental delay or regression  |
| Swallowing problems (including choking with feeds/aspiration) | • mouth/throat sores or pain structural abnormalities swallowing incoordination  
• developmental regression  
• encephalopathy or neurologic changes |
| Poor appetite                    | • anorexia, nausea, vomiting, fatigue, pain  
• decreased taste acuity  
• abnormal taste  
• side-effects of medication  
• psychosocial and emotional distress (e.g., separation, anxiety, depression, parent-child interaction, over/underfeeding) |
| Diarrhea                         | • malabsorption  
• medication side-effects  
• HIV enteropathy  
• altered gastric motility  
• infections (viral, bacterial, or parasitic) |
| Increased caloric demands        | • hypermetabolic state (e.g., fever)  
• infections  
• HIV-related |

5.2.3 Rehabilitation Interventions

5.2.3.1 Inadequate Feeding

- Position (e.g., sidelying 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 mixed with formula instead of water. It is important to avoid adding formula to cereals that are labelled “add water” as these cereals contain powdered milk. If formula is added, the caloric content can be excessive and dangerous. Ensuring the cereal is labelled “add formula or breastmilk” is imperative  
- Use oral stimulation techniques taught by a therapist to improve suck strength and the coordination of the suck, swallow, and breath sequence

5.2.3.2 Self-Feeding Problems

- Use adaptive cups that make it easier to drink  
- Use easy-to-hold finger foods  
- Use adaptive utensils and plates that make it easier to eat  
- 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
5.2.3.3 Difficulty Swallowing

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
- 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

5.2.3.4 Poor Appetite

- 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, cream)
- Give oral nutritional supplements
- Give nutritional supplements via gastrostomy tube for anorexia

5.2.3.5 Diarrhea

- Treat infections, if present
- Assess gastrointestinal motility and use appropriate medications as required
- Use dietary interventions as recommended by a registered dietitian, often low-fat-low lactose foods

5.2.3.6 Increased Caloric Demands

- Control fever with anti-pyretics
- Identify and treat any contributing co-infections

5.3 Movement and Coordination Impairments

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 (although encephalopathy is now uncommon in children with access to antiretroviral therapies)
- Spinal and corticospinal tract degeneration in children versus vacuolar myelopathy (affecting lateral and posterior columns) in adults
- The relatively rare occurrence of peripheral neuropathy in children

The common causes of movement and coordination impairments are shown in Table 5.3.

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

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encephalopathy, developmental delay</td>
<td>HIV infection of brain</td>
</tr>
<tr>
<td></td>
<td>malignancies (e.g., CNS lymphoma)</td>
</tr>
<tr>
<td></td>
<td>CNS infections (less common in children than adults) (e.g., CMV, Candida)</td>
</tr>
<tr>
<td>Cerebral vascular disease</td>
<td>Vasculitis</td>
</tr>
<tr>
<td>Spinal cord lesion</td>
<td>HIV-related spinal or corticospinal tract degeneration</td>
</tr>
<tr>
<td></td>
<td>Wallerian degeneration from white matter disease</td>
</tr>
<tr>
<td></td>
<td>spinal cord infections (e.g., CMV, HSV)</td>
</tr>
<tr>
<td></td>
<td>malignancies (e.g., lymphoma)</td>
</tr>
<tr>
<td>Myopathy (infrequent in children)</td>
<td>AZT-related</td>
</tr>
<tr>
<td>Peripheral neuropathy (infrequent in children)</td>
<td>infection-related</td>
</tr>
<tr>
<td></td>
<td>drug-induced (e.g., AZT, ddl)</td>
</tr>
</tbody>
</table>

Legend: AZT: zidovudine; CMV: cytomegalovirus; CNS: central nervous system; ddl: didanosine; HSV: herpes simplex virus
5.3.1 Rehabilitation Interventions

5.3.1.1 Generalized Hypotonia and Delayed Achievement of Motor Milestones from Static Encephalopathy

- Promote motor activity through play, positioning, and handling (e.g., neurodevelopmental therapy)
- Develop muscle strength and transitional movements
- Use infant seats or chair inserts (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)

5.3.1.2 Hypertonicity from Progressive Encephalopathy

- 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 specialist for botox or other therapies if appropriate

5.3.1.3 Problems of Limited Mobility from Encephalopathy or Neuropathy

- 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

5.3.1.4 Loss of Independence in Self-Care

- Install adaptations to home or school (e.g., bath seat, ramps, handrails)
- Use diapers or special toilet seat

5.4 Behaviour, Memory, and Learning Impairments

Marked delays in development are relatively rare now with early diagnosis and treatment, however, family stress continues to be a potential contributor to behaviour impairments. Encephalopathy can be the primary manifestation of HIV infection in children and can be characterized by developmental delays, delay or loss of motor skills and intellectual abilities, and behavioural abnormalities. However, very few cases of encephalopathy are now seen in areas where children have access to antiretroviral treatment. In infants and young children, language acquisition and use may also be significantly impaired. Although profound encephalopathy is seen in some children, the degree of disability is variable. The trend of decline may be static, slowly or rapidly progressive, or intermittently progressive.

Many of the common causes of behaviour, memory, and learning impairments are shown in Table 5.4.

Clinical studies have identified frequent patterns of neurological involvement in children infected perinatally. These patterns include:

- Microcephaly
- Cognitive deficits
- Cerebral atrophy
- Calcification of the basal ganglia
- Delay or loss of developmental milestones
- Abnormal reflexes
- Electroencephalogram abnormalities

Confounding factors that may contribute to the observed developmental abnormalities include:

- Secondary infections
- Poor prenatal care
- Repeated hospitalizations
- Social isolation
- Neglect
- Nutritional deficiency
- Disrupted social routines
- Medication side effects
- Effects of maternal substance use

In non-perinatally acquired HIV among older children and adolescents, cognitive symptoms are more similar to those manifested by adults. These include decreases in reaction time, attention, and memory, as well as general psychomotor slowing. It is often difficult to ascertain the extent to which these changes are caused by the HIV infection itself, as well as how much is secondary to general feelings of fatigue.

Early identification is a critical factor in maximizing the efficacy of treatment for developmental delays. Scheduling routine developmental evaluations by the multidisciplinary team allows for timely assessment and for implementation of a suitable rehabilitation program.

Red Flag Any acute loss of already mastered skills requires prompt medical referral to rule out a co-infection or opportunistic infection.
### Table 5.4 Clinical Aspects of Behaviour, Memory, and Learning Impairments

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental delays</td>
<td>• HIV encephalopathy&lt;br&gt;• other congenital infections (e.g., cytomegalovirus)</td>
</tr>
<tr>
<td>Motor spasticity or hypotonia</td>
<td>• basal ganglia calcifications</td>
</tr>
<tr>
<td>Poor or absent expressive</td>
<td>• HIV&lt;br&gt;• diminished opportunities to use expressive language&lt;br&gt;• hearing loss</td>
</tr>
<tr>
<td>Language</td>
<td>• HIV&lt;br&gt;• diminished opportunities to use expressive language&lt;br&gt;• hearing loss</td>
</tr>
<tr>
<td>Poor socio-adaptive skills</td>
<td>• developmental delays</td>
</tr>
<tr>
<td>Poor memory</td>
<td>• HIV&lt;br&gt;• fatigue</td>
</tr>
<tr>
<td>Poor learning</td>
<td>• HIV&lt;br&gt;• fatigue&lt;br&gt;• pre-existing learning problems</td>
</tr>
<tr>
<td>Poor attention</td>
<td>• HIV&lt;br&gt;• fatigue&lt;br&gt;• attention deficit disorder&lt;br&gt;• pain</td>
</tr>
<tr>
<td>General slowness</td>
<td>• HIV&lt;br&gt;• fatigue</td>
</tr>
<tr>
<td>Irritability and frustration</td>
<td>• HIV&lt;br&gt;• inability to make self understood&lt;br&gt;• pain</td>
</tr>
</tbody>
</table>
5.4.1 Rehabilitation Interventions

5.4.1.1 Infants

5.4.1.1.1 Slow Acquisition of Developmental Milestones

- Consider developmental testing using standardized psychological measures
- Use infant stimulation programs using bright, interesting toys to stimulate the infant to participate in play
- Provide play materials that stimulate a variety of senses (e.g., toys that have different textures; 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 early enrollment in group activities to provide opportunities for peer modeling, as well as respite for parents

5.4.1.1.2 Poor or Absent Expressive Language

- Administer standardized language measures
- Provide an abundance of speech examples by talking to the infant about everything in his or her environment
- Pause in conversations with the infant to allow him or her to respond with some kind of verbal utterance
- Provide labels for everything and encourage modeling or sound approximations
- Do not anticipate the infant's every wish. Allow the infant to use what language he or she does have (e.g., if the infant gestures and grunts, do not immediately hand the infant the desired item; first attempt to encourage the infant to use a word or sound)
- Expand on the infant's utterances (e.g., when the baby says "juice," the caregiver can say "Do you want some juice?")
- As the infant learns words, ask open-ended questions instead of those requiring only a yes or no response
- Assess for hearing loss, a common cause of language delay in children
- Initiate assessment by a speech-language pathologist

5.4.1.2 Children

5.4.1.2.1 Poor Memory

- 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 n.b. determining whether or not the child is ready for this step is contingent upon his or her cognitive abilities and is variable)

5.4.1.2.2 Attention and Learning

- Administer standardized tests
- Have remedial classes in areas of difficulty
- Provide tutoring or give extra help in areas of difficulty
- Set aside specific time (e.g., 30 minutes every night after dinner) to work on assignments 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 attains goals (e.g., stickers, stars)
- Review 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

5.5 Respiratory Impairments

Respiratory tract problems are among the most frequent complications in children living with HIV. Common respiratory tract infections include:

- Recurrent acute and chronic otitis media
- Recurrent thrush
- Sinusitis
- Pneumonitis

Table 5.5 shows some of the common causes of these types of infection. A common form of pneumonitis in children is lymphoid interstitial pneumonia (LIP), a chronic disease characterized by spontaneous exacerbations, intermittent wheezing, and chronic cough. The chest x-ray pattern varies often, showing migrating interstitial infiltrates. In some cases, the pattern is difficult to distinguish from tuberculosis. Although Pneumocystis carinii pneumonia (PCP) occurs less frequently as a result of widespread prophylaxis, it 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.
5.5.1 Rehabilitation Interventions

5.5.1.1 General
- Positioning to maximize ventilation perfusion matching
- Relaxation techniques
- Breathing control exercises (where relevant)

5.5.1.2 Deep Breathing Exercises
- Diaphragmatic and lateral costal breathing
- Bubble blowing (promotes an excellent breathing pattern and is also fun for younger children)
- Use of an incentive spirometer for children over five years of age

5.5.1.3 Manual Techniques
- Postural drainage
- Percussion
- Vibration
- Neurofacilitation techniques

5.5.1.4 Expiry Techniques
- Forced expiry technique (FET)
- Positive expiratory pressure (PEP)

(Table 5.5 Clinical Aspects of Respiratory Impairments)

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes and Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Otitis media</td>
<td>• bacterial</td>
</tr>
<tr>
<td></td>
<td>• viral</td>
</tr>
<tr>
<td></td>
<td>• serous exudates</td>
</tr>
<tr>
<td>Thrush</td>
<td>• yeast</td>
</tr>
<tr>
<td>Sinusitis</td>
<td>• viral</td>
</tr>
<tr>
<td></td>
<td>• bacterial</td>
</tr>
<tr>
<td>Pneumonitis</td>
<td>• PCP</td>
</tr>
<tr>
<td></td>
<td>• LIP</td>
</tr>
<tr>
<td></td>
<td>• desquamative interstitial pneumonitis</td>
</tr>
<tr>
<td></td>
<td>• bronchiolitis obliterans</td>
</tr>
<tr>
<td></td>
<td>• nonspecific pneumonitis</td>
</tr>
<tr>
<td></td>
<td>• viral or bacterial pneumonia</td>
</tr>
<tr>
<td></td>
<td>• bronchiectasis</td>
</tr>
</tbody>
</table>

Legend: LIP: lymphocytic interstitial pneumonitis; PCP Pneumocystis carinii pneumonia

Manual physiotherapy techniques or the PEP mask should be used only if there is a clear indication that a superimposed acute or chronic lung disease process is present with evidence of lower airway secretions. Those clients with only upper airway secretions do not require manual physiotherapy techniques; they need suctioning only if they are unable to clear their own secretions with coughing.

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

5.6 Pain

Pain is a multifaceted issue that should be addressed in every HIV positive pediatric case. An interdisciplinary team, including but not limited to, a pediatric pain specialist, a pharmacist, a social worker, physical therapists, occupational therapists, and nurses should be involved in a HIV positive child’s course of care as early as possible and both pharmacological and non-pharmacological interventions should be used. 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.
Common types of HIV and AIDS related pain include neural inflammation presenting as cardiomyopathy and myositis, drug toxicities and other negative reactions, secondary infections, pain resultant from invasive procedures or to non-AIDS specific conditions. Any pain is important to note, but of particular importance is pain that has changed from baseline or previous pain-free status. Pain can be measured using modified visual analogue pain scales and rating measures. These measures can be adjusted according to age, degree of illness and other factors, such as cultural background and beliefs.

5.6.1 Nonpharmacological Interventions for Pain

The interdisciplinary team can provide a wide spectrum of nonpharmacological pain interventions to complement pharmacological interventions. These are all examples of pain management interventions. 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.

- Relaxation techniques
- Free play time
- Music
- Sleep
- Rest
- Balanced diet
- Acupuncture
- Transcutaneous Electrical Nerve Stimulation (TENS)
- Whirlpool baths
- Physical therapy

5.6.2 Pharmacological Interventions for Pain

Pharmacological interventions are also important and can include:

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

5_7 Adolescents and Young Adults

Adolescence is a time of transition and growth wherein an individual faces changes on many fronts, including physical, emotional, and mental processes as well as sexual identity (Speigel 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, a diagnosis of being HIV positive can be extremely traumatic and is frequently associated with depression and low self-esteem.

Adolescents constitute the largest growing group of people acquiring HIV in North America. In America for instance, while overall new HIV diagnoses decreased by 4% between 2000 and 2006, it increased by 21% for those aged between 13 and 24 years old (Speigel and Futterman 2009). HIV acquisition in youth is associated with socio-economic status, race, sexual orientation and gender. In the United States, young, black gay, bisexual and other males who have sex with males (MSM) are at a higher risk than any other age group or race for acquiring HIV (Speigel and Futterman 2009). Black, female, heterosexual women are also at a significantly higher risk than other women of acquiring HIV. Notably, intravenous drug use (IDU) is not a significant cause of HIV infection in these women (Speigel and Futterman 2009).

In Canada, Aboriginal adolescents are more likely to be HIV and/or AIDS positive at a younger age than any other non-Aboriginal Canadians (Health Canada 2010). Street youth, defined as Canadians between the ages of 10 and 19 living on the streets all or most of the time, also have higher rates of hepatitis B (HBV), hepatitis C (HCV) and HIV infection. These youth also experience disproportionately high levels of violence, mental health issues, substance abuse and pregnancy compared to non-street youth in Canada (Boivin et al. 2005). Notably, this intersection of substance abuse, mental health issues, race and risk for HIV infection is similar to those in adults who are at high-risk for HIV infection.

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, friends, and loved ones. This can be mitigated by support from friends, family and a interdisciplinary team (Speigel and Futterman 2009). Although HIV and AIDS has been traditionally associated with malnutrition and rapid weight loss, currently more than half of those with behaviourally acquired HIV are, at least initially, overweight or obese.

Another challenge faced by adolescents with HIV is the pending transition to the adult health care system. In most cases, a pediatric care team has been managing the care of the adolescents since birth or early childhood, allowing for a trusting relationship to develop with the adolescent and also with their caregivers. Fair et al. (2010) speak to the need for increased independence by the adolescent in managing their health condition as the adolescent nears transition. 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 adolescents to become accustomed to managing their 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

This chapter 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

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. This includes exercise and nutrition. Primary and secondary prevention through harm reduction are also important components of preventive rehabilitation. Primary prevention strategies are typically described as inhibiting disease 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

Evidence to support these finding are described in Section 6.4. While systematic reviews for aerobic and resistive exercise exist (O’Brien et al. 2010, O’Brien et al. 2008b), no precise exercise prescription guidelines for people living with HIV or AIDS (PHAs) have been developed. The best advice to give PHAs is:
- when starting an exercise program, inform your 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 you enjoy
- do what you can, and use common sense to decide how far you should go (if you have questions, consult your 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 or AIDS (PHAs) include malnutrition, cachexia, micronutrient deficiency, obesity and lipodystrophy (Polo et al. 2007). Optimal health for PHAs 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 PHA 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.

Nutritional status is influenced by a broad range of interacting factors:
- 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 PHAs is accumulating rapidly.

Malnutrition and its complications can help to render a person susceptible 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.

Practising 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 have developed Dietary Reference Intakes (http://www.hc-sc.gc.ca/fn-an/nutrition/reference/dri_using-util_anref-eng.php). The Dietitians of Canada have created an online resource for applying these recommendations in practice (Barr, http://www.dietetic-satwork.com/coursedelivery/index.asp).

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 or AIDS (PHAs) themselves. 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. This 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 certainly 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 pediatric 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 or AIDS (PHAs) 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 or AIDS (PHAs) 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, AIDS service organization (ASO) workers, and nutritionists.
6.1.3.1.5 Explore Use of Nutrition-Based Complementary Therapies

A large proportion of people living with HIV or AIDS (PHAs) 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

PHAs should be encouraged to discuss the complementary therapies of interest to them with peers as well as their health care practitioners. Therapies which incorporate healthy nutritional practices should be reinforced. A systematic review on nutritional interventions to reduce morbidity and mortality in PHAs 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 PHAs 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 include gay, bisexual and other men who have sex with men (MSM), people who use injection drugs (IDUs), anyone working in the sex trade, Aboriginal Peoples, and prison populations. Interventions for at-risk populations can successfully lead to more consistent condom use and a greater likelihood of open discussion about sex and more safe sex choices (DiClemente et al. 2010). A recent study directed at female sex workers determined that while condom use increased with clients, it did not change with non-commercial sex partners (Ulibarri et al. 2010). The study also found that interventions were less successful in female sex workers who were also IDUs (Ulibarri et al. 2010).

Programs are also tailored to men who are IDUs or who use other illicit drugs, with aims to reduce unprotected sex as well as sex under the influence of drugs or alcohol (Calsyn et al. 2010). It was found that interventions which include “motivational and skills training HIV prevention intervention designed for men” were the most effective (Calsyn et al. 2010).

In general, it appears that 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 culturally 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 fairly variable across groups, intervention and education with a specific audience in mind is a commonly-used strategy.

6.1.4.2 HIV and Youth

Youth with either perinatally or behaviourally acquired HIV are at risk for secondary transmission. +CLICK is a web-based intervention aimed at promoting abstinence and condom use for this demographic. This program received significant positive feedback from youth and practitioners (Markham et al. 2009).

6.1.4.3 Online Interventions to Improve Disclosure

HIV positive gay men were found to be more likely to disclose their status after watching a 9 minute online intervention video as long as three months following the viewing. Disclosure is considered an important element of intervention and education and this study found that improved rates of disclosure not only reduced casual sexual encounters, it also lowered rates of unprotected anal intercourse (Chiasson et al. 2009).

6.1.4.4 Women and HIV

In light of the fact that women underuse primary health care services than any other group and women also have fewer positive HIV outcomes than men, some believe that interventions should be specifically tailored to women, and perhaps even disproportionately so (Sohler et al. 2009). Women living with HIV or AIDS face unique challenges as mothers and in having a chronic disease. One study, “Making Our Mothers Stronger (MOMS) Project” compared two interventions for mothers living with HIV to determine the most appropriate coping strategies. A stress-reduction and social support intervention (Healthy MOMS) was compared to parenting skills intervention (Parenting Skills for MOMS) in a randomized controlled trial. Maternal mental, maternal physical health, parenting and children’s behaviors were the outcome measures used. Participants reported that the strategies they learned to help deal with stress, adherence, health care providers, family, friends and co-workers, as well as the educational elements related to sexual health, nutrition and physical fitness were beneficial, and could serve as long-term support in light of living with a chronic disease (Davies et al. 2009).
6.1.4.5 Sex Workers

Sex workers in India were more likely to use condoms, more likely to negotiate sex trade and more likely have a social support network following an empowerment intervention, aimed at diminishing likelihood of HIV or sexually transmitted infections (Swendemen et al. 2009b).

6.1.4.6 HIV and Aging

The negative stereotype of the asexual older adult has led to a paucity of programming aimed at maintaining safer sex practices amongst the older HIV population, in spite of an aging HIV positive population. Project Roadmap: Re-educating older adults in maintaining HIV prevention, is one of the few programs recently launched in an effort to diminish high-risk sexual behaviour in the older HIV community (Illa et al. 2010).

6.1.4.7 Other Factors

More than a third of HIV positive dental clients in five different primary care clinics in Florida did not discuss their oral health status with their doctors. This bears potential implications for people living with HIV or AIDS (PHAs) as infection can affect the efficacy of HIV treatment. A complete intervention should include addressing oral health, as more than 90% of PHAs will experience some form of oral manifestation of HIV. PHAs and health-care providers working with this population should be made aware of the importance of regularly checking dental status (Pereyra et al. 2009).

6.1.4.8 Adherence

Adherence is another issue that requires much education, as taking antiretroviral medications requires a virtually perfect level of consistency to reach full efficacy. Various models can be used in an attempt to improve adherence rates. Recently, one study used “Fisher and Fisher’s Information-Motivation-Behavioral Skills Model” and discovered that actual intervention support coming from one caring individual as well as the “audio-supported computer-assisted survey instruments” are most helpful, whereas electronic adherence monitoring is less well received (Konkle-Parker et al. 2010).

6.1.6 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 or AIDS (PHAs).

The United States Centers for Disease Control and Prevention have developed guidelines for incorporating HIV prevention into the medical care of PHAs (2003). The recommendations are general and apply to incorporating HIV prevention into the medical care of all HIV positive adolescents and adults, regardless of age, sex, or race/ethnicity. They are intended for all persons who provide medical care to HIV positive persons and those who deliver prevention messages. These are available online at: http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5212a1.htm

6.2 Pharmacologic Interventions

6.2.1 Antiretroviral Therapies

6.2.1.1 Background

Although rehabilitation professionals generally cannot prescribe drugs, the effects of pharmacological interventions experienced by people living with HIV or AIDS (PHAs) are simultaneously positively and negatively significant. The following is an introduction to the types of pharmacological interventions used by PHAs to provide rehabilitation professionals with a better understanding of what is involved. A lot is now known about the natural course of HIV infection in the absence of antiretroviral therapy (ART). The first couple of weeks are marked by a huge surge in viral load as the HIV virus is busy replicating. Simultaneously, the body's own immune cells, the CD4 cells, drop as they become compromised. After several weeks, the body is able to recover and sero-conversion occurs marking the beginning of clinical latency which may last for several years. After a period of time, a person will start to develop constitutional symptoms as the immune system weakens, paving the way for opportunistic infections. If HIV is left untreated, death will ensue.

Zidovudine (AZT), the first antiretroviral drug to be used against HIV was introduced in 1987. Over the next several years, other agents similar to AZT, were also introduced, known as reverse transcriptase inhibitors. However, these drugs did not have a significant effect on the rate of death due to HIV. The rate continued to rise.

Significant improvements in mortality did not occur until 1995 when a drug known as lamivudine (3TC) was combined with saquinavir, (a drug from another class of medications known as protease inhibitors) was introduced. At this time, a significant drop in the rates of death due to HIV disease began to occur because of this combination of therapies. Over the ensuing decade, drug research evolved. At the time of writing this manual (summer 2010), there are now over two dozen different antiretroviral therapy compounds and five combination tablets. Several of these compounds have been made into combinations and put into one tablet to improve adherence to what can be significantly challenging treatment regimens. Regimens can also be more than one pill. The term used for these successful regimens is highly active antiretroviral therapy (HAART). Most currently, regimens are referred to as combination antiretroviral therapy (or cART).
Antiretroviral drugs are not a cure to HIV. Rather, they interfere with the life-cycle of the virus to manage and control HIV. HIV therapy does not actually directly improve immunity, although with the decrease in viral load, the immune system is able to recover. However, for antiretroviral therapy to be successful, lifelong adherence is required. In other words, for the best results, the client needs to take his or her medications every single day, without missing doses, for the rest of his or her life. As with every other medication, antiretroviral medications have both short and long term side-effects.

Current research is focusing on new areas which include:

- Pre-exposure prophylaxis (PEP)
- Optimal timing of cART
- Improving adherence, especially in vulnerable populations
- Managing side effects
- Aging with HIV

Current guidelines for the pharmacologic management of HIV are continually being updated. The most current evidence-based guidelines include the Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents by the US Department of Health and Human Services, Panel on Antiretroviral Guidelines for Adults and Adolescents (PAGAA 2009) which were updated in December 2009. These guidelines include new recommendations regarding when to initiate HIV therapy as well as which antiretroviral combinations to prescribe clients who are starting treatment (Wohl 2010).

### 6.2.1.2 Goals of HIV Pharmacotherapy

The goals of HIV therapy are for maximal and durable suppression of viral load. The aim is to decrease the viral load to less than 50 copies/mL, and keep it at less than 50 for as long as possible. In doing so, immune function can potentially be restored - or if the CD4 has not dropped too low - preserved. The goal is to reduce HIV-related morbidity and mortality, and improve quality of life for PHAs.

### 6.2.1.3 Indications for Initiating Combination Therapy for Chronic HIV

Not everybody with HIV is prescribed antiretroviral therapy. This is based on the most recent guidelines from the US Department of Health and Human Services (DHHS) which lists the indications of initiating combination antiretroviral therapy (cART) (PAGAA 2009). However, there are some populations which are always started on antiretroviral treatment, regardless of CD4 count. These include individuals who are experiencing:

- Opportunistic infection or severe symptoms
- HIV-associated nephropathy
- Pregnant women
- Co-infected persons with HIV and Hepatitis B

If an individual is asymptomatic, and their CD4 is less than 350 cells/mm3, the recommendations from the DHHS guidelines are to offer and start antiretroviral therapy (PAGAA 2009). If someone is asymptomatic, HIV positive and their CD4 count is at 350 or higher, the practitioner has the option to offer treatment or to defer treatment. There is some debate whether cART should be started earlier than current guidelines.

Not all people living with HIV or AIDS (PHAs) are offered antiretroviral therapy (PAGAA 2009). The risks of long-term drug related side effects are too large and/or unknown at the moment for this to be a safe step. While there are short-term side effects that usually start at the beginning of treatment and then go away, such as nausea, researchers are becoming increasingly concerned with the long-term side effects of antiretroviral use, including the role antiretrovirals have in the development of concurrent conditions, as well as their overall impact on quality of life and mortality. Increasingly, adolescents are the target of primary research and are included in the most recent guidelines (PAGAA 2009). For example, an individual who is infected during adolescence and started on antiretroviral therapy shortly thereafter will be on treatment for the rest of their lives. The prospect of being on medication for many decades introduces concerns about the associated long-term side effects of antiretroviral medications. Drug regimens are generally changed after five to ten years.

When individuals are started on antiretroviral therapy, drug resistance is thought to be inevitable because antiretrovirals do not fully and completely suppress all viruses in the body. In addition, since the virus copies itself, it can make mistakes, known as mutations. Changes in the genome, or mutations, may then allow the virus to continue to replicate in the presence of HIV therapy that can lead to resistance to the drugs.

The benefits of pharmacologic interventions are quite clear. By decreasing viral load, the progression of HIV to AIDS is delayed and immune function is preserved. Adherence at or very near to 100% to therapy or close to 100% can decrease the risk of resistance. There is also the theoretical societal benefit through the reduced risk of further transmission to others.

### 6.2.1.4 Overview of HIV Replication Cycle and Where Medications have an Effect

The medications available to treat HIV target the areas where viral replication occurs. There are five classes of antiretroviral drugs available on the market work. These classes are targeted to the whole life cycle of the virus:

- entry inhibitors work on the surface of the host cell or the HIV cell
- the nucleoside reverse-transcriptase inhibitors (NRTIs) and the non-nucleoside reverse-transcriptase inhibitors (NNRTIs) work at the site of the reverse transcriptase enzyme
- the integrase inhibitors inhibit the integrase enzyme that incorporates the viral Deoxyribonucleic Acid (DNA) into the host DNA
- the protease inhibitors inhibit the protease enzyme responsible for cleaving large proteins into small viable proteins.

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6.2.1.4.1 Entry Inhibitors

Entry inhibitors work by attaching themselves to proteins on the surface of CD4 cells or to the proteins on the surface of HIV. In order for HIV to bind to CD4 cells, the proteins on HIV’s outer coat must bind to the proteins on the surface of CD4 cells. Entry inhibitors prevent this from happening. Some entry inhibitors target the gp120 or gp41 proteins on HIV’s surface. Other entry inhibitors target the CD4 protein or the CCR5 or CXCR4 co-receptors on a CD4 cell’s surface. If entry inhibitors are successful in blocking these proteins, HIV is unable to bind to the surface of CD4 cells and gain entry into the cells.

6.2.1.4.2 Nucleoside/Nucleotide Reverse Transcriptase Inhibitors

Nucleoside Reverse Transcriptase Inhibitors (NRTIs), sometimes called «nucleoside analogues» or «nukes,” contain faulty versions of the building blocks (nucleotides) used by the enzyme reverse transcriptase to convert Ribonucleic Acid (RNA) to Deoxyribonucleic Acid (DNA). When reverse transcriptase uses these faulty building blocks, the new DNA cannot be built correctly. In turn, HIV’s genetic material cannot be incorporated into the healthy genetic material of the cell and prevents the cell from producing new virus. If the viral RNA is not converted to DNA, it cannot become part of the cell.

Nucleotide analogues are technically different from nucleoside analogues; however they act very much the same way. In order for nucleoside analogues to work, they must undergo a three step chemical change (triphosphorylation) to become active in the body. However, nucleotide analogues bypass one of these three steps, undergoing a diphosphorylation versus a triphosphorylation to become active in the body.

6.2.1.4.3 Non-Nucleoside/Nucleotide Reverse Transcriptase Inhibitors

Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) also known as the «non-nukes» distinguish themselves from the Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs) because they do not bind at the catalytic place of the enzyme but to a site other than the protein’s active binding site. The NNRTIs block the normal enzymatic activity of Reverse Transcriptase and thereby interrupt the replication cycle of HIV. To clarify, NNRTIs are not false-building blocks. These drugs work by blocking the enzyme itself so it is unable to incorporate the nucleosides during reverse transcription.

6.2.1.4.4 Integrase Inhibitors

After the «reverse transcription» of Ribonucleic acid (RNA) into Deoxyribonucleic acid (DNA) is complete, HIV’s DNA must then be incorporated into the CD4 cell’s DNA. This is known as integration. As their name implies, integrase inhibitors work by blocking this process. Integrase inhibitors are oligonucleotides, which are small segments of DNA or RNA that are synthetically prepared. Modified oligonucleotides can serve to block RNA/DNA interactions and modify protein or enzyme synthesis. One drawback to integrase inhibitors is that they have only one chance to act for each cell. If this drug fails, any further attempts are futile since the viral genetic information is already incorporated into the host DNA. In contrast, Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs) have thousands of opportunities to act during the process of reverse transcription.

6.2.1.4.5 Protease Inhibitors

After HIV has become integrated into the Deoxyribonucleic Acid (DNA) of its host CD4 cell, it then instructs the CD4 cell to make new HIV genetic material and HIV proteins. The proteins must be cut up by the protein-cutting enzyme protease in order to make new, functional HIV particles. The Protease Inhibitor class blocks this enzyme and prevents large proteins from becoming viable smaller proteins to be incorporated into a new virus. If this step does not occur, new viruses cannot be assembled.

6.2.1.5 HIV Drugs Under Development

Advancements in HIV drug treatment are essential to allow people to live longer and to improve quality of life. Some areas that are still under development are presented here.

6.2.1.5.1 Cellular Inhibitors

Some anticancer drugs may help certain anti-HIV drugs to work better. Unlike other drugs used to treat HIV, these drugs do not attack the virus but instead target the human immune system itself. Specifically, these drugs reduced the number of nucleotides found within T-cells, making it more difficult for HIV to make more viruses because the building blocks for HIV Deoxyribonucleic acid (DNA) are not available. For example, a known anti-cancer drug called hydroxyurea reduces the amount of one particular type of nucleotide, called adenine. When hydroxyurea is used alone it does not affect HIV very significantly. Although HIV still has enough adenine nucleotides to choose from to build its DNA and make more HIV when used in combination with other anti-retroviral drugs, early research has shown this experimental drug demonstrates favourable outcomes.

6.2.1.5.2 Maturation Inhibitors

Maturation is the last phase in HIV replication. During this phase, HIV «matures» by assembling and budding replicated components from the host CD4 cell to become newly formed infectious HIV. Maturation Inhibitors aim to prevent HIV from properly assembling and maturing, from forming a protective outer coat, or from emerging from human cells. Inhibiting this step is an entirely new way to halt or inhibit HIV replication.

6.2.1.5.3 Immune-Based Therapies

Immune-based therapies focus on finding ways to help a person’s immune system fight the virus on its own rather than combating the virus by interfering with the replication cycle. Several approaches are being explored and include production of important proteins, called «cytokines». Cytokines help regulate a
person’s immune system to stimulate or inhibit the growth and activity of various immune system cells. Another approach is the use of therapeutic vaccines which attempt to «teach» a person’s immune system to fight a virus long after it has infected them. Certain hormones have also been shown to protect and boost key immune system cells that can be damaged by HIV. While these and other immune-based therapies are being intensively researched, it is important to note that no studies to date have proven the ability to prolong a person’s life.

6.2.1.6 Factors to Consider with HIV Therapy

Beyond the clinical indications for starting someone on HIV medications, there are a great number of other factors to consider. This section provides a list of other considerations that can influence the effectiveness of HIV drug therapy.

6.2.1.6.1 Adherence

Adherence is one of the most important factors to consider before starting an individual on antiretroviral therapy. The biggest obstacle to successful treatment is often medication adherence. Successful virus suppression requires very strict adherence. Until significant advances in pharmacologic interventions occur, a person who is HIV positive will need to adhere to therapy every single day in order for the treatment to be effective. Adherence is particularly important as HIV drug therapy requires a virtually perfect level of consistency to reach full efficacy. Thus, for virologic success to occur, strict adherence is essential. The greater the adherence, the higher the chance for virologic suppression. In the absence of adherence to medications, the virus will not be maximally suppressed and the person becomes at an increased risk for developing drug resistance. When there is only moderate adherence or partial drug therapy the result is only partial viral suppression. Consequently, there are more virus replicating, more virus making mistakes, and a higher chance of resistive mutations developing. Moderate adherence therefore is not necessarily better than non-adherence, as it can lead to drug resistance that limits future options for drug therapy.

Various models can be used in an attempt to improve adherence rates. Recently, one study used “Fisher and Fisher’s Information-Motivation-Behavioral Skills Model” and discovered that actual intervention support coming from one caring individual as well as the “audio-supported computer-assisted survey instruments” were most helpful, whereas electronic adherence monitoring was less well received (Konkle-Parker et al. 2010).

6.2.1.6.2 Dosing

Adherence is greatly affected by such things as dosing frequency and pill burden. The more pills a person is required to take, the harder adherence can become. A regimen of one pill once a day will likely result in a greater adherence, however many regimens require an increased number of pills. To gain an appreciation for how difficult adherence can be, many HIV clinics educate clients by having them do the jelly bean challenge. Clients are instructed to try taking jelly beans (to represent HIV medications) daily for 1 week as if they were real antiretrovirals. This will assist in identifying potential problems in scheduling medications and sticking to a strict regimen.

Speech-Language Pathologists can assist clients who have difficulty with swallowing their medications.

6.2.1.6.3 Food and Fluid Intake

With advancements in antiretroviral medications, food and fluid considerations are becoming less of a concern than in the past. Most of the newer drug therapies do not require specific fluid considerations. However, one medication (indinavir) requires at least 2 litres of fluid to be ingested every day to avoid nephrolithiasis (kidney stones). Most Protease Inhibitors tend to be better absorbed when taken with food.

6.2.1.6.4 CD4 Nadir

The CD4 Nadir helps to determine which regimen may be safest for an individual. The term CD4 Nadir is used to refer to the lowest CD4 T-cell count a person has ever reached. This is relevant because some medications have shown better effect when introduced at different CD4 levels while other medications can have toxic effects if initiated at an inopportune time. For example, higher rates of hepatotoxicity have been recorded in women with CD4 count of greater than 250 cells/mm3 and men with CD4 count of greater than 400 cells/mm3 with the introduction of nevirapine. Therefore, the CD4 Nadir may be a factor to consider when choosing therapies.

6.2.1.6.5 Pregnancy Potential

A woman of childbearing age has to consider the effects that any drugs might have on a growing fetus. Some medications have been shown to be particularly useful for preventing HIV from being transmitted from a mother to her child (MTCT). The World Health Organization (WHO) provides up-to-date guidelines on treatment to prevent vertical transmission (WHO 2010). Some medications, particularly when introduced during the first trimester may have negative consequences for the development of the baby. For example, most recent guidelines suggest avoiding efavirenz in the first trimester of pregnancy over concerns of central nervous system birth defects in infants at this vulnerable time of fetal development. Pregnancy-associated nausea and vomiting may affect a woman’s ability to adhere to antiretroviral therapies. Non-pharmacological interventions for nausea and vomiting in pregnancy includes ginger (such as slices of ginger in hot water) and eating several small meals throughout the day rather than three big ones. Diclectin (Doxylamine Succinate and Pyridoxine Hydrochloride) can be taken for moderate to severe morning sickness (vomiting more than 5 or 6 times a day) and might be appropriate for pregnant women with HIV with pregnancy related nausea and vomiting. Ensure the professional providing the prescription check compatibility across drugs and check again with a pharmacist. A recent
Cochrane review concluded that in antiretroviral-eligible pregnant women with HIV infection, cART is a safe and effective means of providing maternal virologic suppression, decreasing infant mortality, and reducing MTCT (Sturt et al. 2010). More research is needed regarding the use of specific regimens and their maternal and infant side-effect profiles.

6.2.1.6.6 Social Support

Adherence to antiretroviral therapy may be influenced by a person's social situation. Added stressors and complexities surrounding housing, family support, intravenous drug use (IDU) and a person's food supply may make starting antiretroviral drugs difficult.

IDU is associated with economic instability that can lead to homelessness and both homelessness and current drug use have been associated with poor adherence (Tesoriero et al. 2003, Gebo et al. 2003). However, when evaluating client readiness for antiretroviral medications, current housing may not need to be the primary concern; depression has been identified as a more potent indicator of non-adherence than homelessness for HIV positive IDUs (Waldrop-Valverde and Valverde 2005). In either case, identifying these issues and working collaboratively to provide support in light of these challenges is essential to consider when initiating drug therapy.

6.2.1.6.7 Previous Medications

Taking a thorough history of a person's medications is important in selecting HIV therapy. Medication tolerance and effectiveness may be influenced by how well medications have been received in the past. Additionally, previous exposure to antiretrovirals may have allowed for the development of drug resistance. In order to determine what drugs a person may have developed resistance to, screening may be necessary to establish the appropriate drug regimen.

6.2.1.6.8 Concurrent Conditions

Other medical conditions or the presentation of opportunistic infections will influence the selection of drug therapies and whether it is appropriate to begin antiretroviral medications. For example, co-infection with hepatitis B virus (HBV) or hepatitis C virus (HCV) as well as concomitant alcohol abuse, older age or obesity raises concerns regarding the possibility of drug-induced liver injury in the management of clients (Puoti et al. 2009). A knowledge of antiretroviral-related liver effects combined with an understanding of the pre-existing risk factors for liver damage will help ensure that a person living with HIV or AIDS (PHA) receives the most benefit with the least toxicity from any given drug regimen. Moreover, tuberculosis (TB) co-infection creates a unique treatment challenge for providers due to interactions between anti-tubercular and antiretroviral medications, overlapping drug toxicities, and a sometimes seen profound pathological inflammatory reaction called immune reconstitution inflammatory syndrome (IRIS). Current consensus guidelines offer strategies for drug management based on the degree of client's HIV-induced immuno-suppression. For example, introduction of antiretroviral medication is recommended after completion of the 2-month intensive phase of TB treatment for clients with CD4 cell counts between 50 and 200 cells/mm3, to reduce the risk of IRIS and to allow better definition of the causes of adverse reactions (McIlerson et al. 2007).

6.2.1.6.9 Concurrent Medications

Drug interactions are an important consideration. Drug interactions can occur between any drugs that a person may be taking, not just antiretrovirals. Treatments for side effects and opportunistic infections also need to be taken into account. Drug interactions can introduce toxicities or alternatively, can lower levels of viral suppression which poses a risk for increasing the individual's viral resistance. Interactions can occur not only between prescription medications but also between with over-the-counter agents, herbs, foods, or recreational drugs.

6.2.1.6.10 Access to Medications

Antiretroviral medications are expensive and unless there is some form of drug coverage program, many people are unable to afford these medications. Every Canadian province and territory offers a program for subsidizing the cost of medications, however the criteria for eligibility differs from program to program. Decisions regarding which drug treatments will be covered by government or insurance programs are based on a number of different factors so it is important to determine whether a person has the appropriate access to medication and if this access will be continuous. Specific information according to each province or territory can be found at the following website http://www.drugcoverage.ca/.

6.2.1.6.11 Indications of Drug Failure

There are three main indicators for treatment failure.

- Clinical indicators that treatment is not working may include introduction of opportunistic infections, weight loss and fever in a person who previously did not present with these symptoms.
- Immunological indicators become evident through evaluating blood work. If a person shows a significant decrease in CD4 count, this suggests a weakening immune system and that medications may be beginning to fail.
- Virological indicators for treatment failure would present with increasing viral loads greater than 100 000 copies/mL. This indicates virological break-through and a failure of the medications to maintain suppression.

Any one or all of these indicate a need for change in HIV medication therapy or may indicate that the client is not actually taking therapy.
6.2.1.6.11.1 Factors Contributing to Failure

There are many reasons why drug failure can occur. When drug combinations are not potent, that can lead to failure. Evidence has shown that mono- and dual therapy regimens are not sufficient to adequately suppress the virus. Therefore a combination of at least three active agents is the minimum that is required to ensure success of therapy. An effective regimen also may fail if it is given or taken at suboptimal doses. A variety of generic antiretroviral agents are becoming available in limited-resource settings that are much less expensive than standard agents. It is important, however, to ensure that these drugs are equal in quality and potency to standard drugs. If a generic drug is used that is not as potent as the standard drug, the therapy may fail and resistance may occur. Suboptimal drug levels may also be caused by drug interactions between antiretroviral agents and other medications. Also, malabsorption due to diarrhea or intestinal parasites, nausea and vomiting, or for other reasons may decrease drug levels within the body.

One of the most common cause of suboptimal drug levels is nonadherence to therapy. Adherence can be related to a variety of factors, including but not limited to:
- reminders
- costs
- storage
- stigma/fear of disclosure
- fatigue
- depression
- side effects

It is also important to note that if medications are not stored properly, there may be degradation of the medication in the tablet or capsule itself resulting in sub-optimal drug levels when ingested.

6.2.1.6.12 Genotyping Result

Sub-optimal drug levels can result in drug resistance. Any mutations in the codon may result in changes that impact efficacy of the HIV drugs. For example, an amino acid substitution at codon 103 will lead to resistance to a drug such as efavirenz. This mutation also results in resistance to dilaferdine and navirapine. Even though there is one mutation and the person may have only been exposed to the one drug, three drugs are no longer effective because of this one mutation. This greatly reduces the number of drugs that can be used to construct an effective regimen.

6.2.1.7 HIV Drug Side Effects

6.2.1.7.1 Entry or Fusion Inhibitors

Presently, maraviroc is the only entry inhibitor available on the Canadian market. This drug is virologically effective only if the client has a population of virus that uses the CCR5 co-receptor for entry into the CD4 cell. This tablet has been most often asso-
6.2.1.7.2.3 Cardiomyopathy
Decreases in mitochondrial Deoxyribonucleic acid (DNA) replication as a result of Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs) ultimately leads to energy deficits and oxidative stress that alter the energetics needed for optimal cardiac function (Kohler et al. 2008). Genetic predispositions, stage of HIV progression, pre-existing cardiac conditions and concurrent conditions as well as medications make determining the causative mechanism for cardiomyopathy in people with HIV virtually impossible (Kohler et al. 2008). However, cardiomyopathies appear to be potentially reversible after discontinuation of offending NRTIs.

6.2.1.7.2.4 Hepatic Steatosis
Hepatic Steatosis (fatty liver) is the collection of excessive amounts of triglycerides and other fats inside liver cells. Often, there are no symptoms associated with fatty liver. If there are symptoms, they can include pain under the rib cage on the right side of the body, swelling of the abdomen, jaundice, and fever.

6.2.1.7.2.5 Pancreatitis
The most common causes of acute pancreatitis in HIV positive clients are drug side effects. In particular, didanosine and stavudine have been associated with an increased relative risk of acute pancreatitis (Moore 2001). The specific mechanism of Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTI)-induced pancreatitis is not known however acute pancreatitis in combination with hepatic steatosis and lactic acidosis syndromes can be fatal. Chronic pancreatitis may lead to diabetes and impaired digestion. Pain is the primary symptom.

6.2.1.7.2.6 Peripheral Neuropathy
Antiretroviral toxic neuropathy is the most common neurological complication of human immunodeficiency virus infection. Up to 15% of HIV positive individuals may develop peripheral neuropathy characterized by distal, symmetric anesthesia and/or painful dysesthesia (Keswani 2002). Although peripheral neuropathy is present in untreated HIV infection, exposure to Nucleoside/ Nucleotide Reverse Transcriptase Inhibitors (NRTI), particularly didanosine (ddI) and stavudine (d4T) places individuals at an increased risk (Hulgan et al. 2005). Among HIV positive individuals with ddC-induced peripheral neuropathy, mitochondria in peripheral nerves were morphologically abnormal, and mitochondrial deoxyribonucleic acid (DNA) content was decreased (Hulgan et al. 2005). At present, there are no reliable clinical predictors of NRTI-associated peripheral neuropathy, and available therapies are of limited efficacy.

6.2.1.7.2.7 Hyperlactatemia
Hyperlactatemia (increased levels of lactic acid in the blood) can be induced by the mitochondrial toxicity of nucleoside analogue reverse transcriptase inhibitors. People who present with extreme fatigue, sudden weight loss, (vague) abdominal pain, unexplained nausea and vomiting, or sudden dyspnea may be developing severe and life threatening lactic acidosis.

6.2.1.7.2.8 Cytopenias
Toxicity to the bone marrow as a result of mitochondrial toxicity can cause a deficiency in the number of any of the cellular elements of the blood. A drop in the level of red blood cells can lead to anemia (the most common cytopenia in HIV). Other blood cells that can be affected include bacteria-fighting white blood cells (neutrophils) leading to neutropenia. Less commonly, all blood cells can be affected and this condition is called pancytopenia. Cytopenias become more prevalent in people with advancing disease.

6.2.1.7.3 Non-Nucleoside Reverse-Transcriptase Inhibitors Class
Rash is the side effect common to the entire Non-Nucleoside Reverse-Transcriptase Inhibitors (NNRTI) class. Most typically, the rash presents as a diffuse, macular papular rash that can spread over the torso, arms, legs and back and in some cases, the face. These symptoms occur most commonly within the first few weeks of treatment and are usually self-limiting (Drake 2000). The mechanism for NNRTI-induced rash is unclear however treatment can be continued with possible use of antihistamines and/or steroids if the person is able to tolerate such treatments.

While all four NNRTIs have associated risk of causing a rash, neviripine has more reports of severe skin rashes such as Stephen Johnson’s syndrome. Also, neviripine has been commonly associated with clinical hepatitis, especially in a client co-infected with Hepatitis B (HBV) or Hepatitis C (HCV).

Efavirenz however is unique because it is associated with central nervous system (CNS) side effects such as dizziness, difficulty falling asleep and trouble concentrating. In some cases while taking efavirenz, people have reported experiencing the presence of vivid dreams that can be either pleasant or unpleasant, as well as hallucinations. Individuals who have underlying depression or psychiatric illness or active suicidal ideation should not be prescribed efavirenz.

6.2.1.7.4 Integrase Inhibitors
Integrase inhibitors have been fairly well tolerated. Common side effects can include cough, headache and rash. Still relatively new to market, the full effects of this class of drug are being monitored over time to determine the full extent of potential side effects.

6.2.1.7.5 Protease Inhibitors
With a large number of protease inhibitors on the market, there are a number of side effects that have been reported with this class of drugs. Most predominantly, protease inhibitors are known to cause some gastrointestinal upset leading to nausea, diarrhea and abdominal pain. In fact these symptoms are the most often reported side effect among all drugs in this class.
In addition to gastrointestinal complications, protease inhibitors have also been linked to conditions of dyslipidemia. Primarily, these drugs are associated with an increase in triglycerides having implications for cardiovascular health as well as glucose metabolism. Manifestations of lipid abnormalities include development of an increase in dorso-cervical fat accumulation commonly called a “buffalo hump” and increases in abdominal girth. Protease inhibitors may also be tied to changes in haemostasis. For people who have haemophilia, this is of particular concern as several protease inhibitors are known to cause an increased rates of bleeding. Although rare, some protease inhibitors have caused users to developed severely or dangerously elevated levels of pancreatic and or liver enzymes in their blood. These complications need to be considered as damage to these organs can be fatal.

6.2.1.8 Staying Current on HIV Medications and their Side Effects

The Canadian AIDS Treatment Information Exchange (CATIE) is the national knowledge exchange broker for information related to HIV prevention and treatment, care and support for people living with HIV or AIDS (PHAs) as well as to those who are vulnerable to HIV. CATIE provides free HIV information services to residents within Canada. This includes a number of resources to learn more about HIV drug side effects, such as the HIV Side Effects Guidebook. This practical guide to HIV drug side effects provides information on the most common HIV drug side effects for PHAs. Where possible, it also provides helpful tips for countering or preventing HIV drug side effects and other symptoms. The CATIE resources (www.catie.ca) are frequently updated and are a good resource for health care providers and their PHA clients.

In summary, the HIV replication cycle has to date, been the key to drug interventions that have reduced viral loads in order to preserve immunity. Within Canada, a number of drugs have been introduced that have demonstrated success in prolonging life for PHAs but these have not been without complications or side effects. Several factors need to be considered in recommending a person to begin antiretroviral therapy and to ensure success of drug therapy.

Advancements in care continue to be made however a knowledge and sensitivity to the complexities of drug therapy is required as a foundation in providing rehabilitation care, treatment and support for PHAs.

6.2.2 Other Pharmacologic Interventions

In their recent guidelines for the primary care management of people living with HIV or AIDS (PHAs), the Infectious Diseases Society of America recommends the guidelines available for some common conditions experienced as a result of HIV, its treatments or concurrent conditions (Aberg et al. 2009).

- Guidelines for the Management of Chronic Kidney Disease in HIV positive Clients (Gupta et al. 2005)
- Diabetes clinical practiced recommendations (American Diabetes Association 2008).
- Management and care of HIV clients with chronic Hepatitis B (European Association for the Study of the Liver 2009, Soriano et al. 2008) and/or Hepatitis C (Soriano et al. 2007, Rockstroh et al. 2008).
- Hyperlipidemia in HIV (Dube et al. 2003)
- Mental health care for people living with HIV or AIDS (PHAs) (New York State Department of Health AIDS Institute 2009).
- Metabolic complications in HIV (Schambelan et al. 2002).
- Opportunistic infections in children and adults (Kaplan et al. 2009).
- Sexually transmitted diseases (Workowski and Berman 2006)

The International Association for the Study of Pain also recently reviewed treatments available for painful HIV-associated sensory neuropathy (Phillips et al. 2010).

6.3 Evidence-Informed Rehabilitation Interventions for HIV

6.3.1 Introduction

The Canadian Working Group on HIV and Rehabilitation (CWGHR) recently conducted a project 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. 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
- **Phase 2:** 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 specific to HIV and its treatment
The methodology used include 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 (Kariak et al. 2006). The following impairments were included in the search strategy: “Altered sensation”, “Diarrhea”, “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 included 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 health care 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 6.3.1). Each citation was assigned a “relevant” if it met the inclusion criteria or “irrelevant” if it did not.

Table 6.3.1: Inclusion Criteria for identification of relevant articles

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<tr>
<th>Include Articles that pertain to:</th>
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<tr>
<td>Guidelines:</td>
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<td>Best practice guidelines</td>
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<td>Management/Treatment guidelines</td>
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<td>Rehabilitation Provider:</td>
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<tr>
<td>Occupational therapist</td>
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<tr>
<td>Physical therapist (Physiotherapist)</td>
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<td>Speech-language pathologist</td>
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<td>Psychiatrist</td>
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<tr>
<td>Mental health therapist/counsellors</td>
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<tr>
<td>Complementary or Alternative therapist</td>
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<tr>
<td>HIV Impairments:</td>
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<tr>
<td>Identified from BC Prevalence Study (Rusch et al. 2004) and Aging Research on Older Adults with HIV (Kariak et al. 2006)</td>
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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 impairments overall 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 on 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 for relevance to project objective and potential for broad use in rehabilitative management of impairments. A reference list of HIV specific guidelines were also identified by the reviewer and provided to the working group. A recommendation was made by the working group to conduct 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 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 provider 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 were most were limited in the evidence used to develop the guidelines or recommendations. Most guidelines were developed using a clinical expert panel, 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.

6.4 Exercise
As people living with HIV or AIDS (PHAs) are living longer, they are living with a range of disability due to HIV, its associated conditions, treatments, along with the general effects of aging. Adults living with HIV have defined disability as any impairments, difficulties carrying out day-to-day activities, challenges to social inclusion, or feelings of uncertainty that may be fluctuate daily and over the course of living with HIV (O’Brien et al. 2008a, O’Brien et al. 2009). Exercise is a key strategy that may be used by PHAs and by rehabilitation providers to address or prevent disability and improve overall health and quality of life. While research on rehabilitation interventions is still emerging, an increasing number of published studies support the benefits of aerobic and resistive exercise for adults living with HIV (O’Brien et al. 2008b, O’Brien et al. 2010b)

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
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. 2010b). For resistance training the exercise time should be approximately 20 to 25 minutes, which includes 1-5 sets of 4-18 repetitions for each session (O'Brien et al. 2008b).

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. More research is needed to explore the specific effects of interval versus continuous aerobic exercise.

6.4.4 Research on the Impact of Exercise for Adults living with HIV
Existing evidence about the safety and effectiveness of exercise for people living with HIV or AIDS (PHAs) is increasing, including narrative reviews that support the benefits of exercise in the context of HIV (Cade et al. 2004, Dudgeon et al. 2004, Hand et al. 2009, Robinson et al. 2007, Scevola et al. 2003).

Two systematic reviews specifically combined results from 20 studies to assess the effect of aerobic and progressive resistive exercise on health outcomes for adults living with HIV (O'Brien et al. 2010b, O'Brien et al. 2008b). 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 may lead to significant improvements in selected outcomes of cardiopulmonary fitness, weight and body composition, and quality of life for adults living with HIV who are medically stable. No changes in CD4 count or viral load were found in studies suggesting exercise has little impact on CD4 count or viral load, but also indicating 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 the table for an overview of the impact of exercise for adult PHAs according to the results of the systematic reviews.

6.4.5 Exercise and Lipodystrophy
Prior to 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, or hyperinsulinemia. Hence, weight, body composition and metabolic outcomes are becoming increasingly important to monitor when prescribing exercise for adults living with HIV or AIDS (PHAs). While improvements to weight and body composition are documented, it is still unclear whether exercise...
investigated the impact of a yoga intervention 2 to 3 times per week for 60 minutes each for a total of 20 weeks among people living with HIV or AIDS (PHAs) 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). 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 PHAs.

6.4.10 Emerging Issues
As an increasing number of individuals age with HIV, more research is needed to investigate the effects of exercise among older adults living with HIV, including 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 or AIDS (PHAs). 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 PHAs, the impact of exercise on bone mineral density is still unclear (Clay et al. 2008, Lin and Rieder 2007).

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. 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. 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

<table>
<thead>
<tr>
<th>Health Outcome</th>
<th>Summary of Effect of Exercise Based on Meta-Analysis of Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 Count</td>
<td>No significant change in CD4 count between adults living with HIV who exercise compared with non-exercisers.</td>
</tr>
<tr>
<td>Viral Load</td>
<td>No change in viral load between exercisers compared with non-exercisers.</td>
</tr>
<tr>
<td>Cardiopulmonary Fitness</td>
<td>Significant and potentially clinically important improvement in maximum oxygen consumption (VO2 max) among aerobic exercisers compared with non-exercisers.</td>
</tr>
<tr>
<td></td>
<td>Greater improvement may be seen by individuals who exercise at heavy intensity compared with moderate-intensity exercise.</td>
</tr>
<tr>
<td></td>
<td>Trend towards potential improvement in exercise time and heart rate maximum among exercisers compared with non-exercisers.</td>
</tr>
<tr>
<td>Weight</td>
<td>Significant increase in body weight among resistive exercisers compared with non-exercisers.</td>
</tr>
<tr>
<td>Body Composition</td>
<td>Significant increase in arm and thigh girth among progressive resistive exercisers compared with non-exercisers.</td>
</tr>
<tr>
<td></td>
<td>Significant increase in leg muscle area among combined progressive resistive and aerobic exercisers compared with non-exercisers.</td>
</tr>
<tr>
<td></td>
<td>Significant decrease in body fat percentage among aerobic exercisers compared with non-exercisers.</td>
</tr>
<tr>
<td>Strength</td>
<td>Due to the differences in the way strength is measured across the studies, meta-analysis was not able to be performed (unable to combine studies together). However, five of six individual studies that measured strength in the systematic reviews found significant increases in strength among exercisers.</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Significant and potentially clinically important improvement in depression symptoms among aerobic exercisers compared to non-exercisers.</td>
</tr>
</tbody>
</table>
6.5 Modalities

This section addresses interventions that are often practiced by regulated health care professionals for people living with HIV or AIDS (PHAs) 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 PHAs. 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 health care professionals. Distinguishing between various treatments can quickly become complicated. The modalities presented below are evidence-based, it is important to note that the treatment is not always specifically geared to the treatment of HIV. Other treatments, which are not generally offered by regulated health care professionals and are often not evidence-based practices, are located in the Complementary and Alternative Medicines and Therapies (CAMT) section 6.8.1. In both of these sections, some treatments are outlined which 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 points. 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. Improvement in daily activities as well as client’s reporting improved well-being support the researcher’s hypothesis. 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 clients gain new insight and perspective of one’s self and others. This process may also help individual develop coping strategies and manage stress. In Canada, CATIE has developed an innovative body mapping, called “Body Map: Women Navigating the Positive Experience in Canada and Africa”, a project which is self-healing and educational. More information can be found at http://www.catie.ca. 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 or AIDS (PHAs) (Rao et al. 2009). 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 clients (Dileo 2006, Cepeda et al. 2006, Bradt and Dileo 2009, Maratos et al. 2008).

6.5.3 Botox

Botulinum toxin type A (Botox) can be used for a number of conditions affecting people living with HIV or AIDS (PHAs), including pain, spasticity (Noguera 2004) and facial lipatrophy (Sadick 2008). Longterm 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 human immunodeficiency virus (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 (Vanelderen et al 2010).

6.5.4 Canabanoids

Smoked cannabis improves symptoms of HIV related neuropathic pain in two recent studies (Abrams et al. 2007, Ellis et al. 2009). A recent review on canabanoids in pain generally, demonstrates that they are effective for “pain, associated sleep disorders, appetite loss, muscle spasm and a wide variety of other symptoms” (McCarberg 2007).

6.5.5 Capsaicin Patch

While an older small study finds no improvement in pain with the use of capsaicin cream in the treatment of HIV related neuropathic pain (Paice et al. 2000a), a more recent study in a much larger HIV population finds that one 60 minute application of a high dosage concentration of Capsaicin Patch significantly improves pain (Simpson et al. 2008).

http://www.catie.ca
6.5.6 Cognitive Behaviour Therapy

Cognitive Behaviour Therapy (CBT) generally uses group therapy 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 practitioners and people with HIV or AIDS (PHAs) turn to CBT in an attempt to:

- Reduce anxiety and depression
- Increase adherence to HIV treatments
- Address issues of substance abuse
- 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 (Crepez et al. 2008). Researchers believe that because anger, anxiety and depression are common in PHAs, and because these three psychological states can negatively affect various aspects of a PHA’s life (including quality of life, adherence, use of health care services and health outcomes) CBT is a promising intervention as it has been shown to successfully address these issues in people with other disorders (Crepez et al. 2008).

CBT has been demonstrated to be beneficial for PHAs to address issues of chronic pain (Pierson 2009), while Cucciare et al. (2009) suggests that these positive effects may be more beneficial for non-Caucasian participants. In their review of the literature as it relates to HIV, Brown and Vanable (2008) caution that the literature is limited by measurement problems, a narrow focus on HIV positive men who have sex with men, and feasibility concerns for intervention dissemination. They recommend that future studies should address these limitations and the unique psychosocial needs of HIV positive clients using briefer, more cost-effective formats.

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 or AIDS (PHAs), 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 PHA who develop plantar verrucae, a type of foot wart, although it does not appear to be more efficacious than other therapies such as bleomycin sulfate or intralesional injections (Barbosa 1998).

6.5.8 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 or AIDS (PHAs). Susceptibility to periodontal breakdown is somewhat enhanced by the effects of HIV disease and cavities (Johnson 2010). Therefore it is concerning that more than a third of HIV positive dental clients in five different primary care clinics in Florida do not discuss their oral health status with their dentists (Pereyra et al. 2009). This bears potential implications for PHAs as infection can affect the efficacy of HIV treatment. A complete intervention should include oral health, as more than 90% of PHA will experience some form of oral manifestation of HIV (Pereyra et al. 2009). PHAs and health-care providers working with this population should be made aware of the importance to regularly check dental status.

6.5.9 Functional Electrical Stimulation

Functional Electrical Stimulation (FES) can be used for neuropathies such as dropped foot syndrome as well as spasticity (Swain et al. n.d.). This therapy can also improve gait strength and control, targeting hamstrings, quadiceps, gluteal and calf muscles, can improve hip and knee extension, hip abduction and knee flexion. Individuals with open sores or easily irritable skin should take caution, especially with adhesives used. Contraindicated conditions include pregnancy, presence of medical implants and uncontrolled epilepsy (Swain et al. n.d.). Paice et al. (2000b) demonstrated that for people living with HIV or AIDS (PHAs) with distal symmetrical polyneuropathy, resting the foot, with or without vibratory-electrical stimulation, proved to be equally effective.

6.5.10 Localized Injections and Radiofrequency Neurotomy

Localized injections are commonly used to treat chronic spinal pain originating in facet joints. A recent systematic review examined a number of facet joint interventions, including radiofrequency neurotomy, radiofrequency cryoneurolysis, medial branch nerve blocks and intraarticular injections (Boswell et al. 2007). These interventions have varying short-term and long-term effectiveness with a moderate response in most joints (Boswell et al. 2007).

A systematic review of therapeutic lumbar transforaminal epidural steroid injections showed both long-term and short-term relief with Level II-1 and Level II-2 evidence respectively for lumbar nerve root and low back pain (Buenaventura et al. 2009).
One systematic review found that with the exception of the short-term pain relief afforded to those suffering from herniated discs or radiculities, blind intralaminar epidurals have limited efficacy (Parr et al. 2009). Cervical epidural steroids (cervical interlaminar epidural injection) is frequently used in the United States to manage chronic neck pain. A recent systematic review of the procedure demonstrated that in spite of a limited number of studies on the topic, what evidence existed demonstrated significance for relief of pain in the cervical area as well as long-term relief (Benyamin et al. 2009). Another review for caudal epidural injections for “chronic pain of post lumbar laminectomy syndrome and spinal stenosis” (chronic low back pain) was also shown to be significant for short and long-term relief (Conn et al. 2009). An earlier review also for caudal epidural steroid injections demonstrated moderate success for relief on chronic low back pain and nerve root pain over the long-term (Abdi et al. 2007). Some experts suggest that spinal catheters should never be used in a haemophiliac person living with HIV or AIDS (PHA) and that needles should always be small (size G-27) (Rodriguez-Merchan 2006). Overall, epidural injections appear to have at least a certain level of efficacy, although the extent to which appears to vary according to various elements, including type of pain and type of injection.

6.5.11 Manipulation

Manual manipulation is a method of care in which 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 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 recent systematic review of chiropractic management found manual-type therapies and some physiologic therapeutic modalities have acceptable evidentiary support in the treatment of Myofascial Trigger Points and Myofascial Pain Syndrome (Vernon and Schneider 2009). Chiropractors do not generally treat HIV symptoms but rather attend to musculoskeletal conditions which many PHAs experience, such as a headache, back and joint pain. They can also assist PHAs with insomnia and stress. While chiropractors generally use spinal manipulation, they also might use ultrasound or heat/light therapy.

6.5.12 Orthoses and Prostheses

Orthoses can be a crucial component of a person living with HIV or AIDS (PHA)'s mobility and independence (Rosensweet and Fink 1992). Unfortunately there is limited evidence for the effectiveness of orthoses and prostheses across all diseases. A recent 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 molded insoles (versus the shoes alone) decrease pain during weight-bearing activities such as standing, walking and stair-climbing. Arthritis patients 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). Effectiveness of these aids may be attributable to the skill of the individual creating the aid although this has not been formally studied.

6.5.13 Osteopathy

Osteopathy is a manual treatment which relies on mobilizing and manipulating procedures in order 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).

6.5.14 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. Injections are often used for chronic low back pain (Dagenais et al. 2007) and plantar fascitis (Tsatsos and Mandal 2002).

6.5.15 Sleep Hygiene Techniques

Insomnia occurs commonly in people living with HIV or AIDS (PHAs) and there are a number of basic sleeping practices, 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
6.6.2 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 (http://familyvillage.wisc.edu/mall.htm).

- **ABLEDATA** [http://www.abledata.com/](http://www.abledata.com/) ABLEDATA is a national database of information on assistive technology and rehabilitation equipment available from domestic and 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/](http://www.ablelinktech.com/)


- **The Boulevard** [http://www.blvd.com/](http://www.blvd.com/) This is a health care site for the disabled by the disabled which provides information about products and services available to health care professionals and individuals with disabilities.

- **National Registry of Rehabilitation Technology Suppliers (NRRTS)** [http://www.nrrts.org](http://www.nrrts.org) NRRTS has created a listing of experienced rehabilitation technology suppliers available to consumers, rehabilitation professionals and payer sources worldwide.

- **Wheelchair Net** [http://www.wheelchairnet.org/](http://www.wheelchairnet.org/) A virtual community for wheelchair-minded people this site contains information on purchasing and using a wheelchair.

6.6 Assistive Devices

6.6.1 Introduction

Many people living with HIV or AIDS (PHAs) experience difficulties with everyday tasks. There are now a large range of assistive, adaptive and accessibility aids 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 through the world wide web.


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6.7 Vocational Rehabilitation

6.7.1 Introduction

This chapter discusses emerging issues regarding vocational rehabilitation and return-to-work decisions for people living with HIV or AIDS (PHAs). Issues relating to structural and institutional changes and supports can be accessed in the work of Worthington et al. (2010) and the work of the Canadian Working Group on HIV and Rehabilitation (CWGHR). This chapter covers a number of issues that are tailored more specifically to the individual PHA considering employment. This chapter is intended to provide a window of insight into the many personal, clinical, vocational and income support considerations a PHA might consider in terms of employment, whether it be for the first time ever or a re-entry to a long held position.
6.7.1 HIV and Employment

The University of Calgary, in collaboration with the University of Toronto and the Canadian Working Group on HIV and Rehabilitation (CWGHR) recently completed a project to develop a conceptual framework of labour force participation for PHAs in Canada (Worthington et al. 2010). Scoping study methodology, consisting of a literature review, interviews and focus groups, led to the conceptual framework for PHAs and employment. The HIV and Employment Framework incorporates six key components related to labour force participation for PHAs. 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 PHAs to participate in the labour force are some of the key challenges in need of attention. This framework can be used by PHAs, employers, insurers, health care providers, and policy makers, to develop strategies and interventions to promote labour force participation of PHAs (Worthington et al. 2010). Factsheets and other materials resulting from this work can be found on the CWGHR websites www.hivandrehab.ca.

CWGHR also offers training for employers, policy makers, rehabilitation specialists and others to better understand barriers to returning to work and barriers to sustaining work PHAs face, understanding the impacts of HIV on the workplace environment, accommodation best practices for PHAs and those with other episodic disabilities and finally, how to reduce fear and uncertainty during the return-to-work process.

Moreover, CWGHR addresses the challenges faced by those living with episodic disabilities considering return-to-work. This encompasses episodic illness including: HIV, arthritis, diabetes, multiple sclerosis, some forms of mental illness and other chronic conditions. CWGHR has recently developed a new national network on employment, the Episodic Disabilities Employment Network (EDEN). EDEN has launched a new interactive website for PHAs and those with other episodic disabilities on employment supports. The EDEN website can be found at www.edencanada.ca.

6.7.2 The Significance of Employment for People Living with HIV or AIDS in 2010

Advances in the clinical treatment of HIV have meant improved health and longevity for many people living with the disease with access to treatments. Labour force participation has been identified as a critical social issue facing people living with HIV or AIDS (PHAs) in Canada. Participation in the labour force provides income stability, promotes social engagement and self-determination for PHAs (Worthington et al. 2010). As a result, returning to or remaining in the work force, despite HIV-related disabilities, has become more feasible and attainable. Over the past decade, an increasing amount of research has assessed the work force participation needs of this population and has evaluated the ability of existing public- and private sector programs to respond to the needs of PHAs. Recent studies suggest that 42% to 62% of PHAs in developed countries are unemployed, many of whom are contemplating a return-to-work (Worthington et al. 2010).

6.7.3 Factors that Might Facilitate Employment/Return-to-Work

A number of 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. Many people living with HIV or AIDS (PHAs) may be able to return-to-work, or may want to engage in other kinds of 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.

For those who feel that employment may be an option, several studies have documented the factors motivating PHAs 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 a stronger personal identity (Braveman et al. 2006).

When addressing vocational rehabilitation for PHAs, it is important to understand the clinical, psychosocial, economic, and infrastructural 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).

In Ontario, contact the HIV/AIDS Legal Clinic Ontario (HALCO) for legal information and support on employment issues. See http://www.halco.org/.

Across the nation, many community-based AIDS Service Organizations (ASOs) advocate on behalf of individuals with provincial, territorial or federal income support programs. Some organizations address the employment needs of PHAs (e.g., through information seminars, benefits information, psychosocial counselling, financial and career planning, and vocational rehabilitation). In addition, some community AIDS housing projects offer vocational rehabilitation programs for individuals with no work history.
6.7.4 Return-to-Work Principles

Consumers, 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 work force participation and vocational rehabilitation.

Key Principles for People Living with HIV or AIDS
- Returning to work must be addressed within the broader context of health
- People living with HIV or AIDS (PHAs) 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 PHA and should be free from coercion
- PHAs must control medical confidentiality in correspondence with employers and private or public payers

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 experience
- 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.

6.7.5 Creating a Network of Support

People living with HIV or AIDS (PHAs) 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)
- Health care providers, particularly those supplying supportive documentation for public or private payers
- People from AIDS Service Organizations (ASOs) who assist with disability issues staff at HIV legal clinics who may help to decipher the fine print in documentation
- Family members and friends
- Vocational counsellors or workers from vocational rehabilitation programs

6.7.6 Accommodation Options for People Living with HIV or AIDS in the Workplace

There are a number of accommodation options that people living with HIV or AIDS (PHAs) might explore with an employer. Some of these options include:
- Modifying the physical workplace (such as changing the layout of equipment)
- 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
- Accessing supportive workplace policies
- Accessing workplace AIDS education and support programs
- Accessing ongoing vocational services
- Accessing community resources, ranging from childcare to transportation
- Using available social supports, including friends and family

Employers in Canada have a duty to accommodate employees (see http://www.chrc-ccdp.ca/portal_portail/duty_obligation-en.asp) with workplace disabilities to the point of undue hardship. This 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/mental 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 can 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 “friendly” negotiation of the accommodation

When a need for accommodation arises, employers should:

- Meet with the employee and review the job duties with employee
- 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 a 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 health care professional that outlines:

- What the limitation is
- What the impacts are on the employees job
- The length of time that the limitation is expected to continue

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

### 6.7.7 Barriers to Employment or Return to Work

A person’s demographic background or social standing are equally as likely to contribute to unemployment as is his or her physical health (Fogarty et al. 2007). Additional specialized challenges may be 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 (IDUs) (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 or AIDS (PHAs) might face in either of these situations. Unfortunately, numerous barriers to work exist for PHAs in Canada and there is a need for collaborative initiatives between multiple stakeholders to promote increased opportunities for labour force participation among PHAs. 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 PHAs (Glenn et al. 2003).

There are significant social and systemic factors limiting employment opportunities for PHAs. 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 PHAs (Canadian Working Group on HIV and Rehabilitation, 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 that while there may be some commonalities across all PHAs (such as disease progression), there are also specific gendered barriers, limitations and challenges facing these individuals.
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. It is only logical that a unique set of barriers will be faced by each respective group, however much they may overlap. A pilot intervention of a bi-weekly training session aimed at bridging the gap between health and employment for PHAs facing multiple barriers demonstrates that, although still a work in progress, it is feasible (Bedell 2008).

There is a need to develop employment-related services such as networking and mentorship opportunities for working and nonworking PHAs (Popiel et al. 2010). There is also general need for any HIV specific employment supports as only one currently exists in Toronto. See 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 PHAs 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 have hazards that may have an impact on health
- Lack of supportive workplace policies
- Little to few workplace AIDS education and support programs
- Little to few to ongoing vocational services
- Little to few community resources, ranging from childcare to transportation

### 6.7.8 Other Potential Barriers

The following section includes general employment factors to consider and three categories of potential issues which have commonly acted as barriers for people living with HIV or AIDS (PHAs) contemplating returning to work. It is important to keep in mind that not all of these issues will be encountered by each PHA. Indeed, a unique set of issues will emerge for each PHA. 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.

### 6.7.8.1 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
- Earnings potentials

### 6.7.8.2 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
- 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

### 6.7.8.3 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
6.7.8.4 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. Given that living with HIV can be accompanied by unpredictable episodes of illness and well-being, 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:

- Emotional readiness to return-to-work, including but not limited to
  - 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 work force
  - 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 work force will provide the stability of income needed for maintaining access to medications

6.7.9 Income Security and Health and Disability Insurance

Because income status closely mirrors health status, people living with HIV or AIDS (PHAs) should be able to pursue their education and employment goals without sacrificing financial security. In Canada, many PHAs rely on a public or private medical insurance benefits to address their health needs. Considering work can change a PHAs’ 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 PHA considering returning to work, particularly in terms of 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 PHAs.

However, the reality is that decisions to re-enter the work force can have a profound impact on long-term health insurance or disability benefits. It is important for PHAs, 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 work force 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 work force participation, particularly for people with episodic disabilities such as HIV (Maticka-Tyndale et al. 2002). In Canada, the current patchwork quilt of federal and provincial or territorial income support programs — with differing rules and definitions governing health insurance, disability, and work force re-entry — make the issue of vocational rehabilitation a difficult one to navigate (Canadian HIV/AIDS Legal Network 2005, Canadian Working Group on HIV and Rehabilitation 2008).

Provincial and territorial programs include health insurance that cover 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 PHAs who would otherwise be unable to afford the drugs. Many people have left work to go on social assistance precisely because they had no drug coverage at work. Drug coverage normally ends as soon as a person stops receiving public assistance, a factor which constitutes a potential barrier to returning to work. 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 continued receipt of benefits. As well, harmonization efforts between federal and provincial or territorial levels of government may impact on the benefit amount that PHAs receive. PHAs 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 PHAs 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. PHAs 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. That being said, 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 cyclical, rehabilitation service 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 chronic 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 or AIDS (PHAs), 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 work force 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 AIDS service organizations (ASOs), 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 PHA who is contemplating returning to work, the following questions should be discussed:

- Can the program be accessed by PHAs? (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 PHAs? 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 PHAs 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 www.employmentaction.org. For those living in the Toronto area, Employment Action can be contacted directly for support services.
6.7.10.3 Alternatives to Paid Employment

Returning to work, or entering the workplace for the first time for people living with HIV or AIDS (PHAs) may not be a desirable move for a number of reasons. PHAs are advised to carefully assess the impact of returning to work and to consult widely before making a decision on whether to re-enter the work force. That being said, PHAs may want to consider daily activity options outside the paid work force, such as voluntary work or education and training. For instance, PHAs are now considering a wide array of options including contract work, self-employment, care giving, 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 work force without endangering private or public disability benefits (Ferrier and Lavis 2003) and may prove more accommodating in light of HIV as an episodic disability.

6.7.11 Summary

The issue of employment for an individual with an episodic disability such as HIV is complex and multifaceted. A number of 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, systemic and institutionalized structures may hinder or facilitate employment access. Despite the multiple disadvantages experienced by many individuals, several studies indicate that people living with HIV or AIDS (PHAs), when provided access to comprehensive and individualized supports, are able to achieve improved rates of employment and retention (Escovitz and Donegan 2005, Kielhofner et al. 2004, Paul-Ward et al. 2005a). Making the decision 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 for one with an episodic disability. The decision should be one that, with the help of a support network, a vocational rehabilitation expert, family and friends, is ultimately determined by the individual PHA.

6_8 Self-Management

For people living with HIV or AIDS (PHAs) who have access to antiretroviral therapies, the meaning of living with HIV has shifted from an acute illness to 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 be used to help individuals living with a chronic disease address some of these challenges. A recent study used 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 health care services and improved rates of self-efficacy over the course of 2 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 PHAs, and can include self-care routines in addition to structured programs. The availability of structured programs may improve the use of health care services as well as burden of illness for PHAs (Thorne et al. 2003). 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 attributes this to three main themes, including a) an avoidance and disbelief of HIV serostatus, b) conceptions of illness and appropriate health care, and c) negative experiences with, and distrust of, health care (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).

Thinking about the way one listens and absorbs the information that a client shares is key. For instance, one qualitative Australian study noted that when interacting with non-Aboriginal health care 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). This is salient in Canada as well, particularly given the high rates of PHAs who are Aboriginal or newcomers to Canada – two groups who may have distrust of institutional powers more so than other individuals living in Canada. 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 under three main pillars:

I. Physical Health
- a framework for understanding illness and wellness
- health promoting behaviors
- treatment adherence
- self-monitoring of physical status
- accessing appropriate treatment and services
- preventing transmission

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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 and the community level. These levels will intersect to varying degrees based on each person’s involvement in his or her care and on 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. Structured self-management programs seem to work best when targeted towards a specific group, such as women (Webel and Holzemer 2009), racialized groups or youth. These structured programs can also be oriented to geographic areas, including, rural, remote and urban or any combination therein. For example, this can include African American women (Tufts et al. 2010), inner-city women (DeMarco and Johnsen 2003), PHAs who are seeking balance between home, work and illness (Bedell 2008), those seeking assistance with depression (Lai 2007), adherence (Smith et al. 2003) and can even emphasize self-efficacy (Kennedy et al. 2007, Shively et al. 2002). A recent scoping review of self-management for chronic pain demonstrated that those programs emphasizing exercising and/or staying active had the most positive outcomes, while programs focusing on education alone had the least (James Henry, McMaster University, personal communication).

The emphasis on structured self-management is usually in a group setting aimed at providing individuals with adequate information to make informed choices around personal wellness. These choices tend to focus on one, all or a combination of “symptom assessment and management, medication use, physical exercise, relaxation, doctor-client communication and nutrition” (Gifford and Sengupta 1999).

In this manual, more information on individual based management strategies can be found in Section 6.8.1 Complementary and Alternative Medicines and Therapies or in Section 6.5 Modalities. Information regarding structured self-management programs 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 or AIDS (PHAs) 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 health care 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 be offered by regulated health care professionals (such as acupuncture provided by a physical therapist). Distinguishing between various treatments can quickly become complicated. For the purposes of this module, those treatments provided by regulated health care professionals can be located in 6.5 Modalities. Other treatments, which are not generally offered by regulated health care professionals and are often not evidence-based practices, are located in this section.

Recent data suggests that the use of CAMT by PHAs is common-place. Many PHAs report the use of these therapies along with conventional medical treatments, in order to get benefits of both. Current Canadian data shows that almost 90% of HIV positive clients are using at least one type of CAMT, including vitamins and minerals (Furler et al. 2003). 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).

Many PHAs report improvement in their overall health after using CAMT and there is preliminary evidence to indicate that these treatments may indeed be beneficial, although more research is still needed in this area (Furler et al. 2003). Unfortunately, some health care providers are unaware of the potential value of these therapies in a treatment repertoire, or they tend to diminish the value of these interventions. While many of these interventions are anecdotally rather than evidenced based, CAMT providers are increasingly attempting to evaluate their interventions. Due to the prevalence of CAMT use among PHAs, 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 have somewhat different implications. Generally, complementary therapies are 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 in lieu 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 dealing with symptoms. There are many CAMT that may help to improve and maintain a client’s quality of life, repair immune damage or treat symptoms, although conclusive evidence for most of these interventions is still lacking.

It is beyond the scope of this chapter to include an exhaustive list of all CAMT used by PHAs. Instead, some of the more commonly used medicines and therapies have been included. 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. It should be noted that some of these, such as acupuncture and traditional Chinese medicine will soon be classified in the modalities chapter, at least in Ontario, where specialists in this field are currently moving towards regulating their profession under the Health Regulation Act (as are currently physical therapists and nurses). This transition is a good indication that these categories and delineations are not static and are often shifting.

6.8.1.3 How are Complementary and Alternative Medicines and Therapies Used?

Most people living with HIV or AIDS (PHAs) 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. However, more recently, PHAs are 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 injected. As such, providers should be aware of possible negative effects, including reduced effectiveness of antiretroviral therapies and/or drug toxicity (Ladenheim et al. 2008). Therefore, promoting open communication with PHAs around CAMT use is vital to ensure that safe and effective use of CAMT is incorporated into their treatment plan.

For some people, CAMT are part of a philosophy of living. For others, they are used to improve quality of life by:

- Increasing energy or decreasing fatigue
- Strengthening the spirit
- Relieving chronic pain
- Relieving specific symptoms such as nausea
- Helping people recover from the complications of drug toxicity
- Relieving stress and allowing people to cope with the difficulties of everyday living

6.8.1.4 Examples of Complementary and Alternative Medicines and Therapies

Below is a list of some of the therapies included that people with HIV may benefit from. For the most part, there is limited evidence for many of these interventions. 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 Aboriginal Healing Traditions

Aboriginal 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 Aboriginal 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. Aboriginal healing traditions include sharing and healing circles, traditional ceremonies, elders, traditional medicine, feasts and gatherings. An elder from one’s Aboriginal community can help Aboriginal people living with HIV and AIDS (PHAs) find a native healer.

There are two practices often used by Aboriginal PHAs. 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 them, and the 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 client’s relationship to the community. Sacred ceremonies, some of which rely on visions and symbolism, are important parts of Native healing. More information about Aboriginal health and traditional knowledge can be found on the National Aboriginal Health Organization website 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 practiced 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. There have been several systematic reviews conducted by the Cochrane Collaboration and other researchers to determine the effectiveness of acupuncture in the management of a wide range of symptoms and conditions. While results from the systematic reviews are for the most part inconclusive, a recent observational study of acupuncture administered in a group setting has shown to potentially reduce symptoms of pain and peripheral neuropathy in HIV positive individuals (Phillips et al. 2004). In Ontario, acupuncture is currently in the transitional phase of becoming a regulated college, a two to three year process. Currently, it falls into the category of transitional Council of the College of Traditional Chinese Medicine Practitioners and Acupuncturists of Ontario and is already covered by many private insurance companies.

6.8.1.4.3 Affirmations and Visualization

Also called guided imagery, affirmations and visualization are practice by some people living with HIV or AIDS (PHAs) 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 group found greater effects for those at mid-stage disease and for those who were previous users of guided imagery, albeit at a low frequency (Eller 1999).

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 odors can relax, stimulate, or help alleviate depression. They are generally 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).

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 comprising observational studies and expert opinions (Adetifa and Okomo 2009).

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. Herbal medicines are sometimes used by Aboriginal healers, herbalists, traditional Chinese medicine practitioners, naturopaths, homeopaths, aromatherapists and Ayurvedic doctors. 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 recent 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 nanopharmacologic and ultramolecular doses of medicines to strengthen a person’s immune and defense 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).
2003 study found that 21% of people living with HIV or AIDS (PHA) participants in Europe were practicing homeopathy (Colebunders et al. 2003). Rastogi et al. (1999) tentatively suggest a role for homeopathy for PHAs based on the statistically significant findings in their study of homeopathy for PHAs 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 effectiveness of homeopathy for PHAs (Mills et al. 2005). It is important to note that the WHO recently 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 and some massages 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 or AIDS (PHAs) include reflexology, therapeutic touch, reiki, shiatsu, Trager, Bowen technique, osteopathy and chiropractic (AIDS Committee of Toronto 2007). A recent 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 PHAs, 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 PHAs receiving Reiki (Schmehr 2003, Miles 2003).

6.8.1.4.10 Meditation
Meditation is an exercise of the mind in 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. Recent findings from a small randomized trial provide an initial indication that mindfulness meditation training could possibly cushion CD4+ T lymphocyte declines in HIV-1 infected adults (Creswell et al. 2009). Meditation is often used in combinations with other interventions. For example, a small randomized trial demonstrated that a combination of meditation and massage had a significantly favorable influence on overall and spiritual quality of life in late-stage disease relative to standard care, or either intervention component alone (Williams et al. 2005). Mindfulness-Based Stress Reduction for people living with HIV or AIDS (PHAs) is a program with Buddhist foundations aimed to be accessible to most people (Gayner et al. 2010). A recently completed randomized trial demonstrated positive outcomes for PHA participants (Gayner et al. 2010).

6.8.1.4.11 Mind-Body Approaches
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 favorable 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 recent 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
The word naturopathy comes from Greek and Latin and translates as “a nature disease.” The emphasis is on the whole client to promote wellness, prevention, and self-care (Fritts et al. 2008). Naturopaths see disease as an attempt by one’s body to get rid of toxins and to restore balance. They use products and procedures to boost the natural healing powers of the body. The client is expected to play an active role in staying healthy. Naturopaths use an holistic approach to healing that can include herbal medicine, nutrition, dietary and nutritional supplements, homeopathy, traditional Chinese medicine, chiropractic, and other therapies. Naturopaths are commonly used in the course of care for HIV as preventative health care 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. Through both gentle and deep pressure massage of these points, reflexologists stimulate the organs and glands. Some people living with HIV have reported using reflexology for peripheral neuropathy (Nicholas et al. 2007), although it was rarely used as compared to other interventions like massage, acupuncture and meditation. A recent 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).

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 which 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 recent evaluation of shiatsu interventions concluded that it is helpful for the control of certain conditions or symptoms, including joint pain, muscle pain, overall well-being and fatigue (Long 2008).

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 chapter 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.

6.8.1.4.16 Tai Chi

Tai Chi is a form of Chinese martial art involving a series of slow, rhythmic movements. This relaxing exercise may have positive both 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 sleep disturbed and cardio functioning (Kuramoto 2006).

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). More information about therapeutic touch can be found at http://www.therapeutictouch.org/

6.8.1.4.18 Traditional Medicine Systems

Traditional Chinese medicine is a 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 (mugwart herb) to reduce diarrhea in persons with HIV found promising improvement in frequency and stool consistency (Anastasi and McMahon 2003).

In Ontario, Traditional Chinese medicine is currently in the transitional phase of becoming a regulated college, a two – three year process. Presently, practitioners work under the Transitional Council of the College of Traditional Chinese Medicine Practitioners and Acupuncturists of Ontario (2010).

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 (Brazier et al. 2006). More recently, yoga has been shown to improve cardiovascular health by lowering blood pressure in prehypertensive 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 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 AIDS service organizations (ASOs) 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 chapter 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 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 ASO as most now have information about how to access reputable CAMT providers in their area. Some ASOs 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 Health Care 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 health care providers would agree that low cost, low harm interventions for which the client reports a perceived sense of benefit can 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 CAMTs or as a result of successful outcomes from the use of CAMTs.

6.9 Educational Interventions
It is now common practice for health care professionals to suggest an educational intervention to assist individuals learn strategies and tricks to manage their chronic disease. Such programs exist for many diseases, including arthritis, diabetes and HIV. These programs usually consist of weekly two hour classes for a period of 6 to 8 weeks.

6.9.1 The Positive Self-Management Program for HIV (PSMP)
The Positive Self-Management Program (PSMP) is a seven week series of seven 2.5 hour workshops. The program has been tested in the form of a randomized controlled trial, with more than 200 people living with HIV or AIDS (PHA) participants. The findings revealed that participation in the PSMP improved symptoms, medication adherence and HIV suppression at the 6 month follow-up (Gifford et al. 1998, Gifford and Sengupta 1999, Gifford et al. 2001, Gifford et al. 2005).

These workshops are led by two trained individuals, with one or even both being PHAs that are not involved in professionally in the health care community. A variety of topics are discussed including:

- How to best integrate medication regimens into daily life so they can be taken consistently
- Techniques to deal with problems such as frustration, fear, fatigue, pain and isolation
- Appropriate exercise for maintaining and improving strength, flexibility, and endurance
- Communicating effectively with family, friends, and health professionals
- Nutrition
- Evaluating symptoms
- Advanced directives
- How to evaluate new or alternative treatments

Each participant in the workshop may also receive a companion manual and a compact disc with relaxation techniques. Rather than replace existing programs and treatments, the PSMP is intended to serve as a complement to existing treatment. Through active participation, the program aims to increase PHA confidence in health management and maintaining a satisfactory quality of life.

6.9.2 Peer Support Interventions
Another method of support are peer support groups or programs. A recent study of Ugandan orphans determined that peer support groups lead to diminished scores of anger, anxiety and depression although self-concept scores do not improve (Kumakech et al. 2009). The context in North America is significantly different, as a large AIDS orphan population does not exist, but the fact that the peer support leads to improved psychological scores is promising for different groups. For example, there is some evidence for the use of peer education program in youths (Mahat et al. 2008). Although peer support in addition to other interventions in adult with HIV improved short term adherence and other symptoms to highly active antiretroviral therapy (HAART), the long-term benefits of such a program are still inconclusive (Simoni et al. 2009, Simoni et al. 2007). These data reflect the findings of a recent systematic review of telephone peer support in a range of diseases which concluded that while there is some evidence that peer support telephone calls can be effective for certain health-related concerns, few of the studies were of high quality and so results should be interpreted cautiously. There were many methodological limitations thus limiting the generalisability of findings (Dale 2008).

6.10 Palliative Care

6.10.1 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, can only assist more people living with HIV or AIDS (PHAs) 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 PHAs 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 anti-retroviral therapies and increased understanding of the optimal timing of interventions. Regardless of the cause of death, palliative care of PHAs is an important part of care and treatment 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 those around him/her.

The World Health Organization (WHO) 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 managing of symptoms is the goal of care and treatment and all efforts work towards making the individual living at the end of life as comfortable as possible. As with all aspects of care, the person (and family and friends) remain key participants in care direction and decisions. Current concepts of palliative care in HIV include the following key 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 or postpone death
- Integrates the psychological and spiritual aspects of care
- Offers a support system to help individual’s 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 individual’s 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

6.10.2 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 balance” (Santiago-Palma and Payne 2001). The ultimate focus, especially as death nears, should be on comfort and facilitation the desires of the client via an interdisciplinary approach that recognizes the physical, social and spiritual aspects of any individual. 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.

6.10.3 Rehabilitation Interventions for Palliative/End-of-Life Care

6.10.3.1 Physical Modalities for Pain Management

The following physical modalities (and their caveats) have been recommended by Santiago-Palma and Payne (2001). 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 Raynaud’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.
- **As health deteriorates**, an individual’s mobility and ambulation can as well. Canes, walkers, shoe horns, and rails in the washroom, bedpans are all 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 between the person and care providers at a time when the person is best able to contribute to those deci-
6.10.4 Programs

There are several examples of palliative/end-of-life programs across Canada, with a number specifically geared towards people living with HIV.

6.10.4.1 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 http://www.caseyhouse.com/en/programs_services/residential/.

6.10.4.2 AIDS Bereavement Project of Ontario

The AIDS Bereavement Project of Ontario (ABPO) consists of an 8 to 10 week intervention for volunteer or professional caregivers, partners, family and friends of people living with HIV and AIDS (PHAs) (http://www.abpo.org/index.php/about_us/).

An initial needs assessment determined that the multiple loss experienced in the first decades of HIV by PHAs and their social and support groups required a standardized response grounded in a clear theoretical framework to address loss felt by PHAs, family and friends and within AIDS service organizations (ASOs). The ABPO’s 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 PHAs to increase communication skills, peer support and community resiliency strategies.
- Timely responses to the changing nature of loss within diverse AIDS-impacted communities.

6.10.4.3 Canadian Hospice Palliative Care Association

The Canadian Hospice Palliative Care Association maintains an interactive database of hospice programs available in communities across Canada. The database can be searched by province, condition and other keywords. 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. http://www.chpca.net

The International Association for the Study of Pain (Phillips et al. 2010) recently reviewed the interventions to treat painful HIV-associated sensory neuropathy. This review focused on the effectiveness of pharmacologic interventions including smoked canabanoids. Some people living with HIV use canabanoids for the palliative control of pain (McCarberg 2007). Health providers need to know any medications being used (both prescribed medications and otherwise “acquired”) so that the awareness of the affects of these interventions can be considered when planning and delivering care.

6.10.3.2 Role for Speech-Language Pathology

Speech-language pathologists (SLPs) can assist with swallowing, breathing and communication techniques (Santiago-Palma and Payne 2001). Early interventions, as soon as it becomes apparent that there may be problems in these areas, is essential.

6.10.3.3 Addressing the Emotional and Spiritual

Many of the complementary therapies and modalities listed in previous sections of this manual are relevant to people living with HIV or AIDS (PHAs) at the palliative care level, it is simply a question of modification. Music movement therapy (Frego 1995) has been suggested, as has group art therapy, which has been found to be effective in addressing the “why me” question that often arises as an individual approaches the end of life (Mayo 1996). Cognitive Behavioural Therapy (Uwimana and Louw 2007) and meditation (Williams et al. 2005) are also common. 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.

6.10.3 Complementary Therapies

Many of the complementary therapies and modalities listed in previous sections of this manual are relevant to people living with HIV or AIDS (PHAs) at the palliative care level, it is simply a question of modification. Music movement therapy (Frego 1995) has been suggested, as has group art therapy, which has been found to be effective in addressing the “why me” question that often arises as an individual approaches the end of life (Mayo 1996). Cognitive Behavioural Therapy (Uwimana and Louw 2007) and meditation (Williams et al. 2005) are also common. 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.

6.10.4 Programs

There are several examples of palliative/end-of-life programs across Canada, with a number specifically geared towards people living with HIV.
CHAPTER 7 HIV REHABILITATION IN CONTEXT

7.1 Access to Care

Rehabilitation can provide valuable services to people living with HIV or AIDS (PHAs) throughout their lives. How HIV is conceptualized affects the role rehabilitation providers can provide to PHAs.

7.1.1 Demand for Rehabilitation Services

When thinking about HIV from the perspective of episodic disability, the roles for rehabilitation expand significantly. Deber and Landry note that the intermittent periods of acute illness in a chronic disease such as HIV can often be prevented and/or minimized with the involvement of a rehabilitative team (Deber and Landry 2010). While on the one hand, this is promising news, people living with HIV or AIDS (PHAs) 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 population
- Workforce pressures
- Rise in chronic and complex multi-system disorders
- Advances in technology
- Changes in health service delivery models

People living with HIV or AIDS are affected by all of these factors.

7.1.2 Rehabilitation as Prehabilitation

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 ‘pre-habilitation’ (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 chapter 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 or AIDS (PHAs) 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 as a means to ensure 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, funding has shifted across the health care system and this has also affected the rehabilitation community. Generally, there are three tiers of funding: public, quasi-public and private. Publicly funded services can be accessed in hospitals, institutions and community care access centres (CCACs) and can be funded by global budgets, Schedule 5 funding (for Ontario Physical therapists only), the CCACs budget and the Veteran Affairs Canada budget. Motor Vehicle Accident Insurance and the Workplace Safety and Insurance Board are both partly 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 health care 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, 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. Clearly, discrepancies within and across institutions and regions related to policies, coordination, funding and more, can often make access to care challenging.
A recently developed framework for organizing healthcare delivery systems for persons with ongoing care needs and their families recommends 10 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. A single funding envelope is critical to maximizing the efficiency, effectiveness and quality of care provided
- Integrated electronic information systems
- Rewards and incentives for evidence-based management
- A single- or coordinated-entry system. Single entry provides for a consistent screening mechanism that ensures that only those with appropriate needs are provided services
- Standardized system-level assessment and care authorization
- A single system-level client classification system
- Ongoing system level case management
- Involvement of clients and families

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).

7_2 Navigation and Advocacy

7.2.1 Background

The Canadian Health Care System can be daunting and confusing for many, including people living with HIV or AIDS (PHAs). Clients may have some difficulty entering or maneuvering through the complex Canadian health system. Assisting clients navigate through the system 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, etc. This is where health care providers may need to assist with advocacy. There is some preliminary work that health care 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 ‘client- or client-centred care,’ has often been used within health care and social service circles. This section briefly outlines some of the key concepts around 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 health care team, including administration and program support workers.

7.2.2.1 Client- or patient-centred care

Client- or patient-centred care attempts to provide health care services that are needed by a client, when and how the client desires. This is a balancing act requiring collaboration between the whole health care team (including administrative staff) and compromise. This comes primarily from a partnership between the health care provider and the client. Designing 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 or AIDS (PHAs) as a part of their practice often describe a sense of discomfort because they do not want to offend the PHA, particularly individuals who may have been marginalized by the health care system in the past (CWGHR 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
- 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 the client may need to see during the course of a health care interaction
- Conversely, there are challenges to of the most vulnerable clients which 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 and valued
- Recognize the fine-line between learning from a client and self-education prior to or after a client interaction
- Recognize how stigma can affect access, disclosure, motiv-
the client discussing the reason for referral and explaining what practice whenever possible, spending adequate amounts of time with making referrals to other sensitive and responsive places of practice.

7.2.3 Navigation
Having a sensitive and responsive practice can facilitate a meaningful relationship with one’s client. Quite often, the expertise of another health care or social service professional or perhaps a community based organization is required. This is when navigation becomes an important skill. As a health care professional, knowledge of this skill can assist people living with HIV or AIDS (PHAs) find their way through the care system and to receive the appropriate service desired.

Assisting a client to navigate the health care 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 health care professional may be a novel and scary experience for a client who is new to the health care 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
- Filling out any required forms before and at the new appointment

Ensuring the client understands his or her rights in this new situation. This includes:

- Confidentiality
- Informed consent
- Having a family member or friend accompany them
- Having answers to questions written down
- Assistance communicating effectively with a health care 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
Inevitably, 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 health care professional to advocate on the client’s behalf or to refer the client to an appropriate advocacy group.

The ideal situation is for the health care professional to work with the client to become his/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 health care providers to reflect on the amount and time and energy they can commit to this cause. On the one hand, health care professionals should not jeopardize the rehabilitation service already provided for the client due to feeling overwhelmed with bureaucratic measures. On the other hand, not helping may mean that the larger system can jeopardize the good rehabilitation work already provided for a client.
Advocacy may be needed when health care professionals are recommending a referral and/or a course of action for a client are access 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 for 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/her own 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
- Channeling 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
- Practicing any of these skills to gain feedback, experience and confidence

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 or AIDS (PHA) has the necessary skills and resources to be his or her own advocate to determine how to assist them with this process.

Keeping the needs of the PHA at the forefront is the important aspect of client-centred care. Collaborative teamwork that includes the PHA as an equal part of the team is the easiest way to facilitate such practice.

### 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. 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. 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 or AIDS (PHAs) 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 health care 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) and/or personal contextual lenses (e.g., gender, 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 from which 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 effect of rehabilitation
- Development and evaluation of outcome measurement tools

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 PHAs in Canada.
### 7.4 Occupational Exposure / Universal Precautions

#### 7.4.1 General Information
HIV is transmitted through unprotected sexual intercourse, exposure to blood, blood components or bloody body fluids, perinatally from mother to child, and through breastmilk. 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 which has been in an artery or vein of a source client who has a high viral load.

#### 7.4.2 Body Fluids Infectious for HIV
- Blood
- Cerebrospinal
- Amniotic
- Pericardial
- Peritoneal
- Pleural
- Synovial
- Seminal
- Vaginal
- Penile secretions
- Breastmilk
- Inflammatory exudate
- Human tissue
- Any other body fluids which contain visible blood

#### 7.4.3 Preventing Occupational Exposure to Any Infection
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, 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

#### 7.4.4 Guidelines for Management of Occupational Exposure
The United States Public Health Service has developed guidelines for the management of occupational exposure to the Hepatitis B Virus (HBV), Hepatitis C Virus (HCV), and HIV (2001). The American Family Physician Society provides open access to summaries of recommendations for post exposure prophylaxis regimens (Preboth 2002), management of occupational blood exposure (Preboth 2002) and implementation for health care facilities (Preboth 2001).

#### 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/AIDS (PHAs), 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/AIDS. The Legal Networks regularly publishes updates on the importance of privacy of health information for PHAs, which includes a discussion of current rights and responsibilities. An information sheet outlining the importance of privacy of health information for PHAs can be found at this link: http://www.aidslaw.ca/publications/interfaces/download-File.php?ref=187.
7_6 Resources

This section contains a list of primarily national organizations involved in HIV care or rehabilitation, plus a list of printed materials specifically on rehabilitation and HIV disease.

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
Email: info@canac.org
Internet: http://www.canac.org

Canadian Association of Occupational Therapists
Tel.: 613 523-2268
Fax: 613 523-2552
E-Mail: cvonzweck@caot.ca
Internet: http://www.caot.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 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: cmto@cmto.com
Internet: http://www.cmto.com

Canadian Chiropractic Association
Tel.: 416 585-7902
Fax: 416 585-2970
E-Mail: idumitrache@chiropracticcanada.ca
Internet: http://www.chiropracticcanada.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: http://www.hmcc.ca

Acupuncture Foundation of Canada
Fax: 416 752-4398
E-Mail: afciweb@afcinstitute.com
Internet: http://www.afcinstitute.com

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 Pediatric 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
7.6.2 National Consumer 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 Hemophilia 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

Canadian HIV/AIDS 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

7.6.2.2 United States

National Association of People With AIDS
Tel.: 240 247-0880/866 846-9366
Fax: 240 247-0574
E-Mail: tku.jawaski@napha.org
Internet: http://www.napha.org

7.6.3 Other Organizations

7.6.3.1 Canada

Centre for Addiction and Mental Health
Tel.: 416 813-1500
Internet: http://www.camh.net

Hospital for Sick Children
Tel.: 416 813-1500
Internet: http://www.sickkids.ca

Victoria AIDS Resource and Community Service Society (VARCS)
Tel.: 250 388-6273
Fax: 250 388-7011
E-Mail: info@varcs.org
Internet: http://www.varcs.org

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@aidsinfo.nih.gov
Internet: http://www.aidsinfo.nih.gov

7.6.3.2 Online HIV Information Resources

Canadian AIDS Treatment Information Exchange
www.catie.ca

BC Coalition of People with Disabilities
http://www.bccpd.bc.ca/publications/healthandwellness.htm#tips
CHAPTER 8 CASE STUDIES
Acute Care, Cardiorespiratory and Neurological

Case #1 - Sonia

Sonia is a 35 year old Aboriginal women who presents to the emergency room at a downtown urban hospital with fever and chills.

Subjective Assessment
Gradually over the last twelve days Sonia noticed decreased energy levels and for the last four days has had a persistent cough, fever and shortness of breath. She went to the local hospital Emergency Room because she is burning up and sweating. During the assessment the doctor discovers that she has a family history of heart disease, and epilepsy and takes antiepileptic medications to control her grand mal seizures.

Social History
Sonia works as a community support worker helping people get supportive housing. She lives alone and has become too weak to care for herself finding it increasingly difficult to make it to work each day. She reports use of marijuana and occasional injection drugs, mainly heroin, over the last year. She has Drug Benefits and Indian Affairs coverage.

Objective Assessment
On physical examination Sonia has a fever of 39 degrees, appears underweight for her size and there is evidence of recent multiple upper extremity injection access sites. Her chest X-ray shows diffuse, bilateral interstitial infiltrates. She is admitted to hospital. The multidisciplinary team receives a referral – “Assess and treat, plan for discharge.”

Lab results consistent with dehydration. Lab results also indicated Sonia was HIV+ (new diagnosis): CD4 count: 50 cells/mm³; viral load: 500,000 copies / ml blood.

Guiding Questions

1. Given Sonia’s chest x-ray (CXR) and physical examination findings, what might you think is her diagnosis?

Notes: Bilateral interstitial infiltrates and dry cough could indicate PCP pneumonia. This is an HIV-associated condition. Given 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 may suggest she is at risk of HIV infection, as well as some of her symptoms. When testing, it is important that the ‘3 C’s’ are considered – counseling, consent, and confidentiality. It will be 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 as to 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: Address the physical, social and emotional and psychological challenges faced and classify using the ICF framework [Chapter 3 – Symptoms and Impairments; Chapter 3.7-Cardiac and Respiratory Impairments]
Some examples include:
- Impairments: (e.g. 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 and uncertainty and stress surrounding the news of her new HIV diagnosis in conjunction with her current medical issue (PCP).

- Activity limitations (e.g. decreased mobility, difficulty with ADLS for self care including dressing and toileting, decreased activity tolerance)
- Participation restrictions (e.g. inability to work, decreased financial status, potential risk for losing housing if lack of income support, potential for cultural dislocation from her Aboriginal community)

4. What 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 (lives alone); raising 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 Indian affairs coverage. Her new HIV diagnosis also introduces a wealth of new challenges to deal with and could be a trigger of an episode of illness that will introduce a variety of HIV-specific services and supports, considerations for future treatment that she may need to consider given her needs. She may also experience cultural dislocation and potential stigma surrounding her diagnosis from the Aboriginal community and in relation to her gender. [Chapter 1_2-Interacting with Communities Affected by HIV]

Analysis Plan

5. What are some of the short-term and long-term rehabilitation goals for Sonia?

Notes: Use the SMART principle (Specific, Measurable, Achievable, Realistic and Timebound). Many of the goals related to her cardiorespiratory status will be short-term:

- To increase ventilation to lung fields throughout in 1 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 analog 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:

- To ambulate 100 metres independently on discharge from hospital in 1 week
- To negotiate stairs independently on discharge from hospital in 1 week.

6. 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 and the process of shared decision-making of developing goals and treatment plan with Sonia.

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 IADLs such as shopping initially after discharge. She may also benefit from stair rails, bathing equipment and education about energy conservation techniques.

Some of the interventions to address her long term goals might include: referrals to social worker / HIV physician to address new HIV diagnosis, referral to vocational rehabilitation specialist to assist with return to work, referral to addictions counselor 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 community based organizations that may be specific to women and Aboriginal communities if available.

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 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.
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 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
- Addictions counselor may help her address her substance use and educate on safe injection practices to reduce risk for HIV transmission.
- 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.
- Vocational rehabilitation specialist to assist with returning to work if/when Sonia is ready.
- Link with community-based AIDS Service Organizations to learn about support services in Sonia’s area and specifically any resources specific to Aboriginals and women.
- [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]

9. What issues might Sonia need you to help her advocate for?

**Notes:**

- To help put her in touch with the necessary services needed in order to help her deal with her new diagnosis; including a primary care physician familiar with HIV.
- Ability to access rehabilitation at an outpatient facility (health care centre, outpatient hospital clinic) if needed.
- Ability to access vocational rehabilitation if/when Sonia would like to return to work.
- 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 Aboriginal women to address any potential forms of cultural dislocation or stigma.
- [Chapter 7-HIV and Rehabilitation in Context, specifically Chapter 7_2-Navigation and Advocacy]

Sonia Part 2: Four months later…

Sonia was discharged from hospital after her first admission and linked with an HIV primary care physician and started a combination of antiretroviral therapy. During that time, she got behind in paying her rent and lost her apartment.

**Current Medical History**

Four months later, Sonia presented to ER by ambulance from detox with uncontrolled seizures. The ER doctors administer 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.

A lumbar puncture was done and it was noted that the patient had Cryptococcus species in her cerebrospinal fluid, confirming the diagnosis of crypto meningitis (now her 2nd 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 lbs).

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.

Sonia was admitted to hospital and ordered high doses of antifungals (Amphotericin B and Fluconazole).

**Objective Assessment**

She quickly became unresponsive with very high blood pressures. 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).

According to the Speech-Language Pathology report, she 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 usage of straws was recommended with this patient, and she was monitored for throat clearing. OT and PT assessments were ordered recently but not carried out as of yet.
Guiding Questions

1. What is Cryptococcus meningitis?
   Notes: AIDS defining illness, neurological condition. [link to Chapter 4_8-Neurological]

2. What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Sonia is experiencing?
   Notes: Address the physical, social and emotional and psychological challenges faced and classify using the ICF framework. [link to 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, decreased ability to grip, falls,
   - Participation restrictions: financial status, drug benefits, homeless, not working.

3. What 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 Indian affairs coverage, her diminished financial status, her homelessness, potential stigma experienced from her Aboriginal community. [Chapter 1_2-Interacting with Communities Affected by HIV]

Analysis Plan

4. What are some of the rehabilitation goals for Sonia?
   Notes: Use the SMART principle (Specific, Measurable, Achievable, Realistic and Time bound). Consider the process of shared decision-making of developing goals.
   a) To be able to be oriented to person, place and time in 3 days.
   b) To be able to ambulate independently with gait aid 100 metres in 1 week.
   c) To be able to carry out ADLS independently (Dressing, bathing, toileting) in 1 week
   d) To be able to swallow pill medications safely without need for crushing pills in 1 week.
   e) To be able to swallow soft-textured foods & thin fluids safely with supervision in 1 week.
   f) To be able to speak intelligibly with assistance from a communication partner in 3 days. [Chapter 2- Rehabilitation Best Practices]

Treatment Plan

5. 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. 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]

6. 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 Cryptococcus meningitis she will require ++ (plus) support in order to help her with housing and getting back onto HIV and antiepileptic medications. She will be likely 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 ASOs as well, potentially geared towards Aboriginals and women living with HIV. [Chapter 6_8-Self Management; Chapter 6_9-Educational Interventions; Chapter 1_2-Interacting with Communities Affected by HIV]

7. 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 social worker, Infectious Disease specialist surrounding her new HIV diagnosis (modes of transmission, available treatment options, etc) for education and considerations of the available supports that she may wish to access.
• Addictions counselor may help her address her substance use and educate on safe injection practices to reduce risk for HIV transmission.
• Social worker can assist Sonia to link with further sources for mental and social. And potential links to income support if not working, and 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.
• Dietician to assist with nutritional requirements.
• Speech-language pathologist to continue with speech and swallowing re-assessment and treatment.
• Physical and occupational therapy to continue with improving grip, mobility, balance, strength, and functional activities of daily living (ADLs)
• Vocational rehabilitation specialist to assist with returning to work if/when Sonia is ready.
• Link with community-based AIDS Service Organizations (ASO) to learn about support services in Sonia’s area and specifically any resources specific to Aboriginals and women. Accessing an ASO with a good peer support or support coordinator and/or peer buddy program can help her navigate the system of rehabilitation.
• [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 3_10-Substance Use]

8. What issues might Sonia need you to help her advocate for?

Notes:
• Housing issues
• Income support
• Addictions issues
• Returning to work (considering graded / part time return to work or alternative duties)

For further information please link to Chapter 7-HIV and Rehabilitation in Context, specifically Chapter 7_2-Navigation and Advocacy; Chapter 3_10-Substance Use.
Musculoskeletal – Knee Pain

Case #2 – Geoff
Geoff is a single 42 year old male who works for a large hotel chain as a service manager who presents to an ambulatory outpatient clinic with right knee pain.

Subjective Assessment (Interview)

Past Medical History
Geoff has been living with HIV for 10 years. He reports his T cells are 700 with an undetectable viral load. He is on triple combination anti-retroviral therapy. He has had few problems related to his HIV and is conscious about taking care of himself through balancing exercise, diet and sleep; plus reducing unnecessary stress and seeking support when needed.

Current Medical History
Recently, Geoff has 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 any 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 in a house.

Objective Assessment
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 Analog Scale (VAS). Geoff denies and 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 is 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 is his exercise regime entail, number of times per week, what activities does the exercise entail, does in include lower extremity work that will be impacted by his injury?, any other concurrent health conditions that he might be living with? What social supports are available to Geoff to assist with IADLS if needed? What support does he indicate 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; Chapter 4.12.5.8-Skeletal System and Bone Health]

Analysis

2. Given Geoff’s physical examination and MRI findings, what might you think is his diagnosis?

Notes: Differential diagnosis may include Avascular Necrosis (AVN), bone disorder in which the bone deteriorates due to interruption in the blood supply. [Chapter 4.6-Musculoskeletal; Chapter 2.3.2-Musculoskeletal and Joint Pain]

3. What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Geoff is experiencing?

Notes: Address the physical, social and emotional and psychological challenges faced and classify using the ICF framework. [Chapter 3-Symptoms and Impairments, specifically Chapter 2.3.2-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, decreased mobility.
- Participation restrictions impact of personal relationships at work, potential impact on his exercise routine and risk for decline in health.
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 – 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: young age, active lifestyle, 'takes care of himself' with exercise, diet and sleep; positive attitude towards his illness. Environmental factors: likes to use the stairs at work, level of social support, home environment – does it have stairs as well, social support from partner, friends or family. [Chapter 1_2-Interacting with Communities Affected by HIV; Chapter 1_3-Introduction to Rehabilitation for Clients, Families and Other Care Providers]

Analysis Plan

5. What are some of the short-term and long-term rehabilitation goals for Geoff?

Notes: Use the SMART principle (Specific, Measurable, Achievable, Realistic and Time bound).

Short Term Goals:
   a) To decrease pain in right knee as measured by decrease in VAS scale at rest and during stairs to 1/10 by 2 weeks.
   b) To be able to negotiate stairs pain free in 2 weeks.
   c) 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.
   a) To return to full exercise routine in 6 weeks.
   b) To return to stair negotiation at workplace in 6 weeks.

Consider patient values and preferences and the process of shared decision-making of developing goals with Geoff. [Chapter 2- Rehabilitation Best Practices]

Treatment Plan

5. What rehabilitation treatment strategies might be used to address Geoff's impairments, activity limitations and participation restrictions?

Notes: Consider patient values and preferences when discussing treatment strategies, prioritizing treatment choices / strategies, and providing a rationale for the choices / strategies. Some treatment interventions might include: range of motion, 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 with reducing the weight bearing and pain in his right knee (e.g. upper extremity work, perhaps stationary bike, walking poles, water running). [Chapter 6-Overview of Interventions; specifically Chapter 6_3-Evidence-Informed Rehabilitation Interventions for HIV]

6. 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, he will require education regarding potential prevention of future exacerbation, and how he might modify his exercise regime to prevent exacerbation. [Chapter 6_8-Self Management; Chapter 6_9-Educational Interventions; Chapter 1_2-Interacting with Communities Affected by HIV]

7. 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.

• Physiotherapy 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; and Chapter 6_8-Self Management]

8. What issues might Geoff need you to help him advocate for?

• Notes: Ability to access rehabilitation at an outpatient facility (health care centre, 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.

For further information please link to Chapter 7-HIV and Rehabilitation in Context, specifically Chapter 7_2-Navigation and Advocacy; and Chapter 6_7 Vocational Rehabilitation.
Case #3 – Louis
Louis is a 63 year old male living with HIV who presents with failure to thrive in community with a referral to home care rehabilitation assessment.

Subjective Assessment

Past Medical History
Louis was diagnosed with HIV infection approximately 2 years ago. Currently his viral load is slightly above detectable and with a CD4 count of 450. Louis is currently not on any antiretroviral medication and you are the first health care provider to visit him at home. Louis has a history of cardiovascular disease and bipolar disorder.

Social History
Louis lives alone in a 1 bedroom apartment in the downtown area. He is a retired classical musician and has moved within the last year to be closer to his extended family. He had been giving private piano lessons to augment his income, until stopping a few months ago due to his deteriorating health.

Louis tells you that he has had increasing difficulty getting out to run errands, some of which require taking the bus. He tells you he has a companion who is 40 years old, who assists him with grocery shopping and to run a few errands. Upon developing a rapport with Louis, he comments that he had to sell his prized cello in order to pay for his companion’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 his companion uses Louis’s debit card to make grocery purchases.

Objective Assessment

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 = 4+ and hamstrings =4+). His has decreased strength of his upper extremities bilaterally (biceps =4+ and triceps =4+). He scored 16/30 on the Mini Mental Status Examination (MMSE). He has difficulty navigating his utensils while eating lunch.

From the assessment, the Occupational Therapist reports that Louis is grossly oriented and his fund of stored knowledge (remote recall), is also grossly unimpaired. His ability to attend to most tasks is also 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 was both impaired, suggesting that there is an impairment of cognitive motor function, whilst 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 is poor in both 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 functions and the occupational therapist 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 as they 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 Occupational Therapist also completes an assessment of the home environment and finds many trip hazards from cluttered furniture and recommends these are moved or removed.

Guiding Questions

1. 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 produces 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 a subcortical 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 4.12.5.10-Central Nervous System-Neurocognitive Functioning]

Analysis

2. What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Louis is experiencing?

Notes: Address the physical, social and 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 3.9-Mental Health; Chapter 4.12.5.10-Central Nervous System-Neurocognitive Functioning;]

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 ADLs, difficulty solving problems and making decisions, decreased ability to carry out instrumental activities of daily living (IADL) such as household chores, grocery shopping, and managing finances.
- Participation restrictions: financial problems, relationship with ‘companion’ potentially problematic – query risk of financial abuse by friend, inability to give piano lessons, query relationship with extended family.

3. What personal and environmental factors might influence Louis’ recovery?

Notes: Personal factors: aging, concurrent health condition of bipolar disorder (are cognitive issues related to bipolar disorder or HIV?). Environmental factors: level of social support – query companion relationship, extended family, access to income supports, 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]

Analysis Plan

4. What are some of the short-term and long-term rehabilitation goals for Louis?

Notes: Consider patient values and preferences when developing goals with Louis. Use the SMART principle (Specific, Measurable, Achievable, Realistic and Time bound).

Short Term Goals:
- a) To be able to complete a simple snack and hot drink with no significant safety problems within two weeks
- b) To be able to safely ambulate within his apartment with a cane in 2 weeks.
- c) To increase strength to upper and lower extremities to 5/5 in 2 weeks.
- d) To be managing all medication doses using a Dosette Box and alarm system within 2 weeks.

Long term rehabilitation goals might revolve around getting back to his exercise and workplace routine.
- a) To be able to carry out independent basic ADLS in 6 weeks
- b) To be able to ambulate outdoors with a rollator walker in 6 weeks.
- c) To be able to identify and engage in one enjoyed activity or social activity outside the home in 6 weeks
- d) To be able to form a realistic weekly budget with assistance from a social carer in 6 weeks. [Chapter 2- Rehabilitation Best Practices]

Treatment Plan

5. What rehabilitation treatment strategies might be used to address Louis’ impairments, activity limitations and participation restrictions?

Notes: Consider patient values and preferences when discussing treatment strategies.

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 community care access centre. [Chapter 6-Overview of Interventions; specifically Chapter 6.3-Evidence-Informed Rehabilitation Interventions for HIV]

6. What kind of educational health promotion, prevention, care, treatment and support materials or information might the team provide for Louis?
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 bilaterally to lower lobes and fine crackles on inspiration in lower lobes.

**Strength:**
Left sided weakness, greater in the leg than arm and leg (quadriceps: 2 and biceps 3). Left truncal weakness resulting in poor postural control.

**Mobility:**
Able to roll to the right and left in bed with minimal assist. Lying to sitting - moderate assist. Requires minimal assist for sitting X 10 minutes tolerance. Sit to stand – maximum assist X 1. Standing tolerance - 10 seconds. Ambulation: 2 steps with 2 high wheeled walker and maximal assist X 2.

**ADLS:**
Assist of 1 for all self-care (dressing, toileting, bathing).

**Cognition:**
Oriented x2 (person & place).

Louis articulates to you with his slurred speech that he would like to ‘get better so that he can get back to his home’.

**Guiding Questions:**

1. What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Louis is experiencing?

**Notes:**
Address the physical, social and emotional and psychological challenges faced and classify using the ICF framework.

Some examples include:
- Impairments: decreased cognition (orientation to time), decreased speech, decreased ability to swallow, decreased strength in left upper and lower extremity, decreased ventilation to lower lung fields bilaterally. Query how potential 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), decreased standing tolerance.
• Participation restrictions: query status of financial problems, relationship with ‘companion’ potentially problematic, inability to give piano lessons, relationship with extended family.

Analysis Plan

2. What are some of the short-term and long-term rehabilitation goals for Louis?

Notes: Consider patient values and preferences when discussing and developing goals. Use the SMART principle (Specific, Measurable, Achievable, Realistic and Time bound).

Short Term Goals:
- a) To increase postural control in sitting by 2 weeks.
- b) To increase ventilation to lung fields bilaterally in 2 days.
- c) To increase strength of left upper and lower extremity in 2 weeks.
- d) To be able to carry out independent bed mobility in 2 weeks.
- e) To improve transfer ability with lying to sitting with minimal assist, independent sitting X 5 min, and sitting to standing with minimal assist, and standing X 5 minutes with minimal assist in 3 weeks.
- f) To be able to swallow an oral diet safely in 1 week.
- g) To be able to communicate functionally with alphabet board supplementation in 2 weeks.
- h) To be oriented X3 in 2 weeks.

Long term rehabilitation goals might revolve around future goals that might be carried out in rehabilitation hospital.
- a) To be able to carry out independent ADLS in 6 weeks.
- b) To be able to ambulate independently with a rollator walker in 6 weeks.
- c) To carry out ADLS independently in 6 weeks.
- d) To be able to swallow a regular diet with thin fluids in 6 weeks.

[Chapter 2- Rehabilitation Best Practices]

Treatment Plan

3. What rehabilitation treatment strategies might be used to address Louis’ impairments, activity limitations and participation restrictions?

Notes: Consider patient values and preferences when discussing treatment strategies, and the process of shared decision-making with Louis, prioritize treatment choices / strategies, and provide rationale for their choices / strategies. Some treatment interventions might include: transfer training, postural control exercises, bridging exercises, isometric strength training, functional exercises (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; Chapter 5.5.1-Rehabilitation Interventions]

4. What other health or social services might Louis also benefit from having access to? Why?

Notes:
- Referrals to PT, OT and SLP. Further cognitive-communication assessment & treatment by SLP may be beneficial for cognitive-communication changes from stroke & 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.
- Dietician
- Follow up with Infectious Disease physician regarding his HIV status.
- Reassess neurocognitive status.
- AIDS Service Organization to assist with social support.

[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?

Notes:
- Explore family relationships and relationship with ‘companion’. Explore what Louis’ goals are and potentially could have ‘family’ meeting with Louis’ to discuss options for rehabilitation if he is unable to return home directly from acute care.

For further information please link to Chapter 7-HIV and Rehabilitation in Context, specifically Chapter 7.2-Navigation and Advocacy.
Complex Case – Musculoskeletal, Episodic, Cardiorespiratory

Case #4 - Stella

Part A

Current Medical History
Stella is a 55 year old female living with HIV who underwent a right total knee arthroplasty (TKA) one week ago due to longstanding and worsening osteonecrosis in the knee. She was recently discharged home post-operative day 5 with referral to home care rehabilitation.

Subjective Assessment (Interview)
Stella was diagnosed with HIV 20 years ago. Stella was discharged home 3 days ago from hospital with a 2 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 when pain increases to 7/10.

Past Medical History
For pain management, Stella is taking Tylenol 3 PRN (about 2 tablets/day). Stella is also taking combination active antiretroviral therapy (cART) consisting of D4T, Nevirapine, Saquinivir and Ritonavir. Her CD4 count is 520 cells/mm3 and her viral load is undetectable. She experiences a combination of side effects from her HIV medications including fatigue, diarrhea, headaches and nausea. Stella also suffers from bilateral peripheral sensory neuropathy in her feet resulting in occasional pain, numbness and parasthesia making it difficult for her to ambulate lengthy distances. She was admitted to hospital 2 years ago with PCP pneumonia. Stella is a previous smoker and also suffers from longstanding chronic obstructive pulmonary disease (emphysema), experiencing occasional exacerbations approximately six times per year.

Social History
Stella lives with her 20 year old daughter who is also HIV positive. They live in a two storey home in a large city. Stella volunteers at the Lung Association twice 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’s mother has been staying with her to assist her in her recovery, assist with meal preparation and with the care of her daughter. Stella would like to get back on her “own two feet” to take over some of the burden her mother has taken on in caring for her and her daughter. 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
Assessment findings include: Range of Motion (ROM) (F/E =95º/5º) and strength (quads = 4+ and hamstrings =4+). She has poor eccentric control of her quads, 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 (including: cardiorespiratory, musculoskeletal and neurological components of assessment, functional mobility, etc.) – IPPA (inspection, palpation, percussion, auscultation), strength assessment, ROM, sensory assessment, functional mobility – ambulation, stairs, etc.

2. What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Stella is experiencing?

Notes: Address the physical, social and emotional and psychological challenges faced by Stella and classify using the ICF framework. [Chapter 2-Rehabilitation Best Practices; Chapter 3_2-Pain; Chapter 4.12.5.8-Skeletal System and Bone Health]

Some examples include:
- Impairments: weakness, decreased range of motion, pain in right knee, pain bilaterally in feet due to peripheral neuropathy, paraesthesia, fatigue, diarrhea, headaches, nausea (from antiretroviral medications).
- Activity limitations: difficulty walking, difficulty negotiating stairs, difficulty dressing, meal preparation, difficulty with long distances prior to surgery secondary to peripheral neuropathy.
- Participation restrictions: difficulty caring for her daughter who is also HIV positive, volunteering at the Lung Association, not currently engaged in paid work, financial challenges – provincial drug support program.
Analysis Plan

3. What are some of the short-term and long-term rehabilitation goals for Stella?

Notes: Consider patient values and preferences when discussing and developing goals. Use the SMART principle (Specific, Measurable, Achievable, Realistic and Time bound).

Short Term Goals:
a) To decrease pain in right knee in 2 weeks.
b) To be able to ambulate independently with cane in 3 weeks.
c) To be able to negotiate stairs independently with a cane in 3 weeks.
d) To increase ROM in right knee to 0 to 90 degrees flexion in 2 weeks.
e) To increase strength in right knee to 4+/5 in 2 weeks.
f) To independently carry out transfers in 2 weeks.
g) To be able to independently ambulate outdoors longer distances in 6 weeks with cane.
h) To be able to independently carry out household chores (laundry, cooking) in 4 weeks.
i) To be able to prevent shortness of breath on stairs.

Consider concurrent health condition on COPD (periodic exacerbations of emphysema) and peripheral neuropathy.

[Chapter 2- Rehabilitation Best Practices]

4. 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's values and preferences along with research evidence...) There are some studies that discuss the success of joint arthroplasty among people living with HIV/AIDS –you should investigate this literature and be able to discuss the potential complications of joint arthroplasty for people living with HIV. [Chapter 4.12.5.8-Skeletal System and Bone Health]

Treatment Plan

5. What rehabilitation treatment strategies might be used to address Stella's impairments, activity limitations and participation restrictions?

Notes: Consider patient values and preferences when discussing treatment strategies and the process of shared decision-making of developing goals and treatment plan with Stella. Some treatment strategies include: stretching, strengthening exercises, functional ambulation, stair training, education to prevent shortness of breath with activity, balance training in conjunction with decrease 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]

6. What kind of educational health promotion, prevention, care, treatment and support materials or information might you provide for Stella?

Notes: Information on TKA, managing your health guide, information on return to work, self management strategies for preventing an exacerbation of COPD, education surrounding proper footwear and strategies to address peripheral neuropathy. [Chapter 6.8-Self Management; Chapter 6.9-Educational Interventions; Chapter 1.2-Interacting with Communities Affected by HIV]

7. 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 you 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]

8. 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 they 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 they might advocate with Stella to enable her to better access the needed services.

- Social worker: to address Stella does ability to care for her daughter, and assess how Stella's mother is coping while have to care for Stella and assist with care of granddaughter.
- AIDS service organizations (women's based ASO). The Theresa Group is supportive AIDS Service Organization for families infected or affected by HIV that provides access to meal programs, supportive counseling for parents and kids... **Note: the Theresa Group is Ontario based so will need to search for similar types of supports in other provinces or locally (http://www.teresagroup.ca/)
- ** Note: The Canadian AIDS Treatment Information Exchange maintains an online database of ASO contact information (http://www.aso411.ca).
- Occupational therapy (if not already involved)
- Vocational rehabilitation (for goals surrounding return to work).
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 required 1-2 days to recover in bed.

Stella has experienced some changes in her body composition due to the antiretroviral medications termed lipodystrophy - 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 Grading 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 her gap in resume, her age, and is hesitant to disclose her HIV status to potential employers for fear that she may be discriminated against.

**Notes:**
- Ability to access vocational rehabilitation services (health care centre, outpatient hospital clinic).
- Ability to return to work
- Ability to access vocational rehabilitation services
- [link to Chapter 7-HIV and Rehabilitation in Context, specifically Chapter 7.2-Navigation and Advocacy]

**Part B: 6 weeks post-op**

The rehabilitation professional has seen Stella in her home once every 2 weeks to monitor the treatment program and re-assess her progress. At 6 weeks post TKA, the rehabilitation professional (e.g. occupational therapist / physical therapist) returns to see Stella for re-assessment and re-evaluation of goals.

### Subjective and Objective Assessment

Stella is recovering well from the TKA and 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 mother 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 basketball games at school due to fatigue. She experiences bouts of diarrhea and nausea from the medications, which further prevent her from carrying out her day-to-day activities. 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...
2. **What added complexity does the episodic and unpredictable nature of Stella's disability have on her overall health?**

**Notes:** Consider the ups and downs that come with living with HIV and the uncertainty that comes with it. Added difficulty re: fear of returning to work (fear of getting sick), fear of coming off provincial funding support – what happens if she returns to work and gets sick again and has to leave work? – is there the potential of having difficulty getting back on income support if needed? Gap in 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. Unpredictability of living with HIV – affects life decisions (return to work), worrying about the future, fear of getting sick, fear of death? [Chapter 1.1-Introduction, specifically Episodic Disability]

3. **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. With her 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 4.12.4-Aging with HIV; Chapter 4.12.5.3.3-Lipodystrophy; Chapter 4.12.5.6-Respiratory Function; Chapter 4.12.6-Stigma; Chapter 3.2-Pain; Chapter 6.7.7-Barriers to Employment or Return to Work]

**Treatment Plan**

4. **What are some of the potential treatment strategies that might be used to address Stella's impairments, activity limitations and participation restrictions?**

**Notes:** Discuss the existing evidence surrounding different rehabilitation interventions for people living with HIV. 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 evidence (e.g., Cochrane Collaboration) on effect of exercise for adults living with HIV – be sure to consider the FITT (Frequency, Intensity, Time, Type) principle. Also consider principles of prioritization on days when feeling fatigued…education on being “balanced” with her activity – reducing cleaning binges… [Chapter 6.Overview of Interventions; specifically Chapter 6.3-Evidence-Informed]

**Rehabilitation Interventions for HIV; Chapter 6.4-Exercise**

5. **You plan to discharge Stella from your case load. Discuss what your discharge plans might be.**

**Notes:** Consider her TKA, bilateral peripheral neuropathy, COPD and risk for future pneumonias, 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]

6. **What kind of educational health promotion, prevention, care, treatment and support materials or information might you provide for Stella?**

**Notes:** Managing Your Health resource published by CATIE (http://www.catie.ca/eng/myh/toc.shtml), information on labour force participation and Return To Work – benefits and navigating the maze. Consider education on episodic disability and uncertainty living with HIV. If she has access to internet, then refer to EDEN (Episodic Disabilities Employment Network, a website where people in Canada living with episodic disabilities, including HIV, can connect with each other to find and generate answers to tough employment questions. (http://www.eden-canada.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.

- Other supports and providers could include: occupational therapy, vocational rehabilitation, supportive AIDS Service Organization for families infected or affected by HIV – access to meal programs, supportive counseling for parents and kid; Supportive counseling.
- Episodic nature of HIV is a barrier to consider in this case
- Considerations/ethics for disclosure of HIV status when referring to other disciplines/services (eg in accessing school/ community based services for Stella’s daughter)
- If she is comfortable, could link Stella with the Employment Action Program at her local AIDS Service Organization to help facilitate her re-entry into the workforce.

[Chapter 1.3-Introduction to Rehabilitation for Clients, Families and Other Care Providers;]
8. What issues might Stella need you to help her **advocate** for?

**Notes:**
- Ability to access rehabilitation at an outpatient facility (health care centre, outpatient hospital clinic).
- Ability to return to work – policy issues related to employment and insurance to enhance the flexibility of return to work.

For further information please link to **Chapter 7-HIV and Rehabilitation in Context**, specifically **Chapter 7_2 Navigation and Advocacy**.
Case #5 – John

John, 46, is admitted to the acute care hospital after a community health nurse found him in his apartment unconscious from drug overdose.

Current Medical History

One day later, with the immediate crisis over, John is now 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 a refusal to eat that is sometimes expressed with a thrown meal tray. The treating physician feels that he still requires another day or two of monitoring and has some concerns about his uncontrolled viral load (>100,000) and low CD4 count (89 cells/mm³) which he does not appear to be concerned with. There is also a question of his ability to care for himself given an extensive medical history and repeat admissions. While John’s personality is usually confrontational he appears to be particularly agitated on this admission.

Subjective Assessment

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 4 years ago. He usually wears a prosthesis. Two years ago he was admitted to the ICU for sepsis from a wound infection on the site of his left below knee amputation and has also been seen at the hospital for two drug-related admissions in the past 18 months. John is currently followed by a community health nurse for dressing changes of a similar wound that has not been healing very well. 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 and hands. At times he finds that he stumbles while walking with his prosthesis and has difficulty with some manual dexterity tasks, and now navigating the wheelchair.

HIV medications have been offered to him in the past however he has declined taking them. He lives in a small 3rd floor apartment (with elevator access) with friends and is very eager to go back as soon as possible. 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, some days he needs to sleep in the afternoon for 2-3 hours. When his energy is low he finds it difficult to do 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 Assessment

Upon entering his hospital room, John is found lying on the floor covered in cereal and the remaining food items from her 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 to transfer back up onto the bed and then into a chair but does so impulsively and recklessly, without regard for use of safety features such as the brakes on his wheel chair or consideration of the positioning of the chair.

Guiding Questions:

Analysis Plan

1. What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that John is currently experiencing?

Notes: Address the physical, social and emotional and psychological challenges faced by John and classify according to the ICF framework. Keep in mind how his 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, 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 3_9-Mental Health; Chapter 4.12.5.10-Central Nervous System-Neurocognitive Functioning; and Chapter 4.8-Neurological]

Some examples might include:

- Impairments: fatigue, weakness, agitation, decreased sensation, decreased dexterity; consider neurocognitive assessment to rule out HAND (HIV-Associated Mild Neurocognitive Disorder), skin integrity.
- Activity Limitations: difficulty carrying out day-to-day activities, decreased mobility (wheelchair and use of prosthesis), decreased balance
- Participation Restrictions: difficulty/barriers in returning to work, financial challenges
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 living with HIV and the uncertainty that comes with it. What happens if he is unable to use his prosthesis, what if he has another wound infection? What if his diabetes remains uncontrolled resulting in him requiring 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; Chapter 4.12.5-Increased Risk of Concurrent Conditions]

Treatment Plan

4. What are some of the potential treatment strategies that might be used to address John’s impairments, activity limitations and participation restrictions?

Notes: First priority is his agitation, safe transfer and mobility training with wheelchair, wound care, ADL training, seating assessment, neurocognitive intervention if demonstrating minor cognitive impairments with HAND assessment. [Chapter 6-Overview of Interventions; specifically Chapter 6_3-Evidence-Informed Rehabilitation Interventions for HIV]

5. What kind of educational health promotion, prevention, care, treatment and support materials or information might you provide for John?

Notes: Managing Your Health resource published by CATIE (http://www.catie.ca/eng/myh/toc.shtml), education surrounding diabetes and how to prevent further deterioration, explore whether John has an eventual goal to return to work. [Chapter 6_8-Self Management; Chapter 6_9-Educational Interventions; Chapter 1_2-Interacting with Communities Affected by HIV]

6. What other health or social services might John also benefit from having access to? Why?

Notes:
- AIDS Service Organization for families infected or affected by HIV.
- Addictions counselor
- OT, PT – seating assessment.
- Eventual link to Employment Action Program at his local AIDS Service Organization to help facilitate his re-entry into the workforce.
- Episodic Disabilities Employment Network (EDEN) website (http://www.edencode.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 6.7-Vocational Rehabilitation and Chapter 6.8-Self Management]

7. What issues might John need you to help him advocate for?

Notes:
- Mobility devices, new prosthesis if needed.
- Vocational rehabilitation services (at the appropriate time if this is a goal of John's)
- Income support

For further information please link to Chapter 7-HIV and Rehabilitation in Context, specifically Chapter 7_2-Navigation and Advocacy.
Case #6– Natasha

Natasha is a 16 year-old living with cerebral palsy and HIV who presents to her pediatric rehabilitation facility to commence planning for transition to adult health and social care services.

Subjective Assessment

Natasha has dysarthria and uses a Zygo Lightwriter (hand held 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 lbs over the last month and now weighs 120 lbs with a height of 5’11”. She stays in bed for most of the day because of dizziness and nausea. There is a history of falls within the home.

She has recently started highly active antiretroviral therapy (HAART) and finds the side effects make her feel weak and nauseous.

Social History

Natasha currently lives with her mother in a 2 bedroom apartment. She has the support from her step-sister and other relatives that come in occasionally to help out with meal prep. It was noted that 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 high school and also does not want the kids in her class to learn of her HIV status.

Natasha attends the rehabilitation centre with her step-sister and mother; you note from the chart they have joint Power of Attorney (POA) in regard to Natasha’s care.

Guiding Questions:

Analysis Plan

1. What are some of the (a) impairments, (b) activity limitations and (c) participation restrictions that Natasha is currently experiencing?

Notes: Address the physical, social and emotional and psychological challenges faced by Natasha and classify according to the ICF framework. [Chapter 5-Pediatrics]

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, Power of Attorney (step sister 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: cerebral palsy, HIV status – potential for episode of illness. [Chapter 5-Pediatrics]

3. What environmental factors and personal factors might influence Natasha’s ability to transition to adult care?

Notes: Environmental Factors: potential and fear of stigma - only her mother knows her HIV status despite both step sister and mother having POA, supports from other family members around meal preparation. Personal Factors: age – getting older and need to transition to adult care. [Chapter 5-Pediatrics]

Treatment Plan

4. 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:

- It is important that the strategies used to address her challenges take into account the ICF framework, by setting goals that address her impairments this can lead to improvements in her activity limitations and participation restrictions. [Chapter 5-Pediatrics]
- Strategies:
  - From a PT perspective, if her weakness is addressed, this can improve upon 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 AIDS Service Organization for families infected or affected by HIV that provides access
to meal programs, supportive counseling for parents and kids… **Note:** the Theresa Group is Ontario based so will need to search for similar types of supports in other provinces or locally (http://www.teresagroup.ca/)

- Linking with public transit for those with a disability could allow her to participate more in her community and promote her independence
- Having a social worker accompany her to the adult clinic for orientation will help with the transition and make the experience less intimidating.

5. **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 instrumental activities of daily living (IADLs), stigma, disclosure issue, link with support group for young adults, drug benefit programs and other assistive programs through various community agencies. [Chapter 5-Pediatrics]

6. **What other health or social services might Natasha also benefit from having access to? Why?**

**Notes:**
- SLP, OT, PT, Dietician [link to Chapter 5-Pediatrics]
- Follow up with augmentative/alternative communication clinic for up-to-date SLP & OT high-tech communication tools. Apple iPads & tablet PC’s are now adapted for use in augmentative/alternative communication and are relatively affordable.
- Self management approach.
- Link to ASOs if interested (may be barriers due to fear of stigma and unwanted disclosure by association to an ASO).
- Any links to service organizations for CP?

7. **What issues might Natasha need you to help her advocate for?**

**Notes:**
- Linking with needed services in Adult Care, access to adult rehabilitation services, will be important for her current team to liaise with whomever will be taking on Natasha’s care to ensure smooth transition. It will be important to check that the partners in this transition of care have sufficient HIV education and resources; if not, you should suggest appropriate contacts. Natasha might not see a major difference in her environments with regards to attitude and personal sense of safety.

For further information please link to Chapter 5-Pediatrics.
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Specific information for prescription drug coverage in Canada according to each province or territory can be found at the following website